Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Volume 3: Country Reports

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Disclaimer

The views expressed in this report are those of the authors and do not necessarily reflect those of the European Commission.

Cost

The cost of this project was €349781.

Contents

Introduction

Julie Beadle-Brown

Overview

These country reports form the third volume of the final report from the European Union Project *Deinstitutionalisation and community living – outcomes and costs: report of a European Study*. There are 28 country reports included. For the most part, the reports have been written by the researchers and in some cases the experts in each of the partner institutions, using a variety of sources, including government policy, web-based documents, statistical reports and academic papers. In a few cases local contacts in the countries concerned were also involved in preparing the country report. The editors inserted the data summaries, checked and where necessary edited reports. For three countries (France, Belgium and Hungary), the editors contributed substantial amounts of information from their own sources in order to make the reports as complete as possible.

The aim of each report is three-fold:

- to summarise the data collated for the template for each of the service types identified for that country
- to comment on the completeness and adequacy of the data collated
- to provide a commentary on the context and current situation for people with disabilities in each country.

Data summaries

In order to analyse, summarise and compare data across countries, information received on each template was recoded into categories. It is these categories which are included in the data summaries at the beginning of the country reports. These categorisations and the key to the tables are outlined below:

Categories for service descriptions

The following tables describe the categorisations used for each of the service description variables.

Size Interval

Categorisation	Description/explanation
1 to 5 places 6 to 10 places 11 to 30 places 31 to 50 places 51 to 100 places 101 to 150 places 151 to 200 places Over 200 places	For some analyses these were collapsed into 30 or less vs. over 30; with those providing over 100 places also highlighted.

Age group

Categorisation	Description/explanation
Services providing for children were categorised as one of the following: • 0 to 5 years • 0 to 11 years • 0 to 18 (or 19 in some countries) years • 3 to 18/19 years (i.e. no infants) • 6 to 18/19years • 0 to 25 (i.e. birth through to young adulthood) • 3 to 25 (as above but not including infants) • Secondary school age only	These categories were designed to include as many of the actual breakdowns as possible. E.g. if a service was recorded as providing for children ages 2 to 8 year old, then it would be within the 0 to 11 year group. However, it seemed important to distinguish initially services providing for infants with disabilities as opposed to older children, therefore a initial breakdown included many categories. For detailed analyses these were collapsed into: • Children • Younger adults • Older adults • Any adult (i.e. over 18). OR • Children • Adults
Service providing for younger adults were categorised as: • 14 to adulthood (up to 60/65) • 18 (in some cases 16) to 60 or 65 (depending on definition of "old age" – i.e. younger adults only) • 16/19 through to 23 (i.e. young adults only) • 20 to 30 years only	
Service providing for older people were categorised: • Over 60/65 • Over 80	
Services providing across age groups: • 0 to 60 or 65 (adulthood but not older adults) • 3 to 60/65 (as above but no infants) • All ages (0 to death) • Over 18 only (only adults but no distinction between younger and older adults) • Service for over 18s but some children do live there • Service type is used for different age groups but not usually in the same home	

Disability Group

Categorisation	Description/explanation
MH	Mental Health
ID only	Intellectual Disability only
PD	Physical disability only
Sensory Impairments	Impairments in vision, hearing, etc.
PD and sensory/other	Mixture of physical and sensory or other impairments
ASD	Autistic Spectrum conditions
Speech impairments	Difficulties with speech (not associated with
Mixed ID with PD, SD, MH, Behaviour or other	People with ID but with other complex needs too
Service type provided for more than one disability group but not mixed in the same home.	Service type listed provided for e.g. ID or PD or MH but not within the same home – ie. there were homes of that type of people with ID, and other homes for people with PD or MH.
Mixed	Service type provided for homes with more than disability group.
Disability not specified	Disability was not specified on the template
In addition, there were several categories which are used in the service descriptions but which were not included in detailed analysis: • Behavioural/emotional/social problems/ learning difficulties • Terminal/chronic Illness • Elderly infirm/mentally ill/dementia	

Level of support provided

Categorisation
• 24 hour support provided • Night and weekend support only • Mixed depending on need • Less than 10hrs per week • Mixed pattern within the same institution (e.g. Externat, internat and demi-internat in French schools) • Mixed pattern between units within the same type – e.g. some group homes provide 24 hour, some less than 10 hours. • Per day only, no night time staffing

Typical provider (who normally provides this type of service)

Categorisation	Description/explanation
State	Services are provided at a national/state level – e.g. NHS in UK
Local authority/municipality/county	Service are provided by local level (whatever that might be called in the local area)
All private	At least 95% of provision is private/for profit
Voluntary/not-for-profit	At least 95% of provision is through the voluntary sector
Mainly independent	At least 50% is either private or voluntary
Mixed	Large mix of providers – eg state, local authority plus independent sector.
State and local authority/municipality	Mixture of state and local level provision.

Typical funder (who normally pays for this type of service)

Categorisation	Description/explanation
State	Services are all funded in some way by the state, at national level. This might be through national insurance schemes or tax systems.
Regional authority/local authority/County and State	Services are funded by local level governments/agencies such as local authorities, counties etc usually with some contribution from the State.
Mainly state/or local authority	Services are funded mainly (More than 75% of this service type) by either the state or the local level government.
Mixed state/local and private contributions (insurance/private)	Some state or local contributions but people also pay some costs themselves – either through insurance or through out-of-pocket payments.
All private/insurance	People pay for the services themselves.
Mixed (any)	Funding for this service type is mixed – no one main funder. May include funding from voluntary organisations.
Benefits/social security	People pay for their services entirely through benefits or social security system.
Mixed benefits/social security and state/local authority contributions	Mixture of funding through social security/benefits and contributions by local level government or the State.
Mixed benefits and private	People pay for services using their benefits and private contributions.

Length of admissions

Categorisation
• Short term • Mainly long-term • All long-term • Mixed • Short to medium term (up to 2 years)

N.B. Only those which included some long-term provision were included in detailed analyses. Service types provided only short-term care were excluded.

Service Age

(ie the typical length of time that institutions within that type have been operating)

Categorisation
• 0 to 20 years • 21 to 50 years • 51 to 100 years • Over 100 years old

Key to tables summarising data on number of places

Some of the categories used in the tables are obviously self-evident e.g. breakdown by size and gender. However, need some explanation. For disability, places were broken down into categories by primary disability where possible. However, a mixed category was used as institutions in some countries provided for people across the whole range of disabilities.

Breakdown by disability

Category used	Description/definition
ID	Intellectual disability
MH	Mental health needs
PSD	Physical and/or sensory disabilities
Elderly/dementia	this group included older people who did not have a pre-existing disability but could include those with dementia. In most countries this category was not used because the service types of this group were distinct but in a few countries the same service type included people in this group. However, for the analysis reported in the main report, these people are not in general included – only older people with a pre-existing disability were included when it was possible to distinguish.
Mixed/dual:	Where institutions/places were for people with more than one disabilities (usually ID and MH or ID and PSD) or where they provided for people from more than one disability group within the same setting.
Other/unspecified:	Disability was classified as something not encompassed within the definition for the project – e.g. people with chronic or terminal illness, those with substance abuse problems, or children with specific educational needs such as dyslexia, or those that have been taken into care for protection. Alternatively, this category was used if classification by disability was not possible.

Breakdown by age

Category used	Description/definition
Children	Generally up to 18 years of age, however, in some cases it was up to 16 years and in others children's services allowed people to stay until 19, 20 and in some cases 23 years of age.
Younger adults	Places for those aged between 18 and 60 or 65, depending on definition of older age in each country. In a few countries, the older age bracket is much older – e.g. over 80..
Older adults	Places for people usually aged over 60/65.
Adults over 18	This category was used when data was only available for adults, without differentiating between older or younger adults.

Staffing

Category used	Description/definition
Care staff/nurses/might include teachers in boarding school	Staff who provide day-to-day support for people but not just daytime staff – might be nurses, staff in boarding schools who provide support outside of classes, care staff in group homes etc. Team leaders, ward sisters are included here if they have some contact with users.
Managers or other administrative staff (not care staff)	The people who run the units and who manage the admin associated with the institution – managers, admin staff etc. Generally don't have contact with users very much.
Educators/ daystaff	Staff who just work with people on a day care basis – educational staff, staff who support people in employment or community activity as a special event – e.g. an activity worker.
Day and care staff (no distinction made)	This category was used when no distinction could be made between day and care staff.
Clinical staff (Drs, therapists, psychologists, etc.)	Staff who provide health care, therapy, assessment, behavioural management etc. They may be employed by the institution but not necessarily a regular contact with users – brought in when needed usually for a particular reason.
Other staff (mainly ancillary staff)	Any other staff which includes ancillary staff such as cleaners, cooks, gardeners
Other staff (without ancillary staff)	Any other staff but not ancillary staff.
Qualifications Where information on staff qualifications was available (only a very few countries) the following categories were used	
Staff with only primary school qualification or less	Staff had a very low level of educational or professional qualification – primary school qualification or less.
Staff with secondary school qualification as highest qualification	Staff had attended and completed secondary school qualifications
Staff with further education qualification	Staff had completed a further education training, such as a national vocational qualification, a certificate level qualification, etc.

Category used	Description/definition
Staff with university degree	Staff who had a university degree level qualification
In service training only	Staff only had in-service training, no formal education.

Completeness and accuracy

Research partners were asked to complete this section for every country for which some data was available, including an account of how complete the data was (in terms of disability groups, age groups and service types in particular) and how accurate it was. Accuracy was established through comparison with data from other sources plus consultation with local contacts/officials in each country.

Commentaries

In general, the commentaries provide information on the current situation and, for the most part, provide information that is as up-to-date as possible. The cut-off point for collecting data for the template was March 2007 but in some cases the country reports have been slightly revised with more recent information where it has become available. A few of the reports also provide some historical context where it is thought to have an important bearing on the present day situation. In some countries, information was limited but in general the commentary included the following sections:

- Political and social context (including disability policy)
- Demography
- Health and Social Care system
- Definition, eligibility and diagnosis
- Prevalence of disability
- Residential services for people with disabilities
- Staffing
- Cost related information
- Current Issues
- Information sources and verification of data for template
- References

Some of the reports also include appendices – for Italy and Germany, this takes the form of more detail information on specific regions, for which additional data had been sought as part of the work on service development and the role of different actors in service development and provision. For Denmark, Sweden, Malta, Finland and Ireland, it was possible to complete a scenario illustrating how an individual with relatively severe and complex needs would receive support in each country.

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Country Report

Austria

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Summary of the available data

No template was completed for Austria.

Completeness and accuracy of the data

Despite intensive efforts data collation for Austria did not produce satisfying results. The Austrian Federal Ministry for Social Security, Generations and Consumer Protection offered available documents on national level that focus on programmatic information. Also web-based information was analysed.

As a result of the Austrian federal system and competence regulations in the Social Care sector data collection competence is decentralised and on the level of the Federal States (Bundesländer). There is no systematic and coordinated system of data collection and statistical reporting in the field of disability services for Austria. The collection of data is practised according to different categorial systems. As the project template was regarded as too complex and extensive by Austrian representatives on Länder level, a 'light version' was developed in German language and sent to the Social Ministries of all Bundesländer. Only few ministries responded, mostly feed back said that data was not available in a systematic form.

On the other hand there are comparatively well developped statistics on the situation of the long-term care system in Austria.

Thus, the following description gives an uncomplete overview on the Austrian situation.

Commentary: Austria

1. Overview

In contrast to other central Europea countries Austria has nearly no tradition of large institutions for people with intellectual disabilities dating back to the 19th.century, neither statutory nor run by religious provider organisations. Until the 1960ies residential care for people with disabilities was mostly provided in statutory psychiatric hospitals. It were parents' associations like 'Lebenshilfe für geisig Behinderte' that lobbied for the implementation of a rehabilitation oriented service system since the Mid-Sixties of 20th century. In this process 'Lebenshilfe' and other voluntary associations lobbied for establishing residential services and established themselves as provider organisations all over Austria. Their institutional model was the '24 places group home', that was later added by residential settings with less places and by supported living-schemes providing support on hourly based system. Residential services for people with disabilities are nearly to a 100% run by private provider organisations that have either a religious or other 'weltanschaulicher' background or are parents' organisations like the 'Lebenshilfe', the national association for people with intellectual disabilities. The national umbrella asscociation for people with autism and their families is 'Autistenhilfe Österreich'.

A typical local service system for people with disabilities would consist of an early intervention service, a parallel system of special and integrated kindergarten education (3 – 6 yrs), various special schools for pupils with disabilities and parallel integrative school education (7 - 18 yrs), family respite care serviceso, ccupation therapy in sheltered workshop (18 – 65) or parallel supported employment, staffed community houses or parallel supported living schemes or group home, leisure time activities and clubs.
The support system for people with mental disorders would see the psychiatric hospital in the centre of the provision arrangements and a complimentary system of services around it or –depending on the region - the normal hospital in co-operation with the normal psychiatric doctor in the community in good cooperation with small residential and other services (day-cafe, counselling, supported employment etc.) in the community.

2 Political and social context

2.1 Government organisation and structure

The Federal Republic of Austria is a federal state, official language is German. It consists of 9 states (Bundesländer), which have between 180.000 and 1.6 million inhabitants. The 'Bundesländer' are divided into districts (Bezirke) and cities (Staturstädte). Districts are furthermore divided into municipalities (Gemeinden). Cities have the competencies of both, districts and municipalities.
According to constitutional definitions, the central government is responsible for basic legislation in the fields of social insurance, labour law and health system, whilst the provincial governments in the Federal States are responsible for implementation and enforcement. The responsibility for most services for disabled people and for rehabilitation lies with the federal states. But the Austrian legal order contains no uniform competency regulation in disability legislation, fragmentation and many

overlaps are given. More than 90 laws and rulings on local, provicial and central government level relate to the situation of persons with disabilities. Regulations for certain services vary from Federal State to Federal State.
Non-governmental organisations (NGO) traditionally play an important role in the Austrian disability field and form a dense network with government boards and actors. As provider and lobby organisations they are mostly organised in the Austrian Council for Rehabilitation (German: Österreichische Arbeitsgemeinschaft für Rehabilitation, ÖAR) which is also representing Austria in the European Disability Forum. The ÖAR has 74 member organisations representing ca. 400.000 members. The ÖAR also plays an important role in the forming and realising of the social laws on all levels of the political system.

2.2 Disability relevant policy

In the past years, the Austrian federal government has published a number of reports on the situation of disabled persons. Of lasting importance was "The Austrian Federal Government's Disability Concept" published in 1993[1] which was translated in French and English and became a major guideline for the development of disability policies in the following years. It stated a deficit in residential support for persons with disabilities and demanded action to create additional residential facilities for people with intellectual or multiple disabilities. In chapter 9.2 'Housing' the government's concept pleads for the 'community-based model' instead of the 'care model' as an orientation for the further Austrian development. "In the care model, the disabled person is accomodated in an old-age or nursing home, or another institution which provides all the assistance the person requires in addition to accomodation. The community-based model follows the prinicple of integration and normalisation and tries to realise these in the form of 'living in the community and community based psychiatry'. This can be achieved with assistance within reach, residential communities with personal care staff and small residential homes that are integrated in their social and physical environment (Federal Ministry 1993: 43).
In an official agreement, following the publication of the Disability Concept, in 1993 the Federal States accepted the obligation to develop a network of area-covering services and facilities for people with disabilities. It was stated that these services should include medical care services, educational services, vocational traing and supporting services for ocuppation and employment and various other services to support housing and leisure time needs of people with disabilities.
In 1998 the Austrian parliament decided to add a non-discrimation passus to the constitution that sanctions discriminative action and procedures against people with disabilities. Explicitly targeted on the European Year of the Disabled in 2003, the Austrian government published a comprehensive "Report on the Situation of Disabled People in Austria"[2], containing conceptual principles on social assurance, rehabilitation and social assistance issues including services concerning people with disabilities in various age groups. As far as epidemiological data is concerned, the report concedes that there is only a weak data base for the prevalence of persons with mental illness and intellectual disability. It is estimated that 1 % of the Austrian

[1] Federal Ministry for Labour and Social Affairs in co-operation with Österreichische Arbeitsgemeinschaft für Rehabilitation (1993): The Austrian Federal Government's Disability Concept, Vienna 2003
[2] Regierung des Bundesrepublik Österreich (2003): Bericht der Bundesregierung über die Lage der behinderten Menschen in Österreich vom 18.03.2003, Wien (in the following quoted as ‚Report 2003')

population (ca. 80.000) have mental disorders, and that the percentage of people with intellectual disabilities is about 0,6% (ca. 48 000). The general problem behind the unclear data situation is that there is no uniformed definition of disability (cf. Report 2003: 15).

Very important for the Austrian development was the action program '1000 places for people with intellectual and multiple disabilities' that was developed and implemented in the mid-nineties by the Federal State of Vienna The conceptual orientation of the program was taken from Swedish models of small staffed houses in combination with suppported living schemes. The service arrangement should allow users to have choices and should foster their individual autonomy and social participation. A similar program was implemented in Upper Austria (cf. Report 2003: 148).

In the mental health field an important step was taken 1998 when the psychiatric provision was officially involved in the Austrian Hospital Plan (German: Österreichischer Krankenanstaltsplan (ÖKAP)[3]. Based on an person-centred approach the new plan contained guidelines for decentralisation of the large psychiatric hospitals that were to be replaced by added psychiatric wards in regular hospitals. Furthermore the plan gave recommendations for the development of community treatment and care services both institutional and home-care oriented. The conceptual objective was to de-stigmazide psychiatric treatment as well as service users and to facilitate their integration in society. The ÖKAP-plan asked the Federal States to structure their area in provision regions for mental health care and to develop a well coordinated network of institutional treatment (German: stationäre Behandlung) and housing, consulting and other complentary services in each region, consisting of

- Psychosocial services (e.g. crisis intervention, consultation)
- Residential facilities
- Employment and occupation facilities
- Day structure-facilities
- Psychiatrists with community orientation.

The 2003 Report of the Federal Governments could document a remarkable effect of the ÖKAP-Plan. According to the 'Report' there were already 22 psychiatric wards in regular hospitals. The number of beds in large psychiatric hospitals in 2003 was ca. 2.600 (cf. Report 2003: 148).

In a series of editions the federal government publishes general overviews on the support system for people with disabilities in Austria, the last edition was edited in September 2005[4]. The overview paper addresses people with disabilities, it demonstrates the clear orientation towards the equal opportunities and non-discrimination approach of the European Disability Strategy. It is also published in 'easy-to-read-language'. Disability policies in the overview-paper are in prinicpal conceived as a 'mainstreaming issue' that cannot be delegated to a special part of the government's administration but needs a cross-sectoral approach (p.14). These overview brochures don't contain detailed data neither on residentials services nor on other disability services.

[3] The information on the ‚ÖKAP-Plan' was taken from the Federal Government Report 2003, pp. 147

[4] Bundesregierung für Soziale Sicherheit, Generationen und Konsumentenschutz (2005): Überblick. Hilfen für Menschen mit Behinderungen im Österreichischen Sozialsystem, 3. Auflage, September 2005

3. Demographics

Austria has a population of approx. 8.2 million. The population growth is at a very low level of +0.8% between 2004 and 2005. The average live expectance (2005) is about 76.65 years (men) and 82.24 years (women); the mortality rate of newborns in 2005 is about 4.2 out of thousand births.

4. Health and Social Care System

4.1 Organisation

The welfare state structure is primarily based on a social insurance system being connected with an employment relation. The system is organised by 24 different agencies for social insurance with specific regional or professional traditions. Especially in the field of health care, accidental risk and pension insurance also family members that have no own income from the regular labour market can get health provision from the insurance system. It is a universal and solidaric system providing services independent of the individual income or property situation. Other social and educational services for people with disabilities are financed on the level of the nine federal states. The legal basis for this system of social assistance (German: Sozialhilfe) derives from a 'Poor-Law-Tradition' and funding follows the principle of subsidiarity, generally meaning that all other legal and private ressources have to be used before statutory support is granted. In practice, this has led to remarkable differences in the regional services systems concerning conceptual issues and quality of provision as well as in the financial contribution regulations for users of disability services. The laws dealing with the support of disabled people are partly in the competence of the federal government and partly in the competence of the federal states. A general federal law was introduced in 1990. This leads to some smaller differences between the different states, but generally all disabled people get the same support, only some services differ. The general laws are made by the federal government, the states deal with the practical services offered to the people, mostly by NGOs.

Since 1993 the Austrian provision of support and services for people with long term care needs is regulated by the Nation Care Law ('Bundespflegegeldgesetz') and corresponding laws on the level of the Federal States. It defines that all people with 50 hours or more of need for care are entitled for services in cash or kind. The law structures care needs in seven steps, that define the amount of payments granted to the individual. In 2004 there were 371.067 persons that received payments under the National Care Law, 66.286 of these persons with recognised care needs of at least 50 hours a months were younger than 60 years. Average amount of payments in 2004 were 408 € (women) and 430 € (men) (cf. Schneider et al. 2006: 11).

4.2 Financing

For people with disabilities and for people with mental illness costs for Group homes, staffed houses or appartments, short-term-care facilities. Cost are mostly covered by the state on the basis of 'social assistance' *('Sozialhilfe')*, users have to contribute from their own budget. Regulations differ widely between federal states. Services by non-profit private provider organisations with partly a religious and partly a nonreligious background.

For older adults with care needs financing of services is organised as a mix of statutory grants for nursing care homes from the federal states, and the 'care budget' that people with recognised care needs get according to the National Care Law from 1993 (Pflegegesetz), and of own income or property. The structure of this mix varies widely between federal states. For all Austria 2004 a total expenditure for long term care costs of 1.32 billion € estimated, around 39, % of these costs were covered by residents also using their care law budget (Schneider et.al. 2006: 13)

5. Definition, eligibility and diagnosis/assessment

In Austria there is no uniformed approach to classify the group of people with disabilities, definitions depend on policy fields. The rather important 'Bundeseinstellungsgesetz' defines disability as an effect of a non-periodical (more than 6 months) functional impairment according to an unnormal state of physical, cognitive or mental conditions (cf. § 3 BeinstG). Parallel to this exists a system that can classify a person's degree of disability (*Grad der Behinderung, GdB*) based on an medical assessment. Having at least 50 % is a condition for receiving a series of disadvantage compensations like tax reductions etc.
The Nation Care Law also contains a specific system for categorization of care needs, that is structured in 7 steps according to the amount of hours of care the person needs per months, starting in step 1 with 50 hours per months until step 7 with more than 180 hours.

6. Prevalence of disability

No national data

7. Residential Services for people with a disability

7.1 Overview

For people with disabilities there are basically three different types of residential services: Group homes, staffed houses or appartments, short-term-care facilities.. Services by private provider organisations with partly a non-religious and partly with a religious background, depending on the region.

For people with mental illness there are three also different types of residential services: Supported living services, staffed houses or appartments, group homes. Services are offered by private provider organisations partly with a non-religious and partly with a religious background, depending on the region.

In the formal sector of nursing care services for older adults there is on the one hand the traditional nursing care home for the elderly (*Alten- bzw. Pflegeheim*), on the other hand there is a rather well-established system of out-patient services ((mobile soziale Dienste'). Thirdly, a system of day-care services is developping offering care and personal support in addition to the system of mobile services.
In 2002 estimately around 55 % of nursing care homes were run by public/statutory providers, 24 % of nursing care homes were run by providers from the non-profit sector, and 21 % were run by providers from the profit sector (cf. Schneider et.al 2006: 12)

7.2 Residential services in federal states (Bundeländer)

Burgenland

For people with disabilities there are two different types of residential services: group homes and institutions. Cost are mostly covered by the state, users have to contribute. Services are offered by 11 provider organisations with partly a religious and partly a nonreligious background.
For people with mental illness there are two different types of residential services: Group homes and institutions. Cost are mostly covered by state, users have to contribute. Services are offered by 5 provider organisations with a mostly non – religious background.
No further data.

Carinthia

No data available

Lower Austria

For people with disabilities there are three different types of residential services: Group homes, staffed houses or appartments, short-term-care facilities. Cost are mostly covered by the state, users have to contribute. Services are offered for 1721 people by provider organisations with partly a religious and partly a nonreligious background.

For people with mental illness there are three different types of residential services: Supported living services, staffed houses or appartments, group homes. Cost are mostly covered by the state, users have to contribute. Services are offered for 911 people by provider organisations partly with a religious and partly with a non-religious background.
No further data.

Upper Austria

For people with disabilities there are three different types of residential services: Group homes, staffed houses or appartments, short-term-care facilities. Cost are mostly covered by the Federal state of Upper Austria, users have to contribute. Services are offered by 14 provider organisations mostly with a religious background.

For people with mental illness there are three different types of residential services: Supported living services, staffed houses or appartments, transitional homes, group homes, short-termcare facilities. Cost are mostly covered by the Federal state of Upper Austria, users have to contribute. Services are offered by 7 provider organisations, mostly private with a religious background.

Salzburg

For people with disabilities there are three different types of residential services: Group homes, staffed houses or appartments, short-term-care facilities. Cost are mostly covered by the state, users have to contribute. Services are offered by 23 provider organisations mostly with a nonreligious background (Lebenshilfe Salzburg)

For people with mental illness there are two different types of residential services: Supported living services, staffed houses or appartments, transitional homes, group homes, short-termcare facilities. Cost are mostly covered by the state, users have to contribute.Services are offered by 10 provider organisations, mostly private with a nonreligious background.
No further data.

Styria
No data

Tyrol
For people with disabilities there are three different types of residential services: Group homes, staffed houses or appartments, short-term-care facilities. Cost are mostly covered by the Federal state, users have to contribute. Services are offered by 14 provider organisations mostly with a religious background.

For people with mental illness there are three different types of residential services: Supported living services, staffed houses or appartments, transitional homes, group homes, short-termcare facilities. Cost are mostly covered by the Federal state of Tyrol, users have to contribute. Services are offered by 7 provider organisations, mostly private with a religious background.
No further data.

Vorarlberg
For people with disabilities there are three different types of residential services: Group homes, staffed houses or appartments, supported living. Cost are mostly covered by the Federal state of Vorarlberg, users have to contribute. Services are offered by 31 provider organisations, partly with a religious and partly with a non-religious background.

For people with mental illness there are two different types of residential services: Supported living services and staffed houses. Cost are mostly covered by the Federal state of Upper Austria, users have to contribute. Services are offered by 21 provider organisations, partly with a religious and partly with a non-religious background.
No further data.

Vienna
For people with disabilities there are three different types of residential services: a) Staffed houses or appartments (in 2006: 1440 places[5]), b) supported living services (in 2006: ca. 900 persons), and b) personal assistance services for people with severe physical handicaps (in 2006: 25 people). Cost are mostly covered by the Federal state of Vienna, users have to contribute. Services are offered by 16 private provider organisations mostly with an non-religious background.
No further data.

[5] http://www.fsw.at/Wohnformen/Wohnen_mit_Behinderung/vollbetreutes_wohnen.htm, accessed on 29/08/06

8. Staffing
No national data.

9. Costs
No national data

10. Acknowledgements
Mag. Menge, Bundesministerium für soziale Sicherheit, Generationen und Konsumentenschutz, A-1010 Wien

11. Information sources on disability used to compile the template and commentary, including people who were interviewed:
Mag. Menge, Bundesministerium für soziale Sicherheit, Generationen und Konsumentenschutz, A-1010 Wien

12. References

Federal Ministry for Labour and Social Affairs in co-operation with Österreichische Arbeitsgemeinschaft für Rehabilitation (1993): The Austrian Federal Government's Disability Concept, Vienna 2003

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Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

Belgium

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Summary of the available data

Description of service types

The table below summarises the descriptions of the 9 service types included in the template.

Type of service	Size interval	Age group	Disability group served	Level of support	Typical provider	Typical funder	Length of admission	Age of service
SRJ (Service Résidentiel pour Jeunes) (Residential service for the young)	51 to 99 places	0 to 25 years	More than one disability group served (no main group) but not mixed	24 hour	Mainly independent (over 50% private or voluntary)	Mainly state or LA (more than 75%)	All long term	.
INTERNAAT (boarding school)	51 to 99 places	3-18/19 years	Mixed ID with PD, SD, MH,Beh and other	24 hour	Mixed	Regional authority/LA/County and state	All long term	.
DIENST VOOR BESCHERMD WONEN (services for sheltered living)	11 to 30 places	Over 18/25 (i.e. adults only)	ID only	Mixed depending on need	.	Mainly state or LA (more than 75%)	All long term	.
NURSINGTEHUIS VOOR NIET-WERKENDEN (nursing home for the non-employed)	151 to 200 places	Over 18/25 (i.e. adults only)	ID only	24 hour	.	Mainly state or LA (more than 75%)	All long term	.
SRA (Service Résidentiel pour Adultes) residential services for adults	51 to 99 places	Over 18/25 (i.e. adults only)	More than one disability group served (no main group) but not mixed	24 hour	Mainly independent (over 50% private or voluntary)	Mixed state/local and private contributions (insurance/private)	All long term	0 to 20 years

SRNA (Service Résidentiel de Nuit pour Adultes) residential night service for adults	11 to 30 places	Over 18/25 (i.e. adults only)	More than one disability group served (no main group) but not mixed	24 hour	Mainly independent (over 50% private or voluntary)	Mixed state/local and private contributions (insurance/private)	Mixed	0 to 20 years
SRT (Service Résidentiel de Transition) residential transition service	.	.	.	.	.	.	.	.
TEHUIS VOOR WERKENDEN (GEZINSVERVANGENDE TEHUIZEN) (home for the employed/ family-replacing home)	11 to 30 places	Over 18/25 (i.e. adults only)	ID only	Night and weekend support only - people out during day	.	Mixed state/local and private contributions (insurance/private)	All long term	.
BEZIGHEIDSTEHUIS VOOR NIET WERKENDEN (occupational home for the non-employed)	51 to 99 places	Over 18/25 (i.e. adults only)	ID only	24 hour	.	Mainly state or LA (more than 75%)	All long term	.

Data available by service type – breakdown by size and disability

Type of service	Places total	Under 30 places	Over 30 places	Size unspecified	ID	MH	PSD	Elderly/ dementia	Mixed/ dual	Other/ unspecified
SRJ (SERVICE RÉSIDENTIEL POUR JEUNES) (Residential service for the young)	3084	319	2765	0	537	1443	125			
INTERNAAT (boarding school)	4855	214	4641	0	.	.	.			
DIENST VOOR BESCHERMD WONEN (services for sheltered living)	1005	847	158	0	1005	.	.			
NURSINGTEHUIS VOOR NIET-WERKENDEN (nursing home for the non-employed)	4388	150	1782	2456	1932	.	.			
SRA (SERVICE RESIDENTIEL POUR ADULTES) (residential services for adults)	4059	1126	2933	0	1764	21	405			
SRNA (SERVICE RESIDENTIEL DE NUIT POUR ADULTES) (residential night service for adults)	526	446	80	0	274	13	20			
SRT (SERVICE RESIDENTIEL DE TRANSITION) (residential transition service)	.	.	.	.	.	.	.			
TEHUIS VOOR WERKENDEN (GEZINSVERVANGENDE TEHUIZEN) (home for the employed/ family-replacing home)	1161	743	418	0	1161	.	.			
BEZIGHEIDSTEHUIS VOOR NIET WERKENDEN (occupational home for the non-employed)	6672	1319	5353	0	6672	.	.			
TOTAL	**25750**	**5164**	**18130**	**2456**	**13345**	**1477**	**550**			

Data available by service type – breakdown by gender and age

Type of service	Places total	Male	Female	Gender unspecified	Children	Younger adults	Older adults	Adults over 18	Age unpecified
SRJ (SERVICE RÉSIDENTIEL POUR JEUNES) (Residential service for the young)	3084	614	1642	828	2081	200	.	.	803
INTERNAAT (boarding school)	4855	2978	1269	608	4855	.	.	.	0
DIENST VOOR BESCHERMD WONEN (services for sheltered living)	1005	520	417	68	.	.	.	1005	0
NURSINGTEHUIS VOOR NIET-WERKENDEN (nursing home for the non-employed)	4388	2443	1945	0	.	.	.	1932	2456
SRA (SERVICE RESIDENTIEL POUR ADULTES) residential services for adults	4059	1540	1984	535	4	3313	243	.	499
SRNA (SERVICE RESIDENTIEL DE NUIT POUR ADULTES) residential night service for adults	526	169	336	21	.	473	37	.	16
SRT (SERVICE RESIDENTIEL DE TRANSITION) residential transition service	.	.	.	.	.	.	.	.	.
TEHUIS VOOR WERKENDEN (GEZINSVERVANGENDE TEHUIZEN) (home for the employed/ family-replacing home)	1161	709	416	36	.	.	.	1161	0
BEZIGHEIDSTEHUIS VOOR NIET WERKENDEN (occupational home for the non-employed)	6672	2177	1988	2507	.	.	.	6672	0
TOTAL	**25750**	**11150**	**9997**	**4603**	**6940**	**3986**	**280**	**10770**	**3774**

Type of service	Total staff	Care staff/nurses/might include teachers in boarding school	Managers or other administrative staff (not care staff)	Educators/ daystaff	Day and care staff (no distinction made)	Clinical staff (Drs, therapists, psychologists, etc.)	Other staff (mainly ancillary staff)
SRJ (SERVICE RÉSIDENTIEL POUR JEUNES) (Residential service for the young)	3394	29	335	1833	.	518	830
INTERNAAT (boarding school)	3854	.	315	.	2226	483	830
DIENST VOOR BESCHERMD WONEN (services for sheltered living)	302	.	25	.	257	20	.
NURSINGTEHUIS VOOR NIET-WERKENDEN (nursing home for the non-employed)	.	.	.	.	.	.	.
SRA (SERVICE RESIDENTIEL POUR ADULTES) (residential services for adults)	5919	91	454	3740	.	802	951
SRNA (SERVICE RESIDENTIEL DE NUIT POUR ADULTES) (residential night service for adults)	674	32	76	354	.	61	165
SRT (SERVICE RESIDENTIEL DE TRANSITION) (residential transition service)	.	.	.	.	.	.	.
TEHUIS VOOR WERKENDEN (GEZINSVERVANGENDE TEHUIZEN) (home for the employed/ family-replacing home)	611	.	100	.	356	3	16
BEZIGHEIDSTEHUIS VOOR NIET WERKENDEN (occupational home for the non-employed)	6940	.	25	.	5146	622	1147
TOTAL	**21694**	**152**	**1330**	**5927**	**7985**	**2509**	**3939**

Staff qualifications

Type of service	Total staff	Staff with only primary school qualification or less	Staff with secondary school qualification as highest qualification	Staff with higher qualification	Staff with university degree	Unspecified
SRJ (SERVICE RÉSIDENTIEL POUR JEUNES) (Residential service for the young)	3394	368	314	1451	286	975
INTERNAAT (boarding school)	3854	.	.	.	.	3854
DIENST VOOR BESCHERMD WONEN (services for sheltered living)	302	.	.	.	.	302
NURSINGTEHUIS VOOR NIET-WERKENDEN (nursing home for the non-employed)	.	.	.	.	.	
SRA (SERVICE RESIDENTIEL POUR ADULTES) (residential services for adults)	5919	366	3236	2085	267	-35
SRNA (SERVICE RESIDENTIEL DE NUIT POUR ADULTES) (residential night service for adults)	674	69	288	285	32	0
SRT (SERVICE RESIDENTIEL DE TRANSITION) (residential transition service)	.	.	.	.	.	
TEHUIS VOOR WERKENDEN (GEZINSVERVANGENDE TEHUIZEN) (home for the employed/ family-replacing home)	611	.	.	.	.	611
BEZIGHEIDSTEHUIS VOOR NIET WERKENDEN (occupational home for the non-employed)	6940	.	.	.	.	6940
TOTAL	**21694**	**803**	**3838**	**3821**	**585**	**12647**

Completeness and accuracy of the data

Data for Belgium were collected from two main sources. AWIPH (Service Études, Statistiques et Méthodes) provided the University of Leuven and EASPD with much of the data. The Vlaams Agentschap voor Personen met een handicap also provided some data and information for the country report. However data was available for Wallonia and Flanders only. It was not possible, despite many attempts, to obtain data for the Brussels region. The comments on completeness below refer only to the data that was available for Wallonia and Flanders. The service types listed do not include psychiatric hospitals and in general little information is available for any group other than those with intellectual disability.

Children services: Information about the typical age of services is not available.

Adult services: Except for SRA and SRNA information about the typical age for these services is absent. Information on the typical number of places is missing. For SRT, most information is absent. For "home for working", "activity-home for people without a job" and "nursing home for people not working", information about who provides the services is missing.

Older services: No information about older adults is present at all.

Size: These data are complete.

Disability type: For the centre for observation, orientation and medical, psychological and pedagogical treatment for the handicapped, the "tehuis voor kortverblijf", and for the SRT, no information is available about the type of disability groups served. In addition, there appears very little information relevant to those with mental health needs. Services listed generally provide for people with intellectual disabilities, with only 2000 places listed as being for those with mental health needs or physical disabilities. No data on older people with a pre-existing disability was available.

Age: For the Flemish part of the country, no age specific information is provided.

Gender: Data on gender is available for all services although in some service types is not complete.

Staff numbers: Information about staff numbers is available for all but one (SRT) service type and the breakdown by type of staff is complete. For most services it was not possible to distinguish between care staff and day care staff from the data available.

Staff training: Information about staff training is only available for SRJ, SRA and SRNA.

In terms of accuracy of the data in the template, there are few other sources of data for Belgium. The Included in Society project (2003), identified 107 institutions (services over 30 places) for people with disabilities in Belgium, for which data on number of residents was available for 22. These 22 institutions provided for 1711 residents,

serving a mixture of ages and disability groups. This study identified many more places in residential care than the earlier study. Another earlier study focusing on intellectual disabilities (European Intellectual Disability Research Network 2003) identified 9130 adults with intellectual disabilities in residential services funded/organised by the Flemish Fund alone. The current study identified 12,808 places for adults with intellectual disabilities in residential services across the two regions. Since there has been a growth in personal budgets over time then it seems that the figures gained at least for people with intellectual disabilities is likely to be relatively accurate.

Commentary: Belgium

1 Overview

As outlined below, the organisation and structure of Belgium as a country is very complex, with strong separation between regions and communities and this has implications for how social care is organised and managed across the country. Data on residential care was not readily available for Brussels, perhaps surprisingly since the Federal government is based in Brussels and has responsibility for social welfare.

2 Political and social context

2.1 Government organisation and structure

Belgium became a federal state after the revision of it's constitution in 1993. There are three levels of government:

- The Federal government which is based in Brussels (manages, among other things, the economy, social welfare, social security, scientific research, with some responsibilities in education and culture, and supervises the taxation by regional authorities).
- Three language communities – The Flemish Community, the French Community and the German Community (responsible for the promotion of language, culture and education mostly in schools, libraries and theatres).
- Three regions – the Flemish Region, the Walloon Region and the Brussels-Capital Region (manage mostly land and property based aspects such as housing and transportation.

The three regions do not relate precisely to the three language communities – The Flemish Region is entirely Flemish-speaking and is led by the government of Flanders. However, the Brussels-Capital region is included in both Flemish and French Communities. The Walloon Region contains the entire German Community but also has part of the French Community. The Flemish and Walloon regions are further subdivided into provinces, which are also administrative bodies.

2.2 Disability relevant policy

Policy on disability is set by each community government but is similar across all three communities. Policy in all three communities focuses on individual support, rehabilitation, prevention, accessibility measures and anti-discrimination. The rights of persons with disabilities are protected by legislation – in particular people with disabilities have the right to health and medical care, training, rehabilitation and counselling, financial security, employment, independent living and participation in decisions affecting themselves. General legislation applies to people with disabilities – with respect to education, employment, marriage, parenthood/family, voting, access to court of law, privacy, and property rights. There are also laws and regulations with regard to accessibility of public places, accessible transport, etc. (Government Action on Disability Policy A global survey Part II).

However, Belgium also has a policy of "extended minority" for those with severe and profound intellectual disabilities. The decision as to whether to grant extended minority is made by a court of law and on an individual basis. Someone who is

considered to need “extended minority” protection is then treated as a minor (under 15) and cannot vote, marry, start a family or manage his/her own affairs in any way (

3. Demographics

As of 2006, the Flemish Region has a population of about 6,078,600, Wallonia 3,413,978 and Brussels 1,018,804. Almost all of the population is urban (97.3% in 1999). 58% of the population is Flemish , 31% Wallonian and 11% mixed or other nationalities.

4. Health and Social Care System

When talking about disability issues in Belgium it is important to keep in mind the complexity of the different policy levels which all have different competences in this field. Four authorities are involved in the field of disability in Belgium. Some of the policy decisions on disability are taken on a national level (for example with regard to health care). For other decisions responsibility lies at the regional level (the Flemish and the Walloon authorities have the responsibility to improve inclusion of people with disabilities, for example) and also the government of the Brussels-capital region has some responsibility in some disability issues (for example with regard to employment). This means that different definitions are used in the different parts of the country to come to different ways of funding and/or support. It is therefore very difficult to give a good overview of the way the health and social care system is organised in Belgium.

4.1 Organisation

In Belgium, support of people with disabilities has long been organised as a charity. Only between the 2 World Wars, did people with a disability start to financial assistance.

After the Second World war, the legislation started to focus on helping people with disabilities to integrate professionally. 1963 saw the creation of the ‘**Fonds National de Reclassement Social des Handicapés’** (F.N.R.S.H.), also called “Fonds Maron”, the Fund’s first leader. Thanks to that Fund, many people have benefited from re-adaptation measures. Sheltered workshops and services for re-adaptation, orientation and training were accredited and subsidised.

Regarding housing, the most important developments were the creation of a Special Assistance Fund in 1956 and the creation of the “Fonds de soins médico-socio-pédagogiques” in 1967. These funds made the recognition and the subsidising of the medical-pedagogical services possible.

With the delegation of certain responsibilities to the Communities, including the disability policies, the issues tackled by the FNRSH were taken over by new bodies such as “le Fonds Communautaire pour l'Intégration Sociale des Personnes Handicapées”. This body was active between 1991 and 1995. In 1994 the Regions became responsible of the integration of people with a disability.

Flanders

In Flanders the “Vlaams Agentschap voor personen met een handicap (VAPH)” (the Flemish Agency for Disabled Persons) is the most important body. The VAPH aims

to promote participation, integration and equal opportunities for the disabled in all areas of social life. The ultimate goal is to help these people lead a better and more independent life. The VAPH does this by subsidising facilities and services for people with disabilities:

Equipment and modifications
To better organise his or her aily life a disabled person is entitled to a benefit to cover the cost of a piece of equipment or modification to his or her home or car.

Services and facilities
The VAPH subsidises services and facilities which provide care for disabled persons through day care or guidance.

Personal assistance budget
Disabled persons who prefer to live at home can apply for a personal assistance budget. This budget can enable them to employ a home-helper.

Work and training
A disabled person who would like to follow a training course or is seeking work can also be supported by the VAPH. However, it is the Flemish Department of Employment (VDAB) which handles the details of each individual case.

Wallonia

In Wallonia, "L'**A**gence **W**allonne pour l'**I**ntégration des **P**ersonnes **H**andicapées (AWIPH)" was created by the regulative decree of the "Conseil Régional wallon" of 6 April 1995. The organization must work out the Walloon policy concerning inclusion of people with disabilities. AWIPH proposes support in employment and training and financial interventions in the acquisition or equipment of specific material that improves the daily autonomy. L'AWIPH approves and subsidizes services (throughout the Walloon Region) that receive, house, employ, train, advise and accommodate people with a disability.

4.2 Financing

In 2005, 65,863 persons with a disability received some support from the VLAAMS AGENTSCHAP (Flemish agency). 8,227 persons received an admission to or treatment from an institution (i.e. not in the home and not in mainstream services; 7.809 received financial assistance for employment. 49,827 people received funding for one or more other areas of assistance (equipment, adaptations etc); The total budget for this was almost €1129 million. (from '2005, Jaarverslag Vlaams Fonds voor sociale integratie van personen met een handicap')

5. Definition, eligibility and diagnosis/assessment

As stated above it is impossible to give one overview of the Belgian situation. In the section below the definition used by the Flemish authorities and the Walloon authorities is presented.

Flanders

The VAPH is dedicated supporting people with a disability. The VAPH uses the following definition of disability:

> " any long-term and significant participation problem experienced by a person and attributable to a combination of functional disorders of a mental, psychic, physical or sensory nature, limitations in the performance of activities, and personal and external factors".

This definition allows for an individual approach to every person who calls on the services of the VAPH. However, there are several other conditions governing access to the services offered by the VAP: 1) the person must be request recognition of his or her disability before reaching the age of 65. 2) the person must be listed on the population register or immigration register and have lived in Belgium for five years prior to registration (or 10 years in the course of his or her life).

Wallonia

In order to benefit from the AWIPH, people must have Belgian citizenship (or be legally married or otherwise related to a Belgian citizen), must live in the Walloon region, should be younger than 65 at the date of registration and must have a significant disability, defined as limitations in their capacity for social and professional integration caused by an alteration of their intellectual, sensorial or physical capabilities. The actual criteria are as follows:

For requests for help in the field of training, employment and material support, the agency must be able to confirm, on the basis of particular documents, an intellectual impairment of at least 20% or a physical impairment of at least 30%. For requests concerning support for day-to-day life, the person should fall into 1 of the 156 categories that the law foresees for this kind of support and medical evidence of the disability is required.

Procedure for diagnosis and assessment

When applying for support a person with a disability fills out a registration form to be recognized by the regional authority and is screened by a multi-professional team which advises a certain type of support, adapted to the person's need.

6. Prevalence of disability

Belgium does not have any global statistics concerning the number of people with a disability as it is not obligatory to declare a disability or to ask for recognition as a person with a disability. The notion of "disability" is not recognized in the same way by the different authorities, dealing with disability-related issues. It is also important to note that available statistics, including those used in the template, come from organisations within the care system – there is no overarching or independent source of statistics on people with disabilities in Belgium. People can dip in and out of services (e.g. be registered as children for special education but then leave the system at 18 only to return as a new client later in adulthood (European Intellectual Disability Research Network 2003).

The best estimation of the number of people with disabilities comes through the applications for support for assistance. In the Flemish region 65,863 people applied for support in 2005 (49,827 were successful in their application).

In Wallonia, data on the number of people receiving assistance is older. In the annual statistics of 'bénéficiaires d'allocations aux handicapés' (over 21 years of age) from the Ministry of Social Affairs, (Disability Administration) it is noted that there were 204,135 beneficiaries of support on 31 December 1998 (allocation de remplacement de revenus, allocation d'intégration ou allocation pour l'aide aux personnes âgées).
From the data available from AWIPH, in 1998 there were 13,202 requests for support.

7. Residential Services for people with a disability

7.1 Overview

In 2000 a personal assistance budget was introduced in the Flemish Region of Belgium. This allowed people to receive cash payments with which to employ a personal assistance to support them in their own home. It was only available for people with disabilities, registered as disabled before the age of 65 and living in the Flemish Region. In 2001 316 personal assistance budgets were allocated (of varying cost from Euro7436 to Euro34,704). It was known that 118 (37%) of these went to people with intellectual disabilities (European Intellectual Disability Research Network 2003). Although this number has increased over the years, the majority of people who cannot or do not want to live in the family home, live in residential care. Services for people with disabilities usually take one of 4 forms in Belgium (European Intellectual Disability Research Network 2003):

- Services in the Community – these are services which are offered in the community to ensure that families and persons with disabilities can participate in the community and have a good quality of life, for example family support services, mental health centres and supported living services where support is funded to help people stay in their own home but this is usually limited in their extent – it takes the form of an outreach service rather than a fully staffed service.
- Semi-residential services – These are services where people get support during the day time or in the case of schools, during the week, but then live with their families in the evenings and/or at weekends. For adults these are day care programmes.
- Residential services – these vary from boarding schools usually linked with special schools through group homes in the community to large residential facilities for adults. These services are presented in more detail below.
- Foster care – usually for children, where a foster family is identified for a child usually on a short-term or fixed-term basis.

The information presented below on types of residential services available for people with disabilities is based largely on the information on the situation for people with intellectual disabilities presented in the European IDRESNET working papers. Information on other user groups was not readily available although it is known that similar services are available for those with physical and sensory disabilities. Little published information is available and the template completed for this study did not identify many places for those with mental health problems.

7.2 Services for children with a disability

There are two main types of residential services for children with a disability – boarding schools and the Service Résidentiel pour Jeunes (SRJ).

The special school system in Belgium is highly segregated. For example in 1970 the Flemish Region legislation on special education created 8 different types of school at primary school level.

- Type 1: Children who have mild intellectual disability
- Type 2: Children who have moderate to severe intellectual disability
- Type 3: Children with emotional and behavioural difficulties
- Type 4: Children with physical disabilities
- Type 5: Children with chronic diseases
- Type 6: Children with visual impairments
- Type 7: Children with hearing impairments
- Type 8: Children with specific learning difficulties (dyslexia, ADHD etc).

At secondary school level, there are also different levels of schooling available to those with disabilities.

- Level 1 Prepares students to live in a sheltered environment and to follow day care activities
- Level 2 Prepares students to work in a sheltered workshop
- Level 3 prepares students to live independently in the community and to work on the regular labour market
- Level 4 organises the same programme as mainstream secondary schools but with special facilities for those with disabilities.

The number of children attending special schools has increased over time but at the same time integrated nursery and primary education has started to emerge but only for some groups. In 2003 (European Intellectual Disability Research Network 2003) Type 2 students could only receive education in a mainstream nursery but then had to return to special schools for primary education. In 2000 only 1555 children were integrated integrated into mainstream education across all 8 primary school types.

The majority of children live at home and attend these special schools during the day. Chidren in Belgium usually leave school at 18 years of age but those with special needs can get permission to stay in special schools until the age of 21. For those who cannot live with their families there are boarding schools and these are generally linked to the special school types described above.

For children with mental health problems and also a smaller number of children with Intellectual disability and some with physical and/or sensory disabilities, there are also residential services – the Services Résidentiels pour Jeunes (SRJ) - which provide 24 hour support for children and young people up to the age of 25 years in accommodation housing usually between 50 and 100 children.

7.3 Services for adults with a disability

The main source for this information was the IDRESNET working paper on Belgium (European Intellectual Disability Research Network 2003). Although this focuses on ID and on the Flemish Speaking part of Belgium, there was overlap between the description of services and the service types described in the template above.

- Adults who work generally live in residential services such as “Tehuis voor werkenden (gezinsvervangende tehuizen)” – homes for the employed or

sometimes called a family-replacing home. These services only provide support at night time and weekends.

- Most other residential services listed in the template provide 24 hour support although in "dienst voor beschermd wonen" (services for sheltered living) the level of support is mixed depending on level of need. In these services get both accommodation and day time activity, e.g. "Bezigheidstehuis voor niet werkenden" (occupational home for the non-employed).
- For people with very intense needs, in particular those with medical needs in addition to support needs, there are nursing homes, e.g. Nursingtehuis voor niet-werkenden (nursing home for the non-employed). These are typically very big services – typically between 100 and 200 places.

Almost all the services for adults listed in the service descriptions in the template, were identified as for people with intellectual disabilities, apart from two of the services from the French Speaking community - the "Service Résidentiel pour Adultes" (residential services for adults) and "Service Résidentiel de Nuit pour Adultes" (residential night service for adults) – both of which did provide for other disability groups but not in mixed settings.

There are also psychiatric hospitals for those with mental health problems but little information was available on these services and how many long-term places was not available. It is known that most people with mental illness were treated in legally closed wards until about 1970, with poor staff ratios and little attention from medical staff (Parent, 1978). From 1970 onwards the role of hospitals has been changed to be more therapeutic in nature and most people with mental health problems are supported within the community. However, large psychiatric institutions still do exist with Belgium such as those in Liege for example. The Included in Society project found that 6 of the 22 institutions for which data was available catered solely for people with mental health problems, with a further 6 catering for people with dual diagnoses of mental health and intellectual disabilities. However, very little is known about these services in general.

8. Staffing

Information on staffing has been provided in the template and is summarised at the beginning of this country report. Data is available on Wallonia and Flanders but not Brussels but only for some service types. In general, the majority of services are staffed by a mixture of care staff and day staff/educators but with substantial numbers of staff in ancillary roles – cleaners, cooks, maintenance roles etc. This is a reflection of the size of the services, which in general are over 30 places. In terms of staff training, 49% of direct care staff/day staff had higher education or degree level qualifications.

9. Issues

As discussed above, the main issue for Belgium in terms of disability policy and provision is the regionalisation of the country, which is itself not a simple regionalisation but complicated by the existence of Language Communities.

There is in general a lack of residential placements for people with intellectual disabilities in particular which is not compensated for by the availability of personal assistance budgets, with most types of services having a waiting list ((European

Intellectual Disability Research Network 2003). The Inclusion Europe report on Justice Rights and Inclusion for People with Intellectual Disability identifies another issue with regard to the regionalisation of Belgium – the lack of national co-ordination of service provision means that services for people with disabilities are not representatively distributed between the regions or communities and quality of services is not necessarily the same across the regions – this reduces the choice people in choosing a suitable place to live.

10. Acknowledgements

Mr. Andre Gubbels, AWIPH

11. Information sources on disability used to compile the template and commentary, including people who were interviewed

AWIPH (Service Études, Statistiques et Méthodes)

Vlaams Agentschap voor Personen met een handicap

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Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

Bulgaria

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Summary of available data

Description of service types.

Type of service	Size Interval (places)	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions	Age of service
Psychiatric wards in hospitals	.	.	.	.	.	.	.	.
Group homes	6 to 10	20-30	ID only	24 hour	Mixed	State	.	0 to 20 years
Homes for adults with sensory disabilities	31 to 50	Over 18/25 (i.e. adults only)	Sensory impairments	24 hour	State	Regional authority/LA/County and state	All long term	21 to 50 years
Homes for children and adolescents with mental retardation	51 to 99	3-18/19	ID only	24 hour	State	Regional authority/LA/County and state	All long term	.
Homes for adults with mental retardation	51 to 99	Over 18/25 (i.e. adults only)	ID only	24 hour	State	Regional authority/LA/County and state	All long term	21 to 50 years
Social vocational boarding schools	51 to 99	14 + to adulthood (60/65)	More than one disability group served (no main group) but not mixed	24 hour	State and Local Authority/municipality	State	All long term	0 to 20 years
Homes for adults with physical disabilities	51 to 99	Over 18/25 (i.e. adults only)	PD	24 hour	State	Regional authority/LA/County and state	All long term	21 to 50 years
36 week residential	51 to 99	6-18 or	ID only	24 hour	State	State	All long term	21 to 50 years

schools for children with sensory disabilities and intellectual disabilities		19						
Homes for adults with dementia	51 to 99	over 60/65	Elderly infirm/mentally ill/dementia	24 hour	State	State	All long term	.
Homes for children and adolescents with physical disabilities	100 to 150	3 into adulthood (60/65)	PD	24 hour	State	Regional authority/LA/County and state	All long term	.
Homes for adults with psychic disorders	100 to 150	Over 18/25 (i.e. adults only)	MH	24 hour	State	State	All long term	21 to 50 years
Psychiatric hospitals	100 to 150	Over 18/25 (i.e. adults only)	MH	24 hour	State	.	Mixed	.
Social-vocational training institutions	151 to 200	14 + to adulthood (60/65)	ID only	24 hour	State	State	All long term	.
Wards in homes for medical-social care for children	201 +	0-5	PD	24 hour	State	State	Mixed	.

Data available by service type – size of service and disability groups.

Type of institution	Places total	Under 30 places	Over 30 places	Size unspecified	ID	MH	PSD	Elderly/ dementia	Mixed/ dual	Other/ unspecified
Homes for children and adolescents with mental retardation	1766	24	1742	0	1766	.	.	.	.	0
36 week residential schools for children with sensory disabilities and intellectual disabilities	2856	.	2856	0	2856	.	.	.	.	0
Homes for children and adolescents with physical disabilities	130	.	130	0	.	.	130	.	.	0
Social-vocational training institutions	1347	.	1247	100	1347	.	.	.	.	0
Wards in homes for medical-social care for children	1213	.	.	.	.	.	.	.	.	.
Group homes	120	120	.	0	.	.	.	.	.	.
Social vocational boarding schools	.	.	.	.	.	.	.	.	.	.
Psychiatric wards in hospitals	.	.	.	.	.	.	.	.	.	.
Homes for adults with sensory disabilities	148	30	118	0	.	.	148	.	.	0
Homes for adults with mental retardation	2513	30	2483	0	2513	.	.	.	.	0
Homes for adults with physical disabilities	1800	12	1588	200	.	.	1800	.	.	0
Homes for adults with dementia	869	.	869	0	.	.	.	869	.	.
Homes for adults with psychic disorders	1376	.	1376	0	.	1376	.	.	.	0
Psychiatric hospitals	.	.	.	.	.	.	.	.	.	.
Totals	14138	216	12409	300	8482	1376	2078	869		0

Data available by service type – breakdown by gender and age.

Type of institution	Places total	Male	Female	Gender unspecified	Children	Younger adults	Older adults	Adults over 18	Age unspecified
Homes for children and adolescents with mental retardation	1766	920	693	153	1766	.	.	.	0
36 week residential schools for children with sensory disabilities and intellectual disabilities	2856	.	.	.	2856	.	.	.	0
Homes for children and adolescents with physical disabilities	130	43	29	58	130	.	.	.	0
Social-vocational training institutions	1347	541	267	539	.	1347	.	.	0
Wards in homes for medical-social care for children	1213	.	.	.	.	.	.	.	1213
Group homes	120	.	.	.	.	.	.	.	120
Social vocational boarding schools	.	.	.	.	.	.	.	.	.
Psychiatric wards in hospitals	.	.	.	.	.	.	.	.	.
Homes for adults with sensory disabilities	148	47	85	16	.	.	.	148	0
Homes for adults with mental retardation	2513	1220	1200	93	.	.	.	2513	0
Homes for adults with physical disabilities	1800	760	724	316	.	.	.	1600	200
Homes for adults with dementia	869	352	386	738	.	.	.	869	0
Homes for adults with psychic disorders	1376	549	799	28	.	.	.	1376	0
Psychiatric hospitals	.	.	.	.	.	.	.	.	.
Totals	14138	4432	4183	465	4752	1347		6506	1533

Staffing data

There is no information available on staffing levels/type etc.

Completeness and accuracy of the data

Statistical information on residential institutions for people with disabilities available on the National Statistics Institute's (NSI) website includes the following tables: "Homes for Medico-Social Care for Children for the Period 2000-2005"; "Health Establishments as of 31.12 for the 2001-2005 Period"; "Specialized Establishments for Social Services in 2005." All tables were published on 30.05.2006. These tables are the source of some of the data included in the template. Data tables from NSI include statistics for the following under the category "Social Services provided outside of the community":

- Homes for the elderly
- Homes for physically disabled adults
- Homes for persons with sensory disabilities
- Homes for mentally retarded children or youth
- Homes for mentally retarded adults
- Homes for physically retarded children or youth
- Homes for temporary accommodation
- Social-educational professional establishments

(Source: NSI. "Specialised Establishments for Social Services in 2005." Published 30.05.2006.)

Requests for additional statistics to those obtained from NSI were met with some confusion. It was explained to me that Bulgaria has not been in the habit of collecting statistical data for the types of questions we were asking. However, the Agency for Social Assistance under the Ministry of Labour and Social Policy was able to provide a list of residential institutions that included capacity, numbers of males accommodated, numbers of females accommodated, and amount provided by state per year per person for each facility. These numbers were used to fill-in the template.

It was not possible to acquire information about specific ethnic groups, e.g., Roma. I was told that data was not gathered according to ethnicity as this would be considered discriminatory. It was also difficult to obtain information about specific disability groups. According to the EUMAP report on Bulgaria, *Access to Education and Employment for People with Intellectual Disability* (2005): "As Bulgaria lacks a unified definition of intellectual disability that is used consistently in law and policy, basic information regarding people with intellectual disabilities is somewhat unreliable" (p. 2). The report adds that "the disproportionately high number of Roma diagnosed with intellectual disabilities is a clear trend indicating that diagnosis procedures should be reformed" (p. 2). According to this report, "Around 8.000 people (presumably with ID) remain in institutions, including residential schools" (p. 2).

Commentary: Bulgaria

1. Overview

Bulgaria shares borders with Serbia, Macedonia, Romania, Greece, and Turkey. Bulgaria is a parliamentary republic still in process of transition to a market economy after 45 years of socialist economy. Facing a dual challenge of transition and EU accession since the onset of reforms in 1989, the Bulgarian society underwent profound political, economic and social changes. Bulgaria is one of the most recent (2007) members of the EU.

2. Political and social context

Bulgaria has a wide network of social welfare institutions that were set up under the Soviet model to provide residential care for people whose needs could not be adequately addressed in a family/home environment. As in the other former Soviet bloc states, the ideology of defectology dictated that individuals with defects—disabilities—would be better cared for in large state-run institutions. This ideology, in effect for forty years, began to be questioned with the fall of communism. However, pressure to place both children and adults with disabilities in institutions continues to come from the general population, a large proportion of which are poor. Traditional, prejudiced attitudes regarding mental and physical disabilities continue to perpetuate social stigma against people with mental disabilities and their families. Traditionally, there has been very little community support for families caring for members with mental disabilities.

Along with the other Soviet bloc countries, Bulgaria has received international attention for the conditions discovered in these institutions in the late 90s and early 2000s. Apparently, the state budget for these institutions was so inadequate the food provision could only be kept at a minimum level. When Amnesty International representatives interviewed social care home administrators in October 2001 and January 2002, most directors complained that state-allocated resources were inadequate for even basic maintenance of facilities. Given that their primary aim was to provide for elemental needs such as food, heating and clothing, few had the time to devote to concerns such as training staff and appropriate rehabilitation.

In October 2006, the Mental Disability Advocacy Centre (MDAC) and the Bulgarian Helsinki committee (BHC) sent a case to the European Court of Human Rights, representing a man who was detained in a Bulgarian psychiatric hospital and drugged against his will and despite psychiatrists' recommendations of outpatient treatment. According to the Executive Director of MDAC, Oliver Lewis: "Bulgaria and Romania are due to join the European Union in 2007, yet many children and adults with disabilities still spend their entire lives in institutions" (Press Release, 4 October 2006).

2.1 Government organisation and structure

Bulgaria is a parliamentary democracy. President**:** Georgi Purvanov (2002); Prime Minister**:** Sergei Stanishev (2005)

2.2 Disability relevant policy

A Law for the Integration of People with Disabilities was adopted in September 2004 and went into force 1 January 2005. It provided for creation of additional bodies to specifically address issues relating to people with disabilities (including education), and for improved data collection. This law initiated for the first time social assessment of the needs of disabled people. After the law came into force, a new National Council for Integration of People with Disabilities was created, consisting of 16 NGOs.

In August-September 2005 the Inspectorate of the Executive Director of the Social Assistance Agency carried out the Second National Monitoring in 27 homes for adults with intellectual retardation and 15 homes for adults with psychic disorders. On the basis of this monitoring a Plan for the Improvement of the Situation of People with Mental Disabilities Accommodated in Specialized Institutions 2006-2008 was elaborated and adopted in December 2005. According to a 2006 report approved by Emilia Maslarova, Minister of Labour and Social Policy, "The activities and measures in the Plan are directed to the carrying out of Third National Monitoring of the situation of disabled people, accommodated in specialized institutions; closure of specialized institutions which do not correspond to the standards and criteria for situation and necessary equipment, by replacement into new buildings; decrease of the capacity of the specialized institutions; entrustment to the non-governmental organizations of the management of the specialized institutions; elaboration and ratification of regional and municipal strategies for social services" ("Report on the Implementation of the Joint Memorandum on Social Inclusion of the Republic of Bulgaria," May 30, 2006, p. 29).

In January 2006, the Ministry of Health and the Minister of Labour and Social Policy signed a Framework Agreement for Coordination Among the Institutions Engaged in the Improvement of the Situation of People with Mental Disabilities, Accommodated in Specialized Institutions. In April 2006 the Government adopted the Concept for Deinstitutionalization of Specialized Institutions for Children and Social Institutions for Adults with Disabilities ("Report," May 30 2006).

3. Demographics

The population of Bulgaria is over 7 million. Sofia is the largest city with population of just over one million. About 84% of the population is Bulgarian; 9% Turk; 5% Roma; 2% other.

4. Health and Social Care System

4.1 Organisation

Until 1990 health care was an entirely public system based on the principles of full coverage and accessibility. Effective health-care reforms began only in 2000, bringing about wide ranging changes in how health care is funded, organized and delivered and establishing a new type of relationship in the chain user-provider-payer. The most active part of the health sector reform was carried out after mid-1997. Three major reform strands can be distinguished: reform of health-care financing, reorganization of primary care and rationalization of the network of inpatient and outpatient facilities (Sectoral Activities Programme, 2005). The national health system consists of: health establishments for hospital care; health facilities for outpatient care; other healthcare and health establishments.

The Ministry of Health provides oversight of homes for medical-social care for children (HMSCC) age 0-3. These homes are founded by the state and are under direct guidance of the Ministry of Health. They are funded totally by the state budget through the Ministry of Health (MH). Approximately 30% of children in these homes have some type of disability. Psychiatric hospitals are also under the Ministry of Health.

The Ministry of Labour and Social Policy (MLSP), Agency for Social Assistance, provides oversight of institutions for individuals with disabilities beyond age three.

The Ministry of Education and Science (MES) has oversight of social educational boarding schools (SBS) and correctional boarding schools (CBS).

In May 2006, a specialized unit at the Inspectorate at the Social Assistance Agency was set up to supervise and monitor institutions for elderly people and children. The rules for implementation of the Law on Social Assistance were amended to enhance the development of alternative services for children.

4.2 Financing

The Ministry of Health provides financing for residential institutions it oversees and the Ministry of Labour and Social Policy provides financing for its social care institutions.

5. Definition, eligibility and diagnosis/assessment

All specialized institutions for intellectually and physically disabled children and juveniles are decentralized municipal institutions. Placement in these institutions is conducted by virtue of a court decision or administrative order of the director of the Social Assistance Directorate on temporary placement. Institutionalization is determined by the provisions of the Child Protection Act as a last resort after exhausting all possibilities for child protection without isolating the child from their biological family. However, according to a 2002 BHC Report, *The Homes for Children with Special Needs*, the majority of children in the institutions for children with intellectual disabilities have moderate to profound ID and have been abandoned by their parents on the basis of their disability. Until August 2002, the law provided that children with moderate, severe or profound intellectual disabilities living in institutions were regarded as "uneducable."

6. Prevalence of disability

The number of disabled people continues to grow. Its portion among persons aged 16 and over reached 17.6 per thousand in 2003 at 12.1 per thousand in 2001. This is two times higher than in the other EU-member countries. The number of mental cases is also rising reaching 4174.4 per 100 000 (Daskalova et al., 2005).

Statistical data is available on the number of people with intellectual disabilities in each district (and their level of disability); however, this data does not include all people with intellectual disabilities and the lack of standardized diagnosis procedures casts some doubt on its reliability. This data is not disaggregated by age, sex, or ethnic

origin. A disproportionately high number of Roma are diagnosed with ID (OSI/EU Monitoring and Advocacy Program, 2005).

6.1 Issues of definition

Bulgaria lacks a unified definition of intellectual disability that is used consistently in law and policy. Definitions from ICD-9 are used in much of the medical legislation, but legislation in other areas uses various terminologies. The four different bodies which assess disability for various purposes use different terminology, which is not used consistently or in line with recognized standards.

6.2 Numbers/rates available

Statistical information on residential institutions for people with disabilities available on the NSI (National Statistics Institute) website included the following tables: "Homes for Medico-Social Care for Children for the Period 2000-2005"; "Health Establishments as of 31.12 for the 2001-2005 Period"; "Specialized Establishments for Social Services in 2005." All tables were published on 30.05.2006. The Methodological Notes that accompany statistical tables available from NSI advise: "When using data about health establishments one should have in mind that the number of health establishments and the number of beds are changed not only as a result of the opening and closing of establishments, but also because of reorganization, connected with transformation and unification of establishments."

Statistical information is collected by The National Centre for Health Information (NCHI) for the Ministry of Health.

Ianna Dimitrova, Senior Expert at the Agency for Social Assistance, Ministry of Labour and Social Policy, was able to provide a list of institutions that included size of facility, gender breakdown, and amount of state-provided funding per person per year. This provided more detail than the (limited) aggregate data from the NSI. I used this data for the template (for individuals over age three). Data on children with disabilities age 0-3 was requested from Dr. Elena Perchiiska, Ministry of Health, but was not provided.

7. Residential Services for people with a disability

7.1 Overview

Residential services for people with disabilities are provided under both the Ministry of Health (MH) and the Ministry of Labour and Social Policy (MLSP). The Ministry of Health provides services for children 0-3 in Homes for Medical and Social Care for Children (MHSCC), and oversees specialized hospitals (including psychiatric). Residential services for other disabled populations are under the MLSP and include:

- Homes for the elderly
- Homes for physically disabled adults
- Homes for persons with sensory disabilities
- Homes for mentally retarded children or youth
- Homes for mentally retarded adults
- Homes for physically retarded children or youth

- Homes for temporary accommodation
- Social-educational professional establishments

7.2 Services for children with a disability

Children age 0-3 with disabilities are accommodated in homes for social and medical care for children (HMSCC) run by the Ministry of Health. HMSCC are medical treatment facilities under the provisions of the Medical Treatment Facilities Act and perform primarily diagnostic and treatment functions (although these may have been reclassified to be considered as facilities providing social services). In terms of the regulatory framework for placement of children in HMSCC the general provisions of the Child Protection Act are usually applied. Although intended for children 0-3, children can stay at latest up to their 7th anniversary in case there is an open adoption procedure or when the child has mild or severe physical disabilities.

According to a report prepared by the Director Directorate "Medical Activities," submitted to Dr. Svetlana Spassova of the Ministry of Health, as of 01/01/2006 the total number of these facilities was 32, with a total of 4044 beds. More than 30% of children in these homes have some type of disability. Children with milder disorders are integrated into the healthy population of the home. Children with severe disorders and malformations, requiring continuous support care, are brought up in special sectors of HMSCC. Although the spectrum of diseases is wide, the most common are neurological disorders—cerebral palsy syndrome, hydrocephalus and some severe chromosomal diseases. In these facilities, HMSCC are funded totally by the state budget through the Ministry of Health (Ministry of Health, 2006).

Children with intellectual disabilities are usually admitted to homes for mentally retarded children and juveniles at age three. In the majority of cases, they are transferred from a Mother and Child home. The diagnosis "mentally retarded" is made early and is clarified; that is, the level of mental retardation is determined as mild, moderate, severe, or profound.

As of 30 September 2006 there were 27 specialized institutions for disabled children and juveniles operable in Bulgaria which accommodated 1,703 individuals. One institution is a home for children and juveniles with physical disabilities and intact intellect (56 children (below age 18), 13 juveniles); the other 26 are homes for mentally retarded children and juveniles accommodating 1,169 children and 465 juveniles. (Note: the terminology used by the National Statistics Institute and the Agency for Social Assistance differs, with the NSI using the term "mentally retarded" children or youth.) The majority (1104) were housed in facilities that accommodate 50-100 residents. In the majority of the children's institutions the practice of keeping individuals above age 18 is common, due to staff's efforts to preserve the capacity of the homes and fears of the worse environment in homes for adults.

The majority of children in these homes have been diagnosed as mentally retarded—mild, moderate or severe—and with accompanying diseases (chronic somatic diseases, mental and neurological diseases, inborn malformations, hypotrophy, and premature birth). In many of these homes the children have mixed pathology of intellectual and physical disabilities. Sometimes there are mildly retarded children and even children with intact intellect (BHC, 2006).

Institutions with status of homes for juveniles admit young people age 18-35, although there are some homes with children age 3-10.

There is only one facility for children from 3 to 25 years with "physical disability and saved intellect," with capacity of 130, accommodating 72 individuals.

Youth with disabilities are also accommodated in specialized institutions that provide social-vocational training. There were nine of these in 2006, with capacity of 1347, accommodating 808 individuals with mild mental disability. These are residential institutions for individuals with ID who wish to continue their education after completing classes available at special schools. These are the only institutions in Bulgaria that provide educational services outside the framework of the national educational system. They were established in 1991 as legal entities under MLSP subordinated to local municipal social welfare assistance services. These institutions were established to qualify all categories of people with disabilities, including people with mild intellectual disabilities and impaired hearing from the ages of 14 to 35 in suitable professions. Funding comes from the national budget and the budgets of the municipal councils (Open Society Institute, 2005).

7.2.1 Transformation

Three homes for children with disabilities were closed down between 2003 and 2006 and capacity of two institutions was decreased by 20-30 places.

A project on monitoring specialized institutions for children implemented by the Bulgarian Helsinki Committee started at the end of 2005 and focused primarily on updating data on the conditions in 89 children's specialized institutions and on evaluation of the processes of transformation of the institutional care system. According to the BHC Report (2006), homes for children and especially the institutions for intellectually retarded children have not been turned into a major engine of the reform of institutional care, at least partly due to the interest of staff in preserving, and even increasing the number of inmates because salaries still depend on the number of institutionalized children. The report cites the major problem as duration of stay. Their data show that 81% of individuals in 19 of the 20 institutions they visited had been there for more than 3 years (BHC, 2006).

The BHC Report continues:

> Institutionalization away from the public's eye remains the basic form of care for severely disabled children neglected by their parents. 17 out of 20 HMRCJ and HMRJ visited are still located in small villages in economically depressed regions. The practice of institutionalization in HMRCJ based on social indicators has not been interrupted (BHC, 2006, p. 10).

In January 2006 the analysis of the implementation of the *Plan for Decreasing the Number of Children Brought up in Specialized Institutions in the Republic of Bulgaria 2003-2005* indicated that the number of children accommodated in specialized institutions decreased by 18.3%, or 2,176 children. The decrease is attributed to the application of the Law of Child Protection. In April 2006 amendments to the Law were adopted which introduced the status of the "professional foster family (Report, 2006).

Also in January 2006, a *Framework Agreement on Ensuring the Coordination between the Institutions Involved in the Improvement of the Living Conditions for Mentally Retarded People Placed in the Specialized Institutions* was signed by the Ministry of Health and the MLSP. In April 2006 the *Concept on the Deinstitutionalization of the Specialized Institutions for Children and Social Institutions for Elderly Disabled People* was adopted, and in May 2006 a *Mechanism for Closing, Reforming or Restructuring the Specialized Institutions for Children* was signed between the MLSP, MES, MH, the State Agency for Child Protection and the Social Assistance Agency. This document identifies the criteria which will be used for evaluation of specialized institutions; criteria are related to location and accessibility of the institutions, the facilities and the quality of care.

7.2.2 Alternatives to institutions for children with disabilities

The infrastructure for community-based alternatives to institutionalization is beginning to be built, but is in early stages. In 2006 there were 33 day-care centres for mentally retarded children and juveniles. BHC monitoring in 7 centres led to the following conclusions:

> The day-care centres for retarded children are the best functioning and developed alternative form of child care for retarded children so far. On the one hand, this is a form of integration of the children with special needs in the society, and, on the other hand, it is an opportunity for a social inclusion of their parents (BHC Assessment Report, Nov. 2006, p. 82).

In 2006 four day-care centres for disabled children from HMSCC were opened, however according to a Civil Report prepared by a network of NGOs they were not functioning due to a shortage of funds from MH.

The most comprehensive government project for encouragement of the development of community-based social services is the project that was implemented by MLSP between May 2001 and 30 June 2006 called "Reform for enhancing the well-being of children in the Republic of Bulgaria." The project's goal is (was) to assist the transitional period from the system of child protection, carried out mainly through institutional care, to community-based services meeting the needs of individual communities. Financial resources for the project included a loan from the World Bank of 8,800,000 Euros and donations from the Japanese Social Development Fund (1,050,000 USD, 543,000 USD), the Swiss Agency for Development and Cooperation (78,600 Euro), Department for International Development, UK (9,870 GBP), International Labour Organization (BGN 7,542), Bulgarian government (BGN 12,857,623) (BHC, 2006).

The activities related to development of alternative forms of social services are carried out on a local level in 10 pilot municipalities and are aimed at all children at risk of institutionalization—children from disadvantaged families, children who are victims of violence, children with deviant behaviour, children with special needs. The BHC *Assessment Report* (November 2006) concludes that a common disadvantage of the functional development so far of all of the complex for social services for children and families (CSSCF) activities is the fact that "the HMRCJ inmates for now stay outside the scope of the focus of the experts from CSSCF. There are occasional

instances of assistance… but there is no system built for provision of assistance on the part of CSSF for the specialized homes for mentally retarded children located in the region" (pp. 86-87).

The BHC *Assessment Report* on the conditions and perspectives of institutions for children in Bulgaria (November 2006) concludes:

> The 2006 BHC monitoring has shown that despite the will for social reintegration of the institutionalized children and juveniles expressed in all documents, including the draft report of the Bulgarian government on the UN Convention on the Rights of the Child, the "machine for social exclusion" is still working. The institutionalization of mentally retarded children in Bulgaria continues. The main problem … remains the duration of the stay. … Despite the legislative changes and the identified measures for deinstitutionalization the HMRCJ [homes for mentally retarded children and juveniles] entrance remains open, while the exit usually does not lead to the community, but to the next institution for adults. The HMRCJ inmates usually remain a group of outsiders without any perspectives for social and educational integration (p. 91).

7.3 Services for younger adults with a disability

MLSP data show 29 homes for adults with intellectual disability (homes for developmentally disabled adults) with a capacity of 2513, housing 2420 adults. There are 15 facilities for adults with psychic disorders (capacity 1376; residents 1348). According to the BHC Report (2006), in many of the homes the categories of residents are mixed. The Report describes these facilities as "institutions for placement of people who as a result of mental illness or a developmental disability are unable to take care of themselves alone; who do not receive any support from their relatives or do not have any relatives, since they have been abandoned by them from early childhood and are thus left to the care of society" (p. 6). Most of the homes for developmentally disabled adults and mentally ill adults are single-sex.

According to the BHC *Human Rights* Report (2006), 52% of residents are in facilities housing 50-100 people; 42% are in facilities housing over 100 people, and only 5.8% are in homes for fewer than 50 people (primarily homes for adults with dementia). None of the facilities for adults with mental illness had a capacity or population of fewer than 50 people. About 70% of facilities are located outside of populated areas. Of concern to the BHC was the fact that developmentally disabled individuals and individuals with mental illnesses reside together in many of the homes, which has led to the death of some residents.

The majority of residents of homes for adults with developmental disabilities have been transferred from homes for children and youths with developmental disabilities or from special schools and Social Vocational Training Schools. The diagnosis of these individuals is usually "moderate or severe and profound mental retardation."

These homes have received much negative international publicity, particularly as a result of the 2002 Amnesty International report, *Bulgaria—Far from the eyes of society*. This report and others made known inadequate material conditions as well as lack of adequate medical care and activities. Most of the social care homes are in buildings constructed for a variety of other purposes between 1930 through the 1960s, from a gunpowder factory and an alcohol distillery to military boot camps, schools, hospitals, and monasteries (BHC, *Human* Rights, 2006). As of 2001 most of the buildings, with a few exceptions, were in dilapidated conditions, with hardly any

funds allocated from the state budget for repairs or new buildings. Since that time, many homes have received money to repair toilet facilities, bedrooms, dining rooms; however, BHC was surprised at the renovation in some of the most problematic homes in remote villages rather than creation of infrastructure that would allow better social integration. In several institutions, construction of new buildings was begun in the early 1990s.

The largest institutions are those for adults with developmental disabilities; one with capacity of 220, another 180. Only six have capacity/occupancy of 50-60. The maximum capacity of any home for adults with mental illness is 114 persons.

Other institutions for adults include 25 institutions for adults with physical disability (capacity 1600; residents 1484); and four institutions for adults with sensory disabilities (capacity 148; residents 132).

7.3.1 Psychiatric Hospitals and Dispensaries

There were 12 state psychiatric hospitals providing inpatient psychiatric care with 2,790 beds in 2005. The buildings and facilities of these establishments are still quite old, neglected, and do not fit patients' needs according to the June 2006 BHC report *Human Rights in Bulgaria's Closed Institutions*. The MH has oversight of these facilities.

7.4 Services for older adults

There are 13 homes for adults with dementia (capacity 869, residents 838). Both men and women are housed in these homes; maximum capacity for homes for adults with dementia is 115.

8. Staffing

In HMSCC, according to the report prepared for Dr. Spassova, 83.4% of personnel are directly occupied with working with the children. Of these, 77.8% are medical personnel, 4.8% pedagogical personnel, 15.4% attendants, 2% other specialists. The personnel are "highly specialized and with appropriate education": 66.8% higher and semi-higher education, 26% vocational and general secondary education, 7.2% elementary education (Ministry of Health, 2006).

Staffing standards provide for a ratio of 100:80 for children and staff respectively in the HMRCJ, but according to the BHC Report, "Whether this standard will be applied in practice is another matter" (2006, p. 24).

The number, type and qualifications of employees in social care homes are designated in MLSP regulations. However, the BHC *Human Rights* Report (2006) found understaffing and low or inappropriate qualifications of staff, with most employees support staff rather than specialists appropriate to residents' specific needs. Specifically, only 11 homes had a staff position occupied by a hired physician, and in most cases they are half-time or even one-fourth time. In most cases, nurses and medical assistants lack supplementary qualifications for work with people with mental disorders, and in only about 20 of the institutions do social workers have degrees in Social Work or Social Education.

9. Information sources on disability used to compile the template and commentary, including people who were interviewed

National Institute for Health Statistics (NICH)
National Statistics Institute (NSI)

10. References

Amnesty International. *Bulgaria: Far from the eyes of society. Systematic discrimination against people with mental disabilities.* October 2002.

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Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

Cyprus

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Summary of the available data

The tables below summarise the data available on some of the service providers in Cyprus.

Descriptions of service types

Type of service	Size interval	Age group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admission
Department of Child and Adolescents Psychiatry (Makarios Hospital/Nicosia)	.	0 - 18/19 years	MH	.	State	State	Mixed
Service for Care and rehabilitation for People with Disability	.	3 into adulthood (60/65 years)	Mixed	0	0	.	.
Athalassa Psychiatric Hospital	201 places +	Over 18/25 (i.e. adults only)	MH	.	.	Regional authority/LA/County and state	.
Home for Severe Mental Retardation (Nea Eleausa)	31 to 50 places	3 into adulthood (60/65 years)	Mixed ID with PD, SD, MH,Beh and other	24 hour	State	State	Mixed
Home for elderly and disable	201 places +	.	.	.	.	.	.
Children's home	.	0 - 18/19 years	Mixed	.	.	.	.
Center for the Professional Re - Integration of People with Disabilities	.	16/18/25 to 60/65 (adults but not older adults)	Mixed	Mixed between units within same type - some provide 24 hr, some less than 10 hrs	State	State	Mixed
Private children's home	.	0 - 18/19 years	Mixed	.	.	.	.
Unit for the Professional Rehabilitation of Clients of the Mental Health Services	.	All ages (0 to death)	Mixed	24 hour	State	State	Mixed
Community Houses for persons with special needs	.	.	.	.	.	.	.

Type of service	Size interval	Age group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admission
Department of Adult and Elderly Psychiatry (Makarios Hospital / Nicosia)	.	Over 18/25 (i.e. adults only)	MH	.	.	Regional authority/LA/County and state	Mixed

Data available by service type – number of places only.
N.B. No breakdown was available by size, disability, gender or age.

Type of service	Places total
Department of Child and Adolescents Psychiatry (Makarios Hospital/Nicosia)	.
Children's home	.
Private children's home	.
Service for Care and rehabilitation for People with Disability	.
Athalassa Psychiatric Hospital	183
Home for Severe Mental Retardation (Nea Eleausa)	45
Center for the Professional Re - Integration of People with Disabilities	.
Unit for the Professional Rehabilitation of Clients of the Mental Health Services	.
Community Houses for persons with special needs	.
Department of Adult and Elderly Psychiatry (Makarios Hospital / Nicosia)	50
Home for elderly and disabled	217
Total	**495**

No information available on staffing.

Completeness and accuracy of the data

The collection of data about residential services for people with disabilities in Cyprus has proven a very difficult task. The establishment of key-contacts within the country has been impossible. We have tried to contact the Ministry of Health and the Ministry of Labour and Social Welfare several times but these tries were unfruitful. We have also asked different key contacts with relationships and expertise working with Cypriot colleagues but they could not provide us with data different to those already collected. Most of the data collected have been found through web searches. We had the collaboration of Ms. María Avraam, a Greek speaking researcher but she confirmed that there were not more information than that presented in English institutional web pages from the Ministries of Health and Work and Social Welfare.

Information about Government, Social Context, Disability Policy, Disability Prevalence and Organization of Health and Social Issues Ministries is complete and updated. However information about residential services typology, number of places and services characteristics is partial and lacks on reliability and accuracy. There is very little information about both residential mental health services and residential social services.

Commentary: Cyprus

1. Overview

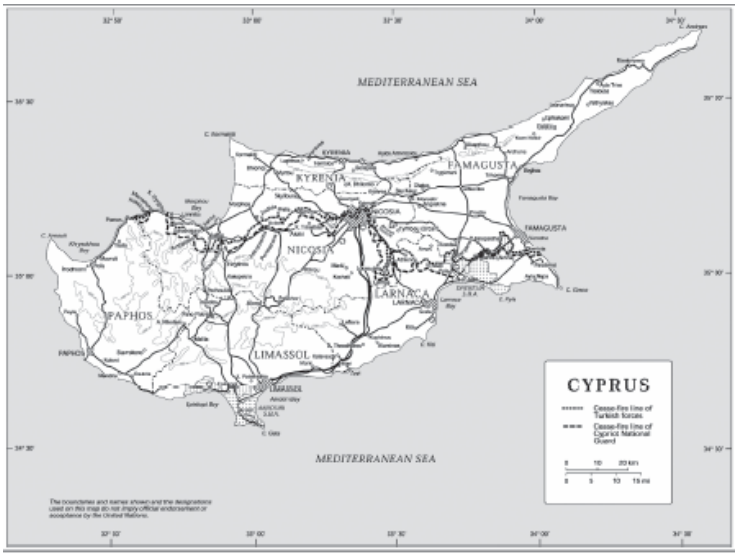
Cyprus, officially the Republic of Cyprus is a Eurasian island country in the eastern part of the Mediterranean Sea, south of Turkey (Anatolia).Cyprus is the third-largest island in the Mediterranean. A former British colony, it gained independence from the United Kingdom in 1960 and became a Commonwealth republic in 1961. The Republic of Cyprus is a developed country and has been a member of the European Union since 1 May 2004.

In 1974, following a period of violence between Greek and Turkish Cypriots and an attempted Greek Cypriot coup sponsored by the Greek military junta of that period, Turkey invaded and occupied one-third of the island. This led to the displacement of thousands of Cypriots and the establishment of a separate Turkish Cypriot political entity in the north. This event and its resulting political situation is a matter of ongoing dispute.

The Republic of Cyprus, the internationally recognized state, has de jure sovereignty over the island of Cyprus and surrounding waters. However, the island is de facto partitioned into four main parts:

- the area under the effective control of the Republic of Cyprus (2/3) in the south of the island;
- the area in the north (1/3), styling itself the Turkish Republic of Northern Cyprus; the United Nations-controlled Green Line, separating the two;
- and two Sovereign Base Areas (Akrotiri and Dhekelia), over which the United Kingdom retained jurisdiction after Cypriot independence (1960 agreement).

Residential medical care and residential social care in Cyprus depend on the Ministry of Health and the Ministry of Labour and Social Insurance. There are available data about services only in the south part controlled by the Republic of Cyprus, there are not available data for the so-called Turkish Republic of Northern Cyprus.



2. Political and social context

2.1 Government organisation and structure

Cyprus's political system is a presidential democracy (Republic of Cyprus) established by the 1960 Constitution that marked the end of the Cypriots' independence fight against British colonial rule. The President is the chief of the state and head of Government, elected by universal direct suffrage for a five-year term. The President appoints the Council of Ministers and the Cabinet of the Republic of Cyprus. Each minister exercises executive power on all subjects within his ministry's domain. The House of Representatives is elected every five years by universal direct suffrage. All citizens over the age of 18 are required to vote. The House of Representatives enacts legislation. According to the constitution, judicial power is vested in the Cypriot courts, namely the Supreme, Assize, District, Military, Rent Control, Industrial Disputes and Family Courts.

Administratively, the country is divided into six districts: Ammochostos, Kyrenia, Larnaca, Limassol, Nicosia and Paphos. Cyprus is a member of the United Nations, Council of Europe, Commonwealth of Nations, Organization for Security and Cooperation in Europe, World Trade Organization and many other organizations. European Union accession talks commenced in 1998 and culminated in a favourable decision at the Copenhagen European Council on 12 December 2002. The official act was signed on 16 April 2003 and Cyprus became a full member of the EU on 1 May 2004.

Cyprus has been divided into the Greek-Cypriot controlled rump of the Republic, somewhat less than two-thirds of the island and the Turkish-occupied approximately one third in the north. Further, British sovereign bases occupy part of the island. The Republic of Cyprus is the legitimate internationally-recognised government of Cyprus. Turkey aside, all foreign governments and the United Nations recognise the sovereignty of the Republic of Cyprus over the whole island of Cyprus.

2.2 Disability relevant policy

The officially recognized disability policy in Cyprus is expressed in guidelines adopted by the Government and in guidelines adopted by a National Disability Council. The emphasis - in descending scale - is on: prevention, individual support, rehabilitation, accessibility measures and anti-discrimination law. The following actions have been taken by the Government in order to initiate and support information campaigns conveying the message of full participation: Relevant celebrations during the International Day of Disabled; Press Conferences by the Ministry of Labour and Social Insurance; Use of mass media; Seminars (All in collaboration with the organizations of the disabled).

The rights of persons with disabilities are protected by a combination of special and general legislation. The judicial mechanisms available for the protection of their rights include: due process (legal remedy through courts). Non-judicial mechanisms include: an Ombudsman, a Government body (administrative) and monitoring bodies (i.e. committees for the protection of the rights of people with a mental handicap).

The general legislation applies to all categories of disabled persons with respect to: employment, the right to marriage, the right to parenthood/family, access to court-of-law, right to privacy. The following benefits are guaranteed by law to persons with disabilities: health and medical care, training, rehabilitation and counselling, financial security.

Thus, the Constitution of Cyprus since 1960 declared that every person has the right to a decent existence, social security and is equal before the law and the administration. In 1967 and 1987, respectively, the State of Cyprus ratified by laws the European Social Charter, safeguarding the rights of people with disabilities for education and vocational rehabilitation and training and the Convention 159 concerning their vocational rehabilitation and employment. It is of great importance that article 4 of Part II of that Convention, which became part of the national law of Cyprus since 1987, fully implements not only the prohibiting aspect of non-discrimination, but also the positive aspect of the principle of equality, by providing expressly that: "special positive measures aimed at effective equality of opportunity and treatment between disabled workers and other workers shall not be regarded as discriminating against other workers". This Law-Convention includes a successful definition of the disabled, which lacks from the Directive of E.U 2000/78/E.C.

A Law, which was passed in 1989 safeguards the rights and provides for the protection of mentally handicapped and establishes a public Board having the care for them. It also specifies their rights and the obligations of the State towards them.

Amongst the new laws enacted is the Law of July 1999 concerning the education of children with disabilities in the mainstream, including their professional training and education. This Law imposes on the State the whole liability and expenditure needed for affording to children with disabilities the opportunity and all the necessary services and means required for their integration in the general system of education.

Another Law recently passed is Law 127/2000 safeguarding the rights of disabled and adopting the principle of non-discrimination as this principle was then provided by the Standard Rules. Unfortunately, this Law embodies only certain of the Standard Rules

of the U.N. of 1993 on the Equalization of Opportunities of Persons with Disabilities, though the scope of the Law, as it is declared in its preamble is to promote and apply the Standard Rules. The Law unfortunately selected only certain provisions from the Standard Rules, which do not impose any expenditure on the State. It is true that it establishes a special fund for financial assistance and support of people with disabilities for their social integration and vocational rehabilitation. It is quite astonishing, however, that according to the Law itself all the resources of that special fund are to be raised from the private sector.

It is obvious that there is a gap in the implementation of a system of legislation and administrative measures, including those for employment, which on the one hand should co-ordinate the private initiative, but on the other hand should extend, above all, the care and the social policy of the State itself, independent from the uncertain and unstable private initiative. It should be said that the above-mentioned Law aims to ensure equalization of opportunities by removing physical and social barriers and to eliminate discrimination by providing people with disabilities with the required services and means. As to the opportunities of people with disabilities to be employed, this Law does not impose a quota system, though such a system exists but only as to the appointments of educational officers on the virtue of another Law in force since 1990 in that field of education. In addition, it must be noted that the quota system is being applied in all fields of employment in the public sector, but only in favour of war veterans and in favour of certain other categories of citizens, who are not persons with disabilities. This amounts to an apparent violation, in our opinion, of the Directive for non-discrimination of the E.U., which consists part of its *Acquis*. Nevertheless, that Law provides the obligation of the Government to introduce schemes for employment of people with disabilities in both the public and private sector, the creating of incentives and the establishment of certain posts in the public sector for the employment exclusively of persons with disabilities.

A reference should be made in this respect to the ratifying Law of the Parliament 27/2000, ratifying the Repealed European Social Charter, thus rendering it part of the domestic law. Article 15 of the Charter is relevant to the employment as it safeguards the right of the disabled for autonomy, social integration and participation to the community life, by affording to them the required technical support and taking the necessary measures.

The policy for mental health in Cyprus was initially formulated in 1985. Cyprus has a Mental Health act. The last legislation was enacted in 1997 following WHO regulations, referring to the admission, treatment and care of those with mental illness. The new Mental Health Act emphasizes the rights of those with mental illness and creates multidisciplinary teams of lawyers, psychiatrists, psychologists and social workers dedicated to ensuring the protection of patient rights and high quality services, primarily in a community setting. The components of the policy are advocacy, promotion, prevention, treatment and rehabilitation. The Mental Health policy is concerned with updating legislation according to European standards, integrating mental health with community care and improving the living conditions of patients in the Mental Hospital in Nicosia. The national mental health programme was formulated in 1995.

In summary, social rights for people with disabilities are guaranteed under the laws for The Rights of Persons with a Mental Handicap (1989), Providing for Persons with Disabilities (2000) and Special Education (1999). In response to the ageing population, the Government Strategic Plan 1999–2003 (Goals of the Department for Social Welfare Services) was developed to improve support for families providing informal care for older family members and to expand formal home care for older people.

3. Demographics

Actual Cyprus population at 2007 is 788.400 inhabitants. Life expectancy at birth is 77.9 years. Literacy reaches to the 97.6% of the population and birth rate per woman is 1.80. Although there are different territories under Greek-Cypriot and Turkish control, the population follows a regular distribution over the territory. 82% of the population speaks Greek and English is broadly spoken. The population comprises Greeks (78%), Turks (18%) and other Europeans (4%).

The territory covers 9251 km2 and the population density is 90 per km2. The population in the Government controlled area is estimated at 766.4 thousands at the end of 2005 compared to 749,2 thousands in the previous year, recording an increase of 2,3%. The population increase during 2005 is mainly explained by an increased net migration balance (14,416 persons) and to a lower extent by the national increase (2,823 persons).

Number of births in 2005 was 8.243. The total fertility rate decreased to 1.42 in and as, since 1996, remained below the replacement level of 2.10. The number of deaths reached 5,420 in 2005. The life expectancy at birth is estimated at 77.0 years for males and 81.7 for females in 2004/05. In 2005 the number of marriages increased to 12,966. Ecclesiastical marriages increased from 3,359 in 2004, which was a leap year, to 3,871 in 2005, and civil marriages increased from 7,572 in 2004 to 9,095 in 2005. In 2005 the number of divorces decreased to 1,514 from 1,614 in 2004.

4. Health and Social Care System

The Council of Ministers has overall responsibility for the state's role in the social protection and health care system in Cyprus. It exercises this authority through the Ministry of Health and the Ministry of Labour and Social Insurance and, to a smaller extent, the Ministry of Finance. All the parties involved with the administration of social protection in Cyprus, including the private sector, are depicted in Fig. 1.

The Ministry of Health is responsible mainly for the organization of the health care system in Cyprus and the provision of state-financed health care services. The ultimate objective of the organization is to promote and protect people's health. The Ministry of Health formulates national health policies, coordinates the activities of both the private and the public sector, regulates health care standards and promotes the enactment of relevant legislation. It is organized into various departments and manpower development institutes including: (i) General Laboratory, which provides laboratory analysis services including inspection of food, water, medicine, police evidence and drugs investigations (but not services for clinical purposes); (ii) Pharmaceutical Services, responsible for the testing, supply and pricing of pharmaceuticals, inspection of pharmacies, etc; (iii) Medical and Public Health

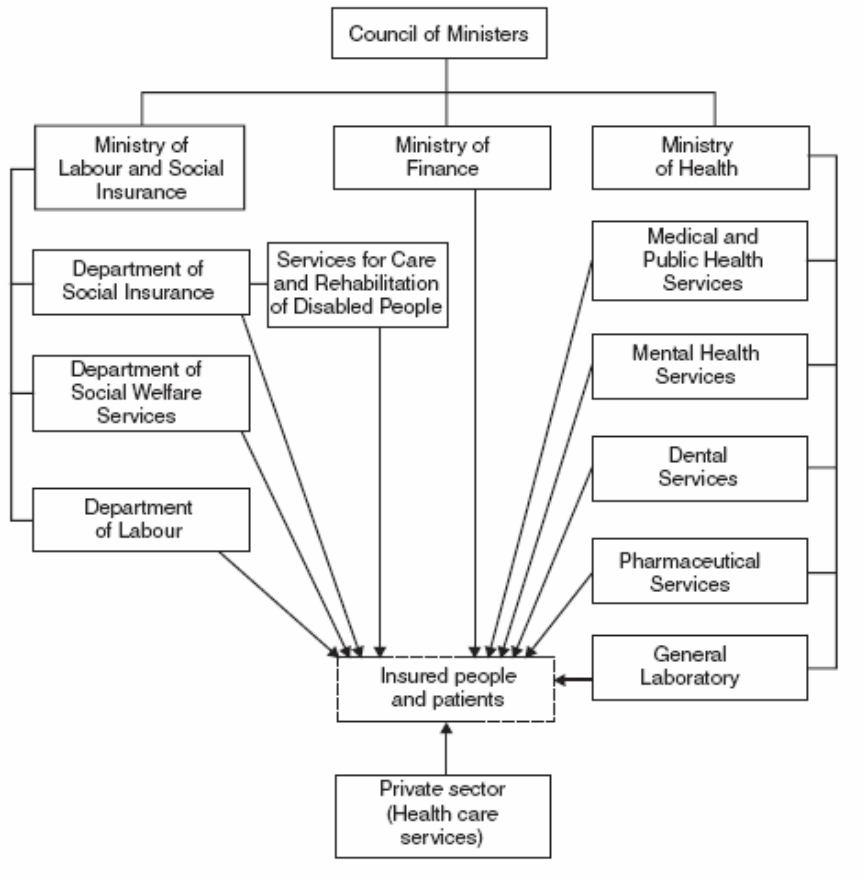
Services, responsible for services in the fields of prevention, primary, secondary and tertiary care; (iv) Dental Services;(v) Mental Health Services.

In 1998 a five-year plan was developed to decentralize mental health services into five administrative sectors and expand prevention oriented services in the community. This has contributed to continued reductions in institutionalization, as evidenced by the decline in the number of psychiatric hospital beds. The government also planned some structural and functional changes to Athalassa Psychiatric Hospital. Of the total mental health costs in 2001, 57.5% were the functional costs of the Athalassa Hospital, the remainder was directed to all other mental health services.

Mental health facilities are part of primary health care system. Actual treatment of severe mental disorders is available at the primary level. There is an ongoing cooperation of the community psychiatrists with general practitioners, and there are regular workshops with the participation of WHO experts. Regular training of primary care professionals is carried out in the field of mental health. In the last two years, about 60 personnel were provided training. Mental Health services offer a three month training course for doctors trained as general practitioners.

The facilities for mental health are present in all regions and there are Community Psychiatric Nurses. In addition to regular services, they make home visits and provide crisis intervention. The country has specific programmes for mental health for minorities, refugees, disaster affected population, elderly and children. The total psychiatrics beds are 5,2 per 10.000 population : the psychiatrics beds in mental hospitals are 4,5 per 10.000 population; the psychiatric beds in general hospitals are 0,6 per 10.000 population and the psychiatric beds in other settings are 0 per 10.000 population. The bed occupancy rates for Psychiatric Departments at General Hospitals was 43.7 in 2005.

Figure 1 Parties involved in the administration of social protection in Cyprus



The Ministry of Labour and Social Insurance is responsible for the implementation of government policy for employment, social insurance, social welfare and industrial relations. The Ministry is further organized into departments and manpower development institutes. The Department of Social Welfare Services is the official state agency for the provision and promotion of social welfare services. The department's main programmes cover family and child services; community work; public assistance and services for the elderly and disabled; and staff development and programme planning services. It also administers the following three laws: (i) Public Assistance and Services – guarantees a minimum acceptable standard of living in keeping with human dignity for every person legally residing in Cyprus; (ii) Homes for the Elderly and Disabled – requires non-government homes for the elderly and disabled to be registered and inspected; and (iii) Children and the Centres for the Protection and Recreation of Children – requires nongovernmental day-care centres and child-minders to be registered and inspected.

The Department of Labour is responsible, among other things, for services for the care and rehabilitation of disabled persons; special financial assistance to disabled persons; and the financial assistance scheme for the purchase of wheelchairs for the disabled.

Social welfare policy was introduced in Cyprus in 1946, initially to regulate the supervision of juvenile offenders, after-care of reform school boys and protection of deprived children. By the 1970s social welfare had evolved into a wide spectrum of activities designed to enable the population to cope with social problems. The

Ministry of Labour and Social Insurance supervises the official state agencies for the provision and promotion of social welfare services. These consist of a central office, six district welfare offices and a sub-office through which services are provided to every community in Cyprus. Voluntary organizations also play an important role in social welfare, working with the Council of Ministers and focusing on specific areas such as ageing, special needs, disability, family violence and drug abuse. The government offers many social services. Public assistance covers the basic and social needs of low-income individuals. Employment incentives are in place to encourage social inclusion and gradual independence from public assistance. District welfare officers provide advice, counselling and support to individuals receiving public assistance. A family support service was introduced in 1991 to provide home help for families on public assistance. Finally, community involvement initiatives such as day care centres for children are in place. The government also operates a variety of housing schemes for vulnerable people (e.g. refugees and low-income households) and for the revival of disadvantaged areas. Other schemes are in place to facilitate employment, lifelong (adult) learning, employment of people with disabilities, and to help individuals to reconcile family life and employment.

The Ministry of Labour provides public-assistance for old persons and persons with disabilities. The main objectives of this service are: (i) Safeguarding of every individual's right to a decent standard of living and (i) provision of financial support and/or services to the most vulnerable groups of society including older persons and persons with disabilities.

Every person legally residing in Cyprus is entitled to public assistance if his/her resources do not meet his/her basic and special needs as determined by law. No discrimination is made on the basis of race, gender, religion, nationality, etc.

Public assistance may be provided in the form of money and/or services depending on individual needs. Rates for basic needs are reviewed annually to comply with the rising cost of living. Special needs may include a rent allowance, a medically prescribed diet allowance, home-care, day-care, house equipment, house repairs, allowance for mortgage interest deriving from a house loan, etc. Residential care may also be subsidized partly or fully.

Legislation incorporates employment incentives to encourage social inclusion and gradual independence from public funds. For example, special categories of vulnerable persons are entitled to public assistance even if they are employed full-time.

In order to meet this need for persons with disability, Social Welfare Services provide both institutional and home care services. Institutional care is provided to people needing continuous, specialized care, which they cannot receive in any other way or through other services and programmes. In parallel, foster carers are registered in accordance with relevant legislation and may care for up to 5 persons in their own homes. A primary objective of Social Welfare Services is the promotion of independent social functioning of elderly and disabled persons for as long as possible in their home environment and, to this end, family and community support services as well as home care services are provided. During 2003, 5,046 persons received home care services from government-employed, private or community carers. In parallel,

within the framework of the philosophy outlined above, day care services are provided in Homes for Elderly and Disabled Persons or through community programmes.

5. Prevalence of disability

5.1 Issues of definition

There are two main sources of information about prevalence of disability in Cyprus. The first one is a Census of population conducted in 1992 and the second one is the "Survey for people with long-standing health problems or disabilities" with was conducted as part of the Labour Force Survey 2002, both published by the Statistical Service of Cyprus.

Results obtained about disability in these two studies were quite different. The definition of disability in the Census of 1992 was different from the one of the Labour Force Survey 2002. In 1992, disability was referred to people with limitations in their activities, meaning the persons that their usual activities are limited as a consequence of: (i) some chronic problem, (ii) some chronic disease or disability having as a result physical or mental incapability. On the other hand, in 2002, disabled persons were considered those who had a longstanding health problem or disability for 6 months or more or expected to last 6 months or more. This survey does not seem to include people with intellectual disability, although we are no sure whether they were included into any other category. The widening of the definition of disability might explain the difference between the total numbers of disabled persons. In order to present a clear picture of disability prevalence in Cyprus and taking into account that there is a difference of 10 years between studies publication we will refer to data from both studies.

5.2 Numbers/rates available

Population Census 1992

According to the population census of 1992, there were a total of 23,785 persons with disability in Cyprus accounting for the 4% of the total population (Table 1). There is a higher percentage of people with disability in the rural areas 5% vs. 3.5% and prevalence is higher among people over 60 years old. 22,689 persons aged more than 15 years suffered from a chronic disease or disability. The majority of people with a disability aged 15+ (73.6%) were not working, while 25.2% stated that they were working and 1.2% was unemployed. From those persons that stated that they were working (5712 disabled persons), 4330 (75. 8%) were male and 1382 (24,2%) female.

Table 1 Percentage of persons with disability by age and sex

All areas	Total	0-14	15-59	60 +
Total	4.0	0.7	3.1	12.9
Male	4.2	0.8	3.6	13.2
Female	3.7	0.6	2.6	12.6
Urban	Total	0-14	15-59	60 +
Total	3.5	0.7	2.7	12.2
Male	3.7	0.8	3.1	12.5
Female	3.3	0.6	2.2	12.0
Rural	Total	0-14	15-59	60 +
Total	5.0	0.8	4.0	13.9

All areas	Total	0-14	15-59	60 +
Male	5.2	0.9	4.6	14.2
Female	4.7	0.7	3.4	13.5

Source: Department of Statistics and Research, Ministry of Finance, Census of Population, 1992, Persons with Limitations in Activities, Vol. VI (1996).

In Cyprus, persons with disabilities (23785) can be classified into the categories displayed in Table 2 depending on the type of disability. Physical disabilities are the most frequent, accounting for more than the 50% of all disabilities.

Table 2. Number and percentage for different types of disability.

Type of disability	Number and %
Disabilities of perceptive organs	4.513 (19.0%)
Physical Disabilities	11.909 (50.1%)
Mental Disabilities	2.059 (8.6%)
Psychological Disabilities	2.140 (9.0%)
Other	2.968 (12.5%)
Not stated	196 (0.8%)
Total	23785 (100%)

Source: *Department of Statistics and Research, Ministry of Finance, Census of Population, 1992, Persons with Limitations in Activities, Vol. VI (1996).*

Survey for people with long-standing health problems or disabilities, 2002

This survey includes tables on the existence of long-term health problems or disabilities, the main categories of long-standing health problems, the cause and duration of the problems as well as the limitations encountered in relation to employment. The Labour Force Survey 2002 covered a sample of 3.500 households from all districts, which were selected proportionately in urban and rural areas. The specific module covered 6.805 persons aged 16-64 years in the 3.500 households of the sample.

The main results of the survey are the following:

- A percentage of 12,2% of the persons aged 16 to 64 years stated that they have a long standing health problem or disability (i.e. 53.426 persons in Cyprus).
- 47,8% of the persons who have a long-standing health problem or disability work, 3,9% are unemployed and 48,3% are retired.
- The most frequent long-standing health problems are problems of the back, heart, blood pressure or circulation problems, problems with legs or feet, mental, nervous or emotional problems (table 3).
- The main causes of long-term health problems are diseases unrelated to occupation, with a percentage of 74,8%, while occupational diseases correspond to a percentage of 4,4%.
- 30,2% of the persons with health problems face considerable restrictions in the kind of work that they could do, a percentage of 28,6% face considerable restrictions in the amount of work they could do and a percentage of 12,1% of the persons face considerable restrictions in their mobility to and from work.

The following table (table 3) provides information for the year 2002, on the distribution of the persons with long lasting health problems or disability, according to the existing legal framework.

Table 3. Disability distribution per type of disability, percentage and sex

	TOTAL	%	MALE	FEMALE
Total number of disabled persons	53,369	100	28,194	25,175
Problems with hands or arms	2,761	5	1,409	1,352
Problems with legs or feet	5,964	11	3,033	2,931
Problems with back or neck	11,393	22	4,987	6,406
Difficulty in seeing	1,819	3	1,138	681
Difficulty in hearing	608	1	302	307
Speech impediment	113	0	61	52
Skin conditions	359	1	224	135
Chest or breathing problems	2,808	5	1,472	1,336
Heart, blood pressure, circ. Problems	11,053	21	6,854	4,198
Stomach, liver, digestive, kidney	4,004	8	1,992	2,012
Diabetes	3,889	7	2,480	1,410
Epilepsy	458	1	240	219
Mental, nervous, emotional problems	5,429	10	2,918	2,511
Other progressive illnesses	2,046	4	623	1,424
Other longstanding health problems	664	1	462	202

Source: Labour Force Survey 2002, Statistical Service of Cyprus

In 2002, 53369 persons with disabilities were registered (aged 16-64), from which 28194 were male (52,8%) and 25175 were female (47,2%). The total employed population in Cyprus for 2002 was 306458 persons, 25513 of which were persons with disabilities (8,3%). The remaining 27856 persons with Long Standing Health Problems (LSHP), corresponding to the 52,2% of the disabled, were not working (Tables 4, 5, 6 and 7).

Table 4 Information on the disabled persons according to their marital status, age, education and activity

Female (%)	Males (%)		Total (%)
11.1	13.4		12.2
	Females	Males	Total
Single	4.9	9.1	7.1
Married	11.6	14.9	13.2
Widowed	36.7	24.4	34.5
Divorced	20.7	21.9	21.0

Source: Labour Force Survey 2002, Statistical Service of Cyprus

Table 5 Information on the disabled persons according to their age range and sex

	Females	Males	Total
16-24	2.1	4.4	3.2
25-29	2.4	6.4	4.3
30-34	3.9	5.3	4.6
35-39	7.4	7.3	7.3
40-44	11.9	13.5	12.7
45-49	13.1	18.9	16.0
50-54	16.0	19.0	17.5
55-59	28.4	28.6	28.5
60-64	35.1	33.6	34.4

Source: Labour Force Survey 2002, Statistical Service of Cyprus.

Table 6 Information on disabled persons according to their education level

	Females	Males	Total
Lower secondary education /2nd stage of basic education	20.6	21.9	21.2
Upper secondary educat.	6.7	10.7	8.7
Diplomated/University	4.5	7.2	5.8

Source: Labour Force Survey 2002, Statistical Service of Cyprus

Table 7 Information on disabled people employment

	Females	Males	Total
Employed	6.7	9.6	8.3
Unemployed	13.7	27.1	19.6
Retired	18.1	29.6	21.5

Source: Labour Force Survey 2002, Statistical Service of Cyprus.

7. Residential Services for people with a disability

7.1 Overview

There are special services for old people and people with disability. The key objective of these services is to promote independent social functioning for as long as possible within the family and the community at large. Older persons and persons with disabilities may be provided with home-care and day-care at a local level. Residential care is used only when other solutions are not sufficient to meet individual needs on a 24-hour basis.

The home-care programme has been expanding in recent years due to its successful implementation throughout Cyprus. There are governmental, non-governmental and, mostly, private home-carers. Day-care programmes have mainly been developed by the non-governmental sector. Through the public assistance law, the government may pay home-care and day-care services in full or in part. The Social Welfare Services inspect day-care and residential institutions by legislation. The aim is to provide the best possible quality care for persons who use the services. A special tripartite board (i.e. consisting of representatives of the public, the private and the non-governmental sectors) has a consultative role in the implementation of the law as regards the standards of operation in residential homes.

There are governmental, non-governmental and private Homes for Older Persons and Persons with Disabilities. The government encourages local communities and NGOs to develop supportive services on a local level because they tend to be more flexible and efficient.

Residential care is provided either in governmental, non-governmental or private Homes. The Social Welfare Services may meet the costs of residential care fully or partly depending on a resident's income.

There are different services for people with disability, but not much data are provided by the Ministry of Labour and Social Services. Data about places is not available in most of the services and even definitions of services are difficult to find. “Homes for elderly and disabled” are specially difficult to define and we do not have information about their characteristics.

Information provided by the Ministry of Labour refers to number of elderly and people with disability attended in services provided by the State. There is no division between elderly and people with disability so we are not able to provide an accurate number. There are 142 Social care institutions providing residential care to 2874 persons during 2003 (table 8).

Table 8 Services for the elderly and disabled (31.12.2003)

Service Provided by the State	Number of Institutions	Number of persons
Residential Care State Home for Elderly and Disabled	7	217
Placement in Community Home	33	1094
Placement in Private Homes	102	1563
TOTAL	142	2874
Home Care By Government Carers	135	608
By Private/Community Carers on Payment	3215	4075
By Community Carers on payment	100	363
TOTAL	3450	5046

There is no information about staff working in social residential services.

Residential services for Mental Health depending from the Ministry of Health are organised around hospital care. There are two units for Child and adolescent psychiatric set in the Makarios Hospital and Nicosia Hospital, two departments of adult and elderly psychiatry again at Makarios and Nicosia Hospitals and a Psychiatric Hospital (Athalassa Hospital) which is going under a deinstitutionalisation process and is reducing the number of beds.

7.2 Services for children with a disability

Department of Child and Adolescent Psychiatry (Makarios Hospital/Nicosia Hospital): Treatment and counselling to children and adolescents with mental disorders. The typical age is between 0 to 18 years old, sometimes 25 years old are

admitted. These Departments provide short – term care and 24 hour support or supervision some hours per week. There are 3 psychiatrists, 2 psychologists and 6 nursing personnel working at this service.

Private Children Homes

Child – minders

7.3 Services for younger adults with a disability

Department of Adult and Elderly Psychiatry (Makarios Hospital/Nicosia Hospital): Treatment and counselling to adults and elderly with mental disorders. The typical age is between 18 to 65 years old. This Department provide short and long – term care and 24 hour support. There are around 50 places, 25 at each Hospital. There are 6 Psychiatrists, 3.5 Psychologists, 51 nursing personnel and 4 Occupational therapists working at this service.

Psychiatric Hospital (Athalassa Hospital): Psychiatric care for people with mental health problems. The psychiatric hospital provides 24h support long term care. There were 183 places at 2003. There are 5 Psychiatrists, 2 Psychologists, 230 nursing personnel and 9.5 Occupational therapists working at this service.

Home for Several Retarded Persons (Nea Eleousa): This Center has got 45 places for people between 5 to 65 years old. It is a service for people with intellectual disability and physical disability or people with more than one disability called "mixed". It is under the supervision of the Ministry of Labour and Social Insurance. In 2006 5 children and 44 adults lived in this residential facility. This facility provides 24 hour support for long and short – term care and educational support.

Service for Care and Rehabilitation for People with Disability: this service has been established in 1989 to confront all problems regarding persons with disability (intellectual, sensory, intellectual, physical, mixed). This service provides assessment, financial assistance, rehabilitation to people with motor severe and tetraplegics problems and information on any subject considering the persons with disability.

Centre for Professional Re–Integration of People with Disabilities: These facilities are for adults with all type of disabilities between 16 to 65 years old. They provide vocational training and educational support. Sometimes this centre provides 24 hour care for short – term for those persons with disability who need it.

Community House for Mental Handicap

Community Houses for Persons with Special Needs

State Home for Elderly and Disabled

7.4 Services for older adults

Department of Adult and Elderly Psychiatry (Makarios Hospital/Nicosia Hospital): Treatment and counselling to adults and elderly with mental disorders. The typical age is between 18 to 65 years old. This Department provide short and long –

term care and 24 hour support. There are around 50 places, 25 at each Hospital. There are 6 Psychiatrists, 3.5 Psychologists, 51 nursing personnel and 4 Occupational therapists working at this service.

State Home for Elderly and Disabled

8. Acknowledgements

Thanks to Prof. Kerim Munir for trying to establish key contacts in Cyprus.
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Thanks to Maria Avraam who conducted the initial web search and translated important documents for the production of this report.

9. Information sources on disability used to compile the template and commentary, including people who were interviewed

Ministry of Health http://www.moh.gov.cy/
Ministry of Labour and Social Welfare Services http://www.mlsi.gov.cy/
Statistical Service of the Republic of Cyprus http://www.pio.gov.cy/

The following websites were also used for information:
http://hwi.osha.europa.eu/topic_integration_disabilities/cyprus/key_national_statistics_html

http://www.pio.gov.cy/mof/cystat/statistics.nsf/All/73CB068779CC1B47C225718F001FC5DB?OpenDocument

http://www.pot-cyprus.com/cyprusbraille4.html

http://en.wikipedia.org/wiki/Greece

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Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

Czech Republic

Jana Vránová and Jan Šiška

Charles University, Prague

Summary of available data

Description of service types

Type of service	Size Interval (places)	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length admissions	Age of service
Créches - boarding maternity school (speciální materská škola internátní)	6 to 10	0-5 years	Sensory impairments	24 hour	State and Local Authority/municipality	Mixed state/local and private contributions (insurance/private)	All long term	.
Secondary profession school (strední odborné ucilište)	6 to 10	Secondary school age (e.g. 11 to 18)	PD and Sensory/other	24 hour	Mixed	Mixed state/local and private contributions (insurance/private)	All long term	.
Conservatory (konzervator)	6 to 10	.	Sensory impairments	24 hour	State	Mixed state/local and private contributions (insurance/private)	All long term	.
Higher profession school (vyšší odborná škola)	6 to 10	.	PD and Sensory/other	24 hour	Local authority/municipality/county	Mixed state/local and private contributions (insurance/private)	All long term	.
Preschool education (prípravný stupen)	6 to 10	0-5	Sensory impairments	24 hour	Mixed	Mixed (any)	All long term	.
Social care institution/residential home for adults (ústav sociální péce pro dospelé)	.	Over 18/25 (i.e. adults only)	More than one disability group served (no main group) but not mixed	24 hour	State and Local Authority/municipality	Mixed benefits and state/LA contributions	Mixed	21 to 50 years
Pensioner´s home (domov duchodcu)	51 to 99	over 60/65	Elderly infirm/mentally ill/dementia	24 hour	Mixed	Mixed benefits and state/LA contributions	All long term	21 to 50 years
Boarding basic school (základní škola internátní)	6 to 10	3-18/19 years	Mixed ID with PD, SD, MH, Behavioural and other	24 hour	Mixed	Mixed state/local and private contributions (insurance/private)	All long term	.

Type of service	Size Interval (places)	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length admissions	Age of service
Sheltered housing (chránené bydlení)	6 to 10	Over 18/25 (i.e. adults only)	More than one disability group served (no main group) but not mixed	Mixed depending on need	Mainly independent (over 50% private or voluntary)	Mixed benefits and state/LA contributions	Mixed	0 to 20 years
Boarding secondary schools (gymnázium a strední odborné školy internátní)	6 to 10	Secondary school age (e.g. 11-18)	PD and Sensory/other	24 hour	Mixed	Mixed state/local and private contributions (insurance/private)	All long term	.
Charity home for nuns - similar to pensioner's home (charitní domov pro reholnice)	.	over 60/65	Elderly infirm/mentally ill/dementia	24 hour	Voluntary/not-for-profit (over 95%)	Mixed benefits and state/LA contributions	All long term	.
Institute/residential home for handicapped youth (ústavy sociální péce)	201 +	3-25	More than one disability group served (no main group) but not mixed	24 hour	State and Local Authority/municipality	Mixed state/local and private contributions (insurance/private)	Mixed	.

Data available by service type – breakdown by size and disability group

Type of institution	Places total	Under 30 places	Over 30 places	Size unspecified	ID	MH	PSD	Mixed/ dual	Other/ unspecified
Créches - boarding maternity school (speciální materská škola internátní)	126	.	.	.	.	.	.	.	.
Secondary profession school (strední odborné ucilište)	1700	.	.	.	.	.	.	.	.
Conservatory (konzervator)	57	.	.	.	.	.	.	.	.
Higher profession school (vyšší odborná škola)	32	.	.	.	.	.	.	.	.
Preschool education (prípravný stupen)	18	.	.	.	.	.	.	.	.
Boarding basic school (základní škola internátní)	1371	.	.	.	.	.	.	.	.
Boarding secondary schools (gymnázium a strední odborné školy internátní)	521	.	.	.	.	.	.	.	.
Institute/residential home for handicapped youth (ústavy sociální péce)	11984	.	.	.	9946	.	610	1428	0
Social care institution/residential home for adults (ústav sociální péce pro dospelé)	8545	.	.	.	6101	870	789	785	0
Sheltered housing (chránené bydlení)	212	.	.	.	.	212	.	.	0
Psychiatric institute: specialised for mental patients	41719	.	9858	31861	.	40	.	.	41679
Special units in prison	580	.	.	.	.	.	.	.	.
Pensioner´s home (domov duchodcu)	37867	.	.	.	.	.	.	.	.
Charity home for nuns - similar to pensioner's home (charitní domov pro reholnice)	1007	.	.	.	.	.	.	.	.
TOTAL	**105739**		**9858**	**31861**	**16047**	**1122**	**1399**	**2213**	**41679**

Data available by service type – breakdown by gender and age

Type of institution	Places total	Male	Female	Gender unspecified	Children	Younger adults	Older adults	Adults over 18	Age unspecified
Créches - boarding maternity school (speciální materská škola internátní)	126	.	.	.	.	.	.	.	126
Secondary profession school (strední odborné ucilište)	1700	.	.	.	.	.	.	.	1700
Conservatory (konzervator)	57	.	.	.	.	.	.	.	57
Higher profession school (vyšší odborná škola)	32	.	.	.	.	.	.	.	32
Preschool education (prípravný stupen)	18	.	.	.	.	.	.	.	18
Boarding basic school (základní škola internátní)	1371	.	.	.	.	.	.	.	1371
Boarding secondary schools (gymnázium a strední odborné školy internátní)	521	.	.	.	.	.	.	.	521
Institute/residential home for handicapped youth (ústavy sociální péce)	11984	.	.	.	.	.	.	.	11984
Social care institution/residential home for adults (ústav sociální péce pro dospelé)	8545	.	.	.	.	.	.	.	8545
Sheltered housing (chránené bydlení)	212	.	.	.	.	.	.	.	212
Psychiatric institute: specialised for mental patients	41719	.	.	.	3292	29101	9326	.	0
Special units in prison	580	455	125	0	.	.	.	.	580
Pensioner´s home (domov duchodcu)	37867	.	.	.	0	0	37366	.	501
Charity home for nuns - similar to pensioner's home (charitní domov pro reholnice)	1007	0	1007	0	0	0	1007	.	0
TOTAL	**105739**	**455**	**1132**	**0**	**3292**	**29101**	**47699**		**25647**

Completeness and accuracy of the data

The data presented in the template is based on statistical data and information from the Czech Statistical Office[6], the Ministry of Labour and Social Affair, the Research Institute of Labour and Social Affairs, the Ministry of Health, the Institute of Health Information and Statistics, the Ministry of Education, Youth and Sports, the Institute for Information on Education and the General Directory of Prison Service of Czech Republic. Interviews with representatives from all mentioned institutions have taken place in summer 2006 – winter 2007. Data on sheltered/supported housing for people with mental health problems were provided by Centre for Development of Mental Health Care (NGO) from their actual project Leonardo da Vinci.

The template contains probably all data that are available on Czech Republic at the moment of finishing the report. Their completeness and accuracy was approved by interviewed persons. The available statistical data are on total numbers of places in the facilities (in the case of boarding schools, the number of children counted every year at September 30th). There are practically no existing data on size of the facilities (but in the description of the services there is typical size of facilities) – the only data on size were available on psychiatric hospitals and penal units. Disability data are collated only for some types of facilities - more specified data were available for social care institutions due to dividing the institutions according to the disability type. In the case of sheltered housing for people with mental health problems (data provided by the Centre for Development of Mental Health Care) and special penal units for people with intellectual disability, the disability data are also clearly accurate by the type of facility defined by target disability group. It is possible to distinguish by age for all facilities on a basic level – children and youth/younger adults/older adults. The official age of maturity (18) is not usually used as youth/adults division, e.g. for social care institutions up to the age of 26 is used . Gender data were obtained on boarding schools, but only on level of total number of children for all types of boarding schools together. Penal units also distinguish between male/female places in total number of places for both types of units counted together.

Staff data (numbers, training) are not available for Czech Republic, except penal units. In the case of penal units it was possible to obtain a very detailed data and information thanks to the well structured system and relatively a small area to be overviewed by disability people in prison as a subject of interest.

The statistical data on sheltered/supported housing are not available from official statistical sources (such as Czech Statistical Office or Research Institute for Labour and Social Affair) as they are not collected in Czech Republic at the moment. These residential facilities belong to the relatively “new types” of services started to open after 1989. The register of social services that will be set in practice from July 2007 and data on them will be collected on compulsory basis.

[6] All data provided by the Czech Statistical Office used in the template are coming from the Research Institute for Labour and Social Affairs as a direct source.

Commentary: Czech Republic

1. Overview

Czech Republic is one of the transitional countries, where the system of residential services for people with disability is undergoing a. This process has been was expressed in *Preliminary National Report on Health and Long-term Care in the Czech Republic* (2005):

> "A general trend in social services has been a shift from the institution-based care towards the community-based care, promoting the idea of an individual care provided in a home-like environment. This trend puts emphasis on the individual approach to clients and their human rights".

At the same time when the changes are incorporated, the previous structure of social services and public perception on disability are still alive even though radical structural change is unavoidable.

2. Political and social context

Czechoslovak Republic was an independent state since 1918 when a federation of two states, Czechia and Slovakia was formed. After the World War II, the state became socialist with the communist party ruling the country under the Soviet Union's influence. In 1989 the "Velvet Revolution" restored independency from the communist government and democracy was re-established. In 1993 the state was divided into two sovereign countries, Czech Republic and Slovak Republic. Since 2004, Czech Republic has been a member of European Union. In the last decade, there have been constant shifts between right wing parties (liberal oriented) and centre parties (social democracy oriented) in leading the country (the last election took place in summer 2006).

2.1 Government organisation and structure

The government of the Czech Republic is the country's central executive organ. Apart from the prime minister, the government currently has 17 members, 14 of which are ministers heading particular ministries: Transport, Finance, Culture, Defense, Labor and Social Affairs, Regional Development, Industry and Trade, Justice, Education, Youth and Sports, Interior and Informatics, Foreign Affairs, Health, Agriculture, Environment.

Public administration, or the management of public services, is decentralized in the Czech Republic. Subsidiarity is the key principle for further development as it sets basic criteria for dividing competences between the state and its administration. This principle ensures that all issues are to be solved at the lowest possible level and in consideration of effectiveness.

The territory of the Czech Republic is divided into 13 regions and the capital city of Prague. The basic territorial units are municipalities (6,249) and corporate towns.

2.2 Disability relevant policy

A general trend in social services has been a shift from the institution-based care towards the community-based care, promoting the idea of deinstitutionalisation since the end 20th century.

3. Demographics

The population is 10.2 million inhabitants. Life expectancy is 72.5 for men and 79 for women. The trend of decreasing mortality (which prolonged the life expectancy at birth) and decreasing birth rate appeared in Czech Republic after the fall of communism with the overall social transformation. The demographic evolution of Czech population is characterised by further intensification of demographic ageing, although birth rate is expected to rise. Infant mortality 3.7 has attained the historical minimum and is one of the lowest values worldwide. These last numbers correspond highly with social care planning: the increasing number of elderly people will need a wider network of elderly care and the low infant mortality number brings alive the question of support services for children with disability which is often the price for their life.

4. Health and Social Care System

4.1 Health care – organisation and funding

Health care system in Czech Republic coordinated by Ministry of Health establishes residential facilities – hospitals and specialised institutions – that provide acute and long-term care that is usually time-limited on length of *three months* (this rule is not legislatively treated though). Exceptions to the rule can occur in hospitals for long-term patients (often because of the lack of places in social residential services for elderly), in hospitals for mental patients and in institutes for infants. Health care is provided to people with disabilities to improve their health state like it is provided to the other patients. If they need a long-term care, in a possible case they are transferred to a social care service (MoLSA).

The system of health care is funded from the state budget through public health insurance. It is mandatory for all citizens to participate in this system by regular financial contributions. In the Czech Republic, health care is provided free of charge to all people on the basis of health insurance.

4.2 Social care – organisation and funding

Czech social care system is directed by Ministry of Labour and Social Affairs (MoLSA). People with disabilities and their families can get support through social assistance benefits, social assistance benefits for the severely handicapped, state social support and disability pension. The present system of financing the social care is undergoing a fundamental change that will soon affect residential services for people with disabilities. Until 2006, the system was residual from the time when the state was the only provider of social services. Within this system, funding went directly to the service providers, not to the clients or their families. In 2006, the Czech Parliament passed a new law that established the Bill on Social Services, and this law comes to force from 1st January 2007. This law is introducing direct payments for provision of social services and allows individuals to purchase services according to their choice. Its aim is to convert the centralized planning and delivery of services into a competitive system with elements of open regulation and to support the growth of

community-based services. This implies deinstitutionalization of all services. The new model of care entails the individual evaluation of client's social situation and permits the user (or his representative) to negotiate and decide where, by whom he will be provided with a service.

In this act, not only a different strategy of redistributing the funding has been introduced. The other changes that are part of the transformation constitute implementing the standards of service's quality. At the same time a system of inspection of social services is established to watch over and to supervise keeping these standards in each service. "Guidance through a good practice" is another tool that is meant to guarantee dignified treatment for clients. All providers are also obliged to register their service at Ministry of Labour and Social Affairs by July 2007. The registration should help to create a transparent network of existing services that are available to clients as well as to keep the quality of the services. It seems already now that this new system also contains some imperfections and gaps. One example is the small budget on the bill for people with mental illness[7]. As a consequence, the lack of money on individual's budget for social services in mental health care is definitely not a stimulating signal for the developing community-based services in this area. In fact it indirectly strengthens the position of the current institutions (i.e. mental hospitals), which are a part of health care and provide a long-term care for mentally ill patients.

5. Definition, eligibility and diagnosis/assessment

There is no unified definition of disability in Czech Republic. The definition varies according to the purposes of disability assessment (e.g. social benefits, social services, education area, etc.).

The Education Act – the main act on education – provides a definition of children with special educational needs as children with a disability and talented children. It stipulates that children, pupils or students with special educational needs shall be entitled to an education the content, form and methods of which correspond to their educational needs and possibilities. The assessment of special educational needs is provided by special-pedagogical or pedagogical consulting centres that are entitled to recommend inclusion of the child in special education setting. Then the act says that also medical recommendation can be required.

For the purposes of social security (social benefits) the assessment of health conditions is made by doctors of the district social security administrations (OSSZ). There are 3 levels of disability recognised, according to the severity of the impairment and the handicap.

In the social services system, assessment is not made by OSSZ doctors. If a health condition is to be assessed, the method of assessment depends on the opinion made by relevant social service authority or on the service provider directly.

For the purposes of disability pension, a type of disability (full or partial) will be assessed by the doctors of District Social Security Administration in the place of permanent residence of the citizen in question. For this reason, medical assessment of

[7] From the interview with L.Vostřáková

the person's health state is required, in case of mental health problems also psychological assessment required.

Medical diagnosis assessed by the International Classification of Diseases and Related Health Problems (ICD-10) is used as a reference for placing a person in a psychiatric institute and other medical institutes and hospitals. This reference is used also by most of the social services. The social services define themselves by their target group that is a certain disability group. The applicant must often attach the medical acknowledgement of his health state to the application form.

Considering the terminology, for people with intellectual disability the broader term "mental disability" (*mentální postižení*) is often used, rather than "intellectual disability". Some professionals, including psychiatrists, continue to use outdated and stigmatising terminology to refer to intellectual disability, such as "debility", "imbecility" and "idiocy". The term "disabled person" is still very widely used instead of "person with disability" in documents, statistics and other official statements, also in those published by the MoLSA or the Ministry of Health.

6. Prevalence of disability

We can estimate that the prevalence of disability is similar in Czech Republic as it is in other central European countries but there are no official numbers or statistics available.

From the statistics on social welfare published by the Czech Statistical Office there is no number on social benefit payments (regarded to for people with disability) available.

7. Residential Services for people with disability

7.1 Overview

In line with the history of many other post-communist countries, social policy in the Czechoslovakian Republic (CR) tended to segregate people with disabilities (especially with intellectual disabilities) by placing them in residential institutions often situated in old buildings in remote regions. During the past years after the fall of communism and the peaceful division of the Czech-Slovakian Federation, the country has undergone a radical transformation within political, economical and social areas. In the early 1990s, an important shift took place with the de-monopolisation of the central state role in delivering social services and the accompanying transfer of responsibility to local authorities. The process has continued when in 2003 regional authorities assumed responsibility for institutions. NGOs (Non-governmental non-profit organisations) have grown in CR as new providers of social services with the aim of supporting people with their families and local communities. The new law on social services (entered into force on January 1, 2007) is based on three principles: quality, accessibility and security. The law contains three categories of social services – services of social care, services of social prevention and social counseling.

Social service institutions still exist in Czech Republic. These institutions (mostly for disabled) were established mainly during the communist era, even though the first of them were established in late19th and beginning of 20th century. They provide to persons with limited abilities mainly personal care and housework. These special

facilities replace the client's homes and the services are not time-limited. These residential facilities are *pensioners´ homes*, *boarding houses for pensioners* and *social care institutions for disabled people* divided according to the types of disability, both for adults, children and youth. Maximum capacity for pensioner's home is 300 beds, for social care institutions 350 beds.

7.2 Services for children with a disability

7.2.1 Social care institutions for children and youth with disability

The new name for these institutions since 2007 is *residential homes for children and youth with disability*. The institutions provide 24-hour care to children and youth from 3-26. Special schools or classes are often a part of the facility, educational and residential staff are different. The stay is long-term or week-stays, they might also provide respite care. The providers are typically regional authorities, 3 facilities provided directly by state (Ministry of Labour and Social Affairs). They are funded from public funds (from state or regional budget) and partly from client's own resources (from social benefits).

The social care institutions for children and youth divide according to the disability of residents[8]:

- intellectual disability – 9946 places
- physical disability – 610 places
- sensory disability – 275 places
- more diagnosis (physical and ID) – 982 places
- disability combined (not specified) – 446 places

7.2.2 Boarding schools

There are some residential facilities for children and youth that are organized by the special schools and they are provided by the Ministry of Education, Youth and Sports. These educational residential facilities are *boarding homes*, where the pupils can stay during the week, when they attend schools. Their existence is established by ministerial regulation 108/2005.

According to the data from 2005[9]:

- Boarding special maternity school (*speciální mateřská škola internátní*) – for children with sensory (deaf, blind, deaf-blind), severe intellectual disabilities, children with speech problems – total 126 pupils in boarding homes
- Preschool education (*přípravný stupeň*) – 18 pupils in boarding homes
- Boarding basic school (*základní škola internátní*) – mostly for children with sensory disability; schools for children with physical, intellectual, combined disability are often established by the social care institution – 1371 pupils in boarding homes
- Boarding secondary school, professional school, conservatory, higher professional school – for pupils with physical and sensory disability – total 2310 pupils in boarding homes

In this number of pupils (3825), there are 2163 male pupils and 1662 female pupils.

[8] Statistic Yearbook Czech Republic 2005 (Statistická ročenka ČR 2005) - data from 2004
[9] Data from 2005 provided by Intitute on Information in Education

Children in Czech Republic start school at the age of 6. The beginning of school attendance can be postponed due to immaturity or disability of the child up to 2 years. All children have a right to education. The Education Act provides a definition of children with special educational needs including children with all types of disability. During the communist era, children with intellectual disabilities were often proclaimed "uneducable" with no right to be educated.

The idea[10] is to place children, who are filling their compulsory school attendance, in the boarding home unless it is necessarily needed (e.g. big distance between home and special school, demanding job of the parents). Mostly the schools establish these boarding homes for pupils with a sensory disability. The units in boarding homes are usually very small, according to the degree of disability of children, similar to the number of places in special school's classes (i.e. 4-6 children with severe disability).
The trend is not to segregate children from their families and to integrate them in normal schools and classes, or to place them into a class (school) for pupils with special needs close to their residence. In last years, the number of places in boarding homes for children within basic schools (fulfilling the compulsory school attendance) has definitely a decreasing tendency.

During the secondary education that is attended by children after finishing the compulsory school attendance – including all types of secondary schools, conservatories and also higher secondary schools – boarding homes (dormitories) are usually provided for their pupils on week-stay basis This applies also for secondary education for pupils with disability (there are special secondary schools for pupils with disability in CR or again, these pupils are integrated in normal schools).

7.2.3 Institutions for children

Institutions for children (*dětské domovy*) – orphanages – are established for children without parents (mostly abandoned children) and for children from malfunctioned families. Apart from these there are also institutions for infants (*kojenecké ústavy*) for children up to the age of 3, who are abandoned. To both of them, children are placed according to the court decision. These institutions serve as children's homes. It is not distinguished in statistics how many of them are with a disability or a different nationality. It is known though, that among the population there is quite a high concentration of children with intellectual disability, with behavioral, educational problems (ADHD, learning disability) and social disability (most of them Romani nationality). The precise number is not collected.

7.3 Services for younger adults with a disability

7.3.1 Social care institution for adults with disability

The new name for these institutions since 2007 is residential homes adults with disability. Social care institution/residential home for adults (*ústav sociální péče pro dospělé*) is the same type of residential facility as social care institution for children and youth. In total they provided 8545 places[11].

[10] from the interview with M.Teplá
[11] Statistic Yearbook Czech Republic 2005 (Statistická ročenka ČR 2005) - data from 2004

The institutions divide according to the type of disability:
- physical (514 places)
- physical and intellectual (397 places)
- sensory (275 places)
- intellectual (6101 places)
- psychotic and psychopathic patients (870 places)
- combined (388 places).

The clients are older then 26 (usually up to 60-65). The institutions are typically provided by regional authorities, 2 facilities provided by state (Ministry of Labour and Social Affairs). They are funded from public funds (from state or regional budget) and partly from client's own resources (from social benefits). The institutions offer 24-hour care (work settings are usually part of the facility), there are typically all year stay residents. Respite care can be also provided.

7.3.2 Sheltered/supported housing

There is no directory of NGOs providing these services to individuals with disabilities in Czech Republic. At this time it is not possible to determine the actual number or extent of community-based services (the estimated number of places for people with ID is not more then in community living for mentally ill, about 150 – 200 places).

7.3.3 Units for persons with disability in prisons

These units are penal facilities[12] as a part of prison. There are two types of units; special units (*specializovaná oddělení*) that are set up especially for men with moderate intellectual disability and units for people incapable of long-term work (*oddělení pro trvale nezařaditelné*), where the population is mixed – people with all kinds of disability, long-term illnesses, mental illnesses and elderly. They can be placed there until the end of execution of the punishment or replaced there temporally during aggravation of their illness. The main aim of these units is to separate prisoners with some kind of handicap from the rest of the population in prison and eliminate chicanery of the weaker prisoners.

These units are run by state (Ministry of Justice) with state funds. They are up to 5 years old, half of the units is not older then 2 years. The capacity of these units is usually not fully used. In total they provide 580 places (455 for male, 125 for female), 40 places are in special units for people with moderate intellectual disability. Special units have 16-35 places, units for long-term work incapable in average 50 places (one unit under 20 places, one over 100 places). Due to continuous changes in process of execution of punishment, it is not possible to give a number of people placed in them. Among the units, the degree of security guard varies according to the degree of gravity of committed crime. Medical, educational staff and social workers are in outreach.

[12] All data and information about these units provided by General Directory of Prison Service, data 2006

7.4 Services for older adults

These services serve to people older the 60-65; this is the age of starting the old-age pension (it is changing during the last years).

7.4.1 Pensioner's homes

Pensioner's homes (*domovy důchodců, domovy pro seniory*) are residential facilities often established by local or regional authorities or charities. In these homes the average age of clients is about 80. Pensioner's homes provide totally 37,366 places[13]. According to a survey of Research Institute of Labour and Social Affairs (by MoLSA), the average number of persons on waiting list for pensioner's homes is once bigger then the capacity (i.e. demand is once bigger then supply).

The typical number of places in these facilities varies according to the provider: average number of places in state facilities is 116, in local-authorities is 92 and in non-state provided (charities, NGOs) is 47. The users of these services are 65 and older, average age is 83[14]. They are provided 24 hour care and their stay there is usually long-term.

In the pensioner's homes, persons can get also nursing care, if needed (necessary health care is available there). They can suffer from various illnesses (polymorbidity), including dementia and permanent changes of health conditions. Pensioner's homes are not divided according to disability types, the population is mixed in diagnoses.
Financing of the pensioner's homes shows a mixed pattern according to the provider: public funding, grant programmes and always it is partly funded by users from old-age pension and social benefits.

A special type of pensioner's homes are charity homes for nuns (*charitní domov pro řeholnice*) – they are similar to pensioner's homes. Generally they are provided by charity and they offer 1,007 places[15].

7.4.2 Boarding homes for pensioners

Boarding homes for pensioners (*domovy s pečovatelskou službou*) serve mostly for those who don't need permanent support and care (only occasional assistance with e.g. shopping, lunch delivery, etc.). The residents must be self-sufficient, with no permanent changes of health state. For this reason these homes are not included in this survey. However, in these facilities might be also beds providing intensive care and support similar as it is in the pensioner's homes, but this is not included in any statistics or information.

7.4.3 Social hospitalisation

Institutes for long-term patients (*léčebny dlouhodobě nemocných*) are part of health care and provide medical care focused mainly on nursing and rehabilitation care for persons with long-term diseases. These patients are often elderly: from 36,009

[13] Statistic Yearbook Czech Republic 2005 (Statistická ročenka ČR 2005) - data from 2004
[14] Data (2005) obtained from interview with L.Průša (MoLSA)
[15] Statistic Yearbook Czech Republic 2005 (Statistická ročenka ČR 2005) - data from 2004

hospitalized persons in 2005 there were 32,212 older then 65. 555 patients out of the total number were hospitalized more then 1 year and 2 patients more then 10 years[16].

As mentioned above, there is a lack of places in pensioner's homes, which are a typical social care residential service and this situation is not rarely solved by "social hospitalization". It means that a patient, who is not self-sufficient, can temporarily get a social care within being hospitalized in a health care facility, typically in hospital for long-term patients. Formally is this type of social/health care service legal, but it is still a subject of discussion, especially its funding which should be from more sources: public source (Ministry of Health, MoLSA), providers budgets (regional and local authorities) and patient's allowance (from social benefits and pension). No numbers of social hospitalisation cases were found.

7.5 Services for people with mental health problems

7.5.1 Psychiatric institutes

Psychiatric institutes (*psychiatrické léčebny*), as a part of health care, provide institutional care for persons (for adults and for children) with mental disorders for whom specialized care is indispensable, and for persons convinced to obligatory therapy. In these institute was the average and also the most usual length of hospitalization almost 3 months (80.4 days). The most common reason for hospitalization was psychoses and alcohol abuse.

Patients with psychical problems can also be hospitalized in psychiatric departments of hospitals; the average length of their stay there is about 3 weeks (21,2).

According to the data from the Institute of Health Information and Statistics, there were 41,719 cases of hospitalizations (among these 3292 children and youth up to 18 years old) in 2005 in 20 existing psychiatric institutes. The total bed availabilty in these institutes is almost 10,000 places (9,858) and it is distributed in following layout:

Capacity of the facilities (number of places and facilities)							
Less then 10 places	10-30 places	31-50	51-100	101-200	201-500	501 and more	Total number
X	x	50 places (1 facility)	327 places (5 facilities)	653 places (4 facilities)	x	8828 places (10 facilities)	9858

They also extracted from their sources, that there are cases of stay in the institute that is longer then 1 year – 1059 patients – and even stays longer then 10 years – 99 patients. It is not clear though from their statistics, why do these patients stay in the facilities for so long. According to the estimation of former director of the Psychiatric Institute Bohnice – Prague, Z. Bašný, 1/3 of the bed capacity of the psychiatric institutes is used by patients in difficult social situation (they are on waiting list for a social care institution with psychiatric care, some of them are hospitalized for more then 1 year).

[16] Data (2005) by Institute of Health Information and Statistics

7.5.2 Sheltered/supported housing

Sheltered and supported housing are the examples of new service types in Czech Republic, which started in the 90´s and are provided typically by NGO´s or charities. In 2006, there were together 212 places in these facilities[17].

Sheltered housing (*chráněné bydlení*) is usually provided in special facilities resembling households. Support is provided flexibly according to the client's needs; homes may have a form of a group home (community living, 8-15 residents) or small individual flats (1-2 residents). These types of services for people with mental illness experience prefer younger clients from 18 to 35 and the length of the stay in their facilities is usually limited up to 2 years. After this time they are expected to live in their own flat and their consultant or case manager, if necessary might support them.

Supported (assisted) housing (*podporované bydlení*) allows the person with disability to stay in the home environment (in his/her own flat, rental flat etc.). The user of this service only receives assistance when it's necessary. It is often not clear and possible to distinguish between these two types of housing; the terms are not well established in Czech yet. Group homes are most typical facilities for people with intellectual disability, while individual flats are more common type of service for people with mental illness experience.

The trend is to provide people after hospitalization a community living (sheltered or supported housing, group or individual living) together with a comprehensive rehabilitation system that slowly starts to be growing. There are still specialized institutions that are organized by MoLSA for chronic mental patients. It is not desirable that psychotic and psychopathic patients, as well as chronic alcoholics and drug addicts, are permanently allocated in institutional establishments, though community care is available just at few places.

8. Other relevant information on residential services

From the statistical data 2005, there are about 10,000 children and youth with intellectual disability (ID) and about 6,000 adults with ID placed in institutional care in Czech Republic. As referred above, the this group of persons was systematically segregated from the mainstream society during the communist regime times, often placed in large, non suitable buildings in remote regions of the country, typically built in the end of 19th or beginning of 20th century. Most of these buildings are former chateaus, hospitals or barracks, with inconvenient layout, large rooms with many beds and architectural barriers.

There are about 140 institutions for people with ID (children & adults). Most of these facilities are still opened and the living conditions have not changed much over the last decade. Just few of them went under reconstruction. Most bedrooms have between six and ten beds, although in newer institutions (20% of the institutions were built during the last 10 years) bedrooms have from three to five beds, with modern furnishings. The number of people in the institutions (as well as capacity) has diminished just very little (about 1,500) since the beginning of 1990s.

[17] Leonardo da Vinci Project, Center for Development of Mental Health Care

There are few attempts of restructuring and decentralization in the institutions themselves. The idea is to organize the institution like a community with small units or individual houses for 6-8 persons and also provide supported living or halfway flats within the institutional walls. Compare these attempts to the community-based services existed in Czech, there are still usually some features of institution that survive – it can be different clothing of the staff or a huge dining room where all inhabitants come to have lunch with different sections for staff and clients. On the other hand, the large net of institutions was originally the only provider of residential services of handicapped persons and the system is definitely not prepared at the moment to change towards an absolute deinstitutionalisation.

9. Issues

9.1 Regionalisation

About 50% of services typically provided by NGO´s (e.g. sheltered, supported housing) are located in Prague. The rest of the services are usually found in bigger cities (regional capitals). The network of community-based services outside the capital - all over the country (especially in the towns under 50.000 inhabitants) - practically doesn't exist.

9.2 Ethnicity

The issue of ethnicity might be seen in the case of infant institutes (a high number of Romany children in there), but the nationality of children is not officially distinguished in any statistics.

10. Information sources on disability used to compile the template and commentary, including people who were interviewed

Ministry of Health with Ludmila Vostřáková (Director of Health Social Schemes Department), 26.6.2006

Ministry of Labour and Social Affairs with Tereza Kloučková (Department of Social Services, Conception of Social Services Section), 26.6.2006

Institute of Health Information and Statistics with Jiří Holub (Assistant Manager of Director of the Institute), 28.7.2006

Research Institute of Labour and Social Affairs with Ladislav Průša (Director of the Institute), 15.8.2006

Institute for Information on Education with Jindřiška Vančurová (charged by the Director of the Institute), 23.8.2006

Director of Bona, NGO with Zdeněk Bašný (previous long-standing director of the biggest psychiatric institute in Czech, Praha Bohnice), 24.10.2006

Prison Service of Czech Republic with Jan Sochůrek and Květa Sluková (both from Department of Research, Institute of Training), 1.11.2006

Ministry of Education, Youth and Sports with Marta Teplá (Director of Special Education Department), 26.3.2007

Statistical data and information on social services from the Ministry of Labour and Social Affairs and the Research Institute for Labour and Social Affair

Statistical data and information from the Ministry of Health and the Institute of Health Information and Statistics

Statistical data and information from the Ministry of Education, Youth and Sports and the Institute for Information on Education

Statistical data and information from the General Directory of Prison Service

Statistical data and information from Center for Development of Mental Health Care, Leonardo da Vinci Project, contact person Vendula Probstová

11. References

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Preliminary National Report on Health and Long-term Care in the Czech Republic: Ministry of Labour and Social Affairs of the Czech Republic, Praha 2005 - available also in English at www.mpsv.cz

Czech Health Statistics Yearbook 2004: Institute of Health Information and Statistics, Praha 2005. English translation is part of the yearbook.

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Psychiatrická péče 2004 (Psychiatric care 2004). Institute of Health Information and Statistics, Praha 2006 – available in Czech

Statistic Yearbook Czech Republic 2005 (Statistická ročenka ČR 2005). Czech Statistical Office; data for 2004 collected by Reasearch Institute for Labour and Social Affair – available also in English in www.csu.cz

Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

Denmark

Robert Hayward

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Summary of the available data

Descriptions of service types

Type of service	Size interval	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions	Age of service
Residential institution person with physical/psychic problems	.	0-18/19	PD and Sensory/other	24 hour	Local authority/municipality/county	Regional authority/LA/County and state	All long term	.
24 hour residential - includes Botildud klienter laegerevarende Til sindslidende (people with mental health problems)	.	16/18/25 to 60/65 (adults but not older adults)	Mixed	24 hour	Local authority/municipality/county	Regional authority/LA/County and state	All long term	.
Other dwellings for elderly persons	.	over 60/65	Elderly infirm/mentally ill/dementia	Per day only - no night time cover	Local authority/municipality/county	Regional authority/LA/County and state	.	.
Municipal/county residence schemes	.	.	.	.	Local authority/municipality/county	Benefits/social security	.	.
24 hour non-subsidised nursing (Botilud klienter laegerevarende Til adv.haem. Fys. Hand.Mv (dogn)	.	16/18/25 to 60/65 (adults but not older adults)	More than one disability group served (no main group) but not mixed	24 hour	Local authority/municipality/county	Regional authority/LA/County and state	All long term	21 to 50 years
Non-subsidised nursing dwellings	.	Over 60/65	Elderly infirm/mentally ill/dementia	24 hour	Local authority/municipality/county	Regional authority/LA/County and state	.	.
Residential nursing homes 24 hour	.	.	.	.	Local authority/municipality/county	Benefits/social security	.	.

Type of service	Size interval	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions	Age of service
24 hours private residential nursing homes (as above)	.	16/18/25 to 60/65 (adults but not older adults)	More than one disability group served (no main group) but not mixed	.	Local authority/municipality/county	Regional authority/LA/County and state	All long term	21 to 50 years
Nursing homes	.	over 60/65	Elderly infirm/mentally ill/dementia	24 hour	Local authority/municipality/county	Regional authority/LA/County and state	All long term	.
Residential institution person with behavioural problems	.	0-18/19 years	ID only	24 hour	Local authority/municipality/county	Regional authority/LA/County and state	All long term	.
24 hour protected housing/protected dwelling	.	16/18/25 to 60/65 (adults but not older adults)	Mixed ID with PD, SD, MH, Behavioural and other	Less than 10 hrs per week	Local authority/municipality/county	Regional authority/LA/County and state	All long term	0 to 20 years
Protected dwellings	.	Over 60/65	Elderly infirm/mentally ill/dementia	Mixed between units within same type - some provide 24 hr, some less than 10 hrs	Local authority/municipality/county	Regional authority/LA/County and state	.	.
Special pedagogical place of residence	.	0-18/19	Mixed	24 hour	Local authority/municipality/county	Regional authority/LA/County and state	Mixed	.
24 hour hostel	.	16/18/25 to 60/65 (adults but not older	MH	24 hour	Local authority/municipality/county	Regional authority/LA/County and state	All long term	0 to 20 years

Type of service	Size interval	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions	Age of service
		adults)						
Dwellings for elderly persons	.	Over 60/65	Elderly infirm/mentally ill/dementia	Per day only - no night time cover	Local authority/municipality/county	Regional authority/LA/County and state	.	.
Residence in boarding school 24 hour	.	3-18/19	Mixed ID with PD, SD, MH, Behavioural and other	24 hour	Local authority/municipality/county	.	Mainly long term	.

Data available by service type – breakdown by age (no information on size, gender or disability available)

Type of institution	Places total	Children	Younger adults	Older adults	Adults over 18	Age unspecified
Residential homes for children	3362	3362	.	.	.	0
Children's institutions (2003)	4438	4438	.	.	.	0
Out of home placements for children (? including foster placements)	14074	12512	1498	.	.	64
Boarding schools	847	847	.	.	.	0
Social Ped. Community	2514	2514	.	.	.	0
Residential institutions	1236	.	1236	.	.	0
24 Hour reception centres (?)	2359	.	.	.	2359	0
24 hour protected housing or dwellings	3506	.	.	.	3506	0
24 hour hostel	231	.	.	.	231	0
24 hour residential	11212	.	.	3709	7503	0
Residential Nursing homes	17819	.	.	.	17819	0
24 hour dwellings for older people	52640	.	.	52640	.	0
24 hour non-subsidised nursing	441	.	.	.	441	0
24 hour other homes for older people	15866	.	.	15866	.	0
Municipal facilities	42	.	.	.	.	42
TOTAL	130587	23673	2734	72215	31859	106

Staffing data: Children's institutions (2003): Staff total = 7874. No additional information available.

Completeness and accuracy of data

Information and data on residential care for persons with disabilities are available from one major source, Statistiks Denmark (StatBank), (primarily statisticians and economists who are unable to offer commentary on the data sets):

1. Statbank tables – routinely collect macro level data for the country as a whole with some regional/municipal-level data on an annual basis. Data, in English, is available for each subset in a variety of forms including MS Excel spreadsheets, tables, maps, bar charts. Data has a high level of accuracy and reliability at municipal level where it is collected by register.

2. A Statistics Yearbook (2005) and other publications in English, providing macro level data, much of it reproduced from Statbank tables. In addition some background information as to context, policies etc. and definition of categories, description of facilities, function, clients. Additional, more detailed, material is in Danish only.
3. Some information on institutional running costs available on registration with Statbank, larger data sets are accessible, but categorised only in Danish. Larger tables are retrievable and can be designed and specified according to preference where the data categories exist, but there is a charge element.

There are problems in accessing national data as information is collected through a register at local/municipal level who report on numbers of clients in each care setting, but do not distinguish them by disability. Data is obtained through administrative registers (with governmental agencies) and provided for the country as a whole, broken down by 273 municipalities. It is grouped into 17 subject areas and divided into subgroups with constituent tables all coded. The information is collected at the institutional level on simple forms that summarise data by enrolment and capacity. This is collated at municipal (sometimes county) level and aggregated for national level. This information is then collated to produce national figures. Within the municipalities there is information on the different types of client, but this information is held at the individual institution level. Information on residential care of mental health problems are only available at county level, and/or may not be available at institutional level (except for "rehabilitation institutions"). There are global figures for people with mental health problems in residential care, but not for hostels (where they are described as making up two thirds of the population) or for other forms of institutional care. No figures have been obtained for prisons or other forensic sites. Many residential institutions are mixed, in that they have a range of people with disabilities living there, but no definitive figures are available. There are indications that some statistics for ID (for children for example) may only be held at county level, some institutions may be clustered with varying care inputs, and care for the elderly may also include significant numbers of people who are also disabled. Therefore it is difficult to disaggregate information along the categories in the template. In addition there is little data on staff is collected – what exists does not allow institutional comparisons.

Specification of Social Resources ('Den Sociale Ressourceopgørelse')
The specification of social resources is based on various statistics regarding social care, which the regions and municipalities report every year in month 10 to Stats

Denmark. It gives a representative picture of the distribution of different social resources for the current year. Statistics included are for 2006 where indicated, but some of them are also for previous years.

Commentary: Denmark

1. Overview

Denmark consists of the peninsula of Jutland and 443 names islands (http://en.wikipedia.org/wili/Denmark), 76 of which are inhabited. Denmark is divided into five regions and a total of 98 municipalities (following recent reform of the system in January 2007). Most of the municipalities have a population of at least 20,000 people.

2. Political and social context

2.1 Government organisation and structure

Denmark became a constitutional monarchy in 1849. The Danish parliament is a single chamber of 179 members elected at 4 year intervals. The administrative powers are distributed on state, regional and local levels. The five regions (created in January 2007) are responsible for the national health service and unlike the former counties, the regions are not allowed to levy taxes (http://en.wikipedia.org/wili/Denmark). Each region has 41 elected politicians, elected as part of the Danish Municipal Elections.

2.2 Disability relevant policy

Information on disability policy in Denmark is taken from DDC, 2002 (http://www.clh.dk/pjecer/danskhandicappolitik/disabilitypolicy.doc).

The umbrella organisation of disabled people (DSI) was formed in 1934, and, from its establishment, was able to exert influence on the relevant policy areas (Bengtsson, 2005), being represented on parliamentary commissions on pensions and special care. In 1980 the Central Disability Council was established under the devolution of special care, with the DSI, government departments and county/municipal organisations all represented. The Central Disability Council became the centre of a network for promoting disability policy in all state areas, where the principle of "normalisation" was mainstreamed via sector responsibility. (Each sector had responsibility to ensure that people with disabilities were able to take part in normal societal activities without special financing). An important aspect of this was the Elderly Housing Act 1987, under which nursing homes were replaced by elderly housing (accessible to people with disabilities), which established independent living on an apartment basis with benefits (cash or services) available on the same basis for all residents of elderly housing. Danish social policy involves:

- Extended care and service functions – care for dependent elderly persons, family policy, activation, rehabilitation and preventative measures.
- Initiatives targeting particular groups – persons with physical and mental disabilities, socially excluded groups mentally ill and drug/alcohol addicts.
- Transfer payments – old age pension, maternity benefits, cash assistance and a variety of special benefits.

In 1993, the Danish Parliament responded to the Americans with Disabilities Act by adopting a parliamentary resolution (B43) on creating equal opportunities for disabled people and non-disabled people. This has formed the basis of disability policy since. There have been three concepts central to disability policy in Denmark: the

environment–based perception of disability, which means that there is no one fixed definition of disability although the basic definition of disability as "the loss or limitation of the opportunities to take part in the life of the community at an equal level with others" is used; the principle of compensation sets up that society should offer disabled people services and help in order to compensate for their disability; and the sector responsibility principle, places responsibility to ensure equal opportunities with the municipality.

Disability policy in Denmark means that there is an obligation to make all public buildings accessible to those with disabilities, that people have a right to access information and methods of communication adapted to their disability (e.g. those who are deaf are entitled to have a text telephone). It is a fundamental principle of education policy that all those meeting the formal admission requirements have access to education and this applied to those with disabilities too. Schools and colleges must be physically accessible and compensatory measures available. Disability policy also focuses on enabling people to access work (through in-service training, preferential access, personal assistance for people in work, physical aids while at work) but for those who cannot work for any reason, the system of social security helps them through benefits and pensions. Under the Danish Act on An Active Social Policy and the Act on Social Service, local authorities/municipalities can also grant compensatory support to disabled people in work, such as adaptations in the work place, social rehabilitation schemes, and flexible working arrangements. For those unable to work in the open market, there is provision for sheltered employment schemes.

In terms of social support, legislation was reviewed in 1998 and reformed to allow new forms of support arrangements and the concepts of institutions abolished. People with disabilities have the possibility of a whole range of support schemes including equipment, personal help and support (home help, training, respite for relatives, personal assistance, attendance, contact person schemes (especially for those who are mentally ill and who are deaf or blind. There are number of other measures included in these but the above plus those on legal capacity and self-determination are probably the most relevant here. With regard to the latter, Denmark introduced a new Act on Legal Guardianship in 1997 which proposed that "a person with limited legal capacity should retain as much of his or her right of self-determination as possible". Guardianship can only be used for legal obligations such as the managements of one's financial funds or the making of contracts.

The Ministry of Social Affairs, together with the Ministry of Employment and the Ministry of Interior and Health, is mainly responsible for social welfare in Denmark. The great majority of welfare tasks are carried out by public employees and not, for example, by private service companies, voluntary social organisations or the family. There is some contracting out. The interaction between voluntary organisations and the public sector plays in increasingly important part in Danish welfare through cooperation between the sectors and different forms of funding. For example, voluntary (paid) social work is supported through obligatory government funding to local authorities.

3. Demographics

Denmark has a population of about 5.3 million with 85% living in urban areas (with 30% in Copenhagen). Almost one fifth of the population is below the age of 16 and 15% is aged over 65, this figure is expected to increase to 33% by 2020. Average life expectancy for men is 74.5 years and for women, 79.2 (lower than the EU average, 2001). The leading causes of death are cardiovascular diseases and cancer, with SDR for cancer the highest in the EU (in 2001). In 1999 the total expenditure on health care in Denmark accounted for 8.4% of GDP (1.5% of that was private expenditure) (Social Policy in Denmark, 2006).

4. Health and Social Care System

4.1 Organisation

The Danish health care system has been the responsibility of the counties and municipalities since 1970. Health care has been funded mainly by local and national taxation. 85% of health care costs are financed through taxes. There had not been any major restructuring since 1970 and the establishment of a national system of health insurance in 1973 until this year (2007). Responsibility for health services now rests with the 5 Regions.

Most social care in Denmark is provided by the municipalities including the provision of social welfare allowances (sickness allowances and disability pensions), non-hospital based homecare of elderly, disabled and people with chronic illness (including mental disorders) and community mental health centres (in some areas). Municipalities are also responsible for providing housing for the mentally disabled and homeless. The counties provide some specialist services for seriously mentally or physically disabled people. The proportion of elderly living in residential homes has fallen noticeably in recent years (Ministry of Foreign Affaires, 2006). Similarly the aim that people with disabilities should stay in their own homes as much as possible, irrespective of income, the necessary aids at their disposal and help given to equip the home and for extra expense as a result of disability. For those that cannot live in their own homes there has for a number of years been a process of reorganisation from large institutions to small communities or individual residencies with common facilities and services.

4.3 National Health Service

The Danish health care service is based on “free and equal access to treatment irrespective of residence, age, health, life style and income” (page 42, DDC, 2002). The NHS is financed by taxes. Hospital treatment of non-emergency care is usually via the patient’s GP. The counties hold the primary responsibility for providing health services as laid down in legislation.

Primary sector

NHS insurance and local authorities finance the sector. The NH Security is a mandatory tax-financed insurance scheme operated by the counties. It also covers between 25-60% of costs of use of all health services supplied by specialists (dentists, psychologists etc). The difference between NH Security and actual price is the charge levied on the user. Local authorities are responsible for home nursing (free if referred by a GP), visiting health nurses and special groups of people with disabilities.

Secondary sector

Hospitals, including psychiatric treatment within hospitals are the responsibility of the counties and the Copenhagen Hospital Corporation which operate the sector.
Social Psychiatry provides social support for persons with mental illness who are not in a psychiatric hospital. It includes a range of different residential facilities, shelters, community centres, home care and support and contact person schemes. Social psychiatry has developed from social work and not from hospital psychiatry – different traditions. Social psychiatry comes under the Ministry of Social Affairs and is practiced by the counties and local authorities in accordance with the Act on Social Services. Hospital psychiatry comes under the Ministry of Interior and Health and is practiced under the auspices of the counties in accordance with the Danish Psychiatry Act.

4.4 Long term social care

All residents of Denmark have direct access to services and individual services are allocated on application to older or disabled people. The local authorities are responsible for provision and finance long-term care through local taxes and block grants from the state. Legislation only allows local authorities limited access to charge payments for permanent help concerning personal care and practical assistance in the home. Residents of nursing homes or non-profit pensioner's apartments pay rent that approximates to meeting the costs of the establishments. Denmark has constructed no conventional nursing homes in the form of institutional accommodation since 1987. Subsidised housing for older people in the form of non-profit housing, homes for elderly with care facilities, where housing areas are separated from service areas is provided. The local council has the right to refer to non-profit homes. Denmark has no centrally specified national standards for the services for older people, which are determined at local council level. Freedom of choice means that all older people and people with disabilities in needs of and eligible for housing/service flats, care homes and sheltered housing are entitled to choose such housing freely within the local authority area and across borders. This means that local councils must provide choice between local providers. Either the local council can enter into an agreement with all providers wishing to provide personal and practical help and meeting local price and quality requirements (the approval model) or a contract may be concluded with a number of providers (tender model).

4.5 Financing

The health service is mainly financed by a national 8% tax combined with funds from both government and municipalities (http://en.wikipedia.org/wili/Denmark).
Welfare services are financed via duties, VAT and income tax (http://www.clh.dk/pjecer/danskhandicappolitik/disabilitypolicy.doc).

The financing of cash benefits

	Municipal	State
Disability benefit	65%	35%
Rehabilitation benefit	50%	50%
Social assistance	50%	50%
Sick pay	50%	50%
Flex job	35%	65%

4.6 Other relevant information

The Centre for Equal Opportunities

Established in 1993 as a unit attached to the Central Disability Council to provide information, lobby and campaign and conduct small scale research. It has become a powerful, lobbying body in Denmark.

Abolition of institutions

In 1998 the legal status of all institutions changed under Danish disability law, becoming defined as "housing", with the inhabitants of housing (the former institutions) provided with disability benefit under the same rules that apply to all citizens. This was achieved by the separation of housing and benefits (cash as well as services). An evaluation in 2003 showed that municipalities are implementing the law faster than counties.

5. Residential services for people with disabilities

5.1 Overview

As late as the end of the 1970s it was normal for people with disabilities to live most of their lives at special State-run institutions for the care of handicapped persons (Danish Disability Council, 2002). In the preceding two decades there had been a growing criticism of living conditions of disabled people living in institutions, which led to goals of providing a life similar to a normal life as possible and therefore integrating people in society on equal terms. 1970-1990 was characterised as the end of the era of State-run institutions replaced by integration based on the principles of normalisation.

5.2 Services for children with a disability

As far as is possible, children with physical or mental disabilities are integrated into the regular day care system and education. Children attain majority at 18 but there are significant numbers of "children" in residential care who are aged 18-23. There are relatively few children with disabilities in institutions – most are cared for in their families who receive financial incentives and other support to enable them to do so. However, even if a child is on the register this does not equate with rights to services which are accessed through a caseworker who is the municipality "gate-keeper" (see below). Children needing special care may be offered a place in a special institution with access to the necessary expertise. Children with disabilities may receive financial assistance (paid to parents) through an allowance (paid by the local authority to care for the child at home) or the local authority may make grant assistance to cover lost wages when caring for a child.

5.3 Services for younger adults with a disability

- It is a guiding principle for persons with disabilities that it is the needs of the individual, rather than the type of accommodation, which decide the type of assistance provided. Consequently provisions on accommodation are separated (see section 4.3). Under Danish housing legislation, specially designed housing may be built that is adapted to the needs of dependent elderly people and people with disabilities.

The numbers of mentally ill requiring special social initiatives is about 30,000. During the 1990s new services were set up, including shelters, group homes and support and contact schemes. Most live in their own homes supported by district psychiatric services (often in the form of a health centre), although this system is under review.

Until the recent reform, local authorities and counties cooperated to provide for socially marginalised people to provide additional residential accommodation and support for normal living activities and more specialised services. Now municipalities and regions have to work together in order to bring together health (responsibility of the Regions) and welfare/social services (responsibility of the Municipalities) to meet the needs of people. Approximately 1000 persons are particularly disadvantaged (Social Policy in Denmark, 2006). Residential support and residential rehabilitation services include:

- Support in one's own home
- Individual apartments with shared communal spaces
- Shared apartments
- Individual rooms in a house (communal space and support)
- Short-term crisis housing
- Longer-term 24 hour support in a home
- Larger institutions (alternatives to a nursing home). For many people with intellectual disabilities, the traditional service was in "institution-like dwellings" – the larger ones had places for 100+ persons and were generally older buildings. Purpose-built institutions housing 40-60 persons were common and even the smaller institutions accommodated up to 40 residents. After 1980 the responsibility for these institutions switched from the national level to county/region. Some municipalities at that time ran small group/community homes (5-20 persons) for people with a "higher level of functioning" as an alternative to the larger institutions. After 1980 there was a separation between "housing" and "services" (botilbud) with different articles under the legislation for different botilbud. However, there was not always uniformity across municipalities and counties and there were many grey areas (for example, renting rights under legislation did not apply to all botilbud).
- Core and cluster supported housing. In many cases Regions provided the finance to build supported housing which is administered through municipalities. The majority of these are not 24 hour care and staff move between dwellings providing daily support and care.

5.4 Services for older adults

Services for elderly people fall under the Social Services Act. No conventional nursing homes have been built for older persons since 1987; instead social housing has been built. People under 65 in care (irrespective of circumstances) are regarded as "handicapped". Access to services within a municipality is determined by a caseworker who is usually a social worker (but not necessarily a specialist in disability) who can provide access to (a) cash benefits and (b) services. Access to services are dependent on costs, so for example the case worker will have to refer to a superior if expenditure on an individual looks to be significantly greater than average spending per individual. The law on rights is not very clear – municipalities have the possibility to do many things, and some do more than they need to (depending upon the local administration). Minimum standards are slowly being introduced and there is

a dynamic in the system whereby other municipalities will follow the trend setters. Each municipality has a Local Disability Council and people with intellectual disabilities may be represented through the Parents organisations who are involved in the Council.

6. Staffing

"Someone working in someone else's home – someone living in someone's working place"

Thomas Gruber (Centre for Social Services)

This is a list of different types of people working in residential care. The Danish name for it, is stated first, then an approximation in English, and then a description of the education level and main functions.

Social- og sundhedshjælpere: "Social and Health helpers"
Education: 9th grade in primary school and the SOSU-helper education (1 year and 6 month (8 month in trainee service))
Functions: Help with personal care and hygiene and daily housekeeping.

Social- og sundhedsassistenter: "Social and Health assistants"
Education: "Social and Health helper" and SOSU-assistant education (1 year (trainee service) and 8 month (school))
Functions: Nursing care and planning of activities.

Sygeplejersker: "Nurses"
Education: High school or "Social and Health assistants" and 3 years and 6 month of nursing education.
Functions: Nursing care.

Pædagoger: "Educationists"

Fysioterapeut: "Physiotherapists"
Education: High school and physiotherapist education (3 years and 6 month).
Functions: Treatment, rehabilitation and prevention of physical problems.

Psykiater: "Psychiatrists"

Uuddannet social- og sundhedspersonale: "Social and Health Staff without education"

Handicapledsagere: "Handicap Attendant"
No specific education
Functions: Follows persons with different disabilities around and helps in different situations – grocery, visiting the doctor, social gatherings.

Handicap hjælpere: "Handicap Helpers"
No specific education, often students or people with different backgrounds in social- or nursing care.
Functions: Help with personal care and hygiene, dressing and so on.

Sygehjælpere: ”Assistant Nurse”
Education: 9.th grade in primary school and assistant nurse education (1 year). Does not exist anymore. Replaced by the SOSU-educations.
Functions: Help with personal care and hygiene, nursing care and planning of activities.

Plejehjemsassistenter: “Nursing Home Assistants”
Education: 9.th grade in primary school and nursing home assistant education (2. years and 3 month). Does not exist anymore. Replaced by the SOSU-educations

Beskæftigelsesvejledere: “Occupational instructor”
Education: 9.th grade in primary school and occupational instructor education (1. year). Does not exist anymore. Replaced by the SOSU-educations.
Functions: planning and arrangement of different activities, such as cultural activities.

Data on staffing levels by municipality exist in Danish only (www.fldnet.dk).
There are variations in staff numbers between the regions – where more institution-like care exists, there are smaller numbers of pedagogues and it is recognised that there is a need for more personal care and there is a current debate on the introduction of a personal assistance model in Denmark.

7. Issues

Under the new structures the majority of people with disabilities will gain – municipalities will be able to provide more services, which will be nearer to the population. In addition, municipalities will know more about the range and extent of disabilities (under the old structures, small municipalities had little knowledge, experience and few people with disabilities, so they did nothing). A problem with the new structure is that people with the biggest needs will gain the least. The reforms will involve a transfer of funds from some municipalities to others (mostly from urban to rural) over 3 years and this is proposal has met with little resistance. There is concern at the level of institutions – in some areas, e.g. counselling services for parents of disabled children, often municipalities dislike those services that threaten them, therefore offices have been lost in the reform process. Conversely, rehabilitation centres have been retained by municipalities largely because they are a source of employment locally. The government has put very little new money into the system, so some municipalities will have to divert monies from other sectors to maintain services.

Denmark is responsible for the administration of services to people in Greenland. There is the widely-held perception that many of the people there are experiencing social and economic problems – homelessness and alcohol abuse being regarded as particularly pressing problems with Greenlanders (also especially those living in Denmark who have emigrated from Greenland).

8. Information sources on disability

8.1 Verification meetings

On-site visit and meetings with sources, 18-20 March 2007.
Søren Andreassen, Ministry of Social Affairs, 19/03/2007
Klaus Mosekjaar, Ministry of Social Affairs, 19/03/2007

Linea Baden, Ministry of Social Affairs, 19/03/2007
Thomas Gruber, Centre for Social Service, 19/03/2007
Steen Bengtsson, Social Research Institute, 20/03/2007

8.2 Data sources

National Board of Health/ Statistical Yearbook 2005
Statbank Denmark (www.statbank.dk).
Danish Expenditure on Health Care (1999)
OECD Health Data 2005 (www.irdes.fr/ecosante/OCDE/506.html
Statistics Denmark & the Association of County Councils in Denmark (1999)

9. Acknowledgements

Thomas Gruber, Søren Andreassen.

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Danish Disability Council (2002) Danish Disability Policy. Copenhagen: DBC.

Ministry of the Interior and Health, Ministry of Social Affairs (2005) Report on health and long-term care in Denmark. Kobenhavn: Socialministeriet.

Royal Danish Ministry of Foreign Affairs (2006) Conditions of Life. www.um.dk/publikationer/UM/English/denmark/kap3/3-2.asp Accessed 29/03/2006.

Social Policy in Denmark (2006). http://eng.social.dk/netpublikationer/eng/dsp1dsp240902/2.htm Accessed 02/11/2006.

Vallgårda, S., Krasnik, A and Vrangbæk, K. (2002) European Observatory on Health Care Systems (2002) Health Care Systems in Transition Summary: Denmark. Denmark: WHO

Appendix 1: Danish "typical" case scenario

Maria is a 22 year old woman with severe learning disabilities who also presents some behavioural problems. Maria is unable to live on her own without constant care. Until her mother died recently, she lived in the family home, receiving some supports from the municipality. There are no other immediate family.

Given that Maria has been living at home until now, and bearing in mind the nature of her disabilities, what would have been her likely pattern of education and care to this point?

Depending on the precise nature and how severe her disability, Maria would probably have received education through either the ordinary elementary school (individually integrated and/or in special classes) or more likely through a special school for children with disabilities. All children – disability or not – are obligated – and have at right to - education. Before the school age, Maria could have gone to a special kindergarten or a special group in a ordinary kindergarten. Also, when finished in the elementary school, she could have had a year in a special folk high school. Regarding the likely care that she would have received, there are (at least) two possibilities: (i) she might have received care from one or both of the parents, who then would have received economic compensation from the local authorities (compensation for lost income and extra expenses, transport etc.); (ii) care and social support/pedagogue support through so called 'home-training-personnel' and health care personnel. These services would be provided by the local authorities. It is also likely, that she would have received a combination of the two scenarios above. Finally Maria would probably have had the opportunity to make use of special designed activity services for people with disabilities (e.g. social café, activity-centre etc.).

Who would have provided and paid for these services? How would have this been decided and by whom?

As above. All these services would (after the structural reform in Denmark, 2007) have been provided, decided and financed by local authorities/municipalities

What is the most likely outcome for Maria now? (What, realistically, might she expect from health or social welfare services?). What input might Maria or her advocate/representative have in this process?

Depending on the nature of Maria's disability, she would probably be offered a combination of housing and social pedagogue support in either a relatively small (4-10 persons) home, or in a larger (10 – 100 persons) more 'institution-like' setting. The larger housing group can (very roughly) be categorised into two groups: (i) old and rather large (40 persons and more) institutions established before the 1960s and (ii) smaller and more modern institutions/housing with bigger and more individualised dwellings. The more severe Maria's disability the more likely it is that she would be offered the old and large 'institution-like' solution.

Who would typically be responsible for providing services? (i.e. what department, which professions would be involved, who would be responsible for determining or managing care and how might this be paid for?)

Maria and/or her representatives are entitled to be involved directly in the decisions about housing and social service. The decision is taken by the local authorities, but Maria and/or her representatives have to be heard. There are in reality often very few choices to choose from. The local authorities are responsible for providing the services. Private or not-for-profit organisations can deliver the services, but the responsibility is only located by the local authorities. Today there are very few private and not-for-profit organisations that deliver these kinds of services.

What factors might influence her pathway or access to services? (for example, entering residential care provided by a church-based organisation versus a state-run facility, or residential care home over nursing home, or day support rather than educational or work facilities). How is one type of service chosen over another? How is this decided and by whom?

The decision-making is made by social workers working in a department of social affairs within the local/municipal administration. Before making the decision the social worker may consult different kinds of health specialist, social care specialist, behaviour specialist etc. Since the reforms in Denmark in 2007, the social worker can seek special counselling in relation to the most difficult cases from a national special counselling organisation (VISO). The day-to-day managing of the social services is handled in the organisation that provides the housing/social service. Most of the staff in these organisations are pedagogues. The social services for people with disabilities are all paid for by the local authorities. The clients only pay for housing, food, laundry etc. Almost all clients in these kinds of housing receive early retirement pension/disability pension etc.

Without going into too much detail, and given the limited information, what can you tell me about the likely next stage in Maria's life and the likely people to be involved, and the way decisions such as patterns of service and funding might be made? A brief and direct answer, without going into too much detail will suffice as long as any complexities or barriers are briefly mentioned.

Continuing care as described above. Maria will have a representative who will advocate on her behalf as and when her needs change. I don't think we have state or church facilities, as far as I know they are all municipal or regional. Apart from that, this question is difficult to answer. My impression is that it is decisive what spokesmen she has. When the parents are dead, there is perhaps no one in the family, but a good caseworker can make a great difference. If the behavioural problems are not too great, she should be offered a place in a form of sheltered workshop or day care centre. But I should not be astonished if she was left in the care institution the whole day. The reason why the caseworker is so important is because there is so much judgment in our social administration.

(Information supplied by Thomas Gruber)

Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

Estonia

Anja Frindt

Centre for Planning and Evaluation of Social Services,
University of Siegen, Germany

Summary of available data

Description of service types

Type of service	Size interval	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions	Age of service
Residential welfare services for children and youth (orbude ja vanemliku hoolitsuseta laste hooldamine hooldekandeasutuses)	3 1 to 50 places	0-18/19	Mixed	24 hour	Mixed	Regional authority/LA/County and state	Mainly long term	0 to 20 years
24 hour welfare services for adults with mental special needs (täiskasvanud psüühiliste erivajadustega inimeste ööpäevaringsed hoolekandeteenused)	51 to 99 places	Over 18/25 (i.e. adults only)	Mixed	24 hour	State and Local Authority/municipality	Mixed state/local and private contributions (insurance/private)	All long term	.
Schools for children with special needs (erivajadustega laste koolid)	100 to 150 places	6-18 or 19	Mixed	Mixed depending on need	Mixed	Regional authority/LA/County and state	.	0 to 20 years
Community living for adults with mental special needs (täiskasvanud psüühiliste erivajadustega inimeste kogukonnas elamise teenus)	11 to 30 places	Over 18/25 (i.e. adults only)	Mixed ID with PD, SD, MH, Behavioural and other	24 hour	All (over 95%) private	Mixed state/local and private contributions (insurance/private)	All long term	21 to 50 years
Wards or units in general hospitals and psychiatric hospitals (children) (Laste, täiskasvanute ning vanurite	11 to 30 places	All ages (0 to death)	Mixed	24 hour	Mixed	Mixed state/local and private contributions (insurance/private)	Mixed	100+

Type of service	Size interval	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions	Age of service
psühhiaatriahaiglad ja -osakonnad üldhaiglates)								
Residential welfare services for adults (Täiskasvanute hooldamine hoolekandeasutuses)	31 to 50 places	Over 18/25 (i.e. adults only)	Mixed	24 hour	Mixed	Mixed state/local and private contributions (insurance/private)	All long term	.
Wards or units in general hospitals and psychiatric hospitals (adults)	201 places +	All ages (0 to death)	Mixed	24 hour	Mixed	Mixed state/local and private contributions (insurance/private)	Mixed	50 - 100 years

Data available by service type – breakdown by size and disability

Type of institution	Places total	Under 30 places	Over 30 places	Size unspecified	ID	MH	PSD	Elderly/ dementia	Mixed/ dual	Other/ unspecified
Residential welfare services for children and youth (orbude ja vanemliku hoolitsuseta laste hooldamine hooldekandeasutuses)	1653	215	1438	0	326	.	255	.	.	1072
Schools for children with special needs (erivajadustega laste koolid)	.	.	.	.	.	.	.	.	.	.
24 hour welfare services for adults with mental special needs (täiskasvanud psüühiliste erivajadustega inimeste ööpäevaringsed hoolekandeteenused)	2220	126	2094	0	955	940	.	.	334	9
Community living for adults with mental special needs (täiskasvanud psüühiliste erivajadustega inimeste kogukonnas elamise teenus)	36	36	.	0	37	.	.	.	.	1
Residential welfare services for adults (Täiskasvanute hooldamine hoolekandeasutuses)	4432	1227	3203	2	627	.	1754	.	.	2051
Wards or units in general hospitals and psychiatric hospitals	14080	201	508	13371	.	.	.	.	.	.
TOTAL	**22421**	**1805**	**7243**	**13373**	**1945**	**940**	**2009**		**334**	**3113**

Data available by service type – breakdown by gender and age

Type of institution	Places total	Male	Female	Gender unspecified	Children	Younger adults	Older adults	Adults over 18	Age unspecified
Residential welfare services for children and youth (orbude ja vanemliku hoolitsuseta laste hooldamine hooldekandeasutuses)	1653	343	238	1072	491	90	.	.	1072
Schools for children with special needs (erivajadustega laste koolid)	.	.	.	.	.	.	.	.	.
24 hour welfare services for adults with mental special needs (täiskasvanud psüühiliste erivajadustega inimeste ööpäevaringsed hoolekandeteenused)	2220	1159	1069	8	0	1774	445	.	1
Community living for adults with mental special needs (täiskasvanud psüühiliste erivajadustega inimeste kogukonnas elamise teenus)	36	20	17	1	0	36	.	.	0
Residential welfare services for adults (Täiskasvanute hooldamine hoolekandeasutuses)	4432	903	1476	2053	0	473	1908	.	2051
Wards or units in general hospitals and psychiatric hospitals	14080	.	.	.	643	.	.	13437	0
TOTAL	**22421**	**2425**	**2800**	**3116**	**1134**	**2373**	**2353**	**13437**	**3124**

Staffing data:

Type of service	Total number of staff	Care staff/nurses/ might include teachers in boarding school	Managers or other administrative staff (not care staff)	Educators/day staff	Day and care staff (no distinction made)	Clinical staff (Drs, therapists, psychologists etc)	Other staff (mainly ancillary staff)	Other staff (does not include ancillary staff)
Residential welfare services for children and youth (orbude ja vanemliku hoolitsuseta laste hooldamine hooldekandeasutuses)	810	.	.	384	.	61	.	365
Schools for children with special needs (erivajadustega laste koolid)	.	.	.	.	.	.	.	.
24 hour welfare services for adults with mental special needs (täiskasvanud psüühiliste erivajadustega inimeste ööpäevaringsed hoolekandeteenused)	793	217	65	396	.	115	.	.
Community living for adults with mental special needs (täiskasvanud psüühiliste erivajadustega inimeste kogukonnas elamise teenus)	14	.	.	11	.	2	.	.
Residential welfare services for adults (Täiskasvanute hooldamine hoolekandeasutuses)	1058	892	20	24	.	112	.	.
Wards or units in general hospitals and psychiatric hospitals	.	.	.	.	.	.	.	.
TOTALS	**2675**	**1109**	**85**	**815**		**290**		**365**

Completeness and accuracy of the data

The data presented in the template refers to the year 2005 and is based on statistical data and information from the Ministry of Social Affairs (Department of Social Welfare, Department of Social Policy Information and Analysis, Health Statistic Department) and the Ministry of Education and Science. Interviews with representatives from all mentioned departments have taken place in autumn 2006. Data and information from the Ministry of Social Affairs is based on Statistical Reports from institutions providing residential care for disabled people. Concerning the accuracy of data, we have to take into account that the presentation of data is difficult, since funding of services and data-collection are "service-based". It is common practice of welfare institutions to provide several services, rather than to focus on one client group, e.g. the disabled. So the collected data covers all residential welfare services in the year 2005, even though not all beneficiaries of residential welfare services are disabled. The number of disabled persons at residential social welfare services is approximately 5,200 (end of 2005). Besides there are 43 schools for children with special needs which provide 24 hour support and wards or units in general and psychiatric hospitals with 44 beds for children and 665 beds for adults.

Statistical data on residential services for disabled people covers all age and disability groups. But there is no differentiation between services for younger and older adults. The collected data covers staff numbers as well (only missing for the service type supported living). With regard to the training of staff there are no statistics, the template contains estimations on this topic. Besides statistical information there were other sources used to write this country report, as listed at the end of this chapter.

It can be summarised that - because of intensive communications with all relevant officials – the presented data is on the most complete and accurate (national) level possible for the year 2005. The existing country report has been authorised by Piret Kokk, Chief Specialist Social Welfare Department, Ministry of Social Affairs, Estonia.

Commentary: Estonia

Anja Frindt
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1. Overview

Since funding of services and data-collection are "service-based", the presentation of data is difficult. In Estonia it is common practice of welfare institutions to provide several services, rather than to focus on one client group e.g. the disabled. So the collected data covers all residential welfare services in the year 2005, even though not all beneficiaries of residential welfare services are disabled. The number of disabled persons at residential social welfare services is approximately 5,200 (end of 2005). Besides there are 43 schools for children with special needs which provide 24 hour support and wards or units in general and psychiatric hospitals with 44 beds for children and 665 beds for adults.

2. Political and social context

The Republic of Estonia is the smallest Baltic state. It has a territory of 45,227 sq km. In the capital Tallinn live 396,000 inhabitants, 37% of them of Russian origin. Estonia has 1,348,000 inhabitants in total. 68 % of them are Estonians, 25.7 % Russians, 2.1% Ukrainians, 1.2% Byelorussians, 0.9 % Finnish people and 1.1% others. The official language is Estonian. In regions, where the Russian population dominates, especially in the north eastern parts of Estonia, Russian is spoken. The main religions are Evangelical Lutheran and Greek Orthodox, with Russian Orthodox dominating in the non-Estonian population. Estonia declared its independence on 24 February 1918. It was occupied in summer 1940 and forced to enter the Soviet Union on 06 August 1940. Estonia regained independence on 20 August 1991.

2.1 Government organisation and structure

The Republic of Estonia is a parliamentary democracy. Estonia's administrative structure consists of 15 districts, 202 municipalities, 39 cities along and eight cities without autonomy. The gross domestic product per head was 6,693.5 Euro in 2004 (higher than in Latvia and Lithuania). Since 1 May 2004 Estonia is member of the European Union.

Municipalitites in Estonia[18]

3. Demographics

Estonia has a population of 1,348,000. The life expectancy is 66 years for men and 78 for women. So, on average, women have a much higher life expectancy than men. Ischemic heart diseases and cerebrovascular diseases are the main causes of death in Estonia. Infant mortality is 10 per 1000 for males and 6 per 1000 for women. Health expenditure as a percentage of GDP was 5.3 in 2003. Total health expenditure per capita was 682 Intl $ in 2003.

4. Health and Social Care System

Since 1991 the Estonian health system has undergone two major shifts:

1. from a centralized, state-controlled system to a decentralized one
2. from a system funded by the state budget to one funded through social health insurance contributions.

The Estonian healthcare system consists of general healthcare, specialised medical care and emergency medical care. Psychiatry belongs to the sphere of specialised medical care and is mainly provided on an outpatient basis. Inpatient psychiatric care is mainly used as a short-term crisis aid or for solving complex differential-diagnosis and treatment problems.

A further field is Social Protection and Social Care, which is divided into social security and welfare services. The provision of assistance is based on the principle of subsidiarity. After regaining its independence Estonia inherited a system of social care based on institutional provisions. Although health care and social care were strictly separate in theory, in practice many chronically ill people were looked after in social care homes, while many socially disadvantaged groups were kept in hospital for long periods. The concept of welfare services (since 2004) defines the general basis of policy of welfare services and measures for improving the situation in the forthcoming years. However, the Social Welfare Act is institution-centred and fails to create a sufficiently effective legal basis for individual needs to be met in the best way possible. Due to lack of choices, the exercise of rights and independence of many people is limited and coping in life is not guaranteed for everybody.

[18] www.de.wikipedia.org/wiki/estland, 15.11.2006

The Minister of Social Affairs authorised a programme for developing special care for the years of 1998-2002. There are also some citizen initiatives like the Estonian Mentally Disabled People Support Organization (EMDPSO), the Estonian Association for Supporters of People with Mental Disorders (EAFPMD), the Estonian Patients' Advocacy Association (EPAA).

There is still no nationwide and integrated mental health policy in Estonia, but attempts are made to obtain this. It is quite obvious that mental health services are based on a medical paradigm in Estonia. The welfare service system is also based on a medical paradigm, despite the fact that the elements of a social paradigm came into being.

4.1 Organisation

Providing residential services for people with disabilities is a mixed pattern. Many are either local authority or central government maintained. In some cases there are also private sector institutions.

Social services are provided by 86 service providers who offer supported living, living in a community, supported employment, supporting everyday-life, 24-hour care, 24-hour care with intensified monitoring and 24-hour care with intensified support.

Special schools for children with disabilities are run by the state, local government or private providers.

According to actual law all health care providers have to be private, so psychiatric hospitals are mainly foundations or companies. But owners are many municipalities or the Estonian state, some are private.

In the social care sector the state provides services for persons with mental special needs. The state pays for all residential services for people with mental special needs, all rehabilitation services and technical aids (people pay 10%). All other social services are provided by the local governments which are closer to persons. The local governments get money from the state, but develop their own priorities. More often than not, social care is not the first priority (these are often roads and education).

4.2 Financing

Social services are financed from the state budget, the budgets of local governments and by households. Services intended for adults with mental special needs are financed from the state budget through the Ministry of Social Affairs and the Social Insurance Board. Services intended for children with severe mental disability are also financed by the state budget, through county governments, and the Social Insurance Board. In cases where children with severe disabilities are placed in an institution on the request of the parents, municipalities usually finance the service. The parents share in the costs.

24 hour welfare services for adults with mental special needs are mostly state funded, cost-sharing with municipalities and clients takes place. The system of funding residential services for people with disabilities in Estonia is a place related one.

County governments have contracts with service providers. In those contracts the amount of places on every service is fixed (if needed, changes can be made of course).

The under-financing of 24-hour-services is a major problem. In the last decade the budgets have increased. There is a big pressure on the care-takers salary. In the past two years extra money to raise the salary of care-takers has been spent, but no money to extend the amount of services. Residential welfare services for elderly are paid by clients themselves and the local government, in some cases a state funding exists (state funded 24h care is provided for those elderly who lived in care homes before this specific law changed in 01.01.1993, before that elderly 24-hour care was state funded).

By law, the education is exempted from costs. The basic education goes from the age of 7 to the age of 17, in special schools for children and youth with disabilities three years more are possible. The state or a local government bear the costs. The state also pays to private schools. There are rates for normal schools which can be five times as high in special schools. Cost of a place in a boarding school depends on the kind of the schools and the clientele. The average cost of a place is 4800 Euro per year.

94 % of the whole population of Estonia are covered by health insurance. Financial resources are allocated back to the regions, according to the number of insured people in each region. So health care is financed through health insurance directly by the state or by patients themselves (for example in the case of drug addiction). The health insurance fund was established in 1991. Contracts for financing medical treatment are entered into with the service providers by the Health Insurance Fund. In psychiatric specialised medical care the providers of inpatient services are paid mainly on the basis of the days of inpatient care. The one hospital with a forensic department is financed by state. Health insurance fund pays to hospitals 674-1099 EEK (43-70 Euro) per day depending on the service provided (e.g. acute, general, children). If patient covers the costs himself it is also approximately 500-1000 EEK (32-64 Euro) per day.

5. Definition, eligibility and diagnosis/assessment

Estonian law and policy use terminology and definitions from the WHO ICD-10 to diagnose and classify intellectual disability. The term “persons with special needs” has been introduced into Estonian Legislation. It replaces the term deviation. The Social Benefits for Disabled Persons Act defines disability as loss of or an abnormality in an anatomical, physiological or mental structure or function, due to which a person may need external assistance, guidance, supervision, special technical aids or conditions. There are three degrees of severity of disabilities:

1) profound disability is the loss of or an abnormality in an anatomical, physiological or mental structure or function of a person as a result of which the person needs constant personal assistance, guidance or supervision twenty-four-hours a day;
2) severe disability is the loss of or an abnormality in an anatomical, physiological or mental structure or function of a person as a result of which the person needs personal assistance, guidance or supervision in every twenty-four hour period
3) moderate disability is the loss of or an abnormality in an anatomical, physiological or mental structure or function of a person as a result of which

the person needs regular personal assistance or guidance outside his or her residence at least once a week.

According to the terminology and definitions from the WHO-ICD 10 the term mental retardation is used, rather than intellectual disability. People with intellectual disability are referred to as people with mental disabilities/mental special needs in legislation and practice.

In the Estonian statistics the term mental special need is used for mental disorders and intellectual disabilities, covering all ICD-codes from F00 to F99. Disability in the statistics of the Ministry of Social Affairs means that the official disability status was appointed to a person by a disability expertise commission.

In Estonia there are different procedures for diagnosis and assessment: for education, for employment and for access to social benefits.

Counselling Committees are responsible for diagnosing disability for **educational purposes**. According to ICD-10 the Counselling Committees diagnose mild, moderate, severe or profound disability. There is one local commission in every county government that gives advice to parents on what curricula to choose for their child. The commission consists of 5-6 people, normally a local doctor, a social worker, a psychologist, if needed a psychiatrist (who has been a constant member of the commission in former times) and other specialists/experts.

To be eligible for **social benefits** a person has to be assessed from Medical Examination Commission of the Social Security Board in the framework of rehabilitation service. Rehabilitation services mean services provided to support the ability of persons to cope independently, their social integration and employment or commencement of employment in the framework of which: a personal rehabilitation plan which complies with the requirements is prepared for a person; services specified in the list established by the Government of the Republic and set out in the rehabilitation plan are provided; a person is instructed how to carry out activities described in the rehabilitation plan. The rehabilitation plan is valid for a term of six months up to three years after what the person is reassessed. Persons entitled to receive rehabilitation service provided by state are
1) persons with disability,
2) children applying for a degree of severity of a disability,
3) persons over 16 years of age if this is necessary for determination of a degree of severity of a disability or the ability to cope independently and social integration of the person;
4) juveniles on the basis of a decision of a juvenile committee (not disabled – these are youngsters who have broken the law) and
5) persons aged 16 until pension able age with mental disorder or disability and their percentage of loss of capacity for work is at least 40.

A person's degree of disability is assessed according to four categories: mild, moderate, severe and profound. A medical assessment committee or a medical expert shall determine the degree of severity of a disability and shall identify the additional expenses. Persons with mild disabilities are not eligible for social benefits. Normally it's a precondition to be assessed by the commission to get any social benefit or

service provided by the state. Only for every-day-life-support a person does not need to be assessed by the Commission – only referral from a psychiatrist is needed. If a person becomes client in a locked ward (5 locked units with 165 places exist in Estonia), this decision is made by a court because the person is a danger for him-/herself or others and only court has authority to limit a persons' liberty.

Mental special needs are assessed in a specialised rehabilitation team within a general rehabilitation system. The first step is usually that the person goes to local governments' social worker as a primary information and advice source, but it is not a must. Person can also turn directly to a regional case manager. There are four regional case managers for special care (north, east, south and west region) who mediate and advise clients, their families, county and local governments, service providers and other partners. Case manager also helps clients to collect all needed documents for rehabilitation service and helps to find a suitable service provider for a client when the rehabilitation plan has approved. The rehabilitation services are a precondition to getting special care services (except everyday life support and 24-hour care in locked ward). Rehabilitation services consists of assessment, appropriate rehabilitation services to complement the assessment and the service concludes with a rehabilitation plan for the client. The Plan is put together in collaboration with the client, his/her family, service provider (for example if client does not have a family and lives in a care home), treating doctor, local social worker or other relevant parties. During rehabilitation service, persons' different needs are assessed (social, medical, educational, employment, psychological, material etc.) and written down to the Plan. Rehabilitation plan consists of peoples' personal data, his/her situation description, measures suggested for improving his/her situation and coping, goals until next assessment. The rehabilitation team goes to the person at home or the client can come to their office. If needed, the client can live in rehabilitation facility up to 6 months for long term assessment (for example to test the clients' abilities and suitability for certain services, client can try supported living or supported work. At the same time his/her independent living skills are developed by rehabilitation specialists). Any rehabilitation team normally consists of at least five persons of following list: a doctor, a social worker, nurse, special doctor (relevant to the case), psychologist-occupational consultant, speech therapist or special pedagogue, physiotherapist, occupational therapist.

Additional specialists can be invited (additional specialist doctors, social pedagogue, probation officer, local government social worker) if needed. Family and or legal guardian or support person (if he/she has one) is asked to participate at some stages (the team needs to speak and watch the person alone without side influences as well). The rehabilitation team is looking for the coping strategies of the client and can teach him or her to cope with everyday-tasks.

6. Prevalence of disability

The Population Census 2000 included detailed questions on disability, but does not provide information disaggregated by the type of disability. According to the census, there were a total of 103,154 people with disabilities or long-term illness out of a population of approximately 1.37 million. This included 4,874 children with disabilities, age 14 and under. Most people with disabilities (97,929) were living in private households. 5,225 people were living in institutions. This group included 288 children, age 14 or under, and 2,291 adults, age 60 and above. In the first half of 2002

social benefits for people with disabilities were paid to 4,580 children under 16 and 84,794 people, age 16 and over. Approximately 45,000 adults with disabilities were receiving an incapacity pension.

There are approximately 113,000 persons who are officially declared "disabled" in Estonia (8.4% of population), 56% of them are over 65 years old. The number of people with special mental needs ranges with great probability from 6,000-7,000. The number of disabled persons at residential social welfare services is approx. 5,200 (end of 2005).

7. Residential Services for people with a disability

7.1 Overview

After regaining its independence, Estonia inherited a system of social care based on institutional provisions. The majority of clients still live in large institutions for more than 30 people. But state and NGO-attempts (and perspectives) are aiming at inclusion. The Ministry of Social Affairs just started a programme for smaller (each house for 10 clients) and more flexible care homes providing a higher quality of care and better qualified staff. The new units shall be spread all over the country to be closer to person's origins and family and in local centres rather than remote places as current huge care homes built in Soviet time. This approach supports social integration and equal opportunities.

In the field of special education the number of students with disabilities in mainstream schools increases, but a widespread special school system still exists. It is an official policy that in the future special schools should be used as competence and advice centres. In some special schools there are no more first grades because most children stay in local mainstream schools. The move forward to inclusive education goes very slowly. School for all is yet not possible, but development follows this direction.

Psychiatric hospitals are in a transition process, too. During Soviet times psychiatric hospitals also had a repressive function and people have been there for long periods of time. The new approach is to reduce the length of stay and the psychiatric hospital treatment. Psychiatric hospitals should provide acute treatment. As soon as possible the patient is to be transferred to community services like day centres and sheltered workshops. That enables her or him to live in her/his own apartment or home. The number of beds and the average length of stay in hospital are decreasing.

7.2 Services for children with a disability

Under the domain of the Ministry of Social Affairs there exist residential services for children and youth in Estonia. Besides there are also boarding schools for children with mental special needs and special wards for children and youth in psychiatric hospitals (44 places).

Residential child welfare services are aimed at orphans and children without parental care, but quite a large share of clients has a kind of disability. In total there were 38 institutions providing residential services to children and youth in 2005, with 1,683 children at the end of the year. 581 children have special mental needs or a physical disability. In 2005 in total 33 institutions listed disabled children among their clients. In nine institutions the disabled children made over 50 % of clients. The typical size

of places in residential child welfare services is 40-50. In the years 1920-1940 first institutions for orphans and single elderly were created. Generally the age limit to live in that kind of service is 18. But there are some exceptions. State also finances the service for 18+ youth while they are studying at a basic school, vocational school or at the university (bachelor level).

Under the domain of the Ministry of Education there are 43 special schools with 4,611 students, all of them provide 24 hour care. Nowadays boarding schools are smaller and more flexible than before. The Bureau of School Network collects statistic data on schools and students for each school year.

7.3 Services for younger and older adults with a disability

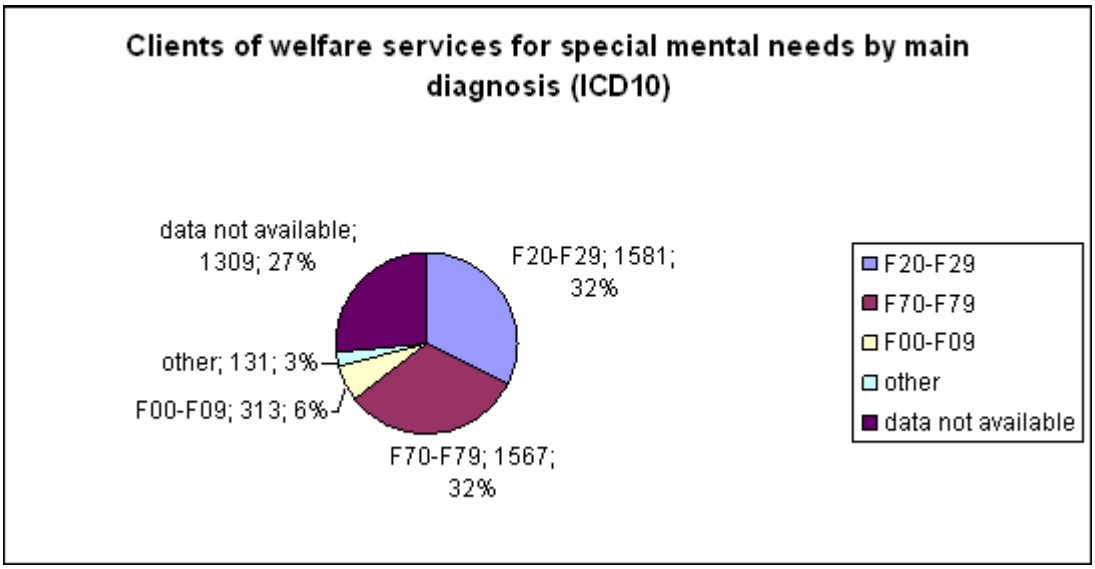
There is no differentiation between residential services for younger and those for older adults in Estonia. Welfare services to adults with mental special needs (both intellectual disability and mental health disorders) are ranging from 24 hour services and community living to supported independent living and supported working. Services are provided by very different institutions ranging from hospital special departments and large residential institutions to small NGOs. Residential welfare services to adults (usually the elderly, but very often also to persons with physical disabilities and other) are also provided by institutions with very varied size.

In 1920-1940 first institutions for orphans and single elderly were created. During the Soviet era institutions were created for persons with mental special needs. It was also often the case that all, the elderly persons with physical disability, and people with mental special needs were taken care of in the same institutions. The only services provided to the persons with mental special needs at that time was 24-hour care and so called therapy manufactures with the psychiatric hospitals which is quite the same what we understand as sheltered workshops nowadays. During the last 10-15 years there have been substantial changes in the provision of services. Care homes for elderly and care homes for people with mental special needs are no longer mixed up. Service providers now specify on client groups for example by type of disability. Clients may still live in the same building but in different departments. A bigger breakthrough in welfare for persons with mental special needs was in the year 1998. In following years new services were introduced: 1999 - 24 hour care service with enhanced support, assistance in daily living; 2000 - 24 hour care service with enhanced supervision, supported living, community living, rehabilitation, 2001 - supported working. All these new services are by large state funded. A big programme for the next 15 years has just started. It is planned to close the old care homes from Soviet times, build normal living houses for ten clients and move clients out care home by care home. The first house is build and will be ready in December 2006. The planned units should consist of four houses, each for ten people, and an extra house for daily activities, laundry and so on, which can be used as a day centre, to interact with local people. They should be located more central than before. The "Special care homes reorganisation programme" from 2006-2021 is funded by the European Social Fund.

There are four types of residential services for adults: care homes for adults with mental special needs, general care homes, mainly for older people, community living and supported living.

7.3.1 24-hour welfare services for adults with mental special needs

The size of residential institutions for the persons with mental special needs varies enormously. There are 27 institutions in total with four to 310 places, the average number of places is 83 per institution. Newer institutions are by rule quite small, but there are some "remains" of the Soviet time, which are very large institutions. Intellectual disability or mental health disorder are the main types of disability served in 24 hour welfare services for adults with mental special needs. Data on the type of disability was collected in 2005 for the first time.



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But these data also include the clients of supporting services for adults with special mental needs, not only the clients of residential services. Besides that, the data is only available for 73 % of service clients.

In residential welfare services for adults with mental special needs 24-hour care with enhanced support and with enhanced supervision is provided. There are 2,220 places in total.

7.3.2 Community living for adults with mental special needs

Community living for adults with mental special needs means, that a group of adult clients form a small community with care workers who also live in the community. They live together as “families”, work in their commune to earn their living (grow their own vegetables and fruits, keep cattle, make candles and all sorts of handicraft). One of the communes emphasizes strongly on learning in regular vocational schools and has initiated several courses adjusted for people with intellectual disability (gardener’s assistant, assistant in timber works etc.). Clients on this service need more support and would not be independent enough to manage on supported living service. In Estonia there are three communes (one of them is based on Camphill-ideology, Steiner pedagogic and Christianity), soon there will be five. The number of places is ranging from 9-16, there are 36 places in total. This service type is provided for adults with intellectual disability. It’s 24-hour support, personnel living together with clients.

[19] Information from the Ministry of Social Affairs

Clients are between 18 and 40 years old.[20] 55 % of them are male, 45 % are female. Clients of community living facilities are more independent and don't need 24-hour care.

7.3.3 Supported Living

Supported living means that person(s) live independently in a flat or house. Accommodation does not belong to the person, but is part of the service. It can belong to the local government or service provider. Along with the accommodation, part of the service is also a support person who visits the clients at their home and guides them in their everyday activities (managing money, doing laundry, cleaning, cooking, paying bills etc.) and keeps eye on how clients are doing and their health condition. Clients on supported living are relatively independent, often there is no need for the support person to visit every day, but just 1-2 times a week. Next step from supported living would be living totally independently. At the moment there are 578 places for supported living in Estonia.

7.4 Residential welfare services for elderly adults

109 residential institutions for adults (homes for the elderly) provided statistical reports which stated, that some of their elderly clients are also disabled. In total there were 114 residential institutions for adults in 2005, including 64 institutions where over 50% of the clients were disabled. Out of a number of 4,432 places in total, 2,381 clients have a kind of disability: 627 mental special needs and 1,754 a physical disability.

7.5 People with mental health problems

Health care for people with mental health problems is provided in 20 wards or units in general hospitals and psychiatric hospitals (2005). These institutions provide 44 places/beds for children and 665 for adults. In 2005 14,080 patients were treated in total, among them 643 children and 13,437 adults. Approximately 20 percent of the treated patients are disabled (official disability status appointed by a disability expertise commission). The average length of stay in inpatient-care was 15 days in 2005. Because clients are moving in and out, it is quite complicated to separate persons who are living there. In principle there is no person living in a psychiatric hospital, only the forensic clients are inpatients for a longer period of time (1 ward exists for forensic clients in Estonia with 75 beds).

8. Other relevant information on residential services

Private Provision: Traditionally health care services are provided by state. 15 years ago NGOs have entered the field and have started to develop services which are mostly innovative and community-orientated.

9. Staffing

Requirements for health care professionals/specialists are provided for in legislation. Doctors are trained in the Faculty of Medicine of the University of Tartu. Training of

[20] State funded service is ensured to people aged 18-63, the pension age. Today the clients receiving this service are rather young because the communes are founded by parents who's children are yet young.

nurses is regulated by the institutions of the Professional Higher Education Act. Training for social care specialists is provided at academic institutions of higher education (universities of Tallinn and Tartu), institutions of professional higher education and vocational educational institutions. In past times staff of welfare services mainly didn't obtained a special training. Many social workers have no professional education. For that reason the Ministry of Social Affairs launched a 160-hour in-service training programme in 2001 for people carrying out the customer work of agencies and organisations providing services for people with special mental needs. Nearly 1,000 people have completed the programme by now. The Ministry of Social Affairs is planning new moduls on special qualification for all services for persons with mental special needs. At this point there are 160-hour basic training and only two special moduls provided: on 24 hour care with enhanced support and on 24 hour care with enhanced surveillance. New training moduls for supported services should start in the next year (2007).

Directors of residential services need to have a higher education (university degree) and have to pass a special schooling for directors/leaders of care homes, average care takers have to pass an 160-hours schooling paid by the state. Educator or day care staff in welfare institutions for children and youth have to meet quite strict regulations on their qualifications. They have to be with special higher or vocational education, or if they have other qualifications, they need to pass 160-hour courses in pedagogy and social work. Still, as these requirements are settled for a certain transition period, there is a certain amount of day-care staff in institutions not meeting these requirements. Most of them are obtaining needed qualification. In welfare institutions for adults with mental special needs staff consists mostly of so-called activity instructors, who need to pass the 160-hour in-service training organised by the ministry of Social Affairs.

The total number of employees has dropped from 1,344 to 1,200 (1998-2001). Social welfare services intended for people with mental disorders are under-staffed. There is a lack of aid-providers associated with low salaries. Jobs are underpaid and it's hard to find good personnel. Especially in residential welfare services who are located far away from local centres, directors have to hire unskilled people from around.

10. Costs

The funds from state budget for 24hour care services, in 2005, are as follows (EEK per month):
Living in community – 2,559 EEK/164 € (client covers accommodation expenses and does her/his own shopping and cooking with the help of the care worker)
24 hour care – 3,693 EEK/236 € (client covers accommodation and catering)
24 hour care with enhanced support- 5,488 EEK/351 € (client covers accommodation and catering)
24 hour care with enhanced supervision – 5,214 EEK/333 € (client covers accommodation and catering)
(1 EUR = 15.6 EEK)

11. Issues

11.1 Ethnicity

According to the high percentage of people of Russian origin living in Estonia (especially in the north eastern parts), there are different schools for the Estonian and the Russian speaking population. Basic school education is provided in both languages. There are also some special schools which teach in Russian.

11.2 Gender

The estimated number of women in residential welfare services for adults is very high. This can be explained by the fact that in Estonia the gap in average life expectancy between men and women is over ten years. Women tend to live to old age. Very often they remain single towards the end of their life and on appearance of a health problem, they often need to be placed into residential care.

11.3 Age

Clients of residential welfare services for adults, end of 2005

	age groups							
	under 18	18-29	30-39	40-49	50-59	60-64	65+	total
Men	0	18	32	109	257	187	1103	1706
Women	2	21	13	50	141	128	2418	2773
Total	2	39	45	159	398	315	3521	4479
incl disabled	0	36	37	111	289	206	1702	2381

Source: Information from the Ministry of Social Affairs

11.4 Regional/geography

Every county of Estonia has service providers. But in some regions in the south of Estonia only supportive services are available for people with mental special needs and 24-hour-care is not provided.

A person with disability who needs 24-hour-care goes where a care home is and where a free place exists. This can be far away from home. For example, in Saaremaa, an Estonian island with around 10,000 inhabitants, are two big care homes with almost 400 places together rather separated from ordinary structures. So it's difficult for the families to go there. Vice versa, for clients it's inconvenient to visit their family. Besides 24-hour-care homes are often difficult to reach as in former times they were build in remote environments (the so called forests), hidden and far away from local centres.

12. Acknowledgements

Piret Kokk

13. Information sources on disability used to compile the template and commentary, including people who were interviewed

Interviews:

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Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

Finland

Robert Hayward

University of Kent, UK

Summary of the available data

Description of service types

Type of service	Size interval	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions	Age of service
24 hour service housing (Tehostettu palveluasimenen)	.	.	.	.	Local authority/municipality/county	Regional authority/LA/County and state	.	.
Health centres (Terveyskeskusten pitaaikaishoito)	11 to 30 places	.	.	24 hour	Local authority/municipality/county	Regional authority/LA/County and state	.	.
Institutions for people with intellectual disabilities (kehitysvammalaitokset)	100 to 150 places	All ages (0 to death)	ID only	24 hour	Mixed	Mainly state or LA (more than 75%)	Mainly long term	21 to 50 years
Psychiatric hospitals and psychiatric wards in other hospitals and municipal health centres	100 to 150 places	All ages (0 to death)	MH	24 hour	Local authority/municipality/county	Mainly state or LA (more than 75%)	Mainly long term	.
Residential homes (Vanhainkodit - clients = asiakkast)	.	Over 60/65	Elderly infirm/mentally ill/dementia	24 hour	Local authority/municipality/county	Regional authority/LA/County and state	Mainly long term	0 to 20 years
Housing services with 24-hour assistance for people with intellectual disabilities (autettu)	11 to 30 places	All ages (0 to death)	ID only	24 hour	Mixed	Mainly state or LA (more than 75%)	Mainly long term	0 to 20 years
Pitkaakaisasiakaat (clients in long-term care)	11 to 30 places	Over 60/65	Elderly infirm/mentally ill/dementia	24 hour	Local authority/municipality/county	Regional authority/LA/County and state	.	.
Housing services with part-time assistance for people with intellectual disabilities (ohjattu)	11 to 30 places	All ages (0 to death)	ID only	Mixed depending on need	Mixed	Mainly state or LA (more than 75%)	Mainly long term	0 to 20 years
Regular care home	6 to 10	0	.	.	Local	Regional	.	.

Type of service	Size interval	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions	Age of service
(Saannollinen)	places				authority/municipality/ county	authority/LA/County and state		
Sheltered housing for seriously disabled people (vaikeavammaisten)	6 to 10 places	All ages (0 to death)	PD and Sensory/other	Mixed between units within same type - some provide 24 hr, some less than 10 hrs	Mixed	Mainly state or LA (more than 75%)	Mainly long term	0 to 20 years
Ordinary service housing (Tavallinen palveluasuminen)	11 to 30 places	.	.	.	Local authority/municipality/ county	Regional authority/LA/County and state	.	.
Housing services for people with mental (psychiatric) problems	6 to 10 places	All ages (0 to death)	MH	Mixed between units within same type - some provide 24 hr, some less than 10 hrs	Mixed	Mainly state or LA (more than 75%)	Mainly long term	0 to 20 years

Data available by service type – breakdown by disability, gender and age (N.B. no information on size available)

Type of institution	Places total	ID	MH	Other/ unspecified	Male	Female	Gender unspecified	Children	Younger adults	Older adults	Adults over 18	Age unspecified
24 hour service housing (Tehostettu palveluasimenen)	2629	2629	.	0	1577	1052	0	230	2054	341	.	4
Health centres (Terveyskeskusten pitaaikaishoito)	0	.	.	.	.	.	.	.	.	.	.	0
Institutions for people with intellectual disabilities (kehitysvammalaitokset)	4691	4691	.	0	2580	2111	0	188	3848	703	.	48
Psychiatric hospitals and psychiatric wards in other hospitals and municipal health centres	2653	2653	.	0	1459	1194	0	.	2282	371	.	0
Residential homes (Vanhainkodit - clients = asiakkast)	2559	2559	.	0	.	.	.	.	.	.	.	2559
Housing services with 24-hour assistance for people with intellectual disabilities (autettu)	5500	.	5500	0	.	.	.	.	.	.	.	5500
Pitkaakaisasiakaat (clients in long-term care)	0	.	.	.	.	.	.	.	.	.	.	0
Housing services with part-time assistance for people with intellectual disabilities (ohjattu)	0	.	.	.	.	.	.	.	.	.	.	0
Regular care home (Saannollinen)	0	.	.	.	.	.	.	.	.	.	.	0
Sheltered housing for seriously disabled people (vaikeavammaisten)	0	.	.	.	.	.	.	.	.	.	.	0

Type of institution	Places total	ID	MH	Other/ unspecified	Male	Female	Gender unspecified	Children	Younger adults	Older adults	Adults over 18	Age unspecified
Ordinary service housing (Tavallinen palveluasuminen)	0	.	.	.	.	.	.	.	.	.	.	0
Housing services for people with mental (psychiatric) problems	0	.	.	.	.	.	.	.	.	.	.	0
TOTAL	**18032**	**12532**	**5500**	**0**	**5616**	**4357**	**0**	**418**				**8102**

Staffing data

Information available by occupational grouping, service type and numbers only (2001).

ALL (2001)	**241028**
Residential homes	20337
In patient health centre (all social care and health staff)	20860
Nurses - residential homes	1500
Nurses – in-patient	5365
Social work instructors (sosiaalialan ohjaajat ju kasvattajat) - residential (all)	187
ditto - in patient	7
Practical nurses (perus) residential home	8018
Practical nurses - in-patient	8022
Attendants (kylvettajat) residential home	121
Attendants - in-patient	127
Assistant nurses (sairaala) residential homes	4649
Assistant nurses - in-patient	2728

Completeness and accuracy of data

The greater part of the information on residential services for people with disabilities comes from the STAKES publication "Statistics Yearbook 2005" which reports on data valid for 31/12/04. The handbook provides comprehensive statistical information on social and health services, service providers, personnel and expenditure in Finland. Information is presented by different client groups and in the form of a long comparative time series. It is mainly derived from statistics and registers maintained by STAKES. Clients in housing services are given for each year based on the client census data (from 31st December) given by region, municipality, type of service provider and age group (under 65, 65-74, 75-84, over 85). More detailed statistics can be located in specific thematic publications from the Office of Statistics Finland. Data from the yearbook is presented for the country as a whole and by region (corresponding to the 20 hospital districts). Much of the information is collected at municipality and collated at regional than national level which means that detail is lost. There is very little available data at the level of institution or individual service provision, so for example, it is comparatively easy to arrive at the number of clients for a service by region or nationally, but it is more difficult to arrive at the number of institutions providing services to them. The case registers and surveys operate at the individual record level and so provide little information on institutions or delivery structures. Data obtained from municipalities about personnel is from a different time period and generally refers to 2001-2003 (as indicated in the template). More detailed information is only available to authorised persons. Much detailed data only available in Finnish, some only in "grey" documents.

SOTKANET launched in 2005 is a compilation of national statistics in 3 languages (Finnish, Swedish & English). It is a central statistical information on-line service, comprising some Register data and results from surveys dating back to 1990 on the health and social care system and on the well-being and health of the population. It offers extended time series data at local, regional and national levels. Indicators are grouped according to target group and uses - data is sorted by gender and there is some demographic and health data, but mostly at a level that does not provide the detail or depth demanded for categories on the template. SOTKANET provides data as absolute or relative numbers where indicators are grouped according to target group and uses. Information is also reproduced visually as graphs and maps.

Accuracy & reliability
There was a poor response to information requests from official bodies contacted (government, academia) with all queries routinely redirected to STAKES. Data is not usually collected by key NGOs, other agencies or similar, so there is a reliance on one key agency where personnel may be primarily academics and/or statisticians and therefore not always familiar with patterns or mode of service delivery. Efforts have been made to cross check information with service providers.

Information gathered from principle sources, (STAKES, 2005), is subject to three provisos: (i) Differing time periods: Information on ID & PSD pertain to 2004 and the best national mental health information is for 2002; (ii) Information on services for children and the elderly are collected differently. Information on children with disabilities is collected by sample questionnaire, but less than 50% of municipalities

publish results, so numbers are extrapolated from these figures; (iii) Only partial data on 24 hour supported housing for elderly is collected – the information on elderly is not disaggregated by care provision. The definition of service types (adults) is not always clear (a) categories may overlap (eg. “ordinary service housing” and “24 hour serviced housing” can be arbitrarily defined) or (b) contain a “mix” of residents with similar needs, but different disabilities.

Completeness and quality:
1. Case records mean that there is little information on institutions or delivery structures. There is no data is available on staffing, data is incomplete on mental health and can only be obtained through municipalities (not a central source).
2. Although separate data is maintained for ID, care is sometimes provided to “mixed” groups at institutional level, so numbers may need disaggregating, and may not reflect actual numbers of either people with ID or other care groups.
3. Data is sorted by gender and some health categories (but not all), but only summated at municipal (rather than the institutional level), so detail and quality is compromised.

Commentary: Finland

1. Overview

Finland has probably the world's most de-centralised decision-making system (WHO, 2002). Finnish municipalities (444) are responsible for the provision of basic services to their residents. Service guidance and monitoring is managed by the Ministry of Social Affairs and Health with the help of State Provincial Offices. The health care system in Finland has changed and developed gradually over a long period of time. Tax-based funding, direct public provision of most services, and governance at a municipal level have been long-standing features of the system. Since the 1970s there has been an increasing emphasis on the role of primary and community care. More recently tighter cost-containment policies have been applied, particularly in social care. Statistics on health and social care are largely provided by the National Research and Development Centre for Welfare and Health (STAKES), who have responsibility for monitoring and assessing developments in health and social welfare, to manage statistics, registers and data gathered at a national level and some aggregated data from the municipalities and to undertake research.

2. Political and social context

2.1 Government organisation and structure

Since 1917 Finland has been an independent republic with its own constitution governed according to the principles of parliamentarianism. Government is a 5 party coalition led by the Social Democratic Party. Legislative power is vested in the parliament and executive affairs of government are decided by the Council of State which is led by the Prime Minister. Finns enjoy individual and political freedoms, and suffrage is universal at 18; Finland was the first country to give full eligibility to women. The country's population is ethnically homogeneous with no sizable immigrant population. Few tensions exist between the Finnish-speaking majority and the Swedish-speaking minority. Finland has had the lowest level of corruption in all the countries for the last several years (Transparency International, 2005). It has been a member of the EU since 1995.

2.2 Disability relevant policy

The equal treatment of people with disabilities and support for their life skills, working and functional capacity and independent living are central objectives of the present Government of Finland. The aims of Finland's disability policy are equitable treatment and support for life management, working capacity, functional capacity and independence. Measures include services, rehabilitation and removal of barriers. The aim is for all general services to be appropriate and sufficient for all citizens; special services such as housing, assistive devices, transportation and interpreter services are never a first resort and measures to develop disability policy include a national disability policy programme to be prepared to guide disability policy actions. The responsibility for disability policy is vested in all the sectors of administration and all societal actors. Also opportunities for independent living are to be supported - housing for people with disabilities is being developed as part of the general housing policy by promoting accessible housing and functional living environments.

3. Demographics

In 2004, the population was 5,236,611, with men accounted for 48.9%. Life expectancy is 74 for men and 81 for women. The average age of the Finnish population is slightly below the EU average, but current projections suggest that the number of people aged 65+ will grow by over 50% in the next 20 years, largely due to rapid decline in cardio-vascular diseases. Circulatory diseases make up a half of all causes of death, with cancer being the second most common cause. Suicide remains a significant cause of death in men under 35. Infant mortality is less than 5 per 1000 (one of the lowest in the world). Health expenditure as a percentage of GDP was 6.8% (1999). Per capita health care expenditure = $PPP 1502 (20% below EU average). The basic structures of society on which the welfare state is grounded have undergone radical changes over the last ten years. People have increasingly gravitated towards the main cities and urban areas to live, as well as to the residential areas of municipalities. Changes in working life have created new labour markets and working relations. People's livelihoods have altered, as have their lifestyles and the role and functions of the family. One consequence of the recession of the 1990s was that the social and health policy environment encountered more risk factors than were previously envisaged. The rise in unemployment demonstrated that paid work and future security could not be taken for granted. Although the livelihood of the population as a whole was not decisively undermined due to the recession and the cuts in social spending, exclusion has become multifarious - because of unemployment and indebtedness, insecurity, uncertainty and helplessness are reflected especially in the situation of children and young people. The universality of social and health services has to now been adequate. But services are undergoing upheavals. There is a special need to develop of new kinds of open services at municipal level.

4. Health and social care system

4.1 Organisational structure

Health care is organised by central government and the municipalities. At the national level, the Ministry of Social Affaires and Health issues framework legislation in health and social care policy and also monitors its implementation. There are several agencies attached to the Ministry, including the National Research and Development Centre for Welfare and Health (STAKES).

There are 5 provinces which promote national and regional objectives of the central administration, supervising specialised and primary health care. The country is divided into 20 hospital districts responsible for providing and coordination of specialist care within their area (consisting of federations of municipalities, with each municipality being a member of a hospital district). The 444 municipalities have responsibility for health promotion and prevention, medical care and rehabilitation. Decisions on health care at a local level are made by the municipal health committee (sometimes merged with the social services committee), the municipal council and the municipal executive board, all of which are politically accountable to the citizens of the municipality.

4.1.1 Management

As the Finnish system is very decentralised, municipalities are responsible for regulation and management of health care. This results in differences and variations between municipalities, but allows for local solutions. Central government role is to steer the system by provision of information, legislation and regulation of some critical aspects such as charges. Municipalities negotiate on an annual basis the provision of hospital services in their corresponding health district.

4.2 Financing

The Finnish health care system provides comprehensive coverage to all of the population and is mainly tax financed. Both the state and municipalities levy taxes. In 1999 43% of health care costs were funded by municipalities, 18% through central government, 15% through a National Health Insurance (NHI) scheme and about 25% through private sources. The central government contribution to municipality health and social care is determined by the population age structure, morbidity plus other computational methods. Approximately half of the municipalities income comes from tax of which a quarter is spent on health care. In recent years there has been a reduction in public spending which has led to an overall increase in private financing (increase in user charges etc). Private health insurance only accounts for less than 2% of health care expenditure.

4.3 Health care

The prime source of health care is provided by health centres. The 1972 Primary Health Care Act created a newly-built network of primary health care centres within which multi-disciplinary teams provide public health services provided at the discretion of the municipalities. The overall responsibility for health status of assigned and geographically defined populations lie within the primary care teams. Health centres provide most preventative services, including child and school health care.

Secondary & tertiary care is provided in public hospitals. There has been an increasing resort to community rather than institutional care, particularly in psychiatry where many long-term patients have been transferred to outpatient, day care, specialised housing or the primary care system. However, beds have been decreasing faster than the expansion of other care systems, and psychiatric services are now a priority area. State subsidies to municipalities for psychiatric services were increased in 2001 and the Ministry of Social Affairs and Health and the Finnish Association of Local & Regional Authorities have recently published new guidelines.

4.4 Social care

Increasingly, emphasis is being placed on preventive action in social welfare in order to safeguard the welfare of individuals. The basic principle is that social aspects and social responsibility need to be taken into account in all policy sectors. A major factor in preventive social welfare is the cooperation between the social and health care sector on the one hand and other authorities on the other, such as those responsible for schools, land use, construction, housing, employment, culture, leisure activities, transportation and other services. It is also important for the service providers to be able to identify and intervene in problems at a sufficiently early stage.

Provision of social services is the responsibility of the municipalities and incorporates care of the elderly and disabled, child day care. These services have experienced financial cuts in the past decade and are subject to new quality measures. Much of Finnish social welfare expenditure is concentrated on the provision of social protection (unemployment payments etc), allowances and benefits to ensure that people can, where possible remain in their homes. For example, there is a system of maintenance payments and allowances to parents, carers and foster carers of children with disabilities to support them where possible outside of care provided by municipally funded institutions.

5. Prevalence of disability

5% of the Finnish population experience significant impairment due to disability or illness and in 2004, over 100,000 people used services for disabled (80% of which were transport services (Ministry of Social Affairs, 2006). 26,500 people used intellectual disability services of whom 45% were living with their families, 29% were in housing services, 10% in institutional care and 4% with special family arrangements. When a law to guarantee rehabilitation services for persons with ID in Finland came into force in 1978, a register was founded for those being served. Based on the standard social benefit registers, the prevalence of intellectual disability in Finland is estimated to be 0.6%, while epidemiological surveys yield 1.1% (Westerinen et al., 2007). From all sources, 5346 children (0-15) were identified with ID, of whom approximately 250 are in some form of residential care.

6. Residential services for people with a disability

6.1 Overview

The provision of services and support measures for the disabled is the responsibility of local authorities (municipalities). Local authorities arrange services such as transport services, sheltered housing, interpreting services and personal assistants. Disability allowance is paid to disabled people aged 16-64. The aim of the allowance is to help the recipient cope more easily at work, in education and with the demands of everyday life. A personal service plan is drawn up for each disabled person to clarify the services and support he or she requires. Officials of the municipality together with the client and his or her carer or relatives prepare the plan. The service plan is designed to improve the clients' autonomy and their possibilities to influence their situation. A counsellor, who is tasked to accommodate the various services together and call meetings of other relevant officials, checks the plan within specified timeframes. Municipal authorities arrange social services for older people on the basis of individual service needs assessments. Such an assessment is based on the client's own views and one or more expert evaluations. Everyone over the age of 80 and everyone with serious disabilities have the right to have a social services needs assessment conducted within a specified period of time. In non-urgent cases, the needs assessment must be conducted within seven days of the municipal authority being contacted; in urgent cases, the needs assessment must be conducted immediately. A personal care and service plan detailing the services and support measures required is drawn up for the older person in question by the municipal authorities together with the client and, if necessary, the client's next of kin or legal representative. The aim of Finland's policy for older people is to promote their functional capacity and independence, with the intention that as many older people as possible could continue to live in their own homes and their familiar environments.

Functional capacity can be maintained and improved with a range of sufficiently early and sufficiently wide-ranging preventive and rehabilitative functions. Living at home can be aided through social and health care services provided by professionals. Opportunities for continuing to live at home can also be improved with a barrier-free environment and the use of assistive devices and new technology. Social welfare housing services and institutional care are available for those who can no longer cope with living at home.

The policy for older people is implemented both nationally and locally. The aim is for every municipality to have a strategy for its policy on older people, in which it lays down guidelines for the development of services. Legislation provides the framework for municipal services. The resources, functional capacity and social networks of older persons are important components for a fulfilling life. Municipal authorities can cooperate with third-sector bodies to promote the welfare and participation of older people.

6.2 Children with disabilities

Officially there are no longer people under the age of 18 in institutional care, although two small units are reported, but no additional information is obtainable. Children with disabilities or special needs mostly live within their own families who are supported by special allowances and community supports and are in mainstream education where possible. Where this does not exist, children are placed outside of homes in private foster care or professional foster homes. There are no residential schools for physically disabled children, or for those with sensory disabilities. Children with mental health problems live in foster homes where not in their own home. Statistics are provided by the bi-annual School Health Project (SHP) which takes the form of a representative sample questionnaire (although there is no information provided with regard to procedures for inclusion of disabled participants). Municipalities then decide whether to publish the results, usually only 100-130 do so, therefore information at a national level is incomplete. There is also a statistics Office of Community Child Welfare, but the statistical focus seems to be on the level of financial supports provided to families and carers.

6.3 Residential services for younger adults (18-65)

Care registers for social welfare and health generally contain client-specific data on institutional care, housing services, regular home care services etc. provided in health and social care. Some also contain discharge data for hospitals and health centre wards, residential homes for elderly people and those for intellectual disability. Individual units may maintain data collected about client characteristics, but this is not collated at a municipal or national level. There is a Local Government Sector Wages and Salaries register that maintains data on personnel across each municipality, but this information is not linked to specific loci of care or service. There is register of visual impairment which contains data on 14,786 individuals.

In the 60s and 70s there were 15 large institutions for people with intellectual disabilities. In the 90s the emphasis shifted to provision of housing services (with supports) for this group. For people with intellectual disabilities “kehitysvammaiset”: (long-term care is defined as more than 90 days/year) in residential care homes (usually referred to as “institutional care” in Finland):

(i) Regular care homes (saannollinen kotihoito) refers to any form of accommodation that has support from either trained or untrained staff, some of which may be 24 hours. Client groups can be mixed. Includes group homes (housing with 24 hour assistance).

(ii) Ordinary service housing (tavaillinen palveluasuminen) refers to day-time only staff or may be non-staffed but supported by a range of professionals on a daily or 5 day basis.

(iii) 24 hour serviced housing (tehostettu palvelsuasuminen) generally non-staffed, with a range of professionals providing day-time support.

Client numbers (figures for 2004):

Intellectual disability institutions	2629
ID 24 hour support housing (care homes)	4691
ID housing part-time support	2653
ID service housing	2559

ID clients by age (2004)

	Institutions	**24 housing**	**P/t-support**	
0-5	8	3	-	11
6-17	118	117	2	237
18-49	1262	2360	1172	4794
50+	826	1403	758	2987
Totals	2214	4066	1930	9200

Source: STAKES, 2005

Separate data is maintained for people with intellectual disabilities, but it is not always possible to identify people with other disabilities across the residential facilities. Some care is provided to "mixed" groups or the type of disability remains undifferentiated.

6.4 Residential care for older adults (65+)

In the 90s, care and services for older people underwent a structural change – institutional care decreased whilst serviced housing (sheltered accommodation) increased. There are few separate statistics or separate information on provision for elderly people for by housing services or in elderly care homes. In 2004 the number of people in residential homes was 20,300 which includes single person dwellings to those that are multiple occupancy. Health care centres have in-patient facilities which have mainly elderly people with strokes etc. Over 11,100 elderly people are cared for in these units. There are some specialised units for the elderly with dementia (but no further information). Most people with dementia are in residential care and form 42.9% of persons in residential and 24 hour care, 5.7% in service housing and 22.3% regular care homes. Some of these elderly adults are people with long-term mental health problems who have been moved from psychiatric institutions, rehabilitation homes or group homes as they have aged and become frailer.

Residential homes (2002)
Homes provided by municipalities under social welfare budgets excluding service housing, 24 hour housing and regular care homes

Residential homes (vanhainkodit) all clients (asiakkast) total (20,738)

Ages:	-64	65-74	75-84	+85
	599	2345	8016	9768

Of those above, in long-term care (pitkaakaisasiakaat)

Ages:	-64	65-74	75-84	+85	
	519	2061	7258	9150	(18,988)

Institutional health care (terveydenhuollen laitoshoito) (this in-patient care is provided by health centres under hospital administration run by municipalities or municipal federations)

Long-term in-patient in health centres (2002)

Ages:	-64	65-74	75-84	+85
	1702	4811	5132	(11,645)

Institutional care & 24 hour housing:
Average stay = 835 days
Average age = 82.8

Figures for 2004 (all older people)

Regular care homes	51323	
Service housing		24835
24 housing	13551	
Residential homes	19424	
Health centres	11069	

6.5 People with mental health problems
Due to changes in statistics and service systems, comparisons between primary and specialised care are increasingly problematic. Some statistical information exists for people with mental health problems (primarily acute) who are in-patients where the primary diagnosis is F00-F99 (DSM 10) (excluding for dementia and intellectual disability) The Hospital Bench Marking Project measures output (episodes of care), but does not contain details on individual long-stay persons. Psychiatric rehabilitation homes and group homes (24 hour staffing) provide for this group but data is only gathered at the individual case record level. Because of the way data is gathered and presented, it is not possible to distinguish between group homes providing for people with intellectual disabilities and those providing for people with mental health problems – there are only broad, global figures as to the numbers of persons and the number of establishments.

Housing for people with psychiatric problems (numbers of clients 2003):

Municipality (social welfare)	384
Municipality (health)	261
Private provision	4090

6.6 Private provision

Private welfare provision includes care for children and young people, services for people with disabilities, intellectual disabilities and the elderly produced by a mix of companies, cooperatives, associations or other community foundations in which the service provider provides a business or professional activity or role for payment – which in most cases comes from the purchasing municipality. Private services paid by municipalities account for 21% of the personnel in the field. Municipalities keep statistics on payments made direct to providers and payments of allowances and benefits to clients in their care, but do not keep aggregate data on clients.

Private provision for people with disabilities (2004)

	Total	Non-profit	Business
Institutions young	431	72	**358**
ID residential homes	7	5	**2**
Group homes	**1273**	**658**	**615**

Source: STAKES, 2005

Numbers of staff in private social welfare provision:

	Non profit	**Business**	**total**
ID institution	850	29	879
Older peoples	3247	231	3778
Service housing	8863	3640	12503
Other	200	48	248

7. Staffing

Statistics exist for staffing at municipal level, but are maintained at the level of service provision rather than occupational grouping and are recorded as "man hours" per year, rather than numbers of each occupation. Therefore it is not possible to indicate the numbers, type or grade of staff in any one institution, nor for any institutional type (intellectual disability, physical disability or mental health).

Figures for 2004 list the numbers of municipal employees by occupational group including:

Managers	3620
Doctors	11500
Social workers	5250
Speech therapists	550
Nurses	3500
SW instructors	6720
Craft trainers	920

Practical nurses	31400
Practical mental nurses	3020
M handicap nurses	2710
SW assistants	1640
Personal care assistants	870
Home care assistants	11600

There is no information available that indicates where the staff are employed or how many of each occupational type work in any particular resource.

8. Issues

8.1 Ethnicity

Ethnicity does not appear to be a major issue in Finland. All major government literature, as many other publications, broadcasts etc. is published in both Swedish & Finnish for historical reasons. Available statistics do not distinguish or provide information on ethnic groupings and there is little information on the effects of any recent immigration.

8.2 Gender

Finnish statistics only provide broad data on gender in health and social welfare as garnered from individual case records/registers. There is some information on the percentages of each gender across the type of service provision which allows some inferences to be drawn. The occupational information does not provide information on gender, only on occupational grouping.

8.3 Age

Data reveal that Finland has an ageing population, with increasing numbers of older people, including people with a range of disabilities in need of support and care. The data held is from a long comparative time series so it is possible to determine numbers of persons by type of residential facility for people in certain age group ranges over 65. The same information does not appear to be available for persons between the ages of 18-65. This information is gathered at individual case register level only.

8.4 Regional/geography

Information provided at municipal and regional level require further analysis to confirm if there are regional or geographical variations in health and social welfare or in the provision of services. There are some indications that there may be regional variations in wealth and availability of health care, with the capital and more populous south east experiencing advantages over the relatively isolated and thinly populated northern areas. The system which gives great autonomy to municipalities also leads to great variations and potential inequities.

The Finnish health care system has survived the severe economic crisis of the 1990s, the quality and quantity of services essentially maintained, although there are marked variations in per capita expenditure and activities between different municipalities. In addition it is unclear if the reduction in capacity and length of stays in hospitals and other institutions has been compensated by expanded community services. Absence of certain kinds of data, for example, on length of stay by institution makes comparisons

between services more problematic and disguises the pattern of provision of social welfare and care to people with disabilities.

9. Acknowledgements

Sari Kauppinen (STAKES)

10. Information sources

10.1 Information sources

1. National Research and Development Centre for Welfare and Health (STAKES, www.stakes.fi)

2. SOTKAnet (central statistical information on-line service) (www.sotkanet.fi)

3. Statistics Finland (Register of Municipal Employees) (www.stat.fi)

10.2 Verification of information

On-site visit and meeting with sources 28-31 August 2006.

Sari Kauppinen, STAKES, 29/08/2006
Olli Nylander, STAKES, 30/08/2006
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Appendix 1: Finland "typical" case scenario

Maria is a 22 year old woman with severe learning disabilities who also presents some behavioural problems. Maria is unable to live on her own without constant care. Until her mother died recently, she lived in the family home, receiving some supports from the municipality. There are no other immediate family.

Given that Maria has been living at home until now, and bearing in mind the nature of her disabilities, what would have been her likely pattern of education and care to this point?

All children living permanently in Finland are legally obligated to complete the compulsory education syllabus. If a pupil (like Maria) cannot achieve the goals of the general syllabus, the syllabus is individualized to fit her personal requirements. If due to the student's severe handicap or illness (like Maria) education cannot be provided according to subjects in line with the planned syllabus, the education is provided by activity areas (motor skills, social skills, cognitive skills, and skills in daily functions, as well as language and communication). Compulsory education also starts one year before the normal prescribed starting age, and lasts 11 years (from 6 years to 16 years). Because her mother's work day lasted longer than Maria's school day, she has been in morning and/or afternoon activities. Before she started the school at the age of 6, Maria was in day care in normal day care centre for a few years. Children like Maria have usually an assistant (financed by municipality) in the day care group. During these 22 years Maria and her mother have been offered both financial and consulting support. After school (at the age of 16) Maria started to go to a centre for daily activities and sheltered work for persons with disabilities.

Who would have provided and paid for these services? How would have this been decided and by whom?

Municipalities are responsible to arrange a cost-free compulsory education for everyone and it is provided by public schools mostly in special groups for pupils like Maria. Extra support (on the base of disability) is funded by municipality. So special care for people with intellectual disabilities is also free and it is provided by municipalities. In day care there is a client fee depending the income level of the family.

What is the most likely outcome for Maria now? (What, realistically, might Maria expect from health or social welfare services?). What input might Maria or her advocate/representative have in this process?

Municipality will organise housing services for her. She will probably move to a group home for people with intellectual disabilities. She also will continue to go to a centre for daily activities and sheltered work for persons with disabilities. She gets normal health care services and financial support (pension and care allowance for pensioners from the Social Insurance Institution) like when she lived with her mother.

Who would typically be responsible for providing services? (ie. what department, which professions would be involved, who would be responsible for determining or managing care and how might this be paid for?)

Municipalities are responsible for organising and funding services. Municipalities collect taxes and receive state subsidies for organising services. Municipalities can produce services by themselves or they can purchase services from other municipalities, joint municipal boards, non-profit organisations or business enterprises. Housing services for people with intellectual disabilities are mainly provided by municipalities and joint municipal boards. Non-profit organisations provide 22% and business enterprises 12%. Also centres for daily activities and sheltered work for persons with disabilities are mainly municipally owned. Non-profit organisations produce 12% and business enterprises only 1% of this service. Maria pays her rent, food, clothes, recreation and other personal costs. Personnel in these services have social and health care education. They can for example be practical nurses or social work instructors and educators.

What factors might influence her pathway or access to services? (for example, entering residential care provided by a church-based organisation versus a state-run facility, or residential care home over nursing home, or day support rather than educational or work facilities). How is one type of service chosen over another? How is this decided and by whom?

The municipality grants social services on the basis of an individual service needs assessment. Such an assessment is based on the client's own views and on one or several expert evaluations. Everyone over the age of 80 and everyone receiving care allowance for pensioners from the Social Insurance Institution (like Maria) have the right to obtain an assessment of social service needs within a specified period of time (within seven days). A personal care and service plan on the required services and support measures will be prepared for the client. These plans are prepared by the municipal authorities together with the client or, where necessary, with a family member or legal representative.

(Information provided by Sari Kauppinen)

Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

France

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Summary of the available data

Description of service types

The table below summarise the descriptions of the 12 service types included in the template.

Type of service	Size interval	Age group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admission	Age of service
Etablissements d'éducation spéciale pour enfants déficients intellectuels	51 to 99 places	3 to 25 years	ID only	Mixed pattern within institutions (internat, externat, demi-internat)	Voluntary/not-for-profit (over 95%)	Mixed benefits/social security and state/LA contributions	All long term	21 to 50 years
Etablissements d'éducation spéciale pour enfants déficients moteurs (annexe 24 bis)	51 to 99 places	3 to 25 years	PD	Mixed pattern within institutions (internat, externat, demi-internat)	Voluntary/not-for-profit (over 95%)	Mixed benefits/social security and state/LA contributions	All long term	.
Maisons d'acceuil spécialisées (MAS)	31 to 50	20 to 60	Mixed	.	Voluntary/not-for-profit (over 95%)	Mixed benefits/social security and state/LA contributions	Mixed	0 to 20 years
Instituts d'éducation sensorielle pour enfants atteints de déficiences visuelles ou auditives (annex	51 to 99 places	3 to 25 years	Sensory impairments	Mixed pattern within institutions (internat, externat, demi-internat)	Voluntary/not-for-profit (over 95%)	Mixed benefits/social security and state/LA contributions	All long term	.
Foyers d'hebergement	51 to 99 places	20 to 60	More than one disability group served (no main group) but not mixed	Night and weekend support only - people out during day	Voluntary/not-for-profit (over 95%)	Mixed benefits/social security and state/LA contributions	All long term	.

Type of service	Size interval	Age group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admission	Age of service
Services d'accueil de jour et /ou d'hebergement (SAJH) pour vieillissant	.	over 60/65	Mixed ID with PD, SD, MH,Beh and other	Mixed pattern within institutions (internat, externat, demi-internat)	Voluntary/not-for-profit (over 95%)	Mixed benefits/social security and state/LA contributions	All long term	0 to 20 years
Etablissements pour enfants polyhandicapés (IME annexe 24 ter)	31 to 50 places	3 to 25 years	Mixed ID with PD, SD, MH,Beh and other	Mixed pattern within institutions (internat, externat, demi-internat)	Voluntary/not-for-profit (over 95%)	Mixed benefits/social security and state/LA contributions	All long term	21 to 50 years
Services d'accueil de jour et /ou d'hebergement (SAJH)	11 to 30 places	20 to 60	More than one disability group served (no main group) but not mixed	Mixed pattern within institutions (internat, externat, demi-internat)	Voluntary/not-for-profit (over 95%)	Mixed benefits/social security and state/LA contributions	All long term	.
Foyers d'accueil médicalisés (FAM) pour vieillissant	11 to 30 places	over 60/65	Mixed ID with PD, SD, MH,Beh and other	24 hour	Voluntary/not-for-profit (over 95%)	Mixed benefits/social security and state/LA contributions	All long term	0 to 20 years
Institut thérapeutiques, éducatifs et pédagogiques - ITEP (décret 6 janvier 2005))	31 to 50 places	3 to 25 years	Beh/Emotional/ Social/Learning Difficulties	Mixed pattern within institutions (internat, externat, demi-internat)	Voluntary/not-for-profit (over 95%)	Mixed benefits/social security and state/LA contributions	All long term	21 to 50 years
Foyers d'accueil médicalisés (FAM)	31 to 50 places	20 to 60	More than one disability group served (no main group) but not mixed	Mixed pattern within institutions (internat, externat, demi-internat)	Voluntary/not-for-profit (over 95%)	Mixed benefits/social security and state/LA contributions	All long term	21 to 50 years

Type of service	Size interval	Age group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admission	Age of service
Maisons d'acceuil spécialisées (MAS) pour vieillissants	.	over 60/65	Mixed ID with PD, SD, MH,Beh and other	24 hour	Voluntary/not-for-profit (over 95%)	Mixed benefits/social security and state/LA contributions	All long term	0 to 20 years

Data available by service type – breakdown by disability

N.B. Breakdown of places by size was not available from official statistics. In addition figures were provided across all children's services and not by service type (except for staffing data) and no distinction made between services for older and younger adults in the official statistics.

Type of service	Places total	ID	MH	PSD	Elderly/ dementia	Mixed/ dual	Other/ unclassified
All childrens services (for type of disability)	129362	66641	26134	23520	.	7840	5227
Maisons d'acceuil spécialisées (MAS)	14037	6738	1123	1263	.	4773	140
Foyers d'hebergement	38243	29830	5354	2095	.	382	582
Services d'accueil de jour et /ou d'hebergement (SAJH)	34141	24582	4780	3414	.	1024	.
Foyers d'accueil médicalisés (FAM)	9044	3979	1628	1899	.	1357	181
Total	224827	131770	39019	32191		15376	6130

Data available by service type – breakdown by gender and age

Type of service	Places total	Male	Female	Gender not classified	Children	Younger adults	Older adults	Adults over 18	Age not classified
All childrens services (for type of disability)	129362	.	.	.	108903	.	.	.	20459
Maisons d'acceuil spécialisées (MAS)	14037	7861	6176	0	.	13616	421	.	0
Foyers d'hebergement	38243	22563	15680	0	.	32095	1147	.	5001
Services d'accueil de jour et /ou d'hebergement (SAJH)	34141	18778	15363	0	.	32434	1707	.	0
Foyers d'accueil médicalisés (FAM)	9044	5245	3798	1	.	.	.	.	9044
Total	**224827**	**54447**	**41017**	**1**	**108903**	**78145**	**3275**		**34504**

Staffing

Type of service	Total number of staff in each type of service	Number care staff/nurses/ might include teachers in boarding school	Number managers or other administrative staff (not care staff)	Number educators/ daystaff	Number clinical staff (Drs, therapists, psychologists etc)	Number of other staff (mainly ancillary staff)
Etablissements d'éducation spéciale pour enfants déficients intellectuels	39870	4386	5183	21540	.	8771
Etablissements d'éducation spéciale pour enfants déficients moteurs	6279	1821	753	2449	.	1256
Instituts d'éducation sensorielle pour enfants atteints de déficiences visuelles ou auditives	5620	674	731	3260	.	995
Etablissements pour enfants polyhandicapés	4530	1178	453	2039	.	860
Institut thérapeutiques, éducatifs et pédagogiques - ITEP	11460	917	1604	6188	.	2751
Maisons d'acceuil spécialisées (MAS)	15310	4899	1358	5971	.	3062
Foyers d'hebergement	16531	661	2645	9092	.	4133
Services d'accueil de jour et /ou d'hebergement (SAJH)	20551	1644	2466	11303	.	5138
Foyers d'accueil médicalisés (FAM)	8239	2554	741	3296	.	1648
Services d'accueil de jour et /ou d'hebergement (SAJH) pour vieillissant	.	.	.	.	.	.
Foyers d'accueil médicalisés (FAM) pour vieillissant	.	.	.	.	.	.
Maisons d'acceuil spécialisées (MAS) pour vieillissants	.	.	.	.	.	.
Total	**128390**	**18734**	**15934**	**65138**		**28614**

Completeness and accuracy of the data

The template for France was completed by contacts with UNAPEI and the data provided in the template for France is mainly taken from "Handicap en Chiffres, 2005" (Disability in Numbers, 2005) produced by CTNERHI, de la DREES et de la DGAS. In addition, the following sources were used for context and information:

Guide du secteur social et médico-social - Edition DUNOD (guide of the social and medical-social sector)
Décret du 11 mars 2005 relatif aux SAVS et Samsah (decree of 11 march 2005)
Décret du 25 juin 2004 relatif au SSIAD (decree of 25th of June)
Les annexes 24 du décret du 27 octobre 1989 relatives aux établissements d'éducation spéciale (enclosures 24 of the decree of the 27th of october 1989 of special education services)
Etat des lieux des pratiques en CAT - CTNERHI (state of practice-places)

The "Handicap en Chiffres" reports are produced on an annual basis and focus on the number of people with disabilities by type of institution. When the figures are compared to those from other sources in earlier years such as the Direction de la recherche, des études, de l'évaluation et des statistiques (http://www.sante.gouv.fr/drees/index.htm and http://www.sante.gouv.fr/drees/tabdbord/doc.htm), the figures are very similar. In all cases, however, there is no distinction made between the numbers who attend the some of the service types during the day and those who are residential there. All of the services listed here appear to have an educational element. Whilst the official statistical sources include over 100,000 places in special services for children, it is likely that only half of these are residential places – for example, Mormiche (1999) reports that in 1995 there were 46,000 children resident in establishments for disabled children. Data collected in 1998 for the Enquête Handicaps-Incapacités-Dépendance en Institution, indicate a figure of just over 48,000 children in institutions in France. These figure are not broken down by type of establishments and the data is quite old but even if the increase from 1995 to 1998 was to continues at the same rate, one would not expect the number of those resident to be greater than 53,000 - it is highly unlikely that the number of children in residential care would have more than doubled in the last 10 years.

In terms of the figures for adults, again there is the problem that at least some of the places included for adult services are for people attending on an "Externat" basis. The template includes just over 95,000 adults in services for people with disabilities, excluding those in psychiatric services. This is very similar to earlier government statistics produced by the Direction de la recherche, des études, de l'évaluation et des statistiques in earlier years – in 2001 the number of places for adults with disabilities (not older people) was just over 99,000. Mormiche (1999) reports a figure of just under 80,000 adults with a disability resident in institutions and the report from the Enquête Handicaps-Incapacités-Dépendance en Institution reports that in 1998 there

were just under 83,000 adults with disabilities in institutions in France. If the numbers of people in institutions continued to increase at the same rate as between 1995 and 1998 then one might expect that in 2005 there would be approximately 90000 adults with disabilities resident in institutions, which would imply that only a small percentage of those listed in the Handicaps en Chiffre data are "externat".

The "Handicap en Chiffres" reports give very little information about the size or other characteristics of the services although do give some information on staffing. They also do not appear to include information on psychiatric services or on smaller community-based services, both of which are known to exist in France. There appear to be no official (or non-official) data on the number of people in smaller community based services – however it may be that these places are included in the places by institution as many of the community based services have been developed by those running the institutions and it is possible that the numbers are included in the places by institution.

With regard to mental health services, earlier reports do give information on psychiatric inpatients – for example, Mormiche (1999) reports a figure of just under 65,000 people in Psychiatric institutions in 1995, which has increased to almost 71,000 in 1998 according to the report from the Enquête Handicaps-Incapacités-Dépendance en Institution.

Commentary: France

1. Overview

The French Republic is a democracy that is organised as a unitary semi-presidential republic. It is a developed country with the sixth-largest economy in the world. Its main ideals are expressed in the Declaration of the Rights of Man and of the Citizen. France is one of the founding members of the European Union, and has the largest land area of all members. France is also a founding member of the United Nations, and a member of the Francophonie, the G8, and the Latin Union.

2 Political and social context

2.1 Government organisation and structure

France is divided into 26 administrative regions. 22 are in metropolitan France (21 are on the continental part of metropolitan France; one is the territorial collectivity of Corsica), and four are overseas regions. The regions are further subdivided into 100 departments. Four of these departments are found in the overseas regions and are simultaneously overseas regions and overseas departments and are an integral part of France (and the European Union) and thus enjoy a status similar to metropolitan departments. The metropolitan departments are subdivided into 342 arrondissements which are, in turn, subdivided into 4,035 cantons. These cantons are then divided into 36,682 communes, which are municipalities with an elected municipal council. Three communes, Paris, Lyon and Marseille are also subdivided into municipal arrondissements.

The regions, departments and communes are all known as territorial collectivities, meaning they possess local assemblies as well as an executive. Arrondissements and cantons are merely administrative divisions. However, this was not always the case. Until 1940, the arrondissements were also territorial collectivities with an elected assembly, but these were suspended by the Vichy regime and definitely abolished by the Fourth Republic in 1946. Historically, the cantons were also territorial collectivities with their elected assemblies.

2.2 Disability relevant policy

The Acts of 2002 and 2005, renewed and modernised the old laws of 1975 on the orientation of disability and the definition of the medico-social structures. The Act of 2002 (Act No. 2002-73) introduces the right to compensation for the consequences of disability and to a guaranteed minimum income.

The Act No 2005-102 (2005) on equal rights and opportunities, participation and citizenship of people with disabilities further extended the right to compensation by introducing a compensatory disability benefit, which is administered through a care package for which people are assessed by local authorities and social security officers, following a request from the person themselves. The Act created a “Maison Départementale des Personnes Handicapées” in each Department. The objective of these bodies is to respond to the needs of each person with a disability through the life plan/project for each person. The 2005 Act also introduced the idea of more personalised assistance through direct payments. This new payment concerns human support, technical support, support in finding housing or “des aides à l’aménagement

du vehicule". The law also gives people the right to education, training and career guidance, the right to employment and it requires improvements in accessibility of public places in order to improve integration in society.

3. Demographics

With an estimated population of 64 million people, France is the 23rd most populous country in the world. France's largest cities are Paris, Marseille, Lyon, Toulouse, Nice, and Nantes.
In 2003, France's natural population growth (excluding immigration) was responsible for almost all natural population growth in the European Union. In 2004, population growth was 0.68% and then in 2005 birth and fertility rates continued to increase. The natural increase of births over deaths rose to 270,100. The lifetime fertility rate rose to 1.94 in 2005, from 1.92 in 2004.

In 2005, net immigration fell slightly in 2005 to 97,500. Despite this, France is an ethnically diverse nation. According to the French National Institute for Statistics and Economic Studies, it has an estimated 4.9 million foreign-born immigrants, of which 2 million have acquired French citizenship. France is the leading asylum destination in Western Europe with an estimated 50,000 applications in 2005 (a 15% decrease from 2004).

4. Health and Social Care System

The sector of "l'Action sociale" must cover 4 major objectives (Code de l'action sociale et des familles, article L.116.1) :
- autonomy and protection of people
- social cohesion
- practice of citizenship
- prevention of exclusion and correction of its results

4.1 Organisation

The French social system is built-up by a wide range of bodies and activities. We find a wide range of temporary or sequential accompaniment, with or without housing, fulltime or part-time, in a service or in the family.

Recent research introduces new categories of establishments or services such as the resource centres and mobile teams which facilitate support of people with disabilities in the community and systems which provide for older people with disabilities.

There are 3 different ways for service providers to manage these establishments and services: private and for profit, private not for profit and public.
The public sector is not very present in the disability-field but much more in the health-sector and the field of elderly people. Private for-profit organisations can basically be found in the field of houses for elderly and "home care"; the private not-for-profit organisations represent 80% of the activities for people with disabilities, the inclusion of people with important social difficulties and children in danger. Most services for adults with disabilities are provided by not-for-profit organisations, in many cases parent-led organisations.

4.2 Financing

There is no longer state funding for residential institutions, except a few experimental services for people with autistic spectrum conditions. All adult services are funded by Local Authorities/Departments and through social security.

The establishments or the services propose provisional budgets, which are negotiated with the financial authorities and which follow the field of competence of these authorities (basically ETAT, Department and Social Security). For example, a specialised day care centre which hosts people with severe disabilities is financed by social security, while a "foyer de déficients intellectuels légers ou moyens", or "un service d'accompagnement" are the responsibility of the Departments. An establishment or service giving support in the field of employment (ESAT) is financed by the Ministry of Labour (when talking about the social framework – the wages of the employees with a disability and the material and technical means they need for their professional activities are financed by the results of the economical activities as in every ordinary firm).

The 2006 paper by the Ministère des Affaires étrangères stated that in 2004 the budget allocated to the policy for the disabled came to €29billion

5. Definition, eligibility and diagnosis/assessment

Concerning to the law "a disability is … all limitation in activities or restriction in the participation of life in the society, which a person undergoes in his surroundings due to a significant, ongoing or lasting impairment of one or more functions be it physical, sensorial, mental, intellectual or psychological, due to a polyhandicap or due to disabling health-problems."

The decisions related to the rights of people in terms of allowance andorientation is guaranteed by the ‚Commission des Droits et de l'Autonomie'. This multidisciplinary team operates within the „Maisons Départementales des Personnes Handicapées".
This organisation is responsible for the orientation of the person with a disability and the choice of which measures are most suitable to guarantee his integration in education or employment. She decides on the level of „disability" of the person which justifies the attribution of the allowance as well as the possible allocation of a „disability card" (giving access to parking places or specific transport facilities for people with disabilities).

6. Prevalence of disability

Initially the decisions concerning orienting a person with a disability had a national dimension. (the person could prevail upon it in the entire country). Lately there has been a tendency to have these decisions taken on the level of the Departments, even if the financial responsibility falls to the state. However the law sets out two main principles: "égale dignité de tous les êtres humains" (equal dignity/respect for all human beings) and "accés équitable sur l'ensemble du territoire" (Equal access across land)

The Ministère des Affaires étrangères (2006) reported that there were five million disabled people living in France, two million of whom have physical mobility problems. However, these figures include those who have become disabilities in later

life – e.g. 30% of physical disabilities are caused by accidents. The 2006 paper reports that 135,000 disabled children attend ordinary schools and 110,000 got to specialised institutions.

7. Residential Services for people with a disability

7.1 Overview

The HID survey in 1998 found that 74% of places were in institutions of greater than 50 places, with 29% of places in institutions of more than 100 places. In fact it appears that there has been a growth in the number of places in institutions to some extent but it is hard to be certain as the data reported within official sources is not complete and not broken down adequately to explore this issue. It is, however, known that over the past decade there has been some development of smaller community based services within France but there is no data available which report the extent of these services, nor for whom they provide. If they are counted at all in the figures presented above, then it is likely that they are counted as places within the institutions which run them, even though not on the same site.

Of those within institutions, the vast majority are older people without any pre-existing disability. The HID survey found that 55% of their sample living in institutional settings (not including psychiatric institutions) were older people. 2001 data from the Direction de la recherche, des études, de l'évaluation et des statistiques indicated that whilst there appeared to be 99,000 places for adults with disabilities, there were 668,500 places for older people, the majority of these living in "maison de retrait".

There appear to be several types of services in France:

- Etablishments Sanitaire, which offer medical care along with rehabilitiation and education, speech therapy etc. – many of these are day services although some will provide some residential care, mainly on a short-term basis.
- Etablishments medico-sociaux, which provide people support in their daily lives, for example Centres d'hebergements, foyer d'hebergement, foyer occupationnel etc.
- Etablissement de travail protégé, which are sheltered workshops and employment opportunities but do not provide residential care.
- Institutions specialisees de scolarisation ou de formation, for example Institut médico-éducatif (IME), Institut médico-pédagogique (IMP) et institut médico-professionnel (IMPro); Institut d'éducation motrice (IEM) – these provide both educational and residential provision, mainly for younger people.

7.2 Services for children with a disability

Almost all services which provide residential provision for children with a disability appear to have an educational component. The types of services on which data is available in the template are described below with additional categories from other sources also highlighted. It is acknowledged that the number of children in "internat" services is declining and these are being placed by domiciliary services to the family.

7.2.1 Etablissements d'éducation spéciale pour enfants déficients intellectuels

Special education service for children with an intellectual disability (Medical-educational Institution): these institutions welcome children and adolescents with a mental disability whatever the degree of their disability.

7.2.2 Etablissements pour enfants polyhandicapés

Institutions for children with multiple disabilities (Medical-educational Institution from the enclosure 24ter): these institutions welcome children who suffer from multiple disabilities where both a severe mental disability and a major physical disability result in an extreme restriction of their autonomy.

7.2.3 Instituts thérapeutiques, éducatifs et pédagogiques

Therapeutic, educational and pedagogical institution: they welcome youth where manifestations and behavioural problems make it necessary, in spite of normal or quasi normal intellectual capacities, to use specialised medical, educational means. These institutions might include some people with autism or mild intellectual disabilities and challenging behaviour. In essence however they are children with emotional and behavioural difficulties.

7.2.4 Etablissements d'éducation spéciale pour enfants déficients moteurs

Institutions providing special education for children with a physical disability: they receive children with physical disabilities, whether or not associated with other disabilities.

7.2.5 Instituts d'éducation sensorielle pour enfants atteints de déficiences visuelles ou auditives

Institution specialising in sensory education for children with visual or auditory impairments: These can be institution of care and special education with a special unit for children with auditory impairments and/or a special unit for people with visual impairments; or they can institutions of care and special education specifically and entirely for those who are deaf and blind

7.2.6 Services d'éducation spéciale et de soins à domicile (SESSAD) :

These are outreach educational services which provide support to disabled children in their own home, in crèches and in ordinary schools.

For children under 6 years of age there are also Centre d'action médico-sociale précoce (CAMSP) for assessment, treatment and rehabilitation of children with sensory, physical and intellectual disabilities.

7.3 Services for adults with a disability

The figures available do not differentiate those over 60 who have a disability, although services specific for older people do exist as illustrated below.

7.3.1 Foyers d'hébergement

This is a residential homes which provides accommodation and support at night and in the weekends for people with disabilities who attend a work-based placement during the day either in a sheltered work place (Etablissements et services d'aide par

le travail- ESAT) or in a normal work environment. The majority of people living in these services have intellectual disabilities. No minimum or maximum stay applied.

7.3.2 Services d'accueil de jour et /ou d'hébergement (SAJH)

Services of day-care and/or accommodation (SAJH) : relief centres for living, relief centres for occupation or daycare. They welcome disabled adults with reduced autonomy but who don't need permanent surveillance or care.

7.3.3 Foyers d'accueil médicalisés (FAM)

These residential services provide accommodation and medical based support for persons with a severe disability or with multiple disabilities, unable to work and in need of support for even the most essential activities of life.

7.3.4 Maisons d'accueil spécialisées (MAS)

These services provide for adults with a severe disability who need 24 hour support with some medical care and cannot engage in any activities without support.

7.3.5 Services for older people with disabilities

In general the same type of services are available for older people. There are:

- Services d'accueil de jour et /ou d'hebergement (SAJH) pour vieillissant
- Foyers d'accueil médicalisés (FAM) pour vieillissant
- Maisons d'acceuil spécialisées (MAS) pour vieillissnts

However, the number of people in these services is not distinguishable from those in services for younger people. There are also “maisons de retraite” which in 2001 provided for 436,000 older people, the majority of people of whom are not thought to be people with a pre-existing disability. However, it is possible, given the pattern in other countries, that some of those in these “maisons de retraite” would include people with disabilities and in some cases younger people with disabilities if a suitable service has not been found elsewhere.

7.3.6 Other services for children or adults with disabilities

The Typologie des Etablissements Specialises (Ministère de la culture et de la communication, 2007) also indicates that there are “centres d’hébergement” which provide support in daily life for an non-determined length of time for children, adolescents and adults with disabilities. The “Foyers à double tarification” and “Foyers de Vie” are similar to the MAS in providing support for adults with severe disabilities judged unable to work or attend a workshop environment. These services are completely residential and have 24 hour staff present, with nursing support provided.

8. Staffing

Data on staffing is available for most of the service types listed through the “Handicap en Chiffres” report and the data are summarised in the tables at the beginning of this report. However, little is known about staff qualifications from official data although those working in institutions are required to have at least a Diploma level qualification in social work, social pedagogy or the equivalent.

9. Current Issues

There don't seem to be specific problems concerning ethnicity in the field of disability in France, but some kinds of disability are still not taken enough into account, as happens for example for people with autism.

There has in France been an evolution towards more „prises en charge à domicile" (care at home) both for children (services of specialised education and care at home) and for adults (SERVICE d'Accompagnement, SAMSEAH), often through the conversion of places in residential settings.

Until some years age the financial responsibility for disability-related issues was almost exclusively with the state or the medical insurance. Now the state withdraws more an more from this sector at the expense of the departments who see their field of competences in the social and medico-social domain increasing more and more. we see that in 20 years the expenditure on social help of the departments have increased more the 160% - 9 % between 2002 and 2003. Due to the transfer of the RMI in 2004 the costs have increased dramatically.[21]

12. Acknowledgements

Julien Schellenberger, IRTS, Paris, who helped to provide information on the definition of each service type and alternative sources for statistics in order to just the completeness and accuracy of the data in the template.

Christine Bon, for reading and commenting on a draft of this report and for providing information to ensure accuracy of the information presented.

13. Information sources on disability used to compile the template and commentary, including people who were interviewed

http://en.wikipedia.org/wiki/France

Direction de la recherché, des etudes, de l'evaluation et des statistiques **(www.sante.gouv.fr/drees/index.htm; www.sante.gouv.fr/drees/tabdbord/doc.htm)**

Interview with Mr. Michel Baelen

14. References

Mormiche, P (1999) Les personnes dépendants en institution. *Insee Premiere,* no 669 August.

Enquête Handicaps-Incapacités-Dépendance en Institution: Octobre-Novembre-Décembre 1998

Ministère de la culture et de la communication (2007) *Le Dictionnaire du Handicap 7th édition*, 01/2007 Editions Ecole Nationale de Santé Publique www.culture.gouv.fr

[21] Source : editions WEKA

Ministère des Affaires étrangères (2006) *La France à la Loupe: Policy for the disabled in France.*

Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

Germany

Prof. Dr. Albrecht Rohrmann, Dr. Johannes Schädler

Center for Planning and Evaluation of Social Services (*ZPE, University of Siegen*)

Summary of available data

Descriptions of service types

Type of service	Size Interval (places)	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions	Age of service
Außenwohngruppen (small group home which is part of a larger residential service)	6 to 10	Over 18/25 (i.e. adults only)	Mixed ID with PD, SD, MH, Behavioural and other	Night and weekend support only - people out during day	Mixed	Mixed state/local and private contributions (insurance/private)	All long term	0 to 20 years
Internat (residential home for children who visit a school in the same organization)	11 to 30	3 - 25	More than one disability group served (no main group) but not mixed	Night and weekend support only - people out during day	Mixed	Mixed state/local and private contributions (insurance/private)	All long term	50 - 100 years
Wohneinrichtungen für psychisch Kranke (residential homes for people with chronic mental health problems)	11 to 30	Over 18/25 (i.e. adults only)	MH	24 hour	Mixed	Mixed state/local and private contributions (insurance/private)	All long term	21 to 50 years
Wohnheime / Anstalten (larger residential home or campus institutions for people with intellectual and multiple disabilities who work regularly in sheltered workshops use a day care service in the same organization)	31 to 50	Over 18/25 (i.e. adults only)	Mixed ID with PD, SD, MH, Behavioural and other	24 hour	Voluntary/not-for-profit (over 95%)	Mixed state/local and private contributions (insurance/private)	All long term	100+
Psychiatrische Kliniken (special hospital for people with psychiatric problems)	31 to 50	.	MH	24 hour	Mixed	Regional authority/LA/County and state	All long term	100+
Pflegeheime für Behinderte (nursing homes particularly for younger adults with	31 to 50	.	PD	24 hour	Mixed	Mixed (any)	Mixed	0 to 20 years

Type of service	Size Interval (places)	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions	Age of service
different types of severe disabilities)								
Berufsbildungswerke (residential home for young people with different types of disabilities who make a vocational training)	201 +	Over 18/25 (i.e. adults only)	PD and Sensory/other	Night and weekend support only - people out during day	Voluntary/not-for-profit (over 95%)	Benefits/social security	.	21 to 50 years
Wohnheime (residential home with internal or external organised day structure for older people)	.	Over 18/25 (i.e. adults only)	Mixed ID with PD, SD, MH, Behavioural and other	Per day only - no night time cover	Mixed	Mixed state/local and private contributions (insurance/private)	Mainly long term	21 to 50 years
Wohneinrichtungen für Menschen mit autistischen Zügen (residential homes for people with autism)	11 to 30	Over 18/25 (i.e. adults only)	ASD	24 hour	Voluntary/not-for-profit (over 95%)	Mixed state/local and private contributions (insurance/private)	All long term	0 to 20 years
Heilpädagogische Kinderheime (residential home for children who visit a day care service or a school in an other organization)	.	0 - 25	Mixed	Mixed depending on need	Voluntary/not-for-profit (over 95%)	Mixed state/local and private contributions (insurance/private)	All long term	.
Berufsförderungswerke (residential home for people with different types of disabilities who make a training for a new job)	201 +	Over 18/25 (i.e. adults only)	PD and Sensory/other	Night and weekend support only - people out during day	Voluntary/not-for-profit (over 95%)	Mixed benefits and state/LA contributions	.	21 to 50 years
Pflegeheim (nursing home)	51 to 99	All ages (0 to death)	PD and Sensory/other	24 hour	Mixed	Mixed state/local and private contributions (insurance/private)	Mainly long term	.
Wohnstätten (smaller residential home for people with intellectual and multiple disabilities who work regularly in	31 to 50	.	Mixed ID with PD, SD, MH, Behavioural and other	Night and weekend support only - people out during day	Mixed	Mixed state/local and private contributions (insurance/private)	Mixed	0 to 20 years

Type of service	Size Interval (places)	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions	Age of service
sheltered workshops or visiting a day care service outside the organization)								
Wohngemeinschaften (small group home)	Less than 6	Over 60/65	Elderly infirm/mentally ill/dementia	24 hour	Voluntary/not-for-profit (over 95%)	Mixed state/local and private contributions (insurance/private)	All long term	0 to 20 years

Data available by service type – breakdown by size, gender and age.

Only information was available for nursing homes.

Type of institution	Places total	Under 30 places	Over 30 places	Size unspecified	Male	Female	Gender unspecified	Children	Younger adults	Older adults
Pflegeheim (nursing home)	676682	2757	7667	666158	676682	2757	7667	241	30941	645500

Staffing

Type of service	Total number of staff	Care staff/nurses/ might include teachers in boarding school	Managers or other administrative staff (not care staff)	Educators/day staff	Day and care staff (no distinction made)	Clinical staff (Drs, therapists, psychologists etc)	Other staff (mainly ancillary staff)	Number of other staff (does not include ancillary staff)
Pflegeheim (nursing home)	546397	374116	114719	20253	.	0	37309	.

Completeness and accuracy of the data

Due to a strong increases of costs, the problems of institutional care for people with disabilities has gradually come into the focus of social policy in the Federal Republic of Germany in the past years. The planning and development of services traditionally has not been a task with high priority for public administration as a whole, but was seen as the autonomy of the service providers. Reliable and differentiated data are only partially available in official statistics. The more new service models that are implemented, the more the need for better data becomes evident for policy makers, administrators but also for service providers.

The statistics for the in-patient nursing care facilities are derived for the most part from the Nursing Care Statistic which has been taken every two years since 1999. The most recent census was taken on 15 December 2005 (Destatis 2007). The report compiles data from both the nursing care facilities and the associations of nursing care insurance providers. This report provides information on the facilities, the personnel employed in such facilities and data regarding the individuals granted services. Regarding the set up of in-patient care facilities for persons with disabilities (integration assistance aid) no official records have been kept. Due to this, there are central points on the table given where only limited information can be given in discussion of such statistics. The lack of valid data is in part due to the fact that no need for public planning was seen as necessary in this field up until very recently. Until this point the official statistics were not integrated into planning needs. The numbers given in the table and discussed here are based on estimations which are derived from various sources.

1. In the official statistical report those receiving benefits as part of integration assistance aid and the costs of the integration assistance aid are taken at the national level (social welfare statistics). This data only allows for limited conclusions to be made on the basis of the number of persons who are granted in-patient facility care due to the fact that funding can occur either on part of the users themselves or on part of the social benefits provider, which is given priority. Regarding the type of benefits granted the data is not differentiated to a satisfactory degree. All cases of residential assistance aid fall under the category ‘other’. As part of the census taken on 31.12.2005 further detailed differentiations in the area of residential assistance aid were added. On the basis of difficulties occurred in the compilation of data this report can only be presented at a later date and only incomplete data can be given.

2. Since 1998 the trans-regional social welfare agencies have been carrying out number comparisons on the basis of which development trends can chiefly be observed. Although the quality of data has improved in the past few years, the report can not be considered reliable as it is incomplete on the one hand and on the other hand involves extreme variation as to what is defined as significant. This report presents data on persons granted benefits but does not present conclusions on the structures of the facilities.

3. Up until 2003 the responsible Federal Ministry had kept statistics on the total number of places available for use in in-patient facilities. This data is based on surveys taken from the responsible body for payment of costs. This report was later

disregarded due to its extreme vulnerability for mistakes. On part of the Federal Ministry a report concerning the situation of foster homes and the care of residents was presented in 2006 (BAGFW 2006) which provides utilizable data only for the area of nursing care facilities.

4. The National Work Association of Private Social Services Organizations (*Bundesarbeitsgemeinschaft der Freien Wohlfahrtspflege)* presents a complete statistical review of services provided every four years; the most recent report being that of 31.12.2004 (BAGFW 2006). Firstly, the data is minimally differentiated and secondly it is incomplete, as the services offered by private and public agencies is not taken into account.

5. The Centre for Planning and Evaluation of Social Services (*ZPE, University of Siegen*) carried out a census as part of a research project presented on 30.06.2003, which compiles data on integration assistance aid in NRW- the largest German state with 18 million residents (ZPE 2006). The service providers and the social benefit agencies were surveyed. Information from the service providers of aid stem from data given on a voluntary basis and are therefore only somewhat representative for the agencies as a whole. In some cases the data resulting from the survey in NRW are taken as the basis for making estimations on Germany as a whole. The results of this official report can be downloaded free of charge at www.destatis.de A summary is given in the Statistical Yearbook which is available in English as well. A more detailed statistical review in professional papers is only available in German.

Commentary: Germany

1. Government organisation and structure

The Federal Republic of Germany is a federal state. Its social policies are determined by national laws which, in some cases, are devised and put into action at the level of 16 federal states (comprising between 660,000 and 18,000,000 residents) by means of laws of enforcement and complementary regulations which execute their implementation. The municipalities are composed of 116 independent cities (cities which do not fall under the jurisdiction of any county) and 323 rural regions composed of smaller cities and local authorities which are granted the right of self governance in certain areas on the local level. However, in other cases these regions follow the federal and state laws that have been implemented. Germany's political system is marked by a high degree of relations between governmental institutions and non-governmental organizations, which in many cases involves the transfer of governmental responsibilities to non-governmental organizations and quasi-governmental institutions (social insurance system, Chamber of Trade, social services organizations, etc).

The responsibility for planning lies first and foremost with the individual states and municipalities in the fields of health care and social welfare. This responsibility is however overridden in many respects due to planning demands of non-governmental organizations. In view of this, political decision making processes in Germany are often complex and depend on a strong sense of societal consensus.

2. Demographics

Germany's population totals 82.5 million as of 2005. Due to the declining birth rate and a restrictive immigration policy the population growth between 2000 and 2005 lies significantly below the EU average. In this period total growth was 0.4% as compared to the EU-25 rate of 2.1%. A population decrease has been occurring since 2002. The projected life expectancy of those born between 2002 and 2004 lies at 75.89 years for men and at 81.55 years for women. Germany has the smallest number of residents under 15 years of age, followed by Italy, and in turn the greatest number of residents over 65. Among the most common causes of death, illnesses of the circulatory system occur with the greatest frequency at a rate of 45%. The child mortality rate is at 4.3 per thousand residents, slightly greater than the average rate of 4.2 per thousand in Europe.

3. Health and Social Care System

The health care and social services system in the Federal Republic of Germany is composed of various units of service providers which are relevant for persons with disabilities:

3.1 Social insurance system

Today's health care and social services system received its strongest influences from the social insurance system introduced in the 1880s which has been developed and expanded since this time. In its beginnings the goal of providing insurance coverage for a minimal group of employees against the potential risk of work disability has continually broadened to include coverage of other benefits such as illness, accident, old age, unemployment and nursing care. The social insurance system is financed by contributions from the employed, from the employer, as well as from government subsidies. In recent years, benefits granted have been cut due to the change in demographics and an extended period of high unemployment. First and foremost is either the status of an individual or of a member of one's nuclear family as employed as the main criteria which allows persons access to compulsory national insurance coverage. At present, most disabled persons are however granted coverage under the national insurance plan irrespective of their employment status. They receive benefits as part of the social insurance system in the case of illness or need for nursing care. Regarding retirement coverage most disabled persons are also insured. In addition to this, they are also provided access to support services as part of career and social rehabilitation. Concerning aid for daily life activities, the social nursing care insurance is most important. Persons with a recognized need for nursing care receive either monetary or non-cash benefits to realize the funding of nursing aid for daily life activities. Ambulatory services and places for persons in in-patient care facilities can be financed from these sources as well.

3.2 Social welfare

Another branch of aid which supplements the health care system covers those areas of need that are not taken care of as part of the social insurance system. This support system stems from the local and religious charitable aid organizations for those in poverty. This system is funded by the taxpayer. To take advantage of services offered, there is no requirement to have paid contributions to this fund; however personal income and savings must first be drawn upon. This field of social security encompasses a tangible basic insurance as well as aid for those in specific life situations which includes in this context the aid provided to promote the integration of persons with disabilities. This includes in particular the fields of early intervention services, aid provided towards the attainment of an educational degree, residential assistance services and the funding of employment at a workshop for persons with disabilities. As part of the reform measures which took place in the field of psychiatry in the 1980s almost all residential assistance services fall under the jurisdiction of social welfare when concerning persons with disabilities who reside long term in clinics or in in-patient facilities who no longer have a need for nursing care. In the field of social services, the municipalities are most directly responsible for youth welfare aid and social security which is not regulated by the system of social insurance. The Federal States have established various administrative bodies which bring together the jurisdictions of multiple municipalities to carry out the

administration of aid for persons with disabilities who are not covered by the social insurance.

3.3 Other Benefits

Apart from the benefits granted as part of the social insurance system and the welfare system, there are numerous situations in life where entitlement to tax-funded governmental cash benefits is granted, such as in the cases of childrearing (*Erziehungsgeld*), financial support for children (*Kindergeld*), the promotion of education, housing allowances or retirement for war veterans. Tax reductions and discounts in public life can be granted upon application in the case of a recognized disability. Another field concerning socio-political measures is concerned with the protection of disadvantaged groups. In the context of support for persons with disabilities most relevant are the employment requirements for employers. All employers are required either to meet a set quota of employees with disabilities or to contribute a set fee.

3.4 Management and Regulation

In all fields of social security the competence to establish laws is in the hands of the federal state. Regulation regarding the provision of benefits is to be carried out by self chartered social insurance providers in the system of social insurance. Regarding the tax-funded social benefits, the administration of benefits occurs both at the national and local levels. While the tasks of the basic insurance and the tasks of youth welfare aid are to be regulated by the municipalities, regarding assistance for persons with disabilities (integration assistance aid) a tradition of transferring responsibility to trans-regional agencies can be noted in the case of aid in in-patient care facilities. The models implemented to accomplish this process vary from state to state. With an amendment, which took effect at the beginning of 2007, the federal legislature attempted to require that all tasks related to integration assistance aid are brought together either at the local or trans-regional level. The Federal States have all achieved this goal in varied manners and are presently in a state of transition.

Only a minor portion of aid is directly financed by responsible public aid agencies. Regarding the tax-financed benefits for persons with disability (integration assistance aid), over 80% of aid is funded by non-profit agencies and a smaller portion of aid is financed by providers from the private sector. Costs incurred by the non-profit agencies and providers from the private sector are financed up to almost 100% by governmental benefits, however these service providers act at the same time as business enterprises. These businesses are organized into varying associations and to a degree can be considered as competitors. The regulation of services on the basis of competition is encouraged at present on the part of the government.

Since 2001 Germany has had as its goal the implementation of personal budgets for the entire field of rehabilitation services. Firstly, the providers of social benefits were invited to initiate trial projects. Since 2004 regulations for the approval of personal budgets have been set up; however the granting of personal budgets is not compulsory. As of 2008, personal budgets are to become a requirement. Up to this point, the use of budgets is quantitatively lower than expected. The processes for the approval of personal budgets prove to be complex. In addition to the improvement of self-determination, the implementation of personal budgets is part of the federal

government's aim to allow more flexibility in the development of services offered by means of a market oriented control system.

4. Funding of residential assistance services

The financing of social support benefits is secured first and foremost by contributions to the social insurance fund. In the case of need for nursing care, benefits are financed primarily by the nursing care insurance. Benefits granted for medical or career rehabilitation (including the financing of housing towards career rehabilitation) are funded on the most part by retirement insurance and by unemployment insurance.

Benefits from the basic insurance fund or any other tax-financed benefits from the social welfare fund can be applied for in cases where there is no right to receive benefits from the social insurance fund, when the benefits can not be granted by the social insurance, or when the amount of benefit granted is not sufficient to cover total costs. In cases of need for educational assistance for daily life activities (integration assistance aid) funding is carried out by governmental institutions.

4.1 Health care

The benefits incorporated in the health care system are paid out by the health insurance providers. Those insured must however carry a percentage of costs themselves during doctor's visits and when purchasing medicine. Long term aid for daily life activities is only granted in the case of need for home care.

4.2 Nursing care

In the case of need for nursing care those insured are entitled to lump-sum benefits on a three tier basis which they can receive either as monetary benefits or non-cash payments. In most cases the lump sum benefits granted do not entirely cover the funding of professional aid. The insured must finance supplementary benefits on their own or apply for social welfare. The amount of the non-cash benefits are agreed upon between the associations of nursing care insurance providers and the provider organizations. For services and care facilities there is an accreditation process which is based upon quality standards. The services and care facilities are in competition with one another. Due to recent demographic changes, the need for such services has dramatically increased in the past few years.

4.3 Social welfare

In the case of need on an extended basis for those whose aid is not covered by the social insurance, individual income and savings has to be implemented to cover funding of services. In such cases the requirement of spouse or caregiver to cover care is examined. In contrast to the social insurance the service providers of social welfare benefits do not grant lump sum amounts, a right to need-based aid exists. Since 1999 the costs of services and aid in care facilities are only covered when an agreement regarding benefits granted exists between the provider and the party responsible for costs payment. The services and care facilities in this field of care are also in a competitive relationship due to this fact and tend to consider themselves more and more as business enterprises. Due to growing structures and traditions and a higher grade of specialization the competition in this area is not as pronounced as in the field of nursing care.

5. Residential services for people with a disability

5.1 Services for children with disabilities

The majority of children with disabilities are raised in their families of origin. They are entitled to home care, nursing care services and family support services. The greatest source of aid for children with disabilities stems from family members for the most part the mother. In some regions a specialized form of nursing care for children is granted. Family support services are available in most regions however they are not sufficient to cover all need due to the difficulty of funding such benefits.

In cases where child custody rights are withdrawn by the state, or where parents feel overwhelmed by the task of raising and providing nursing care for their child in-patient care facilities can be put into use. However, such facilities are not available close to places of residence in many regions. Children and youth with disabilities are normally housed in special sections of facilities set up by the youth aid organizations or in specific facilities set up by disability aid organizations. Specific data on the size and total number of such facilities is not available. The political goal does however exist to provide appropriate offers of long term care in small, regionally oriented facilities. Children with disabilities may also be cared for in foster families as needed. Statistics on such cases do not exist on a national level. This information is taken in varying manners by the various social benefit agencies on a regional level.

Children with disabilities in Germany attend special schools for persons with disabilities as a rule, which are differentiated to a great degree on basis of disability type. Particularly, schools for children with sensory disabilities often have a high number of students whose families live in districts outside of where the school is located, which necessitates housing on school grounds or the accommodation of children in cooperative living communities. Accommodation in a living community outside of school grounds is also possible for older students. In these facilities the majority of employees are professional educators specialized in social care and counsellors. Information on this area of aid does not exist on a national level as it is submitted in varied manners by the relevant school agencies on a regional level.

According to the social welfare census taken end 2004, a total of 27,466 children received integration assistance aid in in-patient care facilities. It can be deduced from a comparison of data reported by the trans-regional social welfare agencies that there are regions where no children are housed in boarding schools or facilities for children with disabilities as compared to others where the actual number lies at a total of 0.49 places per 1,000 residents (Con_sens 2005: 17). It can be determined from the Nursing Care Statistics reported in December 2005 that a total of 241 children and youth under 15 are cared for in nursing care facilities.

Great difficulties exist for youth with disabilities concerning the opportunities for career training. Often career planning measures and career training take place in trans-regional career education centres for persons with disabilities (*Berufsbildungswerk*). Nationally there are 51 institutes providing an approximate capacity for 13,000 students. Many students receive accommodation in residence halls or in living communities outside of the complex. The rehabilitation agencies grant in most cases a travel allowance for two visits home per month. In these institutes primarily professional educators specialized in social care and counsellors are employed.

5.2 Services for younger adults with a disability

Up until the end of the 1970s the majority of adults with intellectual disabilities and chronic mental illness were housed outside of their families of origin in public psychiatric clinics or in mental health institutions, supported by non-profit often religiously affiliated agencies. After 1945 in both West Germany and the former East German Democratic Republic, the structure of care in mental health facilities was revived from the period before the occurrence of national socialism in Germany.

In the former East German Democratic Republic the churches, which were politically criticized in most cases, were reserved the right to be active in the area of disability aid. The church provided support services for over 100 institutes in the former East German states for persons with severe intellectual disabilities who were considered unable to take part in educational training on the basis of the defective classification system established by the health care system in the former East German Republic.

In 1958 the parents association 'Life Aid' (*Lebenshilfe*) was founded in Germany. Its members were looking for an alternative to housing their children in mental health institutions. The impulse for creating specialized alternative facilities came from this initiative and still does today. For persons with intellectual disabilities, housing in in-patient care facilities is favoured; such facilities offered on the average more than 50 places for residents, today housing is being constructed to maintain a capacity of 24 to 36 individuals. These group homes illustrate a 'group' organizational structure- with approximately 8-12 residents per group.

In the conception of such housing facilities a separation between work and daily life exists as can be seen in the in-patient care facilities. This decision has been accepted by the social benefits agencies and the other service providers and is used as a guideline for the development of residential assistance services. The older mental health institutions have experienced a process of internal differentiation since the 1980s which has led to a division of living areas within the institution and also to a separation of residents into living communities of 8-12 persons per group. Many facilities have been designed to accommodate multiple residents in shared rooms however single rooms are becoming standard. Based on the census taken by the Center for Planning and Evaluation in 2003 approximately 75% of residents had been granted single rooms. As part of the care offered at such facilities primarily educational specialists are increasingly accompanied by nursing care specialists. Based on the Center for Planning and Evaluation's survey (2006) in 2003 approximately 65% of persons employed had completed three years of professional training and approximately 10% had attained a university degree. Many housing facilities are not well anchored in the region because of the fact that they represent a cross-regional distribution of residents and are more likely to cooperate in cross-regional structures. On the regional level there are rarely resources or influential advisory boards available for the coordination of facilities.

Persons with autism are normally given care outside of their family of origin, usually in in-patient facilities for persons with intellectual disability. In some cases they have been composed into specific groups on a long term basis. In recent years numerous new facilities have been established which are specialized in the aid of persons with autism. In this case the homes are smaller; they usually have capacity for 12-24 persons.

The development of aid for adults with mental health illness is marked by the psychiatry reform measures that have taken place sine the 1970s. In 1971 the German parliament established a commission for research on the situation in mental health wards. The terrible conditions under which persons with mental illness and chronic psychiatric illness were cared for was made apparent in the resulting report. Approximately 600,000 persons lived in mental health wards in the mid 70s, regardless of whether a need for medical treatment existed or not. Most of these long term patients were housed in halls without any consideration given to privacy. Their physical construction was unacceptable and as far as care givers are concerned, few were professionally trained. At the recommendation of the Commission, the medical care was improved by local doctors and at the regional level, planning structures were developed through which support services integrated into the community were established. As of now the mental health wards and their departments focus on the care of those with mental illness in acute circumstances. Regionally, temporary homes, smaller housing facilities and community integrated support services exist which provides a comparable offer of support services on an individual and regional basis. Apart from the expectations, in-patient care facilities are generally smaller facilities which often work in combination with other services offered towards the development of structuring daily life, as an example. In many regions in Germany the options of support services for persons with chronic mental illnesses are regulated on the local level.

Despite attempts to achieve fewer cases requiring hospitalization there are still long term patients in mental health wards. There is no statistical data regarding this fact. There are however estimates which state that up to 20.000 persons are in such hospitals. They are normally cared for in special departments. In the area of aid for persons with intellectual disabilities in some cases temporary care facilities which are a close derivative of clinics have been converted into long term care facilities in the attempt to decrease the number of individuals in hospital. Here persons with a high need of aid and those who display behaviour disorders o be accommodated.

After the official reunification of Germany, the structuring of aid for persons with disabilities was extensively revamped belatedly in an accelerated process of reformation. In this process investment capital was made available, which made possible a renovation of the existent facilities as well as the construction of new care facilities. The total of in-patient care in the German states located in the former East German Republic has been found as a rule to be higher as compared to the states located in the former West German Republic.

In the area of integration assistance aid based on the most recent available non-official survey there were a total of 178,924 places available in 2003 within a total of 5,118 care facilities. According to claims presented by Germany's government approximately three quarters of the housing facilities have fewer than 50 places, almost 20% can capacitate between 50 and 150 persons, and 5% of all care facilities could provide room for over 150 persons in total. Among these there are some care facilities which have capacity for over 500 persons. According to findings of the German government it can be said that the greatest number of persons with disabilities live in in-patient care facilities which can sustain a capacity of more than 24 persons (BMFSJ 2006:231)

Based on the statistical comparisons of the trans-regional agencies in the field of social welfare it can be said that there are approximately 2.5 places per 1,000 residents in in-patient care facilities as part of integration assistance aid for adults (Con_sens 2005:15). After high rates of increase in the years prior to 2003, there has been a decline in recent years. In some regions total capacity is at a minor decrease which is due to developments in ambulatory aid and the prerequisite of personal expenditure budgets.

Persons with disabilities who became disabled at a point later in life and were previously employed often have to rely on the services provided by career re-orientation training. Such retraining programs are provided on a trans-regional basis by educational institutes for career re-orientation for persons with disabilities (*Berufsförderungswerk*). At this point in time there are approximately 28 of such centres nationwide which can sustain a total capacity of 15,000 persons. These career re-orientation institutes often provide for on campus accommodation. The rehabilitation agencies normally grant a travel allowance for a total of two visits home per month.

A specialized in-patient offer of care for younger persons with physical disabilities only exists in a few regions. Approximately 200 nursing care facilities provide support services primarily for persons with physical disabilities less than 65 years of age. Beyond the use of private funding, younger persons who have severe physical limitations primarily have at their disposal nursing care facilities which are oriented on the approach towards older persons in need of nursing care. In total at years end 2005, 38,758 persons under 65 lived in in-patient nursing care homes. Youth with physical disabilities profit from the benefits received from nursing care insurance which in many cases allows for the ability to remain in one's original home. Persons with physical disability were more often able to obtain an individual right to a personal nurse in the 1980s, which allowed for the sustainability of life in one's own home in cases of high need of assistance. Due to cost-cutting measures today, the need for a personal nurse is however often put into question.

For the entire field of residential assistance services in Germany the clear delineation between ambulatory and in-patient aid is constitutive. Ambulatory care as a rule is provided in one's own home or in small living communities. Professional workers provide assistance at predetermined times or days during the week or during each day. Since 1984 it is legally required that ambulatory aid is assigned in preference to in-patient care. Despite this ruling, shortly following this decision in-patient services were expanded. In 1996 the priority given to ambulatory aid was cut back. Such priority was only considered valid when the ambulatory aid did not cause any in-equivalent extra costs or in cases where in-patient care was in no way an option for persons receiving benefits. In this manner, the promotion of ambulatory aid is prioritized presently from the perspective of the social insurance agencies by means of cost reduction measures. In view of this, it can be said that ambulatory aid is first and foremost taken advantage of by those who display a minor need for aid. Due to this, the majority of persons with mental health illnesses are granted ambulatory aid. In mid 2003 in NRW approximately 40% of persons receiving benefits who have mental health illnesses and approximately 10% of persons with intellectual disabilities took advantage of ambulatory services. The expansion of ambulatory care offered is very

varied from state to state. In all states however in this area of aid a significant increase in number of services provided can be seen in recent years.

5.3 Services for older adults

In response to demographic factors (the growing number of elderly) social factors (a decrease in potential informal networks for nursing care) and institutional factors (shortened duration of hospital stays) the in-patient care for the elderly in Germany is undergoing extremely dynamic developments. More than two-thirds of the 2.13 million persons recognized as in need of nursing care are receiving home care. However, that said, in-patient nursing care facilities are continually expanding in capacity. Approximately 55% of homes are sponsored by non-profit agencies 38% are privately run and 7% are sponsored by public agencies. Approximately more than half of persons in need of nursing care live in single rooms; many nursing homes combine their services with ambulatory nursing care services or with retirement homes where the elderly are not yet in need of nursing aid.

Facilities set up as part of integration assistance aid are now adjusting to the needs of their elderly residents. Due to the euthanasia mass murder during Germany's period of national socialism, the age distribution of elderly persons with disabilities is gradually catching up to that of the age distribution of elderly persons in the total population. In many cases the need for renovation and the introduction of services towards the aim of providing daily structure are necessary.
Due to the fact that care facilities for integration assistance can only accept reduced lump-sum payments from the nursing care insurance, the social benefit agencies aim to accommodate the elderly with disabilities in nursing care facilities and to convert institutes for integration assistance aid into facilities for nursing care.

6. Issues

6.1 Ethnicity

As a result of high immigration rates in the 1960s, ever more elderly with immigration backgrounds are in need of nursing care. In the area of aid for persons with mental health illnesses, professionals are increasingly becoming sensitized to the specific concerns of younger persons with immigration backgrounds. The problematic which this theme addresses is discussed in professional papers and is integrated into some offers in a theoretical manner. As of yet, no means of implementing such data in the current census taxonomy has been identified.

6.2 Gender

More men than women live in care facilities for integration assistance aid due to the varied prevalence of intellectual disabilities amongst individuals. In the field of aid for persons with mental health illnesses there are very few gender specific service offers. Nursing care facilities have predominantly female residents. Due to marriage behavioural trends (many women marry older men) and due to a higher life expectancy women tend to outlive their partners and therefore no longer have an informal network of care at their disposal. Women are employed at a higher rate in both care facilities for integration assistance aid as well as in nursing homes. In Germany the educational and nursing care vocations are considered typical career

paths for women. These careers are marked by comparatively low earnings and by unfavourable working conditions.

6.3 Funding

Increasing costs both in the field of integration assistance aid and in the field of nursing care have currently led to cost-cutting measures. High expectations are being placed on the implementation of personal budgets and ambulatory aid on the one hand, and on models of nursing care which merge informal with professional aid on the other. In both fields, particularly the development of in-patient care is viewed as a problematic cost factor.

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Appendix 1: Detailed information, collected as part of the Phase 2 case studies, on two of the regions within Germany: Nordrhein-Westfalen and Saxony

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Services for people with disabilities in Saxony and Nordrhein -Westfalen

Saxony

In the sixth century AD present-day Saxony was settled by Sorbian tribes. The rule of the House of Wettin, which began in 1089, lasted for 829 years. In 1485 the land was divided between the brothers Albert and Ernst, the former taking the eastern territories largely corresponding to the present-day federal state of Saxony. In 1800 Saxony fought on the side of Napoleon at the battle of Leipzig and lost, ceding substantial territories to Prussia. Early industrialisation at the end of the nineteenth century brought both prosperity and social tension to Saxony. In 1920 a constitution based on parliamentary democracy was adopted, forming the basis for the Free State of Saxony which lasted until 1933 when the parliament stepped down. In 1945 American and Soviet troops occupied the state which later became completely under Soviet occupation, simultaneously incorporating parts of Lower Silesia. When the constitution was revoked in 1947, Saxony was divided into the East German administrative districts of Leipzig, Karl-Marx-Stadt (Chemnitz) and Dresden. In 1990 the Free State of Saxony was born again as a state of the FDR with legislative power in a few basic law areas such as in education, culture, the field of communal rights and police and administrative rules. The Federal government has jurisdiction in all other fields.

In Saxony, the State Welfare Organisation (*Landeswohlfahrtsverband - LWV)* is the responsible body for the *Überörtliche Sozialhilfeträger* (over-regional social care administration) social welfare responsible for the administration and payment of benefits and for the supply of services for individuals in special circumstances (non-ambulatory or partially ambulatory services). The *Örtliche* Sozialhilfeträger (regional or municipality social care administration) is responsible for supplying ambulatory care (ambulante Hilfen, eg. supported living services). The degree of involvement of both bodies differs in the different federal states in Germany. As shown above, there are two systems of financing in *Überörtliche* social welfare – the state system and the communal system: there are slight, but significant differences between federal states in the allocation of duties and responsibilities between the two which means that comparisons between *Überörtliche* bodies is difficult and may only be possible between single services.

The *Überörtliche Sozialhilfeträger* is also the responsible body for the welfare of people with physical or sensory disabilities, individuals in special circumstances (this includes people with mental illness) who are assessed to require institutional care. In recent years the costs in this area have been steadily increasing and "rehabilitation" services made up 71% of all expenditures. The capacities of facilities in the different towns in Saxony show large variations and differences.

Partly institutional facilities *(Teilstationäre Hilfen)*

The largest group using these facilities are individuals employed in rehabilitation/employment facilities. Other recipients are individuals placed in day care institutions for the chronically psychiatrically ill, mentally disabled individuals, day care for children, curative pedagogical day centres, integrative kindergartens.

Common problems

There has been an increase in expenditures in recent years due to an increase in case numbers in the area of integration (rehabilitation) support (up 50% between 1996 and 2002), and the rising costs of labour. In Saxony, the steadily increasing demand for accommodation has been partly off-set by the enhancement of supported living, so the percentage increase institutional accommodation has remained low compared to supported living arrangements. Although the service recipient level is 2.2 per 1000 in Saxony (higher than in neighbouring states), the number of carers is only 1:12 compared to 2:9 in other states. In 2002 Saxony saw an increase of 2.2% in the number of disabled individuals, and a 6.5% increase in expenditures.

In the coming years it is anticipated that:

- case numbers will continue to rise (with a concomitant rise in material standards of facilities to the level of other states);
- increases in supported living will result in smaller expenses for institutional accommodation (with a concomitant increase in relocation of individuals with a lesser degree of disability in supported living)
- expenses for rehabilitation employment (nearly 30%) will continue
- "new" jobs will continue to contribute to increased personnel costs

Comparisons to other Federal states in Germany

- Case numbers in Saxony are comparable to other bodies of *Überörtlichen* social welfare
- The financial burden per resident for the support of individuals in special circumstances is the lowest in Saxony
- Many forms of support are also the smallest amount paid per recipient

Issues

The shift in ratio between supported living arrangements and institutional accommodation exposes the need to examine the roles and task allocation of the *Örtliche* and *Überörtliche Sozialhilfeträger*. The financing of these bodies is mostly operated by cost allocation of municipalities and their own sources of income. (Funds for the enhancement of social services are taken from the budget of the Federal state). Problems arise because service planning is difficult in the absence of good data on people taking up services – for example, there is no case specific information available. In addition, there is a lack of transparency about who is responsible for planning and paying for certain services: different cases with differing degrees of disability may be claiming for the same or different services (provided by one or both bodies). The control of case numbers and financial expenses can only be achieved by improving the quality of available data and information (this is discussed further in section 7).

Nordrhein-Westfalen.

Nordrhein-Westfalen is one of the 16 federal states of the FRG with approximately 18 million people (one-fifth of the total population). Both parts of the state have partially separate administration consisting of the regional Council of Rhineland (*Landschaftsverband Rheinland, LVR)* and the Regional Council of Westfalia-Lippe (*Landschaftsverband Westfalen-Lippe, LWL)* where responsibility for disabilities lie. Some services, mental health for example are provided and administered at an over-regional level (*überörtliche Sozialhilfeträger)*, and other services at lower levels, districts (*Kreis)* or cities (*kreisfreie Städe)*.

In North-Rhine Westphalia in 2003 there were approximately 42,900 places available in total in residential homes for persons with disabilities while individuals using supported living services numbered approximated 11,000. Regarding all major disability groups the institutional care versus supported living ratio amounted to approximately 80:20. In accordance with the principle of subsidiarity in German Social Law, in all areas of assistance facilities were provided in over 80% of the cases by private voluntary organizations (*Träger der Freien Wohlfahrtspflege*), however the number of places available in public agencies continually increases. In North-Rhine Westphalia in the period from 1999 to 2003 the programme costs for integration assistance rose by 22% to €2.35 billion. In the area of intellectual disability services in North-Rhine Westphalia there were 31,329 places available in institutions (to July 2003). This number is the result of a continual expansion in institutional care, which in the previous years ranged between 4% and 8% yearly, and has been sustained to this point. In North-Rhine Westphalia, 2,734 intellectually disabled persons were given support services by supported living programs. The statewide average between supported living and institutional care amounts to a ratio of 7.7% to 92.3%. In mental health/addiction services a total of 20,632 persons in North-Rhine Westphalia received residential services as part of integration assistance planning. A total of 12,390 (60%) of those receiving services were cared for in institutions, while 8,242 persons (40%) received supported living assistance. In North-Rhine Westphalia, the offers of in-patient and out patient forms of residential assistance are very differently developed and fluctuate between 35 and 320 available places per 100,000 inhabitants. The amount of out patient supported living services at the local level varies statewide between 10.6-77.4% of the total offer. As in the past, there are still persons with chronic mental illnesses who are permanently housed in large institutions or smaller ones similar to clinics. Therefore before July, 2003, significant variation existed statewide regarding the development of opportunities in the area of supported living services. The assumption that a disparity exists between the two parts in the region, Rhineland and Westphalia-Lippe, has been proven to be inapplicable. Of the ten districts in North-Rhine Westphalia with the most developed state of supported living services, eight are located in Westphalia-Lippe, and there were more available places for supported living in Westphalia-Lippe than in Rhineland at the time the survey was taken. In each of the areas, there is substantial variation concerning this matter, whereas the variance in Westphalia-Lippe is somewhat broader. This means that the promotional program for supported living set up by the Regional Council in Rhineland (LVR) did not lead to the attainment of a region wide consistency in coverage that provides appropriate offers for supported living. Conversely, the lack of a corresponding program in the district of the Regional Council Westphalia-Lippe (LWL) did not lead to the situation where no offers for supported living were developed. This suggests that the development of out patient forms of assistance is, above all, dependent upon *if* and *how* agencies at the local level respond to impulses

from the professional field and financial incentives. It should be noted that, regarding this point, even though the regional authority Westphalia-Lippe (LWL) in contrast to the regional authority Rhineland (LVR) did not have an official promotional program for supported living services up until 30.06.2003, on a local level services were developed nevertheless.

There are some significant conceptual and structural distinctions between the area of assistance for people with intellectual disabilities and the area of assistance to those with mental illness and addiction. In the field of intellectual disability way the quantitative expansion of supported living services can be seen as an indication of a good local assistance program. This is only partly valid for assistance services for persons with mental health problems and addiction. In these cases, with the implementation of counseling and other appropriate advisory services in the community, it may be the very goal of social intervention to avoid the necessity for the extra services offered as part of integration assistance. Regarding mental illness/addiction assistance services, the implementation of this principle was more often achieved. In total, however, the agencies newly established at that time mainly created services for (partial) in-patient care. Surprisingly, a considerable expansion of institutional care took place during the second half of the 1990s. Parallel to this development, initial steps towards an expansion of supported living can be determined. Approximately 60% of supported living services were not established until the year 2000. This mirrors the internal processes and priorities of provider organization as well as lasting structural and financial incentives, which make an investment in institutional care facilities attractive for agencies. The institutional facilities in the area of intellectual disability in North-Rhine Westphalia mostly display an internal group housing structure. The significance of large facilities as services provider remains unchanged. The majority of intellectual disabled persons live in groups of up to eight persons and more than 15% live with more than twelve individuals in their group home. A little over 70% of the intellectual disabled persons in residential homes have a single room, regardless of this high number; approximately 25% of residents are still assigned double rooms. Groups of three and four persons per room are very rare and larger groups than this do not exist. The smaller the facility is, the greater the number of residents from the community where the facility is located and vice versa. The number of individuals receiving services who are from the district in which the facility is located is around 50% in both regions (Westphalia-Lippe and Rhineland). The average staff to resident ratio lies at 2.34 employees per one disabled person. When compared to supported living services, the qualification level of the employees in institutional facilities is considerably lower. In the area of institutional care, approximately 9% have obtained a post-secondary degree, while in the area of supported living services the number reaches 71%. In total, 70% of the personnel in the area of intellectual disability are female.

Institutional facilities are usually smaller in the area of mental health/addiction assistance, as compared to the intellectual disability assistance area, and concerning the origin of the resident, a significantly greater degree of regionalization is evident in mental health systems. The number of individuals who are from the district in which their facility is located amounts to 62%. The norm of single room residency has also not been achieved for persons with mental disability. Of the individuals who receive in-patient care, 15% live with either one or more persons per room. The qualification

level of the employees lies far above that in facilities for the intellectually disabled persons.

In the mental health/addiction assistance systems, the employees' level of qualification in in-patient facilities is considerably lower in comparison to support living services. Approximately 23% of employees have obtained a post-secondary degree in in-patient care and approximately 80% of individuals in out patient care are educated at this level. Again about 70% of the personnel are female.

In the field of intellectual disabilities the principle of "out-patient before in-patient care," is only rarely reflected in the provision of services. The deep-seated assumption appears to be that persons with intellectual disabilities have a need for institutional care that characterizes how disability planning is dealt with in many cases. In contrast to the area of assistance for mental illness/addiction the relationship between active local planning and the resulting state of development which supported living programs attain is significantly less illustrative. Preventative and relevant socio-psychiatric services, for example, a stay at a temporary institutional facility, are explicitly aimed towards the avoidance of a chronification of the individual's condition. This also explains why local structures have well developed systems of services for community psychiatry, but a below average state of development in the area of supported living programs for people with intellectual disabilities.

Regarding the aid programs for individuals with mental illness or addiction, overall it can be said that most districts and cities in North-Rhine Westphalia have at their disposal complex, formal planning structures that are more pronounced than those carried out for persons with intellectual or physical disability.

The Regional Councils have developed instruments for individual service planning which are employed widely. Both Regional Councils have implemented the "professional services hour" (Fachleistungsstunde) as a new means of financing care in supported living services. They are actively concerned with establishing stronger relations at the regional level in their organizational structure and work processes. In comparison to the period before the changes in jurisdiction, there is a greater presence in the regional settings and in the context of individual service planning. In order for this process to be carried out effectively it seems that a competent local representation that is familiar with regional services as well as the opportunity for staff to meet the individual applicant personally is necessary. Only in this manner is a systematic continuation of individual service planning possible, which then makes the placement of limitations on services granted useful. How this is to be achieved has not yet been sufficiently clarified. Through "up-zoning" the provision of services a statewide standardization regarding the jurisdiction for assistance services in independent living was achieved, although continuing attempts to establish a statewide uniformity in rules have taken a comparatively insignificant role. The Regional Councils differently recognize their instructions to enact the changes in jurisdiction in agreement with the amendment of the decree implementing the Federal Social Assistance Act (AV-BSHG) and, in this manner, they attempt varying initial strategies toward implementation. This is valid for the variance in procedures concerning individual service planning as well as for the official announcement to allow the integration of competitive elements, which has not yet been accomplished due to the legal halting of efforts. This is likewise valid for the efforts made by the LVR to allow

the expansion of admission processes for service providers, which is to be closely examined. An increase in number of service providers could on the one hand work to promote competition, on the other hand however, as a quantitative incentive for improvement, motivating the development of new target groups. The large number of new service providers is more often than not composed of small businesses or legally certified caretakers who expand their offer of services as needed. This could make the coordination tasks more difficult locally, and brings up the question of measures for quality assurance. A variance between the Regional Councils in the organization of jurisdiction provides the opportunity to comparatively research diverse paths of development.

Changes in jurisdiction since 2003 have led to an extreme growth in persons entitled to receive benefits in the area of supported living services. This increase in number is significantly higher in the region of LWL as compared to the region under the jurisdiction of LVR, although the exit numbers were higher in LVR. Currently, an analysis which is differentiated by target group can only be carried out for the area that falls under LVR's jurisdiction. The results show that there has been a growth by two-thirds in the area of assistance for persons with intellectual disabilities. The expectation that offers of supported living services for independent living would be granted to persons with intellectual disabilities to a greater degree has not yet been substantially fulfilled. The expansion of supported living services for persons with disabilities has gained considerable dynamism since the change in jurisdiction in the area that falls under LVR's jurisdiction. This can be seen in the large number of authorized services. The majority of agencies in Rhineland, which only provided institutional care before the change in administrate responsibility now offer supported living assistance as well. Additionally, a number of new agencies have applied for authorization. As of now, however, the effect of the authorization of new agencies on the development of services offered can not be determined. Even before June 30 2003 the trend toward an increased utilization of institutional care and toward the construction of new facilities for institutional care in the region of LVR were able to be halted. After the changes in jurisdiction for assistance, again, a distinctly small increase in the area of institutional services was evident. However, a trend towards the dismantling of services in institutional care can not yet be recognized. In total the number of persons entitled to services for residential assistance has significantly increased and is in 2006 ca. 65.000 disabled persons, of whom 44.500 are accommodated in various forms of institutional care, and ca. 19.500 persons receive support in their own flats by supported living schemes.

Tabelle: Einrichtungsstruktur in Nordrhein-Westfalen

Anzahl der Plätze	**Anzahl Einrichtungen**
bis 9	96
10 bis 49 Plätze	680
50 bis 99 Plätze	99
100 bis 499 Plätze	46
über 500 Plätze	5

Tabelle: Personen in Behindertenheimen in NRW

In Wohneinrichtungen in Nordrhein-Westfalen lebten

1997: ca. 31.900 behinderte Menschen
1998: ca. 33.800 behinderte Menschen
1999: ca. 35.500 behinderte Menschen
2000: ca. 37.600 behinderte Menschen
2006: ca. 44.500 behinderte Menschen

(LVR / LWL 2001: 14 und ZPE Universität Siegen 2006)

3

Ca. 20% of the people with disabilities who used supported living services are categorised as having an intellectual disability, most of the other are categorized as mentally ill. The relation between supported living services and institutional care has changed in favor of supported living services.

Entwicklung der Anzahl von Leistungsempfängern im Ambulant Betreuten Wohnen nach Zielgruppen zu den Stichtagen 30.06.2003, 31.12.2005 und 30.06.2006

LVR / Zielgruppen	Anzahl Leistungsempfänger/innen								
	30.06.2003		31.12.2005			30.06.2006			06.03 - 06.06
	Anzahl	pro 1.000 Einw.	Anzahl	pro 1.000 Einw.	Steige-rung absolut	Anzahl	Pro 1.000 Einw.	Steige-rung absolut	Steige-rung absolut
Menschen mit geistiger Behinderung	975	0,10	1.473	0,15	498	1.676	0,17	203	701
Menschen mit seelischer Behinderung	2.891	0,30	5.467	0,57	2.576	6.184	0,64	717	3.293
Menschen mit Suchterkrankung	906	0,09	1.372	0,14	466	1.434	0,15	62	528
Menschen mit körperlicher Behind.	184	0,02	364	0,04	180	382	0,04	18	198
LVR gesamt	**4.956**	**0,52**	**8.676**	**0,90**	**3.720**	**9.676**	**1,01**	**1.000**	**4.720**
LWL gesamt	**6.025**	**0,71**	**8.946**	**1,06**	**2.921**	**9.739**	**1,15**	**793**	**3.714**
NRW gesamt	**10.981**	**0,61**	**17.622**	**0,98**	**6.641**	**19.415**	**1,08**	**1.793**	**8.434**

7

The expenses for institutional integration assistance facilities for adults with disabilities came to a total of €893,675,607 in LVR in 2004. When applying the total costs to the number of persons receiving services one comes to a total of €41,096. An

average of €36, 443 is spent per person by LWL based on total expenditures of €712,400,000 for 19,548 persons receiving services. Comparatively speaking, the costs for institutional integration assistance facilities come to a total of €37,265,104 in LVR, while supported living assistance comes to a total of €60,200,000. It is not however possible to determine the expenditure per person due to the considerable increase in the number of cases in 2004. While in the area of institutional care it can be assumed that a comparatively constant number of individuals receiving services have been taken into the calculation of expenditure per person, this is not the case in supported living services for independent living. By means of mathematical calculation it should be possible to determine total expenditure. The LVR established that on average 3.5 'professional service hours' were granted in 2004. Based on the hourly rate of €48.10 in 2004, a total expenditure of €8,390.20 per person receiving services can be determined. The costs for living expenses and relevant insurances must be noted in addition. However, this total is not able to be determined due to the fact that the delegation responsible for the granting of funding for living expenses and insurances is not aware of in how many cases and in what amount services were granted. This number, however, rarely comes to more than a yearly total of €7,800 per individual. The costs established so far can not be directly compared with the costs of care in institutional facilities for integration assistance. Based on the average number of professional service hours granted, it can be said that those who took advantage of supported living services for independent living have a comparatively low need of assistance. Total expenditure was therefore only compared with the average costs of groups with a low need of assistance. There is, however, no information on these calculations. The analysis of expenditures for supported living and institutional care, which are to be carried out on the basis of the initial agreement between the statewide associations of local governments and the Regional Councils, show that these statistics do not provide any information regarding the comparison of expenditure for supported living services versus that of institutional care. For this, it would be necessary to analyze a record of costs in each individual case and to then make a comparison between services offered by the program for supported living and those offered in institutional facilities. As a basis for future agreements, such inquires should be carried out, if only to serve as an example.

Summary of findings in NRW based on the ZPE interim report of 2005

1. Supported living services and institutional care, both the Regional Council Rhineland (LVR) and the Regional Council Westphalia-Lippe (LWL) show an increase in the number of persons receiving residential services as part of the integration assistance program. In total the number of persons receiving residential services in NRW grew by 6.5%.
2. There has been an increase in the number of persons receiving institutional care services in both LVR (increase of 265) and the LWL (551).
3. Both areas increased in equivalent numbers regarding institutional care provided at a ratio of 2.4 persons in care per one thousand residents.
4. In the jurisdiction of both regional councils the total percentage of the intellectually disabled is at its highest in the area of institutional care: in the region of the LVR this rate lies at 64.5% and in the region of the LWL the rate lies at 65.5%. The total number of persons housed in institutional care facilities in NRW only decreased in the case of persons with physical disability (33 persons).
5. In the region of the LVR a greater number of persons receive services than there are places available, however, in the region of the LWL there are more

places available to be assigned than there are persons in need of services. Of those who fall under the jurisdiction of the LWL 7% live outside of the council's district in institutional care facilities. In the region of the LVR 13% of disabled persons live outside of their council's district in such facilities. Approximately half of the individuals granted institutional care live in the region where they were born: in the LVR this total comes to 48.6%, in the LWL 56.9%.

6. The vast majority of the disabled who reside in institutional care facilities are subsidized by a private voluntary social service organization: the LVR reports a total of 70.7% and in the region of the LWL 88.31% was reported. In the region of the LWL 6.86% of persons receiving institutional care live in facilities funded by public agencies, in the region of the LVR the total number of persons in such facilities lies at 11.21%. Only a minimal number of disabled live in institutional care facilities funded by private commercial organizations; in the LVR this total lies at 4.76% and in the LWL 1.98% are financed by private commercial organizations.
7. Rhineland and Westphalia-Lippe reported a minor decrease in the average cost per case in 2004-2005. For the LVR the total costs sunk from €41,096 to €39.291 and for the LWL costs decreased from €36,541 to €35,734. In Westphalia-Lippe a minor decrease in cost occurred despite the state of already low average costs per case. However, the total expenditure for social services in the district of each regional council has minimally increased, as did the total number of cases. The LVR reported a total expenditure of €900,553,552 and in the district of the LWL an increase to €718,234,699 was reported.
8. The male to female ratio of persons receiving services has largely remained stable. In the district of each regional council the target group ratio was reported to be 59% men to 41% women.
9. The total number of persons receiving supported living services varies within each district. Looking at the total population there was a greater number of persons granted services who fell under the jurisdiction of the Regional Council Westphalia-Lippe as compared to those who fell under the jurisdiction of the Regional Council Rhineland in December 2005. Specifically, in Westphalia-Lippe 1.06 persons per one thousand residents were granted services as compared to .90 persons per thousand residents in Rhineland. The variance between districts determined at the time of the former study has been annulled due to extensive growth in number of persons granted services in the jurisdiction of Rhineland. Regional disparities do however still exist.
10. The most significant increase in number of persons granted supported living services occurred in each district at varying times. It was determined that the greatest increase in services granted in the district of Westphalia-Lippe took place up until 31.12.2004, while the greatest increase in number of services granted in Rhineland occurred between 2004 and 2005.
11. The biggest beneficiaries of supported living services are persons with mental illness; in the region of the LVR the total number lies at 63.0%. This total lies at 57.4% in the region under the jurisdiction of the LWL. Those with intellectual disability compose the second largest target group. In the region of the LVR this total lies at 17.0%, while the LWL reports a total of 23.0%. Persons with addiction follow as the third largest target group reporting a total of 15.8% in the region of the LVR and 16.3% in the region of the LWL. The

physically disabled were granted a small percentage of services in this context: in the district of the LVR only 4.2% received supported living services and only 3.3% in the district of the LWL.

12. In both the district of the LVR and of the LWL the services approved for persons with mental illness showed by far the greatest increase in the area of supported living services. The rate of increase in supported living services is significantly minimal for persons with intellectual disability. As a result, the question arises as to whether the current arrangement of supported living services is sufficient for this target group or if the assigned service providers only view a small number of persons with intellectual disability as potential users of supported living forms of assistance.
13. The relatively low average number of counseling hours approved leads to the conclusion that supported living services continue to be, above all, a solution for persons with a comparatively low level of need, despite the variance in number of services granted in the respective districts. Bearing this in mind, if it will be possible to carry out a statewide reversal from institutional care to supported living forms of assistance, remains to be seen.
14. Since the government ordinance declaring changes in the allocation of disability care there has been a marked growth in the approval of new providers of supported living services. As a result the regional numbers of service providers in this field has seen a marked increase since 2003. However, not all of the approved service providers actively take part in the distribution of social services. Significantly more than one-third of such providers have only one to five clients throughout both regions. If the considerable increase in agencies has promoted a sense of competition and a subsequent improvement in the quality of services offered or if existent regional support networks have loss some of their importance is a question of further research.
15. In Westphalia-Lippe the great majority of persons receiving supported living services (89.81%) are funded by private voluntary social service organizations. In contrast, public agencies provide 5.36% of services in this area. At this stage there are no statistics regarding the funding agencies for the area of Rhineland.
16. The number of persons receiving supported living services vs. those receiving institutional care has developed in favor of supported living services. Concerning persons with mental illness, a higher percentage statewide are receiving supported living services instead of institutional care as integration assistance. However, persons with intellectual or physical disability are overwhelmingly granted institutional care as was the case up to this point. The changes in the assignment of supported living services as opposed to institutional care are the result of the expansion of programs in supported living services and not due to the decrease in institutional care facilities.
17. The total expenditure for social services in the area of supported living programs grew in each region by year's end 2005, which occurred parallel to the increase in number of persons receiving care. The average cost per case has increased in each jurisdiction: in the region of the LVR the costs reached €7.383 while in the region of the LWL the costs were at €7.776 per case.

Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

Greece

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[3] Ministry of Health and Solidarity, Department for the protection of the people with disabilities. Greece Government.

Summary of the available data

No templates are available for Greece.

Completeness and accuracy of the data

It was not possible to collate official statistics for the template. However, some basic information on services is provided in the report that follows.

Information provided in this report is accurate and updated as it has been collated from the most recent publications, however it is not complete. All the information regarding service provision refers to the last 5 years. Although we have managed to complete a full list of services for children, adults and older adults we do not have much information regarding number of places, places per type of disability or staff numbers. There are only few services reported which include the number of places. Information about services characteristics is not scarce and there are many papers and documents that describe them, but exact number of places per type of care and target group is difficult to get.

Residential care provision in Greece is slowly moving towards the finalisation of a long deinstitutionalisation process. Different services are being or will be closed in the next month what makes also difficult to report number of places per service as services are being closed and created.

Commentary: Greece

1. Overview

Greece is a country in Southern Europe and is bordered by Bulgaria, the Former Yugoslav Republic of Macedonia, Albania and Turkey. Greece is now seen as a developed country and joined the EU in 1981, becoming a member of the Economic and Monetary Union of the European Union in 2001.

Administratively, Greece consists of thirteen peripheries (divisions) which are further subdivided into a total of fifty-four prefectures which are mainly a lower level of self-government organisation. There is also one autonomous area, Mount Athos, in Macedonia Periphery. Attica is the largest of the Peripheries with the capital of Athens(http://en.wikipedia.org/wiki/Greece#Peripheries_and_prefectures).

2. Political and social context

2.1 Government organisation and structure

The Constitution of Greece, describes the country as a parliamentary republic, grants extensive specific guarantees of civil liberties and vests the powers of the head of state in a President elected by parliament for a five-year term.

The Greek governmental structure is similar to that found in many Western democracies, and has been described as a compromise between the French and German models. The Prime Minister and cabinet play the central role in the political process, while the President performs some executive and legislative functions in addition to ceremonial duties.

The Prime Minister of Greece is the head of government, and Executive Power is exercised by that government. Legislative Power is vested in both the government and the Hellenic Parliament. The Judiciary is independent of the executive and the legislature and comprises three Supreme Courts: the Court of Cassation (Άρειος Πάγος), the Council of State and the Court of Auditors. The Judiciary system is also composed of civil courts, which judge civil and penal cases and administrative courts, which judge administrative cases, namely disputes between the citizens and the State.

Greece elects a legislature by universal suffrage of all citizens over the age of 18. The Hellenic Parliament (Vouli ton Ellinon) has 300 members, elected for a four-year term. Since the restoration of democracy the party system is dominated by the liberal-conservative New Democracy and the socialist PASOK, or Panhellenic Socialist Movement. Non-negligible parties include the Communist Party of Greece and the Coalition of the Radical Left.

Administratively, Greece consists of thirteen peripheries subdivided into a total of fifty-four prefectures. There is also one autonomous area, Mount Athos, in Macedonia Periphery.

2.2 Disability relevant policy

In Greece the term "People with special needs" is preferably used; although "invalidity" is a common alternative. In 2001, the Constitution introduced the term "people with disabilities". The 1993 Regulation for the Evaluation of the Disability Degree defined the "disability degree which results from a disease or impairment, or physical or mental ("spiritual") reduction, or the combined presence of such diseases or impairments or weakness, which ought be taken into consideration by the Health Committees of IKA (Social Security Institute), when they judge the invalidity of insured or pensioners".

The rights of persons with disabilities are protected by a combination of special and general legislation. The Article 21 of the Constitution makes reference to disability and constitutes a mandate for legislative and administrative action. The emphasis is on: individual support, prevention, rehabilitation, accessibility measures, and anti-discrimination law. A series of articles of the Greek Civil Code regulate capacity of people with disabilities. The policies come from the Ministry of Health and Social Welfare, the Ministry of Labour and few from the Ministry of Education and Religious Affairs, and they refer to collective houses (institutions), vocational training, education and counselling-leisure activities plus passive measures, such as income supplements and waivers from transportation or taxes and loans. Unfortunately the accumulation of legislation for several decades, without any harmonisation, led to a multitude of specialised schemes and situations. It was difficult for a person with a disability to understand and use effectively current legal provisions. Consequently, the Law aiming to provide a "Disability card" for the granting of a large number of aids provided for a common certification process. This process is the same for all persons whatever their insurance scheme.

3. Demographics

According to the National Service of Statistics of Greece –NSSG-, Greece's total population in 2005 was 11,082,752, of whom 5,486,632 were males and 5,596,119 females). As statistics from 1971, 1981 and 2001 show, the Greek population has been aging the past several decades (http://en.wikipedia.org/wiki/Greece#Peripheries_and_prefectures.

Almost two-thirds of Greeks live in urban areas. Greece's largest cities in 2005 were: Athens (3,190,336), Thessaloniki (980,419), Patra (161,114), Iraklio (137,711), Larissa (126,076), and Volos (124,591). The country is homogenous in nature with very few people from ethnic minorities.

4. Health and Social Care System

4.1 Organisation

The Greek health system was rated 24 at the World Health Report 2000. This ranking was based on 1997 data [WHO 2000]. Entitlement to public health care services is universal (including mental health).

Private health insurance is complementary (hospital daily allowance / cash benefit) and supplementary (faster access and choice of private provider and accommodation), and refers to about 10% of the population. There is no substitutive health insurance. In 1995 it was estimated that there were 2,234,567 contracts for life/health insurance, of

which, approximately 30% were group policies. 25% of the life/health policies are thought to be health insurance policies.

The Ministry of Health and Social Solidarity funds services of the public sector. The Ministry has the responsibility of both health and social care. The National Health System was established by Law 1397 in 1983. Recent administrative (but not financial) devolution of the Health Service, with the creation of 15 Regional Health Systems. This has taken place within the context of decentralization of health and welfare services, and improved management structure, with the appointment of professional managers for the hospitals.

Specialised services for disabilities are predominantly located near Athens, in the Attica region.

The provision of care for people with disabilities in Greece is largely influenced by the health reform started in the mid 1980s, which focused on improving the situation of persons with mental disorders and intellectual disabilities living in psychiatric hospitals. The European Union played a significant role in the reform of the health system in Greece, particularly in the mental health sector, focusing on active measures and on social integration.

The situation of care for disabilities in Greece should be divided in three groups: 1) care for severe mental disorders (and intellectual disabilities living in psychiatric institutions); 2) Care for children with physical disabilities and severe to profound intellectual disability; 3) elderly population with disability.

Care for severe mental disorders

Until the early 80's, Mental Health care was based on 9 overcrowded and understaffed state and 40 private psychiatric hospitals with a mixed population of severe mental disorders (85%) and ID patients (15%) (Madianos et al, 1999). Many of the services for both mental health and intellectual disability initially started as EU projects funded jointly with the Greek state. This is a unique case in Europe, where the European Commission specifically funded mental health care reform in one EU country. The psychiatric reforms began with Law 1397 in 1983 introducing the National Health System and EU Regulation 815/84 through which financial aid was approved and a five-year plan adopted. The main focus of this policy was: improving hospital and in general health care, provision of minimum financial support, support for people who need help in their everyday life and community care.

The development of a network of community based services in geographically sectorised areas was the main goal in order to gradually replace the large psychiatric hospitals by Mental health centres, psychiatric units in general hospitals and many other community services. The implementation of these plans was initially very slow, but the exposure in 1989 of the distressing conditions in the Leros Mental Hospital, which had many patients with ID, resulted in the re-housing of a large number of them to fully staffed community residential facilities near the areas of their origin. The original five-year plan extended to cover a whole decade, by the end of which the improvement of the infrastructure of mental health services was considerable and several pilot community projects developed including staff training projects (Tsiantis et al, 2006).

Prior to 1996, Greece received EEC funds through Regulations 815/84 and 4130/88, which were unusual in the sense that they were only concerned with Greece, and only with Mental Health Care. In the transitional phase, in which funding was for the whole of Europe, 1996-97, Greece received about 2,000,000,000 drachmas. In 1997 the "Psychoargos" Programme of the Ministry of Health came into effect. This is a continuous action programme, funded by the EU with 17,500,000,000 drachmas, to which must be added a further 20% input from the Greek state. It is a continuous program developing over a 10-year period and aimed at gradually meeting the needs of the Mental Health Sector, at a national level. Phase I (1997-2001) placed emphasis on de-institutionalisation, while Phase II (2002-2006) on the development of community services. Mental Health Sectors are the basic structural elements of the new community-based service system. At present the network is constituted of 43 Mental Health Centres (MHC). However MHS had not been fully implemented and the desired network of services is still incomplete, leaving some regions without access to psychiatric care and the old style psychiatric hospitals, though considerably transformed, remaining largely populated.

Part of **Phase I** has been co-funded by EU (Operational Programme "Fight against exclusion from labour market" – Ministry of Labour) and it concerned inpatients in productive age (18-55). Through the operational programme hostels and vocational training workshops have been established. A total of 66 hostels, 14 boarding houses and 10 apartments have been set up during Phase I. In these facilities approximately 1000 patients from mental hospitals all over the country have been settled. In addition, a boarding house for autistic people, a hostel for refugee mental health patients and 35 vocational training workshops for mental health patients have been set up. Furthermore 1200 professionals have been employed to staff these services (newly hired Mental Health professionals) and were offered special training (Spyraki, 2001).

In addition, 69 workshops provide vocational training and preparation for re-entry into the labour market. The second phase of the Psychoargos programme, co-funded by the EU, allowed for the creation of more MHCs, PUGHs and Child Guidance Centres, as well as for the creation of Day Care Centres, Day Hospitals, Vocational Training Workshops, Mobile Units, Social Co-operatives and Crisis Management Units.

Phase II is characterized by the implementation of both residential facilities for chronic inpatients and community mental health services for "new" patients.

Concerning dehospitalisation, there has been an effort to settle all chronic patients in the community. For this purpose, a number of residential facilities (*boarding homes*) were planned especially for aged patients and patients with dual diagnosis and/or multiple handicaps (severe learning disabilities and other mental or physical impairments) that were remaining in the mental hospitals. Each facility has a 15-bed capacity and is staffed with 23-26 professionals, 15 of them having the role of "carer".

Phase II has so far enriched the services by a number of new mental health units, for the period 2002 – April 2007 creating a completely different situation in mental health (table 2).

Table 1 Mental Health Units in April 2007 Phase II

Structure type	n
Hostel	88
Boarding home	111
Apartment	211
Day Centre	22
Mobile Mental Health Unit	16
Home Care Units	2
Autism Units	9
Alzheimer Units	6
Mental Health Centre	28
Child Guidance Centre	10
Psychiatric Unit in General Hospital (with beds)	22
Outpatient Clinics in General Hospital	35
Psychiatric Unit for children in General Hospital (with beds)	4
Outpatient Clinics for children in General Hospital	3
Short Stay Hostel	2
Psychiatric Hospital	5
Child Psychiatric Hospital	1
Total	**575**

There has been also a provision for those patients who were settled in hostels during Psychargos Phase I. The plan provided the establishment of a number of apartments, either semi-sheltered or autonomous, to which these patients could move to live. It was estimated that 6-8 residents out of 12 from each hostel could live in a more autonomous way in these apartments.

The "Independent Living Units" may host 36 persons at maximum. Specifically, 1-3 persons live in each apartment, where they sleep, cook, eat and cover their sanitary needs. A complex of 2-6 apartments consists a Section (2 – 18 persons), where places for common use are provided (kitchen, living room, dining room, laundry, storeroom etc.). A total of 1-6 sections are comprised in a Unit, where the same areas of central support are shared (administration offices, central storehouse etc.). The buildings of a Unit may not be located in the same block or district. In any case, it must be easy for all the residents of its sections to approach the areas of a Unit. Finally, it must be mentioned that legally it is not prohibited for Independent Living Units to be profitable. However, they all are funded by government or communal resources and have no profits (Pandeliadou, 2003)

Care for other disabilities (Child & adolescents, Severe and Profound Intellectual disabilities, Physical Disabilities)

Although the Greek reform project has managed to successfully modify the situation in the mental health services system, it failed to significantly influence the situation within the institutions for people with severe intellectual and physical disabilities. Such institutions, including those for small children and adolescents, still operate as closed care structures, many of them in extremely poor conditions. The country still

has an extensive institutional system comprising of large public institutions, as well as numerous small private institutions created by charitable organisations and scattered across the country. These structures operate under the supervision of the Department of Social Welfare at the Ministry of Health and Social Solidarity.

It has been estimated that there are 34 public closed care institutional settings, with a capacity of 40-200 residents, in Greece. These institutions host about 3,000 people of all ages (with the exception of senior citizens) with mental, physical and motor disabilities. Among them, there are five Care Centres for Children (KEPEP) that provide for children with chronic (incurable) diseases, physical disabilities or severe intellectual disabilities, with a total capacity of 300 residents. In addition, there are tens of small private institutions (created by charitable and church organisations) that care for another 3,000 patients with disabilities. In total, about 6,000 people with disabilities remain in public and private institutional settings, most of them for many years and some of them for their whole life. Approximately 30 per cent of these residents are children, adolescents and young people. These settings have not established explicit admission criteria, according to age, type of disability and degree of functionality. They admit indiscriminately people with many different needs. Most of them (65% of the total) care for people aged 2 to 36. This fact, in combination with the scant resources available for their operation, in terms of finance and human resources, means that the provision of specialised care is limited or non-existent, particularly in relation to children, adolescents and young people with disabilities.

In 2003 there were 37 "Special Centres" in the Attica Region, 15 serve exclusively people with intellectual disability. Special centres can be divided as follows:

- Public Special centres, which are established by the state and are being funded through the Ministry of Health and Social Welfare or the Ministry of Education. The staff is public employees and the families do not pay any fees. Sometimes there is funding from other resources too.
- Private Special Centres are profit oriented businesses, and function with the permission from the Ministry of Health and Social Welfare. However, in some cases there is a gap between what is described in the permission and what is actually provided. Families pay the fees while part of those fees are reimbursed through the insurance funds.
- Private Special Centres, are non-profit oriented and are being run by non-governmental groups, parents groups or the church. The families do not pay fees but a minimal contribution. There are constant financial problems.

In regard to services provided specifically for people with intellectual disability, there were 19 Institutions for chronic illness (which basically includes mental retardation) and 25 Centres exclusively for people with intellectual disability in 2003. There were 13 closed care centres (this is the Greek term for institutions), in 6 there are rooms for 2-5 persons, while in the rest the rooms serve 6-25 persons (Pandeliadou, 2003).

A 2004 study on the rights of people with intellectual disabilities and their access to education and employment in Greece, carried out in the framework of the trans-national programme EUMAP (EU Monitoring and Advocacy Program) revealed that children, adolescents and young people with disabilities that remain in institutions have very little access to education, pre-vocational and vocational training or to employment of any kind (supported, protected, etc.). In particular, there is a complete

absence of education and employment for children and adolescents with severe disabilities, who are therefore entirely abandoned by the society.

The need for the closure of institutions for people with intellectual, physical and other disabilities has been recognised. In 2003, five deinstitutionalisation projects were launched, consisting of staff training and the creation of new community-based structures. These projects are carried out in the framework of a wider programme, co-financed by the European Union, and entitled "Health and Welfare - Gradual reintegration of people with special needs into socioeconomic life and promotion of independent living". As a result, 129 people with disabilities have been deinstitutionalised and five community-based psychosocial rehabilitation hostels have been created. In addition, the central departments of the Ministry of Health have begun to record all operational data concerning institutional structures in Greece. Also, 17 open social care structures for people with disabilities and their families have been created in various regions, in order to provide counselling, help in accessing services, training, functional rehabilitation and social integration.

Services for elderly people

Greece has recognised the need for a more coherent approach to long-term care for frail elderly people. A number of programmes have been set up, while others are in the process of being initiated. The most successful among the programs is the program "Help at Home", which started in 1998 under the direction of the Health and Welfare Ministry. The programme is an extension of the programme of Open Care Centres for the Elderly (KAPI), which has been operating since 1979. It is projected to cover the needs of all frail and elderly people, including rural areas.

The main development in the area of long-term care for the aged is the National Programme for the Aged instituted by Law 2646/98 which reformed the system of Social Welfare. The main philosophy behind the Law is that frail and elderly people should be assisted in every way possible to deal with the problems in their home environment, avoiding the medicalisation and institutionalisation of old age. The programme, supported by a study identifying problem areas is in the process of being implemented through a series of actions, some of which are underway. Such are:

- Multifunction centres, ranging from rehabilitation services on an inpatient basis to day-care for the aged. There is planning for a 7 day care project providing old age clubs on a 10 hours daily service in major urban centres.
- A "Network of Community Solidarity" for old people living at remote villages based on voluntary work of young and appropriately trained people and the promotion of information dissemination and recreation facilities with daily broadcasts on public TV networks.

The new policy for the elderly is supported through the establishment of multidisciplinary research on old age through the establishment of the Gerontological and Geriatric Institute and the sensitisation of health professionals on the special health needs of the frail elderly.

Other developments include Homes for the elderly, renamed under Law 2345/95 as Elderly Care Units, are subject to State supervision and quality control. Quality standards for Elderly Care Units, both for profit and non-profit operations have been

issued. Chronic diseases institutions are gradually being transformed to treatment and rehabilitation centres.

The development of volunteerism has been reinforced through legislation (law 2646/98) and a new unit explicitly addressing volunteerism and NGOs was established at the Ministry of Health and Welfare. The legislative intervention provides the necessary framework for providing incentives both for the elderly to play active roles in voluntary programmes and incentives for volunteers to participate in care provision programmes for the elderly on the other hand. Other government programmes planned are mobile units for home help for ageing people living alone in rural areas and a programme of "Tele Warning" in collaboration with the National Telecommunication Organisation, aiming at providing old people with a sense of security. (OECD, 2000)

Social services

The Department of Social Welfare at the Ministry of Health and Social Solidarity provides social services either directly or through agencies that are funded and controlled by it, such as the PIKPA (Institution for Social Welfare and Care) and EOP (National Organization of Welfare). Based on the Law 2082/1992, EOP is in charge of the services provided to families and PIKPA is responsible for services to people with special needs and the aged population. Other state agencies involved in social services provision are the OAED (Organization of Labour's Employment), the Workers House (dealing with housing) that both belong to the Ministry of Labour. The General Secretariat of Welfare is comprised of different Directories: the directory of public inspection, the directory of family and child protection, the directory of protection of people with special needs and of protection of the aged, the directory of housing and the directory of social work. Based on legislation introduced in the 1980s about the rights of people with disabilities to employment and vocational training, the policy proposed was not based only on monetary issues, such as income supplements but involved active measures such as vocational training programs.

Although there are scarce data referring to the effectiveness of the state sector in provision of social services, there is general agreement that this provision has not been effective, and lately there is a concern regarding the role of local authorities, non-profit making and profit making organizations.

Municipalities

A very minor source of health funding is from local government, which occasionally provide medical advisory services for their citizens. The local authorities have only recently been involved in social services and there are several limitations restricting their contribution. One of the major limitations is the lack of financial resources. The establishment and the staffing of these services were almost always occasional, organized through European initiatives that aimed to the restriction of social exclusion. These acts were funded from both the European Union and Greece (with the European community covering the 75% of the budget). Unfortunately, after the end of European funding, these departments function ineffectively or have been suppressed, due to the lack of financial resources. On the other hand, there is limitation of legal identity restricting opportunities for collaboration with other agencies. Finally, since more involvement on part of the local authorities includes

redistribution of funds and power there is also resistance on part of certain state agencies.
As far as the local authorities are concerned, they have recently been involved in social services provision and their role has not been significantly developed (Greek Association for Local Authorities and Development, 1995). The basic factor that cuts down the municipalities'

Private sector

The role of the profit-making organizations in the private sector is on the rise. Private profit making agencies come to fill in the gaps of the public sector. This does not mean that they substitute public agencies (since they still function) but they function in addition to the public sector.

Charities and NGOs

Charity or religious organisations play a major role in provision of residential care for persons with disabilities in Greece. Non-governmental organizations produce policy for people with intellectual disabilities and play the role of lobby groups. Although in the past those organizations were oriented towards providing segregated services there is currently a trend towards integration and more normalization ideas. Family organizations mostly focus on providing alternative services and on pushing the government for more financial support and more advanced measures. On the other hand, volunteers groups aim mostly at changing the social climate and the attitudes towards people with intellectual disabilities, and they provide informal support such as help at home, social events and walks in the city. They depend mostly on European funds and they do not receive any substantial support from the state.

There is a national umbrella organization for all the organizations of persons with disabilities. Legal provisions mandate the representatives of persons with disabilities to participate in policy-making and to work with Governmental institutions. Organizations are often consulted when laws with a disability aspect are being prepared. Consultations take place at the national, regional and local level. The Government financially supports organizations of persons with disabilities.

Informal care

The current lack of sufficient services for people with severe disabilities is filled in by the informal networks – still very strong in Greece – such as kinship and friends, through which everyday assistance and often employment is guaranteed. These networks have been going through a crisis during the past decade because of the changing financial needs for families

4.2 Financing

Funding Sources

- State Budget
- Public Investment Budget
- Social Insurance Funds
- Private insurance and out of pocket expenditure

Public Hospitals

The regular annual subsidy from the State Budget is the largest source of income, covering 65 - 70%. It is used mainly for salaries.

Income from the Public Investment Budget is used mainly for the purchase of new buildings, or improvements to existing buildings, and for purchase of new equipment and technology (about 3% of all funding).

Per diem payments, which is the system whereby hospitals are reimbursed for services (including hotel services, laboratory and diagnostic tests etc.) at a pre-fixed price (below cost). Payment must be collected by the hospital directly from each Insurance Fund, often after considerable delay. There are more than 300 social insurance funds, with membership being related to profession and not to income, although 98% of the population is covered by 40 of them.

Out of pocket expenditure refers to informal payments (black economy) which are used mainly to queue jump, and to ensure personal attention from the doctor or better quality services.

Primary Health Care

State Budget, as above, for the Hospital Outpatient Departments, and for the Health Centres, which all belong administratively to a designated NHS Hospital.

Social insurance Fund polyclinics funded solely by the Insurance fund to which they belong.

Out of pocket expenditure. There is no cost-sharing at the health centres or polyclinics. Hospital out-patient appointments are charged at €3, and very few insurance funds reimburse this.

Private sector

Out-patient visits and hospital care reimbursed (if approved by fund doctors) by social insurance funds, private insurance or out of pocket payments at the time of service

Table 2. Public and Private Health Expenditure ([1]in million Euros, [2]as % GDP)

Expenditure	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000
Total Health Expenditure[1]	2,38	2,94	3,74	4,56	5,14	5,87	6,596	7,32	8,26	8,72	10,05	10,94
Public Health Expenditure[1]	1,51	1,84	2,28	2,68	2,99	3,44	3,874	4,29	4,76	4,95	5,811	6,27
Private Health Expenditure[1]	8.7	1,09	1,45	1,88	2,15	2,42	2,722	3,02	3,49	3,76	4,24	4,67
Public Health Expenditure[2]	4.7	4.8	4.8	4.9	4.8	4.9	4.8	4.9	4.9	4.7	5.2	5.2
Private Health Expenditure[2]	2.7	2.9	3.1	3.4	3.5	3.4	3.4	3.4	3.6	3.6	3.8	3.9
Total Health Expenditure[2]	7.5	7.6	7.9	8.3	8.3	8.3	8.3	8.3	8.5	8.3	9.0	9.1

5. Definition, eligibility and diagnosis/assessment

The Law 2430/1996 (Journal of the Greek Government 156 A/10.7.96) entitled "Establishment of December, 3rd, as the Day for Persons with Special Needs. Establishment of a Disability card and other provisions". This Law establishes the permanent or temporary disability card, depending on the nature and degree of disability. This card will serve as a proof of disability and will be delivered following a certification process by a Committee. The card will mainly be used for the granting of different benefits delivered by the government and notably the Ministry of Health and Social Care. Up to 2002 the process was applied in a single prefecture. The Article 23 at Law 2556/1997 "Measures against tax evasion, guarantying resources for the National Insurance Institute (IKA) and other subjects"; describes the certification of disability provides that the grant of a Disability Card, whether temporary or permanent, requires a minimum degree of disability of 67%.

Up to date, to become eligible for services, a person with disability needs a diagnosis and a certificate from the First Level Health Committee of the district he/she lives in. The Committee consists of physicians of nearly all specializations. It does not include a psychologist, social worker, special educator or other non-medical specialist. The committee examine the person with disability according to the List of Illnesses in which disabilities correspond to percentages of handicap, (edited by the Ministry of Health), and then decides the percentage of his/her handicap. In most cases, he/she is classified into definite categories of handicap that is 50%, 67% and 80%, and he/she becomes eligible for certain services accordingly. For example, all the insurance and pension funds that provide handicap allowances are based on this committee's verification (in Greece there is not a common insurance and pension fund for all employed people, but several professional categories have one of their own). Moreover, the committee is qualified to judge the capability of a person to do a bread-winning job and to define the duration of the allowance provision. A person with intellectual disability needs the verification from this specific Committee to be eligible for all available public services, monetary and non-monetary ones.

The First Level Health Committee may state that the handicap of a person with intellectual disabilities is considered as a permanent condition and assign that the person can take the allowance for a lifetime. However, decisions are reviewed every 3 to 5 years as a way of ensuring against insurance fraud – the State appears inefficient in its ability to monitor whether people with disabilities are cashing in on more than two insurance policies for the same reason, which is mostly illegal. Consequently, a person with disability in order to be eligible for some services goes through a weary procedure, of which the examination is only a part, many times in his/her lifetime. When the entitlement is denied by the First Level Committee, any citizen has the right to appeal against the decision within 20 days from the date of its announcement. During this period of time, he/she must ask for a new examination from the Second Level Health Committee, which will come to a definitive decision.

People with handicaps/dependency are regarded as legally competent unless the Court determines his or her incapacity. Under the article 1686 of the Greek Civil Code, an individual who, due to permanent mental illness, is deprived by the use of reason and is not able to take care of him/herself or his/her assets, is placed under Judicial Prohibition and cannot participate in any legal act (i.e., sell, buy, sign a contract etc.)

and the court nominates a tutor or a representative when the person is not totally deprived of the use of reason and there are doubts on that issue. In order for a person to be placed under judicial prohibition or Judicial Care, an immediate relative and the family council (6 members of the family) need to apply. The juridical decisions are based on, and bound by, the findings of the 1st Level Health Committee, which is exclusively qualified to adjudicate on medical issues (State Council's Decision 1594/1994). In general people with intellectual disability are considered minors with no real rights and as legally incompetent to control their affairs and there is no system to allow legal appeal against the decision made. The representative for the law plays the key role, either at the family council level or at the court level. What needs to be underlined is that there is no safeguard against mistreatment of any case available either by the state or by any non-governmental organization. (Padeliadu, Idresnet, 2004)

Eligibility for the disablement allowance, which determines the services people get, is based on three major criteria: (a) the percentage of their handicap, (b) the type of their insurance (according to theirs or their parents' job) and (c) the financial assets of the person and the other financial support that he/she receives. Benefits depend on whether a person lives at home, living in institution, other fund s support, As far as total insurance and pension coverage is concerned, when the person is at least 67% handicapped, he/she has the right to choose between the Provident Fund services or the insurance fund services on the grounds of his/her or the parents' job (L. 2072/92). However, this practically never happens, because the Provident Fund services are so poor, that nobody chooses them if he/she has an alternative. Only the non-insured disabled people turn to Provident Fund services.

Housing interventions are available for people with mental health problems, and these are all 100% financed through the health system. (Economic support has been provided through EU funding, as described above). Whoever has been resident in a psychiatric hospital for one year, and who can not afford private housing, or has no family, or whose doctor judges that a return to the family would not be in the patient's best interests, has the right to a housing intervention. This applies to all insurance funds. Those insured through the public employees fund can leave after a shorter time, if the doctor approves the transfer.

6. Prevalence of disability

Unfortunately, there are no extensive national statistics or any integrated and extensive research initiatives in this area. A recent estimate provided a range of 723,000 to 1,147,000 persons with intellectual disabilities in Greece, representing 7% to 11% of the total population (Grammenos, 2002).

The most reliable data come from the census of 1991, although there are several issues raised, such as the data collection method used and the lack of training for the census takers. In 1991, the total number of people with disabilities living in non-collective houses was 232,571, while those living in collective house were 34,432. From those persons living in non-collective houses, 6% were persons with intellectual disabilities. From those living in collective households, 13.3% were people with intellectual disabilities. Half of the total population of people with intellectual disabilities lived in collective houses (6,407). For the ages over 26 the percentages rise (from the total population of people with intellectual disabilities living in

collective houses, 1.9% are 0-10 years old, 13.6% are 11-25 years old, 32.5% are 26-50 years old and 52% are over 51 years old). In terms of age distribution, it appears that most of the people with mental problems in general fall into the 11-25 years old category. Here, it needs to be underlined that intellectual disability is the only category for which the percentage of people living in collective houses is so high (for physical disability, the figure is 9.9% with more than 80% of those being old (i.e. over 60) and for sensory disability to the figure is 3.2% with more than 70% of them being old) (Balourdos, Chrysakis, Soulis & Yfantopoulos, 1998).

There is no official or reliable data concerning the number and type of institutions for children and adolescents, nor is there information on the number, the socio-demographic features, and the kinds of problems children and young people in these institutions experience.

7. Residential Services for people with a disability

7.1 Overview

A detailed description of the available information about residential services for people with a disability is presented in Chapter 4.

7.2 Services for children with a disability

Child Psychiatric Hospital: for children between 0 and 18 years old with mental health. It is scheduled to close by the end of 2007. It is public: funded and financed by the Ministry of Health.

Psychiatric Units for Children in General Hospital: for children from 0 to 18 years old with mental health. They are 40 places in these facilities. They are funded and financed by the Ministry of Health. These acute services are not included in the template data as they are not long-term provision.

Outpatient Clinics for children in General Hospital: for children with mental health between 0 and 18 years old. Funded and financed by Ministry of Health. These acute services are not included in the template data as they are not long-term provision.

Child Guidance Centres: these institutions are for children between 0 and 18 years old. They provide care to children with mental health problems, but they provide care to children with physical disability, intellectual disability and more than one disability called “mixed”. They provide 24 hour support for short and long-term. They are funded, like the other facilities, by the Ministry of Health.

Hostels: are for children between 0 and 18 years old . They provide care to children with mental health problems, but they provide care to children with more than one disability called “mixed”. The provide 24 hour support for long – term and sometimes short - term. They are funded, like the other facilities, by the Ministry of Health and Social Solidarity.

Day Centres: for children with mental health between 0 and 18 years old. Funded and financed by Ministry of Health.

Autism Units: for children with autism only, between 0 and 18 years old. They provide 24 hour care for long and short – term and family support. They are funded and financed by the Ministry of Health .

Care Centres for Children (KEPEP): there arel 60 places in these facilities for children from 0 to 18 years old. They provide care for children with chronic (incurable) diseases, physical disabilities or severe intellectual disabilities. They provide 24 hour support for long-term. They are funded and financed by Ministry of Health Social Welfare or/and Ministry of Education. There are private and non-profit providers too.

Closed Care Institution and Rehabilitation: for children from 0 to 18 years old. They provide care for children with chronic (incurable) diseases, physical disabilities or severe intellectual disabilities. They provide 24 hour support for long-term. They are funded and financed by Ministry of Health Social Welfare or/and Ministry of Education. There are private and non-profit providers too.

7.3 Services for younger adults with a disability

Psychiatric Hospitals: for adults between 18 and 65 years old with mental health problems. They provide 24 hour support. They are funded and financed by the Ministry of Health.

Psychiatric Units in General Hospital with beds: for adults between 18 and 65 years old with mental health problems. They provide 24 hour support. They are funded and financed by the Ministry of Health.

Outpatient Clinics in General Hospitals: for adults between 18 and 65 years old with mental health problems. They are funded and financed by the Ministry of Health.

Mental Health Centres: for adults between 18 and 65 years old with mental health problems. They provide 24 hour support. They are funded and financed by the Ministry of Health.

Mobile Mental Health Units: for adults between 18 and 65 years old with mental health problems. They provide care some hours during the day, sometimes 24 hour support. They are funded and financed by the Ministry of Health.

Home Care Units: for adults between 18 and 65 years old with mental health problems. They provide 24 hour support. They are funded and financed by the Ministry of Health.

Short Stay Hostel: for adults between 18 and 65 years old with mental health problems. They provide 24 hour support for short-term. They are funded and financed by the Ministry of Health.

Boarding Homes: for adults between 18 to 65 years old, the typical age of adults in these services is 55 years old. There are 15 places in each facility for adults with mental health, physical and intellectual disability, and adults with more than one disability. They provide 24 hour support for short and long-term care. There are in total 3443 places in these facilities shared with Apartments and Hostels. The total of

staff is 3628 shared with Apartments and Hostels too and of this total 1168 are nurses. These facilities are funded by the Ministry of Health and Social Solidarity.

Hostels: for adults between 18 to 65 years old, the typical age of adults in these services is 55 years old. There are from 6 to 8 places in each facility for adults with mental health, physical and intellectual disability, and adults with more than one disability. They provide 24 hour support for short and long-term care. There are in total 3443 places in these facilities shared with Apartments and Boarding Homes. The total of staff is 3628 shared with Apartments and Boarding Homes too and of this total 1168 are nurses. These facilities are funded by the Ministry of Health and Social Solidarity.

Apartments: for adults between 18 to 65 years old, the typical age of adults in these services is 55 years old. There are from 6 to 8 places in each facility for adults with mental health, physical and intellectual disability, and adults with more than one disability called "mixed". They provide 24 hour support for short and long-term care. There are in total 3443 places in these facilities shared with Hostels and Boarding Homes. The total of staff is 3628 shared with Hostels and Boarding Homes too and of this total 1168 are nurses. These facilities are funded by the Ministry of Health and Social Solidarity.

Autism Units: for adults with autism only between 18 and 65 years old. They provide 24 hour support for short and long-term. They are funded by the Ministry of Health.

Independent Living Units: For adults between 18 and 65 years old with all disabilities and not severe mental health problems. They have got 36 places for its users. They provide long-term care several hours per day during the week. They are funded and financed by Ministry of Health and Social Solidarity.

Special Centre: For adults with 0 to more than 65 years old with intellectual disability only. They provide 24 hour support for short and long-term. They are funded by Ministry of Health Social Welfare or/and Ministry of Education and there are private and non-profit providers as well.

Closed Centres and Rehabilitation: there are 1600 places in Greece in these facilities. They have from 2 to 25 places in each facility for adults between 18 to 65 years old. The inpatients here have chronic illness and intellectual disability. They provide 24 hour support for short and long-term. They are funded by Ministry of Health Social Welfare or/and Ministry of Education and there are private and non-profit providers as well.

7.4 Services for older adults

Alzheimer Units: For people with more than 65 years old with Alzheimer. They provide 24 hour support for long-term and they are funded and financed by the Ministry of Health.

Elderly Care Units (before called "Boarding Homes for Geriatric Patients): for adults aged over 65 years and any type of disability. They provide 24 hour support and long- term care. They are funded and financed by Ministry of Health.

Rehabilitation Services on Inpatient Basis (In multifunction centres): for adults aged over 65 years, funded and financed by the Ministry of Health.

8. Acknowledgements

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9. Information sources on disability used to compile the template and commentary, including people who were interviewed

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Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

Hungary

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Summary of the available data

The table below summarise the descriptions of the service types in Hungary.

Description of service types

Type of service	Size interval	Age group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admission
Institution for children with disabilities (Gyermekkorú fogyatékosok otthona)	51 to 150 places	0 to 65 years	Mixed ID with PD, SD, MH,Beh and other	24 hour	Mixed	Mixed	All long term
Temporary home for children with disabilities (Gyermekkorú fogyatékosok gondozóháza)	11 to 30 places	0 - 18/19 years	Mixed	24 hour	Mixed	Mixed	Up to 2 years
Special foster home (speciális gyermekotthon)	51 to 99 places	0 - 18/19 years	Mixed	24 hour	Local authority/municipallity/county	Mixed	All long term
Student hostel for students with special needs (speciális diákotthon)	51 to 99 places	6-18 or 19 years	Mixed	24 hour	State and Local Authority/municipality	Mixed	Mainly long term (during schooling)
Care institution for adults with disabilities (Felnőttkorú fogyatékosok ápoló-gondozó otthona)	51 to 200+ places	All ages	Mixed ID with PD, SD, MH,Beh and other	24 hour	Mixed	Mixed	All long term
Rehabilitation institutions for adults with disabilities (felnőttkorú fogyatékosok rehabilitációs intézménye)	51 to 200+ places	Over 18 years	Mixed ID with PD, SD, MH,Beh and other	24 hour	Local authority/municipallity/county	Mixed	Long term (but up to 8 years)
Temporary home for disabled adults (felnőttkorú fogyatékosok gondozóháza)	11 to 30 places	Over 18 (i.e. adults only)	Mixed ID with PD, SD, MH,Beh and other	24 hour	Mixed	Mixed	Short to medium term (up to 2 years if specified)

Group home for adults with disabilities (felnőttkorú fogyatékosok lakóotthona)	8-14 places	16-65 years	Mixed ID with PD, SD, MH,Beh and other	24 hour	Mixed	Mixed	All long term
Institution for people with psychiatric problems (pszichiátriai betegek otthona)	100 to 200+ places	Over 18 (i.e. adults only)	MH	24 hour	Mixed	Mixed	All long term
Temporary home for people with mental health problems (pszichiátriai betegek átmeneti otthona)	11 to 30 places	Over 18 (i.e. adults only)	MH	24 hour	Voluntary/not-for-profit (over 95%)	Mixed	Short to medium term (up to 2 years if specified)
Group home for people with mental health problems (pszichiátriai betegek lakóothona)	8 to 14 places	16-65 (i.e. adults only)	MH	24 hour	Mixed	Mixed	All long term

Data available by service type – breakdown by size and disability

NB: Breakdown of data into the above 11 categories is not available, only aggregate data can be presented for the broad categories of "residential services for people with disabilities" which includes care institutions, rehabilitation institutions, group homes and temporary homes for people with intellectual disabilities, and "residential services for people with psychiatric problems" which includes care institutions, rehabilitation institutions, group homes and temporary homes for people with psychiatric problems.

Type of service	Places total	Under 30 places	Over 30 places	ID	MH	PSD	Elderly/ dementia	Mixed/ dual	Other/ unspecified
home for children with disabilities (Gyermekkorú fogyatékosok otthona)	2329	.	2329	.	.	.	.		2329
Special foster home (speciális gyermekotthon)	.	.	.	.	.	.	.	.	.
Student hostel for students with special needs (speciális diákotthon)	.	.	.	.	.	.	.	.	.
Residential services for people with disabilities	14074	991	13083	.	.	545	.		13529
Residential services for people with psychiatric problems	7987	123	7864	.	5351	.	.	2635	1
Total	**24390**	**1114**	**23276**		**5351**	**545**		**2635**	**15859**

Data available by service type – breakdown by gender and age

Type of service	Places total	Male	Female	Gender unspecified	Children	Younger adults	Older adults	Age unspecified
home for children with disabilities (Gyermekkorú fogyatékosok otthona)	2329	1280	901	148	1015	1156	10	148
Special foster home (speciális gyermekotthon)	.	.	.	.	.	.	.	.
Student hostel for students with special needs (speciális diákotthon)	.	.	.	.	.	.	.	.
Residential services for people with disabilities	14074	7534	6271	269	467	12370	968	269
Residential services for people with psychiatric problems	7987	4137	3808	42	.	6321	1624	42
Total	**24390**	**12951**	**10980**	**459**	**1482**	**19847**	**2602**	**459**

Staffing

Type of service	Total staff	Care staff/nurses/might include teachers in boarding school	Managers or other administrative staff (not care staff)	Educators/ Day staff	Day and care staff (no distinction made)	Clinical staff (Drs, therapists, psychologists, etc.)	Other staff (ancillary staff)	Other staff (excluding ancillary staff)
Home for children with disabilities (Gyermekkorú fogyatékosok otthona)	1044	848	40	68	.	17	.	70
Special foster home (speciális gyermekotthon)	.	.	.	.	.	.	.	.
Student hostel for students with special needs (speciális diákotthon)	.	.	.	.	.	.	.	.
Residential services for people with disabilities	3640	2892	226	147	.	28	.	333
Residential services for people with psychiatric problems	.	.	.	.	.	.	.	.
Total	**4684**	**3740**	**266**	**215**		**45**		**403**

Completeness and accuracy of the data

This report and the data template are based on information obtained during an August 2006 meeting with Zsuzsa Csató, disability consultant with the National Institute of Social and Family Policy (NCSSZI, currently Institute of Social Policy and Labour, SZMI), Renáta Szrena, Department of Disability Affairs and Rehabilitation, and Ákos Erdélyi of the Department for Family and Social Services. All of these offices are under the new Ministry of Social Affairs and Labour. At this meeting I was provided with data tables showing social institutions for temporary accommodation and permanent boarder social institutions according to type for 2004, and employee data, 31/12/2002. I was given a copy of *The Draft Resolution of the Parliament No. 10/2006 (II.16) on the New National Programme of Disability Affairs*. Information was also obtained from the *Yearbook of Welfare Statistics 2004* published by the Hungarian Statistical Office (KSH).

It was not possible to obtain data referring to the Roma. (see section 11)

Commentary: Hungary

1 Overview

The Republic of Hungary is located in Central Europe, bordered by Romania, Austria, Croatia, Serbia, Slovakia, Slovenia, and the Ukraine. Administratively, Hungary is divided into 19 counties. In addition, the capital city (*főváros*), Budapest, is independent of any county government. Since 1996, the counties and City of Budapest have been grouped into 7 regions for statistical and development purposes.
There are also 23 towns with county rights (singular *megyei jogú város*), sometimes known as "urban counties" in English (although there is no such term in Hungarian). The local authorities of these towns have extended powers, but these towns belong to the territory of the respective county instead of being independent territorial units. There are over 3,500 directly elected local governments (települési önkormányzat) with own budgets and extensive powers in social policy and education. Currently an administrative reform is being implemented which aims to devolve more powers to the regions and reduce the responsibilities of counties.

2 Political and social context

Hungary has made the transition from a centrally planned to a market economy, with a per capita income nearly two-thirds that of the EU-25 average. Hungary continues to demonstrate strong economic growth and acceded to the EU in May 2004.

2.1 Government organisation and structure

The government of Hungary is a parliamentary democracy. The President, elected by the Parliament every five years, has a largely ceremonial role, choosing the dates of the parliamentary elections.

The prime minister selects Cabinet ministers and has the exclusive right to dismiss them. Each Cabinet nominee appears before one or more parliamentary committees in open hearings and must be formally approved by the President.

A unicameral, 386-member National Assembly (the *Országgyűlés*) is the highest organ of state authority and initiates and approves legislation sponsored by the Prime Minister. National Parliamentary elections are held every four years; the next are due to be held in 2010.

An 11-member Constitutional Court has power to challenge legislation on grounds of unconstitutionality.

2.2 Disability relevant policy

Coordination of disability affairs and social services for persons living with disabilities until recently were under the Ministry of Youth, Family, Social Affairs and Equal Opportunities (ICSSZEM), established in 2004. After general elections in 2006 ICSSZEM was merged with the Ministry of Labour to become Ministry of Social Affairs and Labor. Coordination of disability issues belongs to this ministry. There is a Disability Unit which is responsible for coordination both within the ministry and with other ministries, agencies, etc. The Department of Disability Affairs

and Rehabilitation under this Ministry is responsible for the National Programme of Disability Affairs.
The New National Programme of Disability Affairs, 2005, sets out the policy framework for 2007-2013. According to this document, "People with disabilities have the same rights and responsibilities—being equal members of society and of the local community—as any other citizen." One of the principles of the Programme is the principle of integration, which "supposes that people with disabilities can make and maintain contacts with other people and with the widest range of social and economic institutions in their everyday lives." It continues: "All action leading to cutting off social contacts in the community and to exclusion should be avoided… All measures and professional principles that result in unfair segregation should be reviewed."

This is the third programme since the Act on the Equal Opportunities of People with Disabilities went into effect in 1999 (Act 26 of 1998). This Act provided for establishment of the National Disability Council with representatives of authorities, people with disabilities, and NGOs working with/for people with disabilities. The Programme is drafted by the Council and adopted by the Government. Implementation of the Programme is monitored by the Council. Efforts have been made to strengthen the implementation of the programmes through greater visibility of budget allocations, but the main weakness of the programme is that it lacks its own funding and relies on monies earmarked by the relevant ministries. The Act also states that by 2010 the "modernization" of residential services should take place and "those people who are capable to live more independently should be cared for in small-scale settings." Modernization of residential services has been on the agenda since 1999 but so far no real structural changes have occurred and there are no signs of strong government commitment or initiative.

3. Demographics

The population of Hungary is 9,956,108 (July 2007). 92.3% of the population are Hungarian; 6.4% other or not listed (2001).

4. Health and Social Care System

Health and social care are two separate systems in Hungary. Health care is predominantly financed by health care (social security) contributions and is under the auspices of the Ministry of Health. The health care system will not be discussed here partly because it is currently undergoing major reform and partly because it is less relevant; residential services are part of the social care system.

Act III of 1993 on Social Services and Administration, and its implementing regulations set out the main framework of social care. The Act distinguishes three types of social assistance: financial assistance, in kind benefits and services, including residential and day care services for people with intellectual disabilities and psychiatric problems. (see 7.1 for more details)

4.1 Organisation

As a rule, county and local governments are responsible for the provision of social care services. The Act stipulates which services should be organised by which tier of government on the basis of the number of their residents. Services can be provided either directly by local and county governments (this is the most common) or

outsourced to voluntary providers. Under some conditions the Act allows the operation of independent voluntary, private or church providers as well.
Residential services fall into the responsibility of county-level governments (i.e. counties, towns with county rights and Budapest), however all local governments are free to provide residential care if deemed necessary and have the resources.
Currently the majority of places in long-term children's (57%) and adult (73%) homes are maintained by the counties and Budapest. A smaller percentage (11%; 7%) is maintained by other local governments (towns); 24%, 5% by churches. Only 5% of places in both children and adult provision are provided by voluntary organisations. An additional 5% is provided by central state (national) institutions.

4.2 Financing

Social care is financed from state budgets (central government and local government budgets) and contributions of service users. All social service providers should be licensed (i.e. to certify that it meets the minimum standards and requirements) and receive a fixed monthly sum for each service user (so-called statutory funding). This is a fixed sum, does not take into account variations of individual needs. It is set according to the type of service each year when the State Budget is approved by the Parliament.

The statutory funding gets to the providers either directly from the central government (in case of independent private and voluntary providers) or via the local government (in case of public, state providers). Statutory funding is estimated to cover around 60% of total operating costs of services.

In addition service providers owned or contracted by local governments usually get additional funding from the local budget. However there is anecdotal evidence of some local governments withholding state funding for service providers.

The third source of income for service providers are fees paid by service users. Their maximum amount is regulated by laws, and depends on the income of the individual and/or their families. Most users of residential services are entitled to disability-related cash benefits which provides a very modest own income.

Finally, public money is available for capital investments either from central or local budgets. According to the calculations of Kézenfogva Alapítvány, based on budgetary figures and reports, Hungary has spent over 13 billion HUF on capital investments in large institutions (renovation or construction of new institutions) and less than 1 billion HUF on smaller scale community provision (group homes) since the adoption of the Act XXVI of 1998.

5. Definition, eligibility and diagnosis/assessment

There are different definitions of disability for different purposes—education, employment, social assistance, etc. There are several assessment committees for determining eligibility for financial and other support. Assessment procedures are to be revised to simplify and introduce more person-centered approaches.

6. Prevalence of disability

The number of people with disabilities was assessed at the 1990 and 2001 censuses; according to the latter there were 577,000 people with disabilities (5.7% of population). This figure concerns self-reported disability and therefore probably under-represents some types of disability, such as intellectual disability. There is a large number of elderly people among them: "Among people with disabilities, the proportion of those older than 60 years is 44.8%, twice as much as the proportion … within the whole population." There are no general prevalence estimates or studies.

6.1 Issues of measurement

Since 1993 the assessment of intellectual disability is carried out by specialist teams (tanulási képességet vizsgáló szakértői bizottság) that assess every children in compulsory schooling age who is referred to them by parents or professionals (teachers etc.) They assess special educational needs and advise parents on available education services. Therefore there are fairly accurate prevalence figures for younger generations, however for older cohorts only estimates could be made.

6.2 Numbers/rates available

According to the 2001 census, people with physical disabilities represent the largest proportion (43.6%) within the disabled population, while the proportion of people with intellectual disabilities is approximately 10%, the proportion of people with visual disabilities is 14.4%, and 10% of people with disabilities suffer from hearing disabilities and communication disabilities. The proportion of people with other disabilities increased from 6.7% (1990 census) to 21.6% (2001).
A recent report prepared by Kézenfogva Alapítvány puts the number of people with severe and multiple disabilities at around 12,000. (Bass 2004)

7. Residential Services for people with a disability

7.1 Overview

As in other post-communist countries, Hungary has historically evolved large (typically between 90-200 places) boarding institutions which hinder social inclusion. "Often children's homes and boarding social institutions (rehabilitation institutions, small group homes, caring-nursing homes for people with disabilities) providing long term care and dormitories (students' homes) are the venues for the lives of people with disabilities" (*The Draft Resolution on the New National Programme of Disability Affairs, 2005*). According to *Hungary, 2004* (Hungarian Central Statistical Office, www.ksh.hu), at the end of 2004 sixty-nine thousand people were living permanently in social care homes. About two-thirds of places were for elderly; nearly one quarter for people with disabilities; 11% for psychiatric patients.

Residential accommodations for individuals with disabilities are found under three government bodies: social care homes are under the Ministry of Social Affairs and Labour; vocational/educational institutions are under the Ministry of Education; psychiatric hospitals are part of the health care system. The types of "Social Care with Accommodation" are defined by Act III of 1993 on Social Services and Administration. These include the following:

Care institutions provide long-term residential care for people with higher support needs and dependency, and often need nursing care as well. Types of care institutions:

- For elderly people
- for people with a disability
- for psychiatric patients
- for addicts
- for homeless persons

Rehabilitation institutions are intended to prepare residents for return to the community or independent living. Length of admission is up to 8 years. Usually service users have lower support needs. Types of rehabilitation institutions:

- For people with a disability
- For psychiatric patients
- for addicts
- for homeless persons

Temporary homes provide essentially the same services as care institutions, length of admission up to 2 years (1+1 year). In practice they are usually not separate services, but places licensed within care institutions. Types of temporary homes:

- For elderly people
- for people with a disability
- for psychiatric patients
- for addicts
- for homeless persons

Group homes are facilities for 8-12 (or up to 14) service users, providing either care or rehabilitation services. (Yearbook of Welfare Statistics 2004, 2005) Types of group homes:

- For people with a disability
- For psychiatric patients
- For addicts

(Note: even though residential institutions can provide nursing, they are still part of the social care system and fully funded from social care budgets.)

7.2 Services for children with a disability

Young people and adults must be cared for separately in social care institutions under the Ministry of Social Affairs and Labour. This however means that they should be in separate units, but can be cared for in the same institution. Although there are homes for children with disabilities and homes for adults with disabilities (however they both are "care institutions for people with a disability") residents are allowed to remain in children's institutions after the age of 18. The rationale behind this decision was on the one hand to avoid the stress of relocation, however more importantly the difficulty of transferring individuals between institutions due to the lack of places and coordination between service providers. In the children's homes, 46% of residents are under age 18; 47.6% are between age 18 and 39. Most of the remainder are 40-59 (Table 8.15, "Number of Residents in long-term residential social institutions by sex and age, 2004," *Yearbook of Welfare Statistics 2004*, 2005).

In 2004 there were 31 permanent boarder homes for children with disabilities, with 2,347 licensed spaces, 2,329 functioning spaces (capacity) and 2,181 attendants (residents) (= at 94% capacity). There were 3 temporary homes with capacity of 75 and 45 residents (60% capacity). (see remark below on temporary homes)

7.2.1 Vocational Residential Services and special student hostels

There are residential services under the Ministry of Education for youth with "moderate" intellectual disability which provide education and/or vocational training for young people in schooling age. In these "special boarding schools" people with intellectual disabilities represent 43.9% of residents (Open Society Institute, 2005).

7.3 Services for younger adults with a disability

In services for adults with disabilities the majority of residents are aged over 18 years, although 3-4% are younger. There were 260 residential facilities for adults with disabilities (14,143 licensed spaces; 14,074 functioning spaces; 13,805 residents; 98% capacity). Of these 260 facilities, 100 were group homes housing 969 individuals (992 licensed spaces; 991 functioning; 97.8% capacity), the remaining 160 were large institutions. There were 9 temporary homes for adults with disabilities with capacity of 115 and 95 residents (82.6% capacity) (Table 8.7, Yearbook of Welfare Statistics 204, 2005). As regards temporary homes, there are no specialist temporary or respite services, these places are found in long-stay facilities and often not very different from the long-stay places…

The 2001 population census surveyed residential institutions and found that the average size of institutions for people with intellectual disability was 97 places; 45% of the institutions had more than 100 places. Seventy-eight percent of residents lived in institutions that had more than 100 places, while only 1% lived in institutions with less than 20 places. Size of homes for disabled children is typically about 100; size for homes for disabled adults is larger, 100-200.

Many institutions are located in remote and isolated places with little possibility of social participation or integration: 22% of institutions (where nearly one in four residents live) are found outside communities. Forty-two percent of the buildings were built before 1945; 59% had never been renovated; 22% had been renovated or refurbished before 1989. Institutions had altogether 3551 rooms, out of which 32% had 1-2 beds, 36% had 3-4 beds, 28% 5-10 beds, and 3% more than 10 beds. This means that around 60% of all residents shared a room with at least 4 other people and 8% shared a room with more than 10 people. The majority of these rooms lacked their own bathroom and toilet facilities; those were shared by more than one room.

7.3.1 ***Services for psychiatric patients***

The system of social care homes for mentally ill individuals was established in the 1950s to care for psychiatric patients who were not able to maintain their living conditions alone and needed social care. People admitted to these facilities are chronic patients (often following acute hospital treatment) who cannot return to the community for various reasons. Size of these facilities is 100-200; the largest long-stay residential institution has about 700 places. The picture is fairly grim for psychiatric institutions; these are larger and rooms are more crowded than facilities for individuals with other disabilities. According to the 2001 census, two-thirds had

more than 100 places and 44% of rooms had 5 or more beds. Otherwise, characteristics are similar to those of institutions for disabled people: remote and isolated location, poor facilities and run-down buildings.

Individuals with intellectual disability (and autism) are often found in psychiatric institutions with the diagnosis "behavior problems." Gábor Gombos reports the results of a survey conducted by the National Institute of Family and Social Affairs among institutions in 2001. According to this report, more than 8000 patients were in the 52 institutions that responded the questionnaire (out of the 66 institutions in total). Not all residents were psychiatric patients as 29 care institutions have a mixed profile with elderly people, people with learning disabilities and addicts as well as patients with psychiatric diagnoses. These, in addition to 7,315 people with psychiatric problems provided for another 2,500 people with different needs. Another remarkable finding of the survey is the number of people on waiting lists: altogether 1,818 people were waiting to be admitted to one of the institutions, 985 people for more than a year. This suggests a considerable shortage of places: an increase of 25% would be necessary to meet the demand for services.

7.4 Services for older adults

Currently there are no specialist services for older people with intellectual disabilities. Homes for the elderly primarily provide nursing and care for persons over retirement age whose health is such that they do not require regular hospital treatment. Also eligible for admittance to homes for the elderly are persons over 18 years of age who, owing to illness, are unable to look after themselves. No figures are available on the number of younger PWID admitted to elderly care homes. Furthermore, some public institutions are so-called mixed profile which means that they have places for elderly people, PWID and people with psychiatric problems. A fair percentage (≈40%) of elderly in residential care are physically disabled; about the same percentage have dementia. There are some facilities for elderly with dementia (private homes, department in elderly homes).

8. Other relevant information on residential services

8.1 Psychiatric facilities other than those under Social Care

Care for individuals with psychiatric problems is carried out through two structures: the health sector and the social sector. Special psychiatric hospitals, and psychiatric wards in general hospitals fall under the health sector. These are funded from the health care budget (social security contributions) and provide acute, short term treatment or community mental health services. Strictly speaking these are not residential services in Hungary. There is very little joint planning with social services or provision of psychiatric services. Acute beds that are lost in the health care system as a result of the reform are not reprovisioned in the social care system, increasing the already large unmet demand for psychiatric services.[22]

9. Staffing

Staff requirements in residential care facilities – job categories, minimum numbers and qualifications – are regulated by Act III of 1993 On Social Services and Administration and Decree 2/2000, Annexes 2 and 3. The Decree distinguishes:

[22] According to the Hungarian Psychiatric Society this concerns 24% of the acute beds.

Group homes: # residents 8-12
Rehabilitation homes: 1 manager, 2-3 caregivers (includes 1 social worker)
Care homes: 1 director, 4 caregivers (includes 1 social worker)
Small homes for psychiatric patients: 1 director, 1 doctor, 2 part-time caregivers

Rehabilitation institutions: for each 50 residents:
5 nurses or support workers;
2 teachers/development professionals;
1 work coordinator;
1 leisure coordinator, 2 physiotherapists and 2 activity supervisors.

Care institutions: for each 50 residents
15 (or 20 in case of children) nurses or support workers;
2 teachers/development professionals;
1 social and mental health worker;
1 physiotherapist;
1 activity coordinator;
1 leisure coordinator.

(Management and administrative staff are in addition to the above categories and numbers.)

Staff categories in residential institutions for **children** with disabilities consist of the following:
1 head nurse;
1 nurse, social welfare worker;
1 physiotherapist;
1 social, mental health workers;
1 activity coordinator;
20 nurses or support workers;
1 head teacher
Larger institutions (over 50 places) should, in addition, have a doctor, a head nurse, a dietician and a head social worker.

The job category with the greatest number of workers in institutions of all sizes is Nurse, social welfare worker.

10. Costs

Residential service providers are entitled for normative state funding based on the number of their residents. This amount increased considerably – by 35% – between 2002 and 2005, however it declined (by 2-5%) from 2006 to 2007 in an attempt to reduce the budget deficit and curb public spending. Currently it is 950,000 HUF/resident/year for children, 800,000 HUF/resident/year for adults in care institutions and group homes, 700,000 HUF/resident/year for adults in rehabilitation institutions and group homes.[23]

[23] Act CXXVII. of 2006 on the Budget of the Republic of Hungary for the year of 2007.

To illustrate the total costs: in 2007 Hungary spends approximately 0.13% of its annual budget expenditure on the normative support of residential care services for people with disabilities (excluding people with psychiatric problems and children, and any additional funding by local governments etc.).

See also section 4.2

11. Issues

11.1 Rehabilitation institutions

Rehabilitation institutions for people with a disability have come under debate recently. These services are supposed to prepare service users for independent living and return to the community, however they lack the resources and facilities for this. Moreover there are no alternative services available for after discharge. Most of the rehabilitation institutions are found in isolated rural settings, with hardly any connection to neighbouring settlements. As a result most of the discharged service users end up in care institutions.

11.2 Ethnic minorities (Roma people)

Statistical data on institutionalized individuals with disability do not include a breakdown by ethnicity. Collection of ethnic data is strictly regulated by the law and it is only possible with the consent of the individual. This is a very sensitive issue and public institutions do not collect data on ethnic background of service users.

According to the 2005 EUMAP report, "The extent of the misdiagnosis of Hungary's Roma as having intellectual disabilities is revealed by the fact that Roma made up 29.4 percent (16,700 people) of the total number of people with intellectual disabilities, while representing just 1.9 percent of the population" (p. 2). Nevertheless this figure concerns children with learning disabilities in special education. No data (or estimates) are available for residential institutions. Based on site-visits Roma people do not seem to be over-represented in care homes (i.e. among people with moderate or severe intellectual disabilities) and are somewhat over-represented in rehabilitation institutions accommodating people with mild or moderate disabilities often coming from extremely underprivileged background. (It could be argued that rehabilitation institutions fill in the gaps of the social system by accommodating people who would otherwise need social housing or would be homeless.)

12. Acknowledgements

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13. Information sources on disability used to compile the template and commentary, including people who were interviewed

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Ákos Erdélyi, Department for Family and Social Services, Ministry of Social Affairs and Labour

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Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

Ireland

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Summary of the available data

Description of service types.

Type of service	Size interval	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length admissions	Age of service
5 day community group home (goes home for holidays)	6 to 10 places	Service type groups similar ages together but not usually in the same home	ID only	Mixed depending on need	State	State	Mainly long term	0 to 20 years
Independent unit in dedicated complex no support	6 to 10 places	All ages (0 to death)	PD and Sensory/other	Mixed depending on need	State	State	Mainly long term	0 to 20 years
Welfare home - PSD, older adults	31 to 50 places	Service type groups similar ages together but not usually in the same home	Mixed	.	State	State	Mainly long term	.
Living in	6 to 10 places	Service	Mixed	.	State	State	Mainly long	.

Type of service	Size interval	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length admissions	Age of service
community in agency provision with agency support		type groups similar ages together but not usually in the same home					term	
7 day community group home (goes home for holidays)	6 to 10 places	Service type groups similar ages together but not usually in the same home	ID only	Mixed depending on need	State	State	Mainly long term	0 to 20 years
7 day x 52 week community group home	6 to 10 places	Service type groups similar ages together but not usually in the same home	ID only	Mixed depending on need	State	State	Mainly long term	0 to 20 years
Dedicated unit,	6 to 10 places	Service	Mixed ID	.	State	State	Mainly long	0 to 20

Type of service	Size interval	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length admissions	Age of service
high support nursing care		type groups similar ages together but not usually in the same home	with PD, SD, MH, Behavioural and other				term	years
District/community hospital	11 to 30 places	Service type groups similar ages together but not usually in the same home	More than one disability group served (no main group) but not mixed	Mixed between units within same type - some provide 24 hr, some less than 10 hrs	State	State	Mixed	.
Specialist hospital	11 to 30 places	Over 18/25 (i.e. adults only)	MH, ID and PSD	Mixed between units within same type - some provide 24 hr, some less than 10 hrs	State	State	Mainly long term	.
Specialist unit	31 to 50 places	Service type groups similar	More than one disability group served (no main	Mixed between units within same type - some	State	State	Mainly long term	.

Type of service	Size interval	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length admissions	Age of service
		ages together but not usually in the same home	group) but not mixed, mainly ID and PSD	provide 24 hr, some less than 10 hrs				
ID 5 day residential centre (goes home for holidays)	31 to 50 places	Service type groups similar ages together but not usually in the same home	ID only	Mixed depending on need	State and Local Authority/municipality	State	Mainly long term	50 - 100 years
Independent unit in dedicated complex high support	6 to 10 places	Service type groups similar ages together but not usually in the same home	Mixed (usually PSD, older adults)	.	State	State	Mainly long term	.
Intensive placement - challenging behaviour	31 to 50 places	Service type groups similar	Mixed ID with PD, SD, MH, Behavioural	Mixed depending on need	State	State	Mainly long term	0 to 20 years

Type of service	Size interval	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length admissions	Age of service
		ages together but not usually in the same home	and other					
5 day residential centre (goes home for holidays)	31 to 50 places	Service type groups similar ages together but not usually in the same home	ID only	Mixed depending on need	State	State	Mainly long term	0 to 20 years
Dedicated unit high support nursing care & therapy - ID, PSD, older adults	31 to 50 places	Service type groups similar ages together but not usually in the same home	Mixed	.	State	State	Mainly long term	0 to 20 years
7 day residential centre (goes home for holidays)	31 to 50 places	Service type groups similar	ID only	Mixed depending on need	State	State	Mainly long term	.

Type of service	Size interval	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length admissions	Age of service
		ages together but not usually in the same home						
independent unit in a dedicated complex with low support	31 to 50 places	Service type groups similar ages together but not usually in the same home	PD and Sensory/other	.	State	State	Mainly long term	0 to 20 years
7 day x 52 weeks residential centre	31 to 50 places	Service type groups similar ages together but not usually in the same home	ID only	Mixed depending on need	State	State	Mainly long term	21 to 50 years
Nursing home	31 to 50 places	All ages (0 to death)	Mixed	.	Mixed	Mainly state or LA (more than 75%)	Mainly long term	21 to 50 years
Mental health	31 to 50	All ages (0	More than	Mixed	State and	State	Mainly long	0 to 20

Type of service	Size interval	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length admissions	Age of service
community residence	places	to death)	one disability group served (no main group) but not mixed	depending on need	Local Authority/municipality		term	years
Occupying full-time residential support place	.	Service type groups similar ages together but not usually in the same home	ID only	Mixed depending on need	State	Mixed (any)	Mainly long term	0 to 20 years
Psychiatric hospital	.	All ages (0 to death)	More than one disability group served (no main group) but not mixed	.	State	State	Mainly long term	100+
Mental health community residence	31 to 50 places	All ages (0 to death)	ID only	.	State	State	Mainly long term	0 to 20 years
Intensive placement - profound or multiple handicap	31 to 50 places	Service type groups similar ages together	Mixed ID with PD, SD, MH, Behavioural and other	Mixed depending on need	State	State	Mainly long term	0 to 20 years

Type of service	Size interval	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length admissions	Age of service
		but not usually in the same home						
Other residential service	31 to 50 places	Service type groups similar ages together but not usually in the same home	Mixed	.	State	State	Mainly long term	.

Data available by service type – size of service and disability groups.

Type of institution	Places total	Under 30 places	Over 30 places	Size not classified	ID	MH	PSD	Elderly/ dementia	Mixed/ dual	Other/ unclassified
District/community hospital - PSD	46	.	.	.	.	.	46	.	.	0
Specialist unit	24	.	.	.	.	.	24	.	.	0
Specialist hospital	12	.	.	.	.	.	12	.	.	0
ID 5 day residential centre (goes home for holidays)	111	.	.	.	111	.	.	.	.	0
Occupying full-time residential support place - ID	396	.	.	.	46	.	.	.	.	350
5 day community group home (goes home for holidays) - ID	524	.	.	.	524	.	.	.	.	0
Living in community in agency accommodation with agency support - PSD	44	.	.	.	.	.	44	.	.	0
Independent unit in dedicated complex no support - PSD	6	.	.	.	.	.	33	.	.	-27
Independent unit in dedicated complex high support - PSD	33	.	.	.	.	.	6	.	.	27
Dedicated high support (nursing) - ID, PSD	49	.	.	.	.	.	4	.	.	45
7 day community group home (goes home for holidays) - ID	659	.	.	.	659	.	.	.	.	0
7 day x 52 week community group home -	2679	.	.	.	2319	.	.	.	.	360

Type of institution	Places total	Under 30 places	Over 30 places	Size not classified	ID	MH	PSD	Elderly/ dementia	Mixed/ dual	Other/ unclassified
ID										
Dedicated unit high support (nursing & therapy) - ID, PSD	186	.	.	.	.	.	160	.	.	26
Welfare home - PSD	12	.	.	.	.	.	12	.	.	0
Intensive placement - challenging behaviour - ID	338	.	.	.	338	.	.	.	.	0
7 day residential centre (goes home for holidays) - ID	544	.	.	.	544	.	.	.	.	0
Nursing home - ID, PSD	218	.	.	.	126	.	92	.	.	0
Mental health community residence/facility - ID, PSD	74	.	.	.	55	.	19	.	.	0
Psychiatric hospital - ID	396	.	.	.	396	.	.	.	.	0
Intensive placement - profound or multiple handicap - ID	244	.	.	.	244	.	.	.	.	0
7 day X 52 weeks residential centre	2679	.	.	.	2679	.	.	.	.	0
Independent unit dedicated complex low support needs	45	.	.	.	.	.	45	.	.	0
Other full-time residential	50	.	.	.	32	.	18	.	.	0
TOTAL	**9369**				**8073**		**515**			**781**

Data available by service type – breakdown by gender and age.

Type of institution	Places total	Male	Female	Gender not classified	Children	Younger adults	Older adults	Adults over 18	Age not classified
District/community hospital - PSD	46	.	.	.	.	.	.	.	46
Specialist unit	24	.	.	.	.	.	.	.	24
Specialist hospital	12	.	.	.	.	.	.	.	12
ID 5 day residential centre (goes home for holidays)	111	72	39	0	18	92	1	.	0
Occupying full-time residential support place - ID	396	244	178	-26[1]	9	293	141	.	-47
5 day community group home (goes home for holidays) - ID	524	253	271	0	39	480	5	.	0
Living in community in agency accommodation with agency support - PSD	44	.	.	.	6	12	6	.	20
Independent unit in dedicated complex no support - PSD	6	.	.	.	0	6	0	.	0
Independent unit in dedicated complex high support - PSD	33	.	.	.	0	30	3	.	0
Dedicated high support (nursing) - ID, PSD	49	.	.	.	1	42	7	.	-1
7 day community group home (goes home for holidays) - ID	659	307	352	0	23	611	25	.	0
7 day x 52 week community group home -	2679	1159	1160	360	71	1919	329	.	360

ID									
Dedicated unit high support (nursing & therapy) - ID, PSD	186	.	.	.	6	159	27	.	-6
Welfare home - PSD	12	.	.	.	1	8	3	.	0
Intensive placement - challenging behaviour - ID	338	233	105	0	16	310	12	.	0
7 day residential centre (goes home for holidays) - ID	544	248	296	0	37	475	32	.	0
Nursing home - ID, PSD	218	77	49	92	1	133	84	.	0
Mental health community residence/facility - ID, PSD	74	27	28	19	0	49	25	.	0
Psychiatric hospital - ID	396	.	.	.	.	.	.	.	396
Intensive placement - profound or multiple handicap - ID	244	133	111	0	24	208	12	.	0
7 day X 52 weeks residential centre	2679	1408	1271	0	53	2066	560	.	0
Independent unit dedicated complex low support needs	45	.	.	.	4	35	18	.	-12
Other full-time residential	50	18	14	18	8	9	1	.	32
TOTAL	**9369**	**4179**	**3874**	**463**	**317**	**6937**	**1291**		**824**

[1] In some cases the figures provided did not add completely add up – i.e. more data was available on gender than had been available on number of places. This accounts for the negative numbers in the Gender/Age not classified column.

Staffing data: Information not available.

Completeness and accuracy of the data

Data description
The National Intellectual Disability Database (NIDD) & the National Physical and Sensory Disability Database (NPSDD) are the main sources of data for disability services within Ireland. The NIDD contains 3 basic elements: demographic details (profile of the population in terms of age, gender, level of disability etc); current service provision and future service requirements. The data provided in the reports of the committee are broken down by Health Services Executive Area and by local health boards within each area.

The NPSDD consists of 5 elements:

1. Administration details (including HSE area, agency returning data form, preferred correspondence format)
2. Client details (including type of living accommodation and living arrangements, primary carer details, next of kin details)
3. MAP data (barriers & challenges, Participation, WHODAS II)
4. Service use and requirements (therapeutic intervention and rehabilitation services, personal assistance and support services, respite services, day services, residential services and technical aids and appliances)
5. Details of disability (type of disability, primary and secondary diagnosis)

NIDD and NPSDD data is held on individual records (database form although it is noted that HRB do not have access to personal information about individuals (e.g. name and address) – the data is analysis anonymously). NIDD is a register of persons in receipt of services and is completed by service providers and supplied to Local Health Offices, where a local database is compiled. The Health Research Board (HRB) extracts this information annually to compile national figures. NPSDD is managed by the HRB using data collated by the Health Service Executive and non-statutory service providers providing specialist health and social services meeting the needs of people with physical or sensory disability under the age of 66. The data form is completed by a keyworker or an assigned data collector.

Information on diagnosis/type of disability is included in the Physical and Sensory Disability database but only level of intellectual disability (rather than diagnosis) is included in the NIDD. Data held is up-dated whenever there are changes to an individual's circumstances or during annual review. The Central Statistical Office (CSO) maintains on-line and other data on social surveys (information on disability in the labour force, NHS surveys). There are differing levels of access to the databases, and only authorised persons can pull down more detailed or complex information.

The National Intellectual Disability Database (NIDD) collects information on the users of services for people with intellectual disability. (See above). It currently has over 25,000 registrations. The database informs the regional and national planning of these services by providing information on trends in demographics, current service use and future service need. Data is reported regionally, including information on residential circumstances by age group and degree of disability. Like the NIDD, the National Physical and Sensory Disability Database (NSPDD) is a service planning tool that aims to provide a profile of people with physical or sensory disabilities who

are receiving specialised health and personal social services and who are waiting for specialised health and personal services. Data is collected for service users who began their usage before the age of 66 and it currently has over 27,000 registrations. An important feature of the NSPDD is its incorporation of International Classification of Functioning concepts into the administrative form. This ensures that data is collected on important life areas such as education, as well as salient contextual factors that impact on impairment. The Long-Stay Activity Statistics reports annually on the number of people in statutory long-stay care facilities and in private nursing homes. Data is categorised by age, medico/social status and level of dependency.

No comprehensive statistics exist for people with mental health difficulties. Usage of acute services is reported under the National Psychiatric In-Patient Reporting System maintained by the HRB, however no equivalent service database that covers community-based treatment and support exists for people with mental health difficulties.

Completeness and quality

It is evident from the above that there could be questions about the extent to which the administrative databases reflect the full picture of needs for people with disabilities. Even the most complete of the three, the NIDD, does not take account of people with intellectual disabilities who, for whatever reason, have not come in contact with formal services. However from the point of view of the current report the people who are accessing services are those in whom we are interested.

The NPSDD 2006 report points out that there were 27,056 people registered on the NPSDD database in June 2006 which represented 65.5% of the estimated number of people with physical disabilities receiving services in Ireland. Data on older people (66 years and older) is not included in the figures provided in the report bringing the total number of people for which data is presented to 25,692.

With regard to people with intellectual disability, data is available for the 24,556 people who were receiving services in April 2006 (this is 96% of all those registered on the NIDD). Data covers numbers and prevalence of disabilities and inferences can be made with regard to gender, age differences and to recent trends over time.

Information on people with long-term mental health problems is incomplete. Data is thought to be deficient in some way for (i) Private sector provision for mental health; (ii) Church-based provision (people for whom places are funded by the State will be on the register but anyone who funds themselves in these settings will not); (iii) Travellers (approx 11% population, but not all registered on the databases/accessing services); (iv) Long–stay elderly (DHC annual survey not located); (v) No data available on staffing levels/qualifications from publicly accessible sources; (vi) NPIRS and community care database do not record individual lengths of stay, duration etc. The data is collected as a register of people who use services and therefore does not give detailed information about nature of the residential services themselves. However, some information is available in the research literature which has helped to identify factors such as general service types and service size.

Accuracy and reliability

NIDD & NPSDD: The HRB oversees a system of on-going validation that aims to identify and correct gaps and inconsistencies in the data. Database guidelines and protocols are revised in response to issues highlighted by HRB and service providers that ensures a high degree of standardisation throughout the country. In addition, NIDD software contains routine technical checks on data. The extent of current service provision ensures that almost complete ascertainment of all persons with a moderate, severe or profound ID is possible. Children with even a mild level of disability will be included if they are in special classes or special schools. The NPSDD is not as complete possibly because individuals themselves may be more likely to withhold consent than the family members, carers or advocates of those on the NIDD database.

The template was completed early in late 2006 and early 2007. Since then other reports and information has become available – the data in the templates has not been changed but the more recent information has been in included in the country report which follows.

Commentary: Ireland

1. Overview

Ireland is an island situated off the coast of Great Britain, which constitutionally is divided into two parts. Six counties in the North of the Ireland make up Northern Ireland which is part of the United Kingdom. The remaining 26 counties make up what is known as the Republic of Ireland or Eire (initially known as the Irish Free State after the Irish War of Independence in 1922. It was 1948 when the Republic itself was established. Although it is acknowledged that there is substantial overlap between the two parts of the island and there remain many situations when the Island operates as a whole, the systems of health and social care are sufficiently different to warrant separate treatment. This report will focus on the Republic of Ireland (Northern Ireland will be covered in the UK country report).

2. Political and social context

2.1 Government organisation and structure

Ireland is a republic state with a parliamentary system of government. The president of Ireland who serves as head of state is elected for a seven-year term. The role is largely as a figurehead but the president does have some constitutional powers and functions. The prime minister is appointed by the president but on the nomination of parliament. Since 1989 the government of Ireland has been made up of a collation of the main parties – currently three parties (Fianna Fail, the Green Party and the Progressive Democrats). The parliament is made up for two parts – the Senate (a mixture of appointed and elected members who are public representatives) and the Dail Eireann (166 elected members representing constituencies across the state).

The 26 counties in Ireland are grouped together in different ways for statistical purposes. There are 29 administrative counties/county councils since County Dublin was divided into three county councils in the 1990s. In addition there are 5 cities (Dublin City, Cork, Limerick, Galway and Waterford) which are administered separately from the counties in which they are located. In addition there are five boroughs (Clommel, Dogheda, Kilkenny, Sligo and Wexford) which have a level of autonomy within the county but not a separate council.

2.2 Disability relevant policy

There are a number of relevant policies to be mentioned here (NDA, ageing and Disability paper). In terms of rights-based policy, there have been 4 main policy initiatives:

- The Equal Status Acts (2000 and 2004)
- The Employment Quality Acts (1998 and 2004)
- The Human Rights Commission Act (2000)
- The Disability Act (2005).

The first two of these are concerned with providing protection against discrimination on the basis of age and disability. The Human Rights Commission Act established the mandate of the Irish Human Rights Commission to promote and protect human

rights in keeping with the Irish constitution and international agreement to which Ireland had signed up.

The Disability Act (2005) was part of the National Disability Strategy implemented by the Irish government in order to bring about the equal participation of people with disabilities in society. The Act allows provision for the assessment of health and educational needs to be made for people with a disability and importantly includes the aspects of social and cultural life as well as participation in economic activity. This is important because it includes older people who are past retirement age. The Act also mandates an independent assessment of need and an individual service statement and puts a duty on public bodies to make public buildings accessible.

Another important element of the National Disability Strategy, is what is called the Comhairle (amendment) Bill – this Bill makes provision for personal advocacy services, specifically for people with disability who have problems accessing a social service, without the help of someone else.

In addition, the Health Bill (2006) had some implications for people with disabilities in terms of the quality of services provided, in that it introduced the role of the new Health Information and Quality Authority (HIQA) which will, among other things, set and monitor health and safety standards in health services, undertake work to assess the "safety, quality and standards of areas where there is serious risk to the welfare of people receiving services" and have the power to inspect services (www.medicalprotection.org).

The National Disability Authority is an important body in Ireland, set up as part of the National Disability Authority Act in 1999. It leads on disability issues, providing advice and guidance to the government in terms of disability relevant policy (http://www.nda.ie/). The NDA consists of four main departments:

1. Policy and Public Affairs;
2. Research and Standards Development;
3. Corporate Services;
4. Centre for Excellence in Universal Design.

As these four divisions suggest, the NDA also conducts research and develops statistical information to help in the planning of services and it monitors the implementation of standards and code of practice. Finally it is instrumental in promoting equality of people with disabilities in Ireland (http://www.nda.ie/cntmgmtnew.nsf/0/D2E2BF6F07A969B880256C790064011E?OpenDocument).

3. Demographics

The population of Ireland in 2006 was 4,239,848 (http://www.cso.ie/statistics/Population1901-2006.htm). Almost all Irish residents are believed to be fluent in English now. In addition 39% consider themselves fluent in Irish (www.wikipedia.org/wiki/Republic_of_Ireland). 94.8% of the population were recorded in the recent Census as white ethnic/cultural background. 1.1% were black and 1.3% Asian. The total number of non-nationals resident is recorded as 419,733

(approx 10% of the population). The biggest source of immigration is the UK, then Poland and Lithuania.

4. Health and social care system

4.1 Organisational structure

Until 2005 the provision of health care and personal social services rested with 8 Regional Health Boards. Following the Health Act (2004), these have now been replaced by the Health Service Executive (HSE), a single body aimed at ensuring access to cost effective and consistently high quality health and personal social services (http://www.hse.ie/en/AbouttheHSE/). The HSE provides a range of services for people with disabilities including, basic health services, assessment, rehabilitation, income maintenance, community care and residential care.

The HSE comprises 10 administrative areas and is responsible for providing health and social care for everyone in the Republic. Health and social services are divided into three service delivery units: Population Health promotes and protects the health of the entire population; Primary, Community & Continuing Care (PCCC) delivers care in the community and National Hospitals Office (NHO) provides acute hospital and ambulance services. The services are delivered by 4 administrative areas according to geographical location (http://www.hse.ie/en/AbouttheHSE/).

Traditionally services have been organised around distinct populations (i.e. those with intellectual disability, older people, people with intellectual disabilities and people with mental health needs. Within the HSE this categorisation has remained to a certain extent with responsibility assigned to three different "Care Group Managers" (National Disability Authority – Ageing and Disability, accessed 10/10/2007, chapter 4), each of which has their own budgets. The groups currently are older people, disabled people and people with mental health difficulties. (some of the issues with this are discussed in Section 8.4). Older people with disabilities already accessing services usually remain in disability services at present but there is no evidence as to how their changing needs are being met in that environment (NDA paper).

4.2 Health care

All residents can access health services which are free for those people classed as "Category 1" patients. This applies to approximately 29% of the population (www.eUser-eu.org/). Category 1 cards are allocated on the basis of age and income – so those with low incomes, children and older people can access health care, in particular primary care, without cost. Category II patients have to make a contribution towards most services although have cover for public hospital services.

Voluntary Health insurance is an important factor in health care provision in Ireland. 50% of the Irish population are covered by Voluntary health insurance which can be used to pay for health treatment in state, voluntary or private hospitals. However, almost ¼ of the population do not have either a Category 1 card or health insurance.

The public sector includes both HSE and voluntary hospitals. Both are funded by the state (at least primarily) but voluntary hospitals are owned and operated by religious organisations or lay boards of governors. There are a small number of private

hospitals. General practitioners are self-employed and the majority treat both private and public patients.

4.3 Social care

Responsibility for the provision of social care rests with the Health Service Executive, but also important is the Department of Social and family affairs, formally the Social Welfare Appeals Office and renamed in 2002, which is responsible for social protection policies and administers and managers the delivery of both statutory and non-statutory services and other schemes (http://www.welfare.ie/about/overview.html). It oversees the delivery of social insurance and benefits schemes, including unemployment, illness, disability etc. There are three groups of payments made by the Department:

- Social Insurance (or contributory) payments – made on the basis of pay-related social insurance – similar to the national insurance payments in the UK.
- Social assistance (non-contributory) payments which are benefits subject to means testing.
- Universal payments, such as child benefit or free travel for those over 65 which everyone gets whatever their financial situation or employment history.

The types of benefits available to people with disabilities come mainly from the social insurance and social assistance streams – contributory pensions, invalidity pensions, and disability benefits would be the most common social insurance payments made to people with disabilities. In addition people with disabilities might also access unemployment assistances, and rent allowance, under the social assistance schemes. Particularly important to people with disabilities are:

- Disability allowance – a weekly benefit paid to people with a disability over 16 years of age and under 66 years when the person has a disability expected to last for at least one year. The allowance is awarded subject to a medical assessment and a means test. Although this is usually a short term payment, it can be paid long-term.
- Invalidity pension – payable to people who are permanently unable to work because of illness or disability.

Important for those living in rented accommodation and receiving domiciliary support would be "rent benefit". (http://www.citizensinformationboard.ie/publications/entitlements/downloads/Disabilities.pdf)

People who attend a recognised training scheme or sheltered workshop are allowed to keep there benefits (usually Disability allowance) and also can receive a Rehabilitation Training Allowance. (http://www.citizensinformation.ie/categories/health/health-services-for-people-with-disabilities/rehabilitation_and_training_services_for_people_with_disabilities)
Those in Health Board run hospitals and residential settings are also eligible for Long-stay Institution Spending Allowance but this is means tested and only for those who are not receiving disability allowance. In essence this gives the person a small amount of spending money for basic essentials (http://www.welfare.ie/publications/sectoralplan.html).

Mulvany et al (2007) note that services in Ireland mainly evolved locally, often led by religious organisations, who brought those with disabilities into their religious communities in order to care for them. This was particularly true for children and adults with intellectual disabilities. By the 1960s the use of ordinary housing began to be promoted and by the 70s and 80s voluntary organisations were using ordinary housing to accommodate people who had previously lived in residential centres. Private sector involvement was never significant in the Republic of Ireland.

4.4 Funding

The annual budget (2005) for the Department of Health and Children (DOHC) was Euro 12 bn of which 7% is directed at mental health. The health service remains mainly tax funded. The rest is made up through payments for pharmaceuticals, some primary care services and private hospital treatment. Expenditure on health accounts for 8.2% GDP and has increased substantially, but this has been masked by strong economic growth. Health service funding is determined annually in negotiations between the Department of Finance and the HSE and is based on commitments to service provision, national pay policies and demographic factors.

Funding for social care comes from pay-related social insurance and from the exchequer, which picks up the deficit between expenditure and the social insurance fund.

5. Definitions and Prevalence of disability in Ireland

5.1 Definition

The Employment Equality Act of 1998 defines a broad definition of disability as:

- The total or partial absence of a person's bodily or mental functions including the absence of a part of a person's body.
- The malfunction, malformation of a person's body
- A condition, illness or disease which affects a person's thought process or judgement

The Disability Act (2005) defines disability as "disability, in relation to a person, means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participation in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment".

5.2 Prevalence

The 2002 Census of Population included two direct questions on disability and the table below summarises the data on the number of people with disabilities within different age groups and by gender.

Persons, Male and Females with a Disability Classified by Age Group and Percentage Disabled, 2002. Summarised from Central Statistics Ireland http://www.cso.ie/statistics/HealthandSocialConditions.htm

Age	Males	Females	Total	Percentage of population for respective age groups
0-14	10927	6384	17311	2
15-19	5029	3806	8835	3
20-64	84077	77788	161865	8
65 upwards	51773	83923	135696	38
Total	**151806**	**171901**	**323707**	**8**

The census was followed up by a quarterly national household survey and the update published in 2004 (http://www.cso.ie/qnhs/documents/qnhsdisabilityupdate.pdf) showed that there had been little change in the prevalence of disability since the 2002 census. It was reported that 298,300 people (just under 11% of all those aged 15-64) indicated that they had a longstanding health problem or disability. It is important to note that these statistics included people with chronic health problems, not just disabilities. The number of those with "mental, nervous or emotional" problems is recorded at 30,500; those with visual impairments at 5000; those with disabilities in the arms, hands, back, neck, legs or feet totalled 88,200. However, no indication of the severity of these impairments is given.

The National Disability Authority have recently carried out a comprehensive survey on the situation of persons with a disability or longstanding health condition but results of this survey are not yet available.

According to the Central Statistics for Ireland, there were 3475 inpatients in Psychiatric hospitals and units in 2005 (http://www.cso.ie/statistics/psychiatric_units_no_of_inmates.htm). However, the Daly et al report (2004) on the Activities of psychiatric units and hospitals, using the ICD10 classifications, records 22,279 admissions for people with mental health diagnoses. However, this included 3217 people with alcoholic disorders, 724 with drug related problems, 210 with intellectual disability, 26 with development disorders and 1568 unspecified)

The most up-to-date information on intellectual disability is probably the National Intellectual Disability database. In 2006 there were 25,518 people registered on the NIDD, which gives a prevalence rate of 6.51 per 1,000 population. The prevalence of mild intellectual disability is presented as 2.18 per 1,000 and 3.74 per 1,000 for moderate, severe and profound intellectual disabilities.

With regard to people with physical disabilities, the 2006 Annual report of the National Physical and Sensory Disability Database(NPSDD) includes 27,056 people – which is estimated at 65.5% of the population of people with PSD in Ireland, which would imply that there are at approx 44,800 people who receive health and personal social services support because of their disabilities. Of those for which data was available on services (25,691), 77% had only physical disabilities, 6% had hearing impairment, 5 % had visual impairment and 2% had primary speech and language problems only. 10% had multiple physical disabilities.

6. Residential services for people with a disability

6.1 Overview

The NPSDD gathers information on the specialised health and personalised social service needs of people with a physical and/or sensory disability. It monitors current service provision for people who:

- have a persistent physical or sensory disability arising from disease, disorder or trauma
- in the case of dual disability, have a disability that is predominantly physical or sensory
- are less than 66 years of age
- have consented to be on the database.

In 2006 there were 25,692 people registered on the NPSDD as receiving services, (data from all persons over 66 were excluded). People with moderate, severe or profound intellectual disabilities (who also have physical or sensory disabilities) were included in the Intellectual disability register. In 2006, 630 persons on the database (2.5%) were in full time residential services. 77.1% of people on the database were living in private accommodation and 19.6% in rented accommodation. The majority of the latter (86% of the total sample) were living with family members. Only 9.2% lived alone. Information on service types are provided in Section 6 below.

With regard to those with intellectual disability, there were 8,181 people registered on the National Intellectual Disability database as receiving long-term residential services in 2006. In addition, 91 people were receiving regular part-time care (2/3 days per week, which increases to 167 if those receiving part-time care on weekends and alternate weeks are included. 861 people were living at least semi-independently (table 3.8 in the NIDD 2006 Annual Report). The number of people living in community group homes (usually about 6 places per home), independent settings and those receiving residential support services (e.g. outreach, respite and emergency centres) has shown substantial increases since 1996. A corresponding although smaller decline is in evidence for residential centres (traditionally bigger) and psychiatric hospitals.

6.5 Children with disabilities

The Department for Education has responsibility for the primary and secondary education of all children including those with intellectual or physical and sensory disabilities. Education is not compulsory until a child reaches 6 years of age. Provision includes:

- Specialist residential primary school (intellectual disability)
- Specialist residential primary school (physical & sensory disability)
- Specialist residential secondary school (intellectual disability)
- Specialist residential secondary school (physical & sensory disability)

The Health Research Board and Social Services Inspectorate have produced a directory of residential service providers for children with disabilities (2004) and this indicates that residential care for children is provided through full-time residential care (five-day or seven-day residential services); residential care attached to specialists schools; respite residential care (planned or emergency) and holiday care.

In terms of full-time or residential support places, there were 42 organisations who provided 104 residential units plus the HSE which ran 24 residential units. The directory includes details on 128 residential units (including those that provide respite and holiday provision) 111 provided for children with intellectual disabilities, 11 for children with physical or sensory disabilities and 6 for those with PSD and intellectual disabilities. The 128 units provided a total of 375 full-time residential places (253 for children with ID, 101 for children with PSD and 20 for those with mixed disabilities) and 544 residential support places.
In terms of size, 54 units provided between 2 to 5 places, 37 provided between 6 and 11 places and 15 units provided more than 11 places.

According to the National Intellectual Disability Database report for 2006, 213 children attended 5 or 7 day residential services (including residential schools) and 12 were receiving residential support services only (i.e. without day services/education). The majority of children (7123) on the database attended services on a day basis only and almost all of these lived at home with families.

Children with physical disability also tended to live at home – 446 of those under 18 had a personal assistant. Only 33 children with physical or sensory disabilities were placed in some form of residential placement and almost all of these were in what was called dedicated high-support with nursing care environments.

6.6 Residential services for younger adults (18-65) – intellectual disabilities

Traditionally people with intellectual disabilities had been provided for by the State either at home or in larger mixed disability settings. In the 1920s and 30s voluntary organisations (including religious orders) started to provide services (usually bigger institutional settings) for people with intellectual disabilities. The types of services available within Ireland for people with intellectual disabilities usually fall into three main categories (Mulvany et al., 2007):

- Special Living settings (53% of people in residential care)
- Ordinary Housing (40% of people with intellectual disabilities in residential care)
- Hospital accommodation. (7% of people in residential care)
-

Ordinary Housing

5-day community group home: a standard domestic-style house in a residential neighbourhood where a small number of people (typically 4 people) with a disability live together with appropriate staff supervision. They go home for the weekend and holidays.

*7-day x 48-week community group home***:** as above. They go home for holidays only.

*7-day x 52-week group home***:** as above, no periods away.

Special living settings

5-day village-type/residential centre: goes home for weekends and holidays: A residential centre is usually based on a campus. The aim is to provide accommodation which is domestic in scale and as home-like as possible. Accommodation may be in the form of a village-type complex or in smaller clusters of 3-4 houses at one location.

The mean size for these residential centres is 41 persons but can go up to 220 people (Mulvany et al., 2007).

*7-day x 48 week residential centre***:** as above, but goes home for holidays only.

7-day 52 week residential centre: as above, no periods away.

Intensive placement (challenging behaviour/profound disability): Intensive residential service for people with challenging behaviour/profound disability which usually involves a higher level of service (eg. 7 days/week) and higher staff ratio. This may take the form of an independent unit within a dedicated complex.

*Nursing home***:** where the care of two or more persons who need assistance with act of daily living by virtue of physical or mental illness. Regulated by the HSE, there are certain minimum standards of care and provision. These are sometimes described as dedicated high support with nursing care (ID, PSD) or dedicated high support with nursing care and therapy (ID, PSD and elderly).

*Specialised units***:** for example a group home for people with brain injuries

Hospital accommodation

*Specialised hospitals***:** eg. National Rehabilitation Hospital/Cappagh. State-managed hospital accommodation is usually in wards of 20 people with staff generally being nurses and nursing assisntants (Mulvany et al., 2007).

In May 2002, the UN Committee on Economic Social and Cultural Rights (CESCR) expressed its concern "that a large number of persons with mental disabilities, whose state of health would allow them to live in the community, is still accommodated in psychiatric hospitals together with persons suffering from psychiatric illnesses or problems, despite efforts by the State party to transfer them to more appropriate care settings." The 2001 Health Strategy promises a 'complete programme' to transfer people with intellectual disabilities who are currently in psychiatric hospitals to 'appropriate accommodation' as soon as possible and by the end of 2006 at the latest. The Inspector of Mental Hospital's report for 2002 records 197 people with intellectual disabilities still residing in psychiatric facilities, and details a number of completed transfers, and plans in train in other services to provide alternative placements for this group. "Notwithstanding these welcome advances, while people with intellectual disabilities remain inappropriately accommodated in psychiatric institutions, Ireland is failing to comply with human rights standards" (Amnesty International, 2003). The report notes that "many people with intellectual disabilities with a diagnosed mental illness are not accommodated in psychiatric hospitals, but in de-designated former psychiatric units and hospitals, or in privately owned facilities run by voluntary bodies and religious organisations. There is no independent inspectorate system for these facilities".

6.7 Residential care for older adults (65+)

In Ireland, there are approximately 436,000 people over the age of 65 years, representing 11.1 per cent of the population, 67.8 per cent of whom are female. Long-term care facilities in Ireland comprise health board geriatric homes/hospitals, health

board welfare homes, health board district/community hospitals, voluntary geriatric homes/hospitals and private nursing homes. Estimating the number of older people in long-stay care is more difficult than simply counting the number of beds in the long-stay sector. First of all 1,716 beds are designated for assessment/rehabilitation, respite and convalescent care for older people. These beds are not part of the long-stay sector although they do impact on placement decision-making for admission to long-stay care. This means that the actual number of long-stay beds currently in the system is 22,336. Not all of these beds will be occupied, however, as occupancy rates are unlikely to be 100 per cent, making it necessary to make an adjustment to take account of the actual number of patients in long-stay care at any given time. In addition, some of the beds are likely to be occupied by people under 65 years of age. These people must, by definition, be excluded from calculations of elderly residents in long-stay care. The Department of Health Survey of Long-Stay Units recorded that on December 31st 2002 there were 20,959 older people resident in such long-stay units. The number of beds in the long-stay sector in Ireland is just over 24,000. The estimated number of older people in long-stay care in long-stay facilities is 19,548, or 4.6 per cent of the elderly population. The gap between beds and residents is due to average occupancy rates of 93 per cent, the omission of beds that are not long-stay and a small but significant number of people in long-stay care who are less than 65 years of age.

Welfare home

This is a residence provided by the HSE that provides extended care such as a Community Nursing Unit. Generally for elderly people with disabilities due to age and described as dedicated high support with nursing care (and/or therapy).

6.8 People with mental health problems

There has been a significant increase in community psychiatric facilities in recent years and a corresponding increase in the numbers treated in the community. In 1960 the Irish psychiatric hospital population stood at 21,000 (including 3000 people with ID), in 2006 it was 3,389 (of whom 46% were long stay, HRB, 2006). Because of social/cultural considerations there is no re-housing along the lines of the UK boarding house. Although in theory the legal responsibility for providing sheltered housing for the mentally ill rests with housing authorities in practise virtually all such accommodation is made available by the mental health services themselves. Community residences cater for both short and long term stays the number that existed in 2002 was 392 offering 2934 places. There are now specialised mental health rehabilitation teams in many Irish psychiatric services.

Mental health community residence: A standard style domestic-style house in a residential neighbourhood where a small number of people live together, with appropriate staff supervision. The service is provided by mental health services and provides approximately 3000 places.

*High Support Group Home***:** 24 hour nursing support (50% of places)

*Medium Support Group Home***:** Nursing or trained care (usually 24 hour)

*Low Support Group Home***:** visits by CPN and other support workers.

Psychiatric hospitals: Walsh and Daly (2004) explored the changes in psychiatric provision up to 2002 and reported that there had been a large reduction (80%) in the number of inpatients resident in psychiatric institutions and units between 1963 and 2002, with the last 10 years from 1992 to 2002 seeing a 35% reduction alone. The number of people resident in hospitals was 3389 in 2006. Of those who were in psychiatric hospitals in 2001 (Irish Psychiatric Hospitals and Units Census, cited in Walsh and Daly, 2004), just under 30% had been hospitalised for 5 years or more. Gender balance in 2001 was approximately 55% male, with higher rates of older people than younger people. Most common mental illnesses in 2006 were schizophrenia (34% of residents) and depressive disorders (15%). In 2006 the census recorded 251 (7%) of residents had an intellectual disability. Seventy-five percent of places were provided by the HSE, 23% in units in general hospitals and 17% in private hospitals.

Daly et al., (2005) report that figures for admissions rather than inpatients. The average length of stay for the 22,279 admissions for 2004, with admissions more common 35-44 age range for men and 45 to 64 age range for women. Schizophrenia and alcoholic disorders most common for men, depressive disorders most common for women. The majority of admissions were discharged within 3 months of admission. 48% occurred within 2 weeks. 98 people died after more than 5 years in hospital, 42 (0.4%) were discharged after more than 5 years (20 of these had been there for 25 years or more). In terms of admissions 35% were to psychiatric hospitals and 47% to general hospital psychiatric wards, with 18% to private hospitals. People generally stayed longer in private hospitals than in other settings.

The Mental Health Commission report from in Annual Inpatient survey in 2006 (http://www.mhcirl.ie/docs/Books1-6.pdf) indicated that there were 3,332 persons on the registers of approved centres with 3,897 beds in those centres in Ireland. The report also highlights that there had been a decrease in the number of inpatients and an increase in the number of people in community based services (3174 people). Of the 3332 people, 510 were in independently provided services. In terms of diagnosis of inpatients, by far the biggest group remains those with Schizophrenia, schizotypal and delusional disorders (1154 – 35%), closely followed by depressive disorders (449 – 14%) and then intellectual disabilities (385 – 12%). 1077 (32%) of inpatients had been in the hospital for more than 5 years. Almost all of these patients were in long stay wards or Old age wards. The trend for long stay beds to be for older people remains. Over 50% of people were in psychiatric hospitals, with 23% in psychiatric units in general hospitals, 15% in independent service providers, 2.5% in Central Mental Hospital, and 5.5% in St. Joseph's Intellectual Disability Service.

There is information that suggests that the prison population is growing with the addition of people with long-term mental health needs and there are ~~16~~ 3 Forensic services in the country. Dublin's Central Mental Hospital is the national centre for Forensic Psychiatry, and provides high, medium and low-risk security. The current bed capacity is 89, 7 of which are for females. 25 beds are acute and take 160 admissions per year (O'Neill, www.irishpsychiatry.com/forensicservice.htm, accessed 10/10/07). O'Neil notes that 30 of the long-term beds are occupied of patients of low risk who could be managed within the general psychiatric services if adequate community services were available.

In general, it considered that the CMH does not have sufficient beds for the demand, while much of its infrastructure has been condemned due to insufficient capital funding (Amnesty International, 2003). However, plans for the redevelopment and extension of the forensic service at CMH are in progress. (O'Neil).

6.9 Independent Sector provision

Non-profit organisations contribute to the delivery of health services in a variety of ways including the direct provision of services, rehabilitative care and respite. They are also involved in advocacy and the provision of information and support.

The health strategy documents published by the Department of Health and Children acknowledge the unique role and contribution of non-profit organisations in the provision of health and personal social services and confirm a commitment to the development of the State's relationship with them. In 2004, for example, the 8 former health boards paid €877m to non-profit organisations providing services to disabled persons. Each non-profit organisation's relationship with the health service is influenced to some extent by the materiality of the funds provided to the organisation and the nature of the services it provides. Managing that relationship poses particular challenges since the services, while forming part of the overall health service, are largely negotiated rather than the result of contested procurement; they result from a historical pattern of provision in particular areas contrasting with other delivery methods in other regions; the scope of the services provided on the ground may be more extensive in the case of non-profit organisations; there are tensions between the demands of accountability and partnership. The DoHC collects aggregate data on activities of over 550 long-stay units (public and private nursing homes) in the various health board areas in order to compile statistics on the number of beds available for long-term care, how the beds are used and the types of patients occupying them (classified by age, gender, level of dependency, socio-medical status and other criteria). In 2002, 495 or 87% of these homes made returns covering 20,000 patients of whom 66% were over 80.

Nursing homes for people belonging to religious groups (includes priests, nuns) fall outside the jurisdiction of HSE. The private nursing home sector has become increasingly important in the provision of long-stay care for older people, with the number of beds in the private sector now accounting for more than 50 per cent of all long-stay beds in the country. Substantial numbers of people, particularly the elderly, are in care provided by church-based organisations such as the St John of God Hospitaller Services which provides mental health services, care for older people and services for adults and children with disabilities. It has over 2000 staff caring for 3000 individuals. The St John of God provide 320 residential places in Kildare, 650 at St John of God North East, 200 at Carmona and 425 in Menni (Kerry). Similarly, the Irish Christian Brothers provide orphanages and schools for children who have hearing impairments and communication difficulties; the Sisters of Charity provide residential care for elderly persons. In Ireland, 'church based' doesn't strictly mean that. Daughters of Charity for St Vincent de Paul - one of the largest in Ireland- has been historically run by RC nuns as were many others - however that does not describe the present day service which has long had a secular admissions policy and management. The same applies to Stewarts which traditionally was Church of Ireland – but has been secular for many years. Virtually all services are now run on a catchment basis as with admission based on address. Almost all services are

'voluntary', which in Ireland means that an agreement was reached with the government (in the sixties when free health and educational provision was first provided) for the organisation to maintain a degree of independence from the state. This generally means that the service agrees to contribute 5% or something similar and the state provides 95% of costs. All services simply receive a budget based on assessment of need/ numbers of clients etc. Independence means buildings/property etc were not relinquished. Also as the services were already in place the government has never developed state services. This means that services in Ireland are like a patchwork of indigenous relatively independent organisations providing community/ residential and day services- all operating under the state umbrella. (Many of which are interesting, innovative and good quality). Commercial provision, such as Mowlam Health Care, provides 150 nursing homes in Ireland with approximately 14,000 beds (i.e. 60% all nursing home places).

7. Staffing

Little information is available about staffing in services for people with disabilities.

It is known that the HSE is the largest employer in Ireland, with over 65,000 staff in direct employment and a further 35,000 funded by the HSE

8. Current issues

8.1 Ethnicity

Almost 11,000 travellers were identified during the course of the 1996 Census of Population representing 3 per thousand of the overall population of the country. Information on numbers, location and employment of travellers was collected, but there is little information on health needs or uptake of services. Apart from the fact that they are often poorly served by services and may slip through, there are a number of specific demographics that set them apart. For example, 50% of the traveller's population is under 15 years old (compared to 24% of the general population).

8.2 Age

Ireland is a comparatively young population, but conversely, is also an ageing population (see below).

8.3 Regional/geography

A number of other issues impact on residential care and provision in Ireland. These issues are cross-cutting and exacerbate trends. Migration is a significant factor, both with the shift of population to the cities from rural areas (with concomitant shift from agricultural to industrialisation), but also significant migration, particularly of younger people, abroad (a process that has been on-going for 2 centuries). This leaves an increasingly older sector of the population, often living in poorer conditions at the margins, increasingly being cared for by an ageing carer population (particularly so in faith-based care), yet within the context of an overall younger population. In addition there has been an influx of foreigners and tourist buying second homes in rural areas which tends to have an excluding effect by driving up house prices etc.

8.4 Funding issues

The allocation of separate budgets and organisation of services on the basis of client groups, creates some funding problems especially for older people or for younger people with intellectual disabilities who develop dementia. It is possible for each of the divisions under a care group manager, can argue that a particular person is not their responsibility when the person does not fit neatly into any one group. The NDA paper (Ageing and Disability: A Discussion Paper) argues that this system creates barriers to meeting changing needs in a person-centred way.

8.5 Reform in 2008

In January 2008 a new way of accessing and charging for long-term care in Ireland comes into effect. This new system, Fair Deal on Nursing Home Care, was announced in December 2006, by the Minister for Health, Mary Harney, acknowledging the problems with the current system stating that "at the moment, the support systems around long-term nursing home care are scrappy, inconsistent and unfair." She recognised that individuals on the same incomes can end up with vastly different care costs and that even with subventions the cost of private nursing home care is unaffordable for many; some family members pays as much as EUR 35,000 per annum for a parents care. The Minister cited one of the worst aspects of the current system to be the imputed 5% income from the value of individual's home that is taken into account in the assessment of means. The new system is intended to end the difference in support between those in private and public beds and ensure that contributions are clearly based on an assessment of means and assets by the HSE, and that these contributions will always be below disposable income. Only those with high dependency needs will be eligible for nursing home care; others will be eligible for community care with support through home help packages. Under the new system older people will contribute no more than 80% of their disposable income towards the costs of care. There will be no need for family members to voluntarily contribute towards the costs of care; instead, a charge will be made against the older person's home to a maximum of 15% of its value. If a spouse lives in the house then this is reduced to 7.5%; in all cases the charge is deferred until an individual's and their spouses estate is settled. Moreover unlike the current system, where 5% of the value of one's house must be contributed in cash for every year of residence in a nursing home, under the new system charges made against property will not be made after three years, regardless of how long someone will be in a nursing home. This, it is claimed, will mean that no one will in future have to mortgage or sell their homes. Legislation detailing the new system is expected in Autumn 2007.

9. Acknowledgements

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Ann Doyle, Health Research Board
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10. Information Sources

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6. Central Statistics Ireland (www.cso.ie)

10.2 Verification of information

On-site visit and meetings with sources in the Health Research Board 26-30 September 2006:
Caraiosa Kelly, National Intellectual Disability Database, Disability Databases Unit 27/09/2006
Mary Ann O'Donovan, National Physical & Sensory Disability database, Disability Databases Unit 27/09/2006
Dr Dermot Walsh, Mental Health Unit, Health Research Board, 28/09/2006, 29/09/2006.

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12. Appendix – Ireland "typical" case study

Marie is a 22 year old woman with severe learning disabilities who also presents some behavioural problems. Marie is unable to live on her own without constant care. Until her mother died recently, she lived in the family home, receiving some supports from the municipality. There is no other immediate family.

Given that Marie has been living at home until now, and bearing in mind the nature of her disabilities, what would have been her likely pattern of education and care to this point?

Given that Maria is 22yrs old i.e. born in 1985 and has a severe intellectual disability with some challenging behaviours, the following is likely to be the educational input:

(i) Maria would have received a care-based type of support most likely in a Child Education and Development Centre, with no formal support from education. This service would have been provided by a voluntary / non-statutory service provider;
or
(ii) She could have attended a special segregated school - however as she had challenging behaviour she most likely would have a care-based service.

Who would have provided and paid for these services? How would have this been decided and by whom?

(i) Care Based Model of service - funded through the Department of Health & Children/ Health Boards up to 2005, since then Health Service Executive (HSE). The type of service would be decided by a multi-disciplinary team - parents & psychologist most likely following assessment funded through Health.

(ii) Funded from Education - decided by multi disciplinary team - psychologist & parents most likely following Assessment funded through Health. The multi-disciplinary element would be funded by Health.

What is the most likely outcome for Marie now? (What, realistically might Marie expect from health or social welfare services?). What input might Marie or her advocate/representative have in this process?

Under 5yrs assessment as a right under the Disability Act 2005 as became mandatory in July 2007, (responsibility Health Service Executive), over 5yrs not yet implemented, however there is provision for collaboration between Health and Education. EPSEN Act (Education) also applies but will be implemented incrementally not yet mandatory.

Who would typically be responsible for providing services? i.e. what department, which professions would be involved, who would be responsible for determining or managing care and how might this be paid for?)

Multidisciplinary Team, statutory & non-statutory service providers together with parents – (reference the Disability Act and EPSEN Act). Education would be provided as per the constitutional right of a child as enshrined in Irish law (refer to precedent as per O'Donoghue and Sinnott cases v. the Depts. of Education & Health). In 2007 special needs organizers: Education, National Education Council, Assessment Officers and Liaison Officers Health Service Executive. Lobby groups including the National Federation of Voluntary Bodies etc. to influence national policy, funding etc. The National Intellectual Disability Database for statistical planning purposes.

Funding:

- Education funded through Education
- Assessment funded by either HSE or Education
- Pre School funded mainly through HSE Funds
- Sometimes risk funded by non-statutory service providers, especially where there is a death/emergency as there is no access to contingency funding.

What factors might influence her pathway or access to services? (for example, entering residential care provided by a church-based organisation versus a state-run facility, or residential care home over nursing home, or day support rather than educational or work facilities). How is one type of service chosen over another? How is this decided and by whom?

Decided by the HSE / Service Provider / planning committees, sometimes emergency respite provided and the individual then blocks a bed and by default becomes residential. Day services are supported by respite as the policy is to maintain individuals in their own community. Where residential is required the policy is small group homes as homelike as possible. In Ireland currently the involvement of religious service providers is declining as most services and formerly religious providers are becoming companies, that are governed by a Board of Directors.

Without going into too much detail, and given the limited information, what can you tell me about the likely next stage in Marie's life and the likely people to be involved, and the way decisions such as patterns of service and funding might be made? A brief and direct answer, without going into too much detail will suffice as long as any complexities or barriers are briefly mentioned.

Currently Health & Personal Social Service funding is provided based on the available new development funding/multi-annual basis. Unfortunately demand outstrips supply and we have to prioritise as best we can. Service providers have to provide services within budget and are therefore less likely to risk fund as there are no guarantees, no bail outs or contingency funding available.

Adults with ID would receive a day service; some receive training usually 3 years (either Rehabilitative or Vocational funded). Education for adults with ID is the responsibility of HSE which includes life-long learning. For individuals with dual diagnosis, for example someone with learning disability and mental Health problems, the HSE is responsible for funding under the Mental Health Act 2002.

(See also National Disability Strategy which 6 Government departments have signed up to, including National Development Plan (Capital Funding). Advocacy falls under the auspices of Comhairle - National Policy.)

(Information provided by Brian O'Donnell, Federation of Voluntary Organisations, Ireland)

Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

ITALY

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Summary of the available data

Description of service types

The table below summarise the descriptions of the 19 service types included in the template.

Type of service	Size interval	Age group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admission
Comunitá socio educativa per minori	6 to 10 places	6-18 or 19 years	Mixed	24 hour	Mainly independent (over 50% private or voluntary)	Regional authority/LA/County and state	Mixed
Comunitá socio-riabilitativa per minori	6 to 10 places	6-18 or 19 years	Mixed	24 hour	Mainly independent (over 50% private or voluntary)	Mixed state/local and private contributions (insurance/private)	Mixed
Comunitá alloggio per minori	6 to 10 places	0 - 18/19 years	Mixed	24 hour	Voluntary/not-for-profit (over 95%)	Mixed state/local and private contributions (insurance/private)	Mixed
Comunitá familiare per minori	6 to 10 places	0 - 18/19 years	Mixed	24 hour	Mainly independent (over 50% private or voluntary)	Mixed state/local and private contributions (insurance/private)	Mixed
Altre strutture per minori	6 to 10 places	0 - 18/19 years	Sensory impairments	24 hour	Voluntary/not-for-profit (over 95%)	Mixed state/local and private contributions (insurance/private)	Mixed
Residenza Sanitaria Assistenziale	31 to 50 places	6-18 or 19 years	Mixed	24 hour	Mainly independent (over 50% private or	Mixed state/local and private contributions (insurance/private)	All long term

Type of service	Size interval	Age group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admission
					voluntary)		
Istituti per minori	11 to 30 places	0 - 18/19 years	Mixed	24 hour	Voluntary/not-for-profit (over 95%)	Mixed state/local and private contributions (insurance/private)	Mixed
Private Psychiatric Inpatient Facilities	31 to 50 places	.	MH	24 hour	All (over 95%) private	All private/insurance	Mixed
Comunitá socio-riabilitativa per adulti	11 to 30 places	16/18/25 to 60/65 (adults but not older adults)	PD	24 hour	Mainly independent (over 50% private or voluntary)	Mixed state/local and private contributions (insurance/private)	All long term
Non-Hospital Residential Facilities	11 to 30 places	40 years and older	MH	24 hour	Mixed	Mixed (any)	All long term
Comunità familiare per adulti	6 to 10 places	16/18/25 to 60/65 (adults but not older adults)	PD	24 hour	Mixed	Mixed state/local and private contributions (insurance/private)	All long term
Residenza assistenziale per autosufficienti	31 to 50 places	40 years and older	Mixed	24 hour	Mixed	Mixed state/local and private contributions (insurance/private)	All long term
Residenza socio-sanitaria	31 to 50 places	40 years and older	Mixed	24 hour	Mixed	Mixed state/local and private contributions (insurance/private)	All long term
Altre strutture per adulti	11 to 30 places	16/18/25 to 60/65 (adults but not older adults)	PD	24 hour	Mixed	Mainly state or LA (more than 75%)	All long term

Type of service	Size interval	Age group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admission
Comunitá alloggio per adulti	6 to 10 places	16/18/25 to 60/65 (adults but not older adults)	PD	24 hour	Mixed	Mainly state or LA (more than 75%)	All long term
Comunitá socio-riabilitativa per anziani	31 to 50 places	over 80	Mixed	24 hour	Mainly independent (over 50% private or voluntary)	Mixed state/local and private contributions (insurance/private)	All long term
Comunitá alloggio per anziani	31 to 50 places	over 80	Mixed	24 hour	Mixed	Mixed state/local and private contributions (insurance/private)	All long term
Residenza Sanitaria Assistenziale	31 to 50 places	40 years and older	Mixed	24 hour	Mixed	Mixed state/local and private contributions (insurance/private)	All long term

Data available by service type – breakdown by size and disability group

Type of service	Places total	Under 30 places	Over 30 places	Size unclassified	ID	MH	PSD	Elderly/ dementia	Mixed/ dual	Other/ unclassified
Comunitá socio educativa per minori	175	175	.	0	.	20	10	.	18	127
Comunitá socio-riabilitativa per minori	361	175	.	186	.	5	251	.	28	77
comunitá alloggio per minori	93	34	59	0	.	11	.	.	55	27
Altre strutture per minori	98	2	96	0	.	.	81	.	1	16
Comunitá familiare per minori	72	72	.	0	.	20	10	.	18	24
Istituti per minori	201	109	92	0	.	.	97	.	22	82
Private Psychiatric Inpatients Facilities	3,975	.	.	3975	.	3,975	.	.	.	0
Comunitá socio-riabilitativa per adulti	13,281	5,042	8,239	0	.	5,303	1,116	.	5,413	1,449
Non-Hospital Residential Facilities	17,138	.	.	17,138	.	17,138	.	.	.	0
Comunità familiare per adulti	945	945	.	0	.	529	75	.	197	144
Residenza assistenziale per autosufficienti	10,434	1,333	9,101	0	.	443	249	.	7,663	2,079
Residenza socio-sanitaria	51,444	4,653	46,791	0	.	1,186	382	.	44,354	5,522
Altre strutture per adulti	273	204	69	0	.	89	88	.	59	37
Comunitá alloggio per adulti	4,699	2,807	1,892	0	.	2,355	355	.	1,495	494
Comunitá socio-riabilitativa per anziani	2,038	116	1,922	0	.	89	51	.	1,516	382
Comunitá alloggio per anziani	520	351	169	0	.	62	10	.	379	69
Comunità familiare per anziani	57	57	.	0	.	7	.	.	38	12
Altre strutture per anziani	252	209	43	0	.	3	18	.	219	12
Residenza Sanitaria Assistenziale	75,930	4,949	70,981	0	.	3,361	1,175	.	65,600	5,794
Total	**181,986**	**21,233**	**139,454**	**21,299**		**34,596**	**3,968**		**127,075**	**16,347**

Data available by service type – breakdown by gender and age

Type of service	Places total	Male	Female	Gender unclassified	Children	Younger adults	Older adults	Adults over 18	Age unclassified
Comunitá socio educativa per minori	175	76	71	28	73	74	.	.	28
Comunitá socio-riabilitativa per minori	361	196	88	77	268	16	.	.	77
comunitá alloggio per minori	93	28	38	27	60	6	.	.	27
Altre strutture per minori	98	44	38	16	82	.	.	.	16
Comunitá familiare per minori	72	24	24	24	42	5	.	.	25
Istituti per minori	201	94	53	54	144	4	.	.	53
Private Psychiatric Inpatients Facilities	3,975	.	.	3,975	.	.	.	.	3,975
Comunitá socio-riabilitativa per adulti	13,281	6,441	5,394	1,446	235	10,445	1,153	.	1,448
Non-Hospital Residential Facilities	17,138	7,506	8,437	1,195	.	.	.	.	17,138
Comunità familiare per adulti	945	443	358	144	27	736	37	.	145
Residenza assistenziale per autosufficienti	10,434	1,872	6,482	2,080	0	1,032	7,321	.	2,081
Residenza socio-sanitaria	51,444	11,194	34,728	5,522	0	2,833	43,086	.	5,525
Altre strutture per adulti	273	99	136	38	0	198	31	.	44
Comunitá alloggio per adulti	4,699	2,481	1,721	497	40	3,803	359	.	497
Comunitá socio-riabilitativa per anziani	2,038	321	1,335	382	0	239	1,398	.	401
Comunitá alloggio per anziani	520	157	294	69	0	77	371	.	72
Comunità familiare per anziani	57	18	27	12	0	5	38	.	14
Altre strutture per anziani	252	44	195	13	0	18	215	.	19
Residenza Sanitaria Assistenziale	75,930	18,555	51,581	5,794	70	7,489	62,577	.	5,794
Total	**181,986**	**49,593**	**111,000**	**21,393**	**1,041**	**26,980**	**116,586**		**37,379**

Staffing

Type of service	Total staff	Care staff/nurses/might include teachers in boarding school	Managers or other administrative staff (not care staff)	Educators/ Day staff	Day and care staff (no distinction made)	Clinical staff (Drs, therapists, psychologists, etc.)	Other staff (mainly ancillary staff)	Other staff (excluding ancillary staff)
Comunitá socio educativa per minori	228	62	20	88	.	29	16	13
Comunitá socio-riabilitativa per minori	565	117	66	144	.	153	70	15
comunitá alloggio per minori	157	23	8	19	.	28	15	64
Altre strutture per minori	71	.	6	17	.	17	12	19
Comunitá familiare per minori	115	40	11	20	.	11	33	.
Istituti per minori	177	14	16	63	.	25	30	29
Private Psychiatric Inpatients Facilities	.	.	.	.	.	.	.	.
Comunitá socio-riabilitativa per adulti	15,870	5,013	1,207	2,807	.	3,523	1,896	1,424
Non-Hospital Residential Facilities	18,666	.	.	2,085	.	12,157	.	4,424
Comunità familiare per adulti	979	211	83	223	.	183	279	.
Residenza assistenziale per autosufficienti	6,785	3,213	492	352	.	1,027	1,019	683.
Residenza socio-sanitaria	40,056	20,145	3,234	1,383	.	6,833	6,170	2,291
Altre strutture per adulti	394	151	26	45	.	119	34	19
Comunitá alloggio per adulti	5,405	2,086	596	1,117	.	727	567	312
Comunitá socio-riabilitativa per anziani	1,847	838	84	103	.	431	121	158
Comunitá alloggio per anziani	409	144	47	44	.	78	76	20
Comunità familiare per anziani	71	18	10	7	.	25	2	9
Altre strutture per anziani	213	70	19	14	.	45	53	12
Residenza Sanitaria Assistenziale	71,667	34,009	4,785	2,782	.	16,288	9,715	4,088
Total	**163,676**	**66,154**	**10,710**	**11,313**		**41,699**	**20,061**	**13,739**

Completeness and accuracy of the data

Data collated in these report have been obtained from the most recent and accurate sources. We have contacted and interviewed different experts in the area, who have collaborated providing information and updated data. All the information is based in specific registries, databases and national and regional surveys in the area of the disabilities. Some surveys are specific for residential services in Italy for people with disability thus the data presented are accurate. The data have been collated from databases and surveys dated 2003-2005.

List of services
The list of services has been produced consulting Italian experts in the area. Although the terminology of services can be different from region to region, the names of the services are equivalent in a national level and the list of services covers all the services typology in Italy. Division of services for age served is sort of complicated for some types of services. For example Residential Health Assistance services for people with disability serve children, adults and elderly and data can not be disaggregated.

Size of services
Total number of places is available. Number of places per services size is also available for the whole range of residential services.

Type of disability
Data on number of places per type of disability is available. However the most detailed the information is requested the most difficult to get disaggregated data. Thus, we can only account the type of disability for just the half of the total number of places.

Age and gender
Data on age and gender can only be provided again for just half of the places.

Staff number and Staff training
Detailed data about staff number for every type of service is provided. However there is not data available for staff training as this data is not collected by any survey or database.

Costs
Data regarding cost have been provided. There is precise information about costs for mental health services and for social services.

Commentary: Italy

1. Overview

Italy's health care system is a regionally based national health service that provides universal coverage free of charge at the point of service. The system is organized at three levels: national, regional and local. The national level is responsible for ensuring the general objectives and fundamental principles of the national health care system. Regional governments, through the regional health departments, are responsible for ensuring the delivery of a benefit package through a network of population-based health management organizations (local health units) and public and private accredited hospitals.

The Chapter V of the Constitution was modified to promote more autonomy to the regions, provinces and municipalities in order to move to a federal organisation. The decentralization process to the regions took place during the 1990s. The social care was mainly a responsibility of the provinces until the 2000s. After the publication of Law 328/2000, there has been a transfer process of social care to the municipalities.

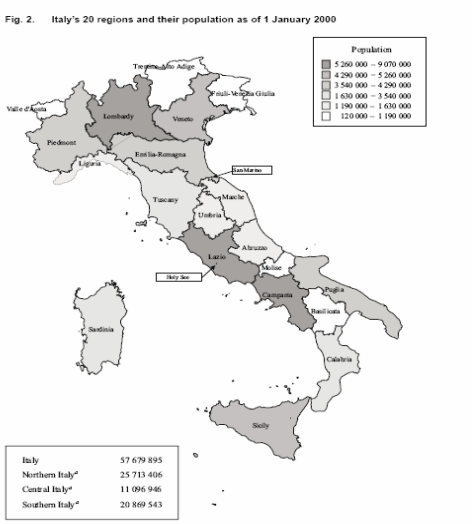
2. Political and social context

2.1 Government organisation and structure

Italy's Constitution has administratively organized Italy's territory into 20 regions, which are extremely varied. They differ in size and in population as well as levels of economic development. The regions also differ in age distribution. The 20 regions are subdivided into 94 provinces. The basic unit of local government is a municipality, which may range in size from a small village to a large city such as Naples. Italy has about 1000 municipalities, many of which are small villages with an ancient tradition of independent self-government.

The constitutional framework distinguishes between ordinary regions and those governed by special statute. Italy has five special regions, one of which is further divided into two autonomous provinces, which also enjoy constitutionally based self-government rights. Their special status, based on specific statutes approved by constitutional laws, derives from the fact that they are border regions with a historically distinctive identity and specific language, demographic and socioeconomic traits.

Fig. 2. Italy's 20 regions and their population as of 1 January 2000



The federalism process significantly extended the powers transferred to regions through the principle of subsidiarity. In particular, responsibility for regulating, planning and organizing health care delivery has been transferred to the regions, and the central government retains responsibility for such functions as approving the National Health Plan, allocating funding and defining clinical and accreditation guidelines. The gradual devolution of political power during the 1990s is now running parallel to the fiscal reform passed in 2000, which will grant regions significant autonomy over revenue in the regional budget and complete autonomy over the allocation of funds.

2.2 Disability relevant policy

Law on people with disabilities in Italy is founded on constitutional principles. The Constitution recognizes and guarantees their inviolable human rights and requires the performance of certain fundamental duties, including the duty to work. These rights and duties apply to citizens equally, without regard to social and personal conditions. The duty to work, consequently, also applies to persons with disabilities, who must contribute, within the limits of their abilities, to the community. An additional constitutional consideration is the provision on the protection of the health of the individual. Furthermore, the Constitution specifically addresses the situation of citizens unfit for work in a provision that constitutes the focal point for the constitutional protection of people with disabilities. It establishes that every citizen unfit for work and without means of livelihood has the right to maintenance and social assistance and that people with disabilities have the right to vocational instruction and training.

Legislation for the protection of persons with disabilities developed over the years in a fragmentary fashion until 1992 when Parliament approved the first organic law, a type of charter for disabled people that incorporated some of the previous provisions and established the general principles from which appropriate rules may be developed in specific areas to better address the needs of people with disabilities, and to guide the government institutions in their actions.

Before 1992 Law 118/1971, covered issues related to the education system, the institution of rehabilitation, research and prevention centres, architectural barriers elimination, job market for disabled, pension or Disability Living Allowance, developed the social benefits system for the disabled, thus promoting their integration. After the Law 118, the first decrees regarding education were introduced and Law 517 on Right to Education and inclusion of disabled children in ordinary classes was issued. This Law promoted social and working integration of disabled people.

Law 180/1978, abolished the 'institutionalization' of people with psychiatric pathologies and ID, resulting in the closure of mental hospitals. Law 104/1992 is concerned with care, social integration and rights of people with ID (further amendments to the Law 104/1992 are the Law 53/2000 and the legislative decree 151/2001). Law 104 represented a revolution in the history of social policy in Italy, because it promoted the civil rights and integration of people with ID in social life. According to these aims Law 162/1998 on further healthcare interventions and social integration for people with severe disabilities was issued. This regulation, aiming at the amendment and integration of the Law 104/92, promoted new forms of domiciliary care, daily assistance, welcome and emergency services, and projects aimed at promoting self-sufficiency in the disabled. Law 68/1999 aimed at promoting inclusion and working integration of "people at working age suffering from such physical, psychological or sensorial disorder, and people with intellectual disabilities that involve a reduction in working ability over 45%, recognized by qualified experts, through support services and targeted employment".

The general policy Law 328/2000 "for the realization of the integrated system of interventions and social services" was addressed to both people with disabilities and to their families. Its aim was the integration of rehabilitative interventions with social issues such as equal opportunities, right of citizenship, removing or reducing awkwardness in situations arising from financial difficulties and/or physical/mental disorders that limit the self-sufficiency of the person. The main aims of this law were individual projects for people with severe disability (art.14), domiciliary support for elderly people lacking self-sufficiency (art.15), and the promotion and support of family responsibilities (art.16). Law 388/2000 introduced a number of innovative regulations on severe disability issues, such as:

- leave of absence for parents of severely disabled children with pay for up to two years;
- two-month notional income for every working year up to a maximum of 5 years for the pension of severe disabled (over 74%) and deaf-mute workers;
- extension of the deductions for the elimination of the architectural barriers, and also for the realization of elevators and good lifts;
- financial resources.

The provisions on people with disabilities include:

- Support services and job placement, plus protection against dismissal. (Quotas are based on the size of the business – e.g. enterprises employing more than 50 workers must hire seven percent disabled workers.)

- Education, which must be available at all levels, with specific technical and educational assistance for disabled students attending universities.
- State and private facilities open to the public that must be accessible; new buildings and renovations are subject to rules on removal of architectural barriers.
- Public transportation that must be as available to people with disabilities as to anyone else.
- Grants and reduced tax rates which apply to the purchase of specialized motor vehicles; special parking spaces must be reserved.
- Companies licensed for the distribution of radio, television, and telephone services who facilitate access by persons with disabilities.

3. Demographics

Italy is a parliamentary republic with a population of 58.5 million in 2005. The structure of the population changed significantly between 1990 and 2005 because fertility rates declined and life expectancy increased. Italy has one of the lowest total fertility rates in the world: in 2004, it was 1.33, far below the replacement level. The population growth rate is therefore very low and immigration causes most of the growth.

In 2005, Italy had 138 people aged 65 years or older for each 100 people 14 years or younger, the highest ratio in the EU. The percentage of the population 65 years or older is increasing steadily: 19.6% of the population in 2005, with 24.6% aged 80 years or older. Life expectancy at birth rose substantially during the 1990s to just above the EU average in the late 1990s. Estimate for 2006 point out that the Life expectancy for men is of 78.0 years while for women the value reach the 83,3 years. The infant mortality rate has remained one of the highest in the EU. The rates is for male 4.8‰ and 3.9‰ for female.

4. Health and Social Care System

4.1 Organisation

The decentralization of the health care system has been a key issue in the development of the National Health System (NHS) since its inception in 1978, and especially during the last decade. The 1978 reform defined an integrated, centralized system in which a few specific administrative responsibilities were allocated to the regional and local levels. Following a process of informal expansion of regional power, Legislative Decree 502/1992 started an explicit, formal process of devolving political power and fiscal authority to regions. This process provided the regional health departments more autonomy in policy-making, health care administration and management, resource allocation and control. Several legislative measures approved during the period 1997–2000 have further promoted the devolution of political power to the regions. In addition, during this same period, a process of transition towards federal reform of the state ran parallel to the progressive introduction of fiscal federalism, transferring the funding of the NHS from the central to the regional level, thus strengthening the fiscal autonomy of the regional health departments (European Observatory on Health Care System, 2001). In addition, the NHS underwent a process of delegation (*aziendalizzazione*) during the 1990s. All local health units as well as tertiary hospitals were transformed into autonomous bodies. This delegation process was based on a more general set of structural

changes aimed at introducing managed competition among public and private (accredited) providers. In the health care sector, in contrast to other traditional state domains (such as utilities), the public sector owns most hospitals and service providers. In addition, no privatization initiatives are underway. Nevertheless, collaboration between private firms and public health care providers is being piloted for some project financing experiments devoted to promoting the renovation (and new construction) of public hospitals with private funding, with a subsequent public-private mix in the management of health care activities (European Observatory on Health Care System, 2001).

In recent years the growing demand for rehabilitation and long-term care on the part of old people has led to health policy giving increased weight to the development of non-hospital facilities and services. At present nursing homes, for which provision was first made in the Finance Law for 1998, constitute the cornerstone of the system of residential non-hospital care. According to the Law, these facilities are intended to "provide persons, regardless of age, who are not self-sufficient and suffering from physical, mental or sensory illnesses that cannot be treated at home with an adequate level of medical, nursing and rehabilitation services and a high level of assistance and board and lodging". At the moment only some regions are in a position to meet the need for residential assistance of old people who are not self-sufficient. (OECD, 2001). The services for disability over 65 years of age with mental health problems are provided with those services for the aged in most regions.

Care for psychological disabilities (psychiatric disorders and intellectual disabilities) has a distinct history in Italy due to the community care model which inspired the deinstitutionalisation process in this country. Prior to 1978 a person with ID or a mental disorder could be hospitalised in a psychiatric institution not only due to his or her condition but also due to “deviant” behaviour. The Mental Health Act, law 180, passed in May 1978 by the Italian Parliament. The Act called for a gradual dismantling of all psychiatric hospitals by stopping new admissions to these institutions after 1978 and all admission after 1982. According to the Italian psychiatric reform, since 1980, all admissions to State mental hospitals were stopped and psychiatric hospitals were expected to close within the following years. In 1998, all Italian psychiatric hospital were definitively closed. A separate policy, registers and surveys have been carried out for mental health in Italy. The 1978 psychiatric reform law established four principal components: (1) a gradual phasing out of mental hospitals (MHs), with the cessation of all new ad-missions; (2) the establishment of general hospital psychiatric wards (GHPW) for acute admissions, each having a maximum of 15 beds; (3) the restriction of compulsory admissions; and (4) the setting up of community mental health centres (CMHC) providing psychiatric care to geographically defined areas. Over time, these conditions have led to an uneven national situation, with regions adopting different standards in terms of service provision and organization, and sometimes approving different statutes for the formal organization of mental health services. In order to overcome this national lack of homogeneity, the Ministry of Health has launched a series of multi-year "National Target Plans for Mental Health." (Pinto, 2002). The regulation of social/health care has been mainly defined at the *Progetto Obiettivo Nazionale “Tutela*

della salute mentale 1998-2000". Integration via social and health interventions plays a determinant role in the health policy for mental health, particularly focused in chronic psychotic disorders tending to coordinate the interventions through individualised therapeutic planning (piani terapeutici individualizzati -PTI). The interventions are divided in health interventions (diagnosis, treatment and rehabilitation); health interventions with significant social implication (interventi sanitari di rilevanza sociale) (primary, secondary and tertiary prevention, and fight against stigma); and social interventions with significant health implications (re-socialization, economic benefits, cultural initiatives, housing, and vocational support). Psychiatric hospitals still exist in Italy. The Progetto Obiettivo "Tutela della Salute Mentale 1998-2000" and Dlgs 230/99 promote transfer of care from the Ministero della Giustizia to the National Health System and regions.

In Italy there are different mental health care systems for 1) Adult and ageing population, 2) Child & Adolescent Population (*neuropsichiatria infantile), 3*) Alcohol and drug addiction *(Dependenze)*. The way these systems coordinate with each other varies from region to region. There is also a separate system for psychology care which is more extended in some regions (Lombardy) than in others (Piedmont).

The Department of Mental Health (Dipartimento di Salute Mentale - DSM*)* is the main territorial unit for mental health care. It is the coordination interdisciplinary organisational structure which provides and warrants unity and integration of mental health services (DGR 6 agosto 1998 n. 38114 "Linee guida per la regolamentazione del Dipartimento di Salute Mentale). The Project National Objective on Mental Health Monitoring *(Progetto Obiettivo Nazionale "Tutela della salute mentale 1998-2000")* provides a definition and framing of the mental health departments: The head of DSM manages the budget for the whole area and health resources, he or she should coordinate care delivery within the area. DSM should provide and guarantee 24 hour emergency care, prevention, care of severe mental illness*,* continuity of care, promotion of a better quality, and data and information gathering within the limits of the existing economic resources.

Care programs in mental health include: continuous community care local services, local institutions, Mental Health Departments and other collaborating private services. Mental Health Departments coordinates with continuous community care local services, Hospitals, day care centres, residential care services and social network. However the coordination structures vary greatly among the 20 Italian regions. For instance a Coordination committee exists in Lombardy (Organismo di coordinamento per la salute mentale, Tavoli a livello di distretto socio-sanitario). The management structure also varies across regions. In Lombardy the DSM management committee (Comitato Tecnico di gestione del DSM) incorporates heads of the hospital units (both psychiatric and psychological hospital units).

There are different types of services within the DSM: public, mixed and private (profit and not profit). Private services are encouraged to promote partnership and to organise in more complex structures of care delivery ("Operative units").

A quick note to remark that in Italy there is no national policy guidance from government that relates specifically to people with ID. General proposals about health and welfare may have an important impact on ID. There is some evidence of policy support for school integration in childhood, but for segregation in adult age, especially in severe degrees of ID. The central axis of policy, especially for people with severe ID is institutional provision. There is a strong tradition of institutional provisions in Italy run by religious or other organisations. Alternative solutions (family houses, small scale community based residential placements, etc) are often restricted to those with mild or moderate disability. Only four Regional Health Plans (Toscana, Lazio, Umbria, Basilicata) included intellectual disability as an objective. This confirms that specific attention to ID is rare as compared to disability in general; there is nearly a total absence of interest in the co-existence of ID and mental health problems (La Malfa, in press).

The social care sector has had a parallel legislative reform. In November 2000, the parliament, after 4 years of work and discussions, succeeded in passing a general policy law (Law 382/2000) reforming Italy's social care system according to universal principles. The reform provides new benefits for people with difficulties (as defined by article 38 of Italy's Constitution), such as subsidizing the integrated home care system and the service sector (not-for-profit associations, private structures etc.), more financial help for low-income families, more opportunities for disabled people or the institutionalization of the minimum income and of social services charts. Municipalities, regions and the state are the institutional actors responsible for implementing and furthering the integrated network of social services foreseen by the reform. Municipalities have managerial functions, and their role is central in the actual delivery of social services. Regions have planning and policy tasks: for example, they define, based on the state's minimum requirements, criteria for accrediting, authorizing and supervising public and private social service providers and define the quality requirements for managing and providing services. The central government grants financial resources (a National Social Fund) and defines the minimum levels of social care (a sort of social benefit package) that every region has to guarantee. Every 3 years, the government, together with local authorities, defines the National Social Plan. The National Social Plan sets the main objectives of social policy and the activities to be undertaken on behalf of non-self-sufficient elderly people, disabled people, children and their families and immigrants. The National Social Plan also implements measures against alcoholism and drug abuse. (European Observatory on Health Care System, 2001).

4.2 Financing

Health and Social care system are currently financed through a regional tax on productive activities (which replaced social health insurance contributions in 1997), general taxation collected centrally, various other regional taxes and users' co-payments, but also private sources of financing. Italy has two main types of out-of-pocket payments. The first is demand-side cost-sharing: a co-payment for diagnostic procedures, pharmaceuticals and specialist visits. The second is direct payment by users for the purchase of private health care services and over-the-counter drugs.

During the late 1990s, the administrative and institutional settings of Italy started to become those of a federal state. The reforms that contributed to this transition including several packages that will modify the architecture of health care financing. The progressive move towards fiscal federalism started in 1997, and regional taxes finance most health care expenditure, with general taxation playing a complementary role. In fact, central funding is intended to be used primarily to redistribute resources to the regions with a narrower tax base, to ensure all residents adequate levels of care.

A general overview about mental health financing in relation to other European countries can be found at McDaid et al, 2006 and a more extensive picture of the mental health financing system at Italy has been reported to the MHEEN network by Prof. F. Amadeo, F (2005).

5. Definition, eligibility and diagnosis/assessment

The legal definition and eligibility criteria use different terms and parameters. In Italy "Disability" (*disabilità*) is legally defined as: loss of ability of the person to perform basic daily activities unaided (Law 104/1992). "Invalidity" (*invalidità civile*) has been defined as: the right to receive financial benefits when the disability is a consequence of biological damage with no reference to general self sufficiency (Law 118/1971).

The official assessment is made by a medical committee at the ASL. It provides a balance between general functioning and labour capacity on the one side, and the general health status and condition on the other. In the case of mental disorders this is made in coordination with representatives of the Mental Health Department (DSM). There are regional regulations to that purpose. The assessment provides a rating in a thermometric scale (0-100) for invalidity and an additional rating related to the intensity of support for severely disabled people. A person with level of 33% of invalidity can have the use of the "*Collocamento mirato*" to enter in work support programs. Instead persons with disabilities are entitled to receive pension benefits when the invalidity rating is over 75%.

The national databases and registers use different functional classifications (ICIDH (International Classification of Impairment, Disease, Disability and Handicap -1980), ICF (International Classification of Functioning Disability and Health, local classification and ICDIX and for mental disease ICDX). Although the new WHO International Classification of Functioning (ICF) (WHO, 2001) has been actively used by several organisations and research groups in Italy, it has not been statistically operationalised, for this reason the Italian Statistical Institute (ISTAT) is still using the previous coding system.

6. Prevalence of disability

It is really hard to get to know the exact number of disabled persons in Italy. The definition of disability is not universal, but it changes according to the statistical survey and who performed it. Therefore, people often are inexactly named disabled, handicapped, incapable, invalid and so on. If we put together data belonging to different data sources in order to supply an overall assessment of the number of disabled persons, as a matter of fact, we are gathering together aggregates referring to persons having

different characteristics. For example, disability and invalidity are two different notions: the first refers to the ability of a person to perform autonomously (even if with helping devices) the basic activities of daily living, the second refers to the right to receive an economic advantage as a consequence of a biological injury. If a person with disabilities has never put forward a claim for the acknowledgment of his health status, he is not invalid.

A more than valuable data source in order to assess the number of disabled persons might be represented by certificates. In every ASL, there are some Commissions issuing several kind of certificates, aimed at the assessment of the invalidity and of the handicap condition, at the certification of the diagnosis for the handicapped student, at the definition of the set of welfare interventions towards the non self-sufficient elder, at the statement of residual abilities and work skills of the disabled person. Shamefully, anyhow, such certificates are not the same in the whole national territory, but in each ASL (or in each Region) different forms are used. In addition, such certificates usually have neither been introduced in a database nor a national-wide statistical survey has been provided for.

The main source used to estimate the number of persons with disability living in a family is the ISTAT survey on "Health Conditions and Access to Health Services". Based on the estimates of this survey, there are 2,610,000 persons with disability in Italy, or about 4.8% of the population of 6 years and over living in a family (Table 1).

Table 1 Rates of persons with disability of 6 years and over by sex and age group. Years 2004-2005.

	6-14	15-24	25-34	35-44	45-54	55-64	65-69	70-74	75-79	>80	Total
Males	1.6	0.6	0.7	1.0	1.4	2.2	4.3	7.7	13.4	35.8	3.3
Females	1.6	0.6	0.6	0.9	1.3	2.7	6.5	11.4	20.8	48.9	6.1
Total	1.6	0.6	0.6	0.9	1.3	2.5	5.5	9.7	17.8	44.5	4.8

Source: ISTAT, Survey on "Health Conditions and Access to Health Services", 2004-2005.

This estimate is based on a very restrictive definition of disability, for what disabled persons are those who declared a total absence of autonomy in one activity of daily life. In general, if we consider persons who showed a significant difficulty in doing these activities, the estimate increases until 13% of people over 6 years living in family. This estimate is near to the figure of the main industrial countries.

For those persons with disabilities living in care rather than in the family, results from the Survey on State Residential Homes indicates the presence of 190,134 persons with disability or un-self sufficient elderly persons living in State Residential Homes (Table 2)

Table 2 Numbers of disabled and un-self sufficient elderly persons living in state residential homes, 2003

	Disabled persons		Un-self sufficient elderly persons	Total
	<18	18 - 64		
Males	898	17,919	34,216	53,033
Females	725	14,417	121,959	137,101
Total	1,623	32,336	156,175	190,134

Source: ISTAT-CISIS, Survey of state residential homes 2004

Disability is obviously correlated to ageing of population. The disability rates of persons aged 65 and over is 18,7%.

7. Residential Services for people with a disability

7.1 Overview

In Italy data on residential care institutions, both private and public is collected annually by ISTAT with a questionnaire dealing with characteristics of people living in these Institutions (children, persons with disabilities, elderly), as well as of the services offered. In general the response rate is of about 80%. This e survey is the most important source to know the number of persons with disability or un-self sufficient elderly persons that live in institution.

The definitions used to consider people living in Institutions as persons with disabilities are different in age:

- people less then 18 years old with a physical, sensory, intellectual or multiple disability;
- people aged between 18 and 64 years old with a physical, sensory, intellectual or multiple disability or psychiatric problems;
- people aged 65 years and over non independent due to permanent infirmity or chronic disease that reduces their personal freedom till requiring help from other people for daily needs inside and outside the home.

Data include also general information on the institution (identification data, type of management, organization of the institution), information on staff in the institution (number of person with a specific profession by sex and type of contract), information on people living in the institution (number of people living in institutions by sex, age-groups, citizenship, type of problem, etc.) and economic information.

In Italy there are a number of social residential services for general population that also provide assistance to people with disabilities. Local characteristics may influence that a high proportion of people with disabilities are attended in these setting, although they are not disability services.

The division between health care and social care is not clearly defined. There are mixed social/health care residential units. The adscription to health or to social care of some residential facilities may vary from region to region. Residential care could be divided in

hospital care, non-hospital health care for rehabilitation and long-term care, health/social residencies, and a series of social care settings.

Information regarding rehabilitation residential care is annually collected by the Ministry of Health. The national objective is 1 bed per 1,000 population in rehabilitation / long-term care settings. The mean in Italy was 0.5/1000 in 2002. There were large differences in Italy with higher availability in Trento and Lazio and lower level of provision in Valle d´Aosta, Friuli Venezia Giulia, Umbria, Puglia, Basilicata, Sicilia and Sardegna. In mental health, rehabilitation residential services are intended to provide medium and long-term care for patients with special health needs (Comunità Residenziali Terapeutiche riabilitative -CRT)

Mixed social/health care (Assistance care)
In mental health the "assistance care" is intended to provide residential care for persons with needs that are not so intensive than rehabilitation services but where health is prevalent over social aspects of care. This includes sheltered communities (Comunità Protette CP) with several levels of intensity of care.

Social care
As in other European countries the division between social and health services in Italy is more a problem than a solution for classifying services for disabilities and long term care. There is not a clear definition of the boundaries between the two sectors. A series of settings do provide social care "Mixed social-health care centres" are truly social centres, since they provide housing for general social needs including elderly people not able to live alone, child without tutorship, women with special needs and people with disabilities. In 2001 there were 8.182 centres with 334.718 beds.

In psychiatry and in geriatrics, there are also individual programs including: casa alloggio CA, casa famiglia CF, appartamenti autonomi AA (all of them sheltered accommodation) with a high range of time limits. There are problems in differentiating care between social residential services and rehabilitation services. There are plans to rename the services according to the intensity of care.

Italy's Health and Social Systems provide facilities for children, adults and elderly with disability. Here we provide the lists of services we have identified and their characteristics by number of places, places per type of disability, personnel, etc. Services are listed depending on the population they serve. When we provide number of places depending of sex, centre size, type of disability and so on the total number of places that should maintain the same along the report can present some variations. This is due to the use of different sources of information or different reports presented at different years. However it has been checked that no great variations are presented in the number of places within this report.

7.2 Services for children with a disability

"Comunitá socio-educative per minori" (Socio-educative community for children): This type of service attends children with disability aged between 6 and 18 years. The

typical age is 15-17. In general the children in these institutions have multiple disabilities. These institutions provide between 4 and 12 residential places to children with a disability and they also provide educational support. The care is 24 hour support for long and short term. These residential facilities are funded by the State (61%). Regarding to the number of places there are 175 places in the "**Comunitá Socio-educative per minori**" in Italy: 97 have less than 10 places and 98 have between 10 and 30 places. There are 52 places for children between 6 and 17 years old. There are 147 places in these institutions: 76 for males and 71 for females. The number of the staff is 228: 62 of them are care staff, 88 are education or day care staff, 29 clinical staff, 20 administrative staff and 16 ancillary staff.

"Comunitá socio-riabilitativa per minori" Socio-rehabilitation community for children: in total there are 361 places: 22 for settings with less than 10 persons, 164 for 10 to 30 people, 115 for 31 to 50 people and 60 between 51 and 100. There are 171 places for children with sensory disability, 80 for physical disability and 18 mixed. There are only 5 places for intellectual disability. These places serve mainly children from 15-17 years old, 110 places, and 105 for children between 11 and 14 years old. The total of males is 196 and the total of females is 88. There are 565 persons working in these residential facilities: 117 are care staff, 144 are education and day care staff, 153 are clinical staff, 66 are administrative staff and 70 are ancillary staff. These facilities are public (59%) and private.

"Comunitá Alloggio per minori" (Community residence for children): There are only 93 places at these institutions: 4 for less than 4 people, 30 for 10 to 30 people and 59 for 31 to 50 people. There are state and private institutions (100% non profit) and provide 24 hour care support for short and long term. There are 55 places for children with more than one disability (mixed) and only 11 for children with intellectual disability (total: 66). From these 66 places, 22 are for children until 6 years old, 20 are for children aged 6-10 years, 12 are for 11-14 years and 6 for children with a disability aged 15-17 years. There are 28 males and 38 females. There are 157 people working in **"Comunitá d´Alloggio"**: 23 care staff, 19 education or day care staff, 28 clinical staff, 8 administrative staff and 15 ancillary staff.

"Comunitá Familiare per minori" (Family community for children): There are 72 places for children with a disability in these facilities: 62 are for less than 10 people and 10 for 10 to 30 people. There are 47 places children with a disability: 20 are for persons with intellectual disability and 18 are mixed. 9 are for physical disability and only 1 is for sensory disability. 16 places are for children between 15 to 17 years old and 14 are for children from 11 to 14 years old. There are 24 males and 24 females. These institutions are public and private and provide short and long term care and 24 hour support. There are 115 persons working in **"Comunitá Familiare"**: 40 care staff, 20 education and day care staff, 11 clinical staff and 14 ancillary staff.

"Istituti per minori" Institute for children: This service attends children with disability between 0 and 17 years. The typical age is from 6 to 14 years old. The children in these institutions have sensory disability (86 places). These institutions provide educational

support. The care is 24 hour support for long and short term. These residential facilities are public and private. There are 201 places in the "**Istituti per minori**" in Italy: 92 facilities have between 51 and 100 places, 109 facilities have between 10 and 30 places. There are 128 places for children between 6 and 17 years old. There are 147 places in these institutions: 94 for males and 53 for females. The number of staff is 177: 14 of them are care staff, 63 are education or day care staff, 25 clinical staff, 16 administrative staff and 30 ancillary staff (29 are "other staff").

"Altre strutture per minori" (Other settings for children): There are 98 places for people with a disability: 2 places in institutions with less than 10 people and 96 with 51 to 100 people. The typical number of places ranges from 5 to 30 and the age group served is between 15 and 17 years old. There are 81 places for people with sensory disability and 1 for mixed disability. There are 44 males and 38 females in these institutions. 82 places are all for children between 0 and 14 years old. There are 71 persons working in this kind of institutions**:** 0 care staff, 17 education and day care staff, 17 clinical staff and 12 ancillary staff, 6 administrative staff and 19 other staff. These institutions provide 24 h support care, long-term care and these institutions are public (88%) and private.

7.3 Services for younger adults with a disability

"Comunitá socio-riabilitativa per adulti" (Socio-rehabilitation community for adults): The typical number of places is between 20 and 25 places. The age group served is usually from 25 to 64 years old and the typical age of these services is from 45 to 64 years. There are 11,834 places for persons with a disability in these facilities: 143 for sensory disability, 1,456 for mental health, 973 for physical disability, 5,413 for people with more than one disability and 3,849 for intellectual disability. The "Comunitá socio-riabilitativa per adulti" provides 24 hour support for long-term care and there are public (73) and private institutions. There are 235 places in these institutions for people with disability from 0 to 17 years old, 10,445 places for people with disability from 18 to 64 years old and 1,153 places for people disable with more than 64 years old. In these institutions there are 6,441 males and 5,394 females. The number of staff is 15,870: 5,013 of them are care staff, 2,897 are education or day care staff, 3,523 clinical staff, 1,207 administrative staff and 1,896 ancillary staff and 1,424 another staff.

"Comunitá d´Alloggio per adulti" (Community residence for adults): in total there are 4,699 places for people with disability: 1,183 places in facilities with less than 10 people, 1,624 with 10 to 30 people, 260 with 31 to 50 people, 117 with 51 to 100 people, 115 with 101 to 200 people and 1,400 places with over 1,000 people. The typical number of places are 5 to 10 and the age group served is between 45 and 64 years old. There are 89 people with sensory disability in these institutions, 357 with mental health problems, 266 with physical disability, 1,495 mixed and 1996 with intellectual disability. There are 2,481 males and 1,721 females in these institutions. There are 40 places for people from 0 to 17 years old and 359 with more than 64. The majority of places are for people between 18 and 64 years old: 3,803. There are 5,405 persons working in this service: 2,086 care staff, 1,117 education and day care staff, 727 clinical staff and 567 ancillary staff, 596 administrative staff and 312 other staff. These institutions provide 24-hour support and

sometimes only day or night care, usually on a long-term basis. These institutions are public (80%) and private.

"Comunitá familiare per adulti" (Family community for adults): In total there are 945 places for people with disability: 466 places for "Comunitá Familiare" with less than 10 people and 479 with 10 to 30 people. The typical number of places are 5 to 10 and the age group served is between 45 and 64 years old. There are 10 people with sensory disability in these institutions, 169 with mental health problems, 65 with physical disability, 197 mixed and 360 with intellectual disability. There are 443 males and 358 females in these institutions. There are 27 places for people from 0 to 17 years old and 37 with more than 64. The majority of places are for people between 18 and 64 years old: 736. There are 979 persons working in "Comunitá Familiare": 211 care staff, 223 education and day care staff, 183 clinical staff and 121 ancillary staff, 83 administrative staff and 158 other staff. These institutions provide 24-hour support, usually on a long-term basis. These institutions are public and private.

General Hospitals Psychiatric units (mental health): The typical number of places in these facilities is between 20 and 100 places. The age group served is usually from 45 to 64 years old. There are 3,997 places for persons with disability in these facilities: all the places are for people with mental health problems. These institutions provide 24 hour support, if there is an emergency or only day care. They are usually short term care and are public (98%). These services are not included in the template data presented at the beginning of the report because of their short-term nature.

University Clinics (mental health): The typical number of places in these institutions is between 10 and 15 places. The age group served is usually from 45 to 64 years old. There are 1,155 places people with mental health problems. These institutions provide 24 hour support, usually on a short-term basis. They are predominantly public (98%). Again, because of the short-term nature of these services, they are not included in the template data.

Private Psychiatric Inpatient Facilities (mental health): The typical number of places in this type of institutions is between 40 and 50 places. The age group served is usually from 45 to 64 years old. There are in total 3,975 places for people with mental health problems. These institutions provide 24 hour support, usually on a short-term basis. They are predominantly public facilities (97%).

Non-hospital Residential Facilities (mental health): The typical number of places in this type of institutions is between 15 and 20 places. The age group served is usually from 40 to 60 years old and the typical age of these services is from 40 to 59 years old. There are 17,138 places for persons with a disability in these facilities: all for mental health. The "Non-hospital Residential Facilities" provide 24-hour support on a long-term basis. The majority (80%) are public and there are private institutions as well. There are 7,506 male and 8,437 female service users. The number of the staff is 17,840: 2,085 are education or day care staff, 12,157 clinical staff and 4,424 another staff.

"Altre strutture per adulti" (Other settings for adults): in total there are 273 places for people with a disability: 23 places for these institutions with less than 10 people, 181 for 31 to 50 and 69 with 51 to 100 people. The typical number of places is 5 to 30 and the age group served is between 25 and 64 years old. There are 5 places for sensory disability in these institutions, 56 for mental health, 83 for physical disability, 59 mixed and 33 with intellectual disability. There are 99 males and 136 females in these institutions. The majority of places are for people between 18 and 64 years old: 198. There are 394 persons working in this kind of institutions: 151 care staff, 45 education and day care staff, 119 clinical staff and 34 ancillary staff, 26 administrative staff and 19 other staff. These institutions provide 24-hour support on a long term basis. These institutions are public (88%) and private.

7.4 Services for older adults

"Comunitá socio-riabilitativa per anziani" (Socio-rehabilitation community for the elderly): The typical number of places in this kind of institutions is 55 places. The age group served is the over 64 year-olds. There are 1,656 places for persons with a disability in these facilities: 9 for sensory disability, 37 for mental health, 42 for physical disability, 1,516 for people with more than one disability (mixed) and 52 for intellectual disability. The **"Comunitá socio-riabilitativa per anziani"** provides 24-hour support and sometimes only day care and long-term care. There are public (69) and private institutions. There are 239 places for people with a disability aged between 18-64 years, and 1,398 places for people aged 65 or over. In these institutions there are 321 males and 1335 females. The number of staff in these institutions is 1,847: 838 of them are care staff, 103 are education or day care staff, 431 clinical staff, 84 administrative staff and 251 ancillary staff and 140 another staff.

"Comunitá alloggio per anziani" (Community residence for the elderly): The typical number of places is 55 places. The main age group served is more than 64 years old. There are 451 places in these facilities: 23 for mental health, 10 for physical disability, 379 for people with more than one disability (mixed) and 39 for intellectual disability. The **"Comunitá alloggio per anziani"** provides 24 hour support and sometimes only day care and long-term care. There are public (69) and private institutions. There are 77 places for people with a disability aged 18-64 years, and 371 places for people aged 65 years or over. In these institutions there are 157 males and 294 females. The number of staff is 409: 144 of them are care staff, 44 are education or day care staff, 78 clinical staff, 47 administrative staff and 76 ancillary staff and 20 other staff.

"Comunitá familiare per anziani" (Family community for elderly people): The typical number of places in this type of institutions is 15 places. The age group served is people aged 75 years or older. There are 45 places for persons with a disability in these facilities: 3 for mental health, 38 for people with more than one disability (mixed) and 4 for intellectual disability. The **"Comunitá familiare per anziani"** provides 24 hour support and long-term care. There are public (22%) and private (88%) institutions. There are 5 places for people aged between 45 to 64 years and 371 places for people with aged 65 years or over. In these institutions there are 18 males and 27 females. The number of staff is 71: 18 of them are care staff, 7 are education or day care staff, 25 clinical staff, 10

administrative staff and 2 ancillary staff and 9 other staff. There are 41 places for institutions "Familiare" with less than 10 people and 16 places for institutions with 10 to 30 people.

"Residenza assistenziali per autosufficenti" (Residence for non-dependents): in total there are 10,434 places for people with a disability: 84 places are in facilities with less than 10 people, 4,596 in the range of 10 to 30 people, 8,291 in the range of 31 to 50, 17,978 places in institutions with 51 to 100 places, 13,459 places in 101 to 200 and 7,063 places in institutions with over 1000 residents. The typical number of places are 20 to 100 and the age group served is from 45 to 80 years old. There are 37 people with sensory disability in these institutions, 130 with mental health, 212 with physical disability, 7,663 mixed and 313 with intellectual disability. There are 1,872 males and 6,482 females in these institutions. There are 35 places for people from 18 to 24 years old and 7,321 with more than 64, 33 from 25 to 44 and 664 from 45 to 64. There are 6,786 persons working in these facilities: 3213 care staff, 352 education and day care staff, 1027 clinical staff and 1019 ancillary staff, 492 administrative staff and 158 other staff. These institutions provide 24 h support care, usually long-term care and these institutions are public and private.

"Residenza socio-sanitaria" (Socio-health residence for the elderly): The typical number of places in these kind of institutions is 60 places. The age group served is more than 75 years old. There are 45,922 places for persons with disability in these facilities: 37 for sensory disability, 130 for mental health, 7,663 for people with more than one disability (mixed), 212 for physical disability and 313 for intellectual disability. The **"Residenza socio - sanitarie per anziani"** provides 24 hour support and long-term care. There are public (57%) and private institutions. There are 66 places for people with disability from 18 to 24 years old, 568 from 25 to 44 years old, 2,203 from 45 to 64 and 43,086 places for people disable with more than 64 years old. In these institutions there are 11,194 males and 34,728 females. The number of the staff is 40,056: 20,145 of them are care staff, 1,383 are education or day care staff, 6,833 clinical staff, 3,234 administrative staff and 6,170 ancillary staff and 2,291 another staff. There are 57 places for these institutions with less than 10 people and 4,596 places for institutions with 10 to 30 people, 8,291 for 31 to 50, 17,978 for 51 to 100, 13,459 for 101 to 200 and 7,063 for institutions with 201 to 500.

"Altre strutture per anziani" (Other settings for the elderly): in total there are 252 places for people with disability: 9 places for these institutions with less than 10 people, 181 for 31 to 50 and 200 with 10 to 30 people and 43 with 31 to 50 people. The typical number of places are 10 to 30 and the age group served is between 75 and 80 years old. There are 5 places with mental health problems, 3 with physical disability, 219 mixed and 13 with intellectual disability. There are 44 males and 195 females in these institutions. There are 215 with more than 64 and 18 for people between 45 and 64 years old. There are 213 persons working in this kind of institutions: 70 care staff, 14 education and day care staff, 45 clinical staff and 19 ancillary staff, 53 administrative staff and 12 other staff. These institutions provide 24-hour support on a long-term basis, and these institutions are public and private.

8. Other relevant information on residential services

"Residenza Sanitaria Assistenziale" (RSA) (Residential Health Assistance for people with a disability): The typical number of places in this type of institutions is 20 to 100 places. The age group served is from 0 to more than 64 years old. There are 70,136 places for persons with disabilities in these facilities: 90 for sensory disability, 997 for mental health, 65,600 for people with more than one disability (mixed), 1,085 for physical disability and 2,364 for intellectual disability. The RSA provides 24 hour support and long-term care. There are public (49%) and private institutions. The number of staff is 71,667: 34,009 of them are care staff, 2,782 are education or day care staff, 16,288 clinical staff, 4,785 administrative staff and 9,715 ancillary staff and 4,088 another staff. There are 72 places for these institutions with less than 10 people and 4,877 places for institutions with 10 to 30 people, 9,495 for 31 to 50, 26,864 for 51 to 100, 19,539 for 101 to 200, 12,960 for institutions with 201 to 500 and 2,123 with 501 to 1000 people.

9. Costs

There is a significant number of studies on the cost of residential services in Italy. The ISTAT has published data regarding Mental Health Hospitalisation Costs and social residential facilities costs.

Mental Health

The estimated hospitalization cost for mental disorders is about €1,223 million, giving an average of almost €3,700 per admission. The relative weight in relation to total hospital expenditure (amounting to €45,489 million) is 2.7%. Hospital costs for mental disorders increased by about 13% compared with 1999. However, if the costs are recalculated at constant values (with the year 2000 as reference), they increase by only 1.2%.

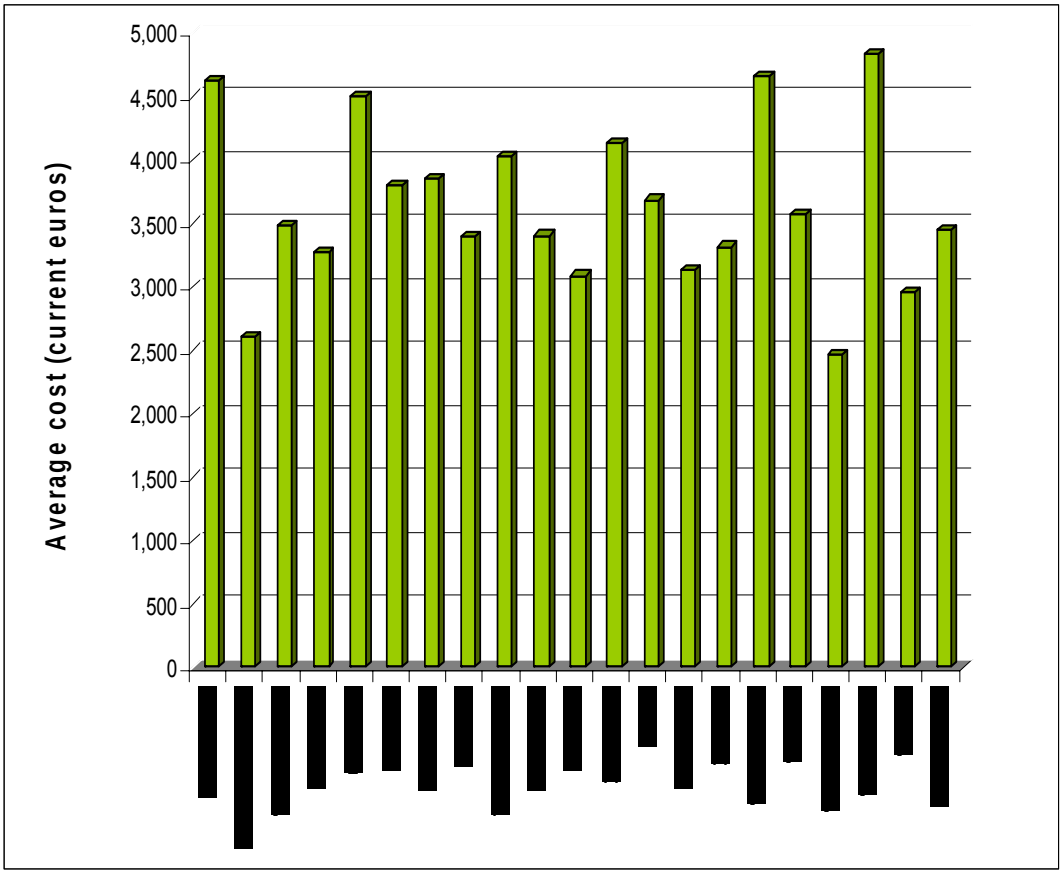
Hospitalisation for mental disorders shows a strong regional variability. In 2003, while the hospitalisation rate for Italy as a whole was 574 per 100 thousand residents, its minimum was 367 in Friuli Venezia Giulia followed by 388 in Umbria, and its peak was 992 in the autonomous province of Bolzano. Other regions with particularly high rates included Valle d'Aosta, Liguria, Lazio, Abruzzo and Sicily. Nevertheless, as there is currently no National Information System on local healthcare services for people with psychological disorders, it cannot be established if the latter regions invested less in alternatives to hospitals (Figure 1).

The variability in average cost per hospital admission is more limited: the national average is €3,700 with minimums of €2,500 in Basilicata, €2,600 in Valle d'Aosta and almost €3,000 in Sicily. Costs of €4,500 to €5,000 per admission were incurred in Piemonte, the autonomous province of Trento, Campania and Calabria.

As with admissions as a whole, inpatient care over time has decreased while day hospital treatment has increased. Compared to the total admissions for psychological disorders, the latter rose from 13% in 1999 to 20% in 2003 (almost 70,000 cases). The DRG rates established for day care by Italian law are much lower than those for inpatient care. Thus 98% of the estimated costs for mental disorders went to inpatient care and only 2% to day care (in 1999 it was 1.2%). The increased transfer of patients from inpatient care to day

care may have a significant positive effect on the containment of hospitalisation costs as a whole. The average cost per inpatient admission is about €4,500, while for the day hospital it is only €350.

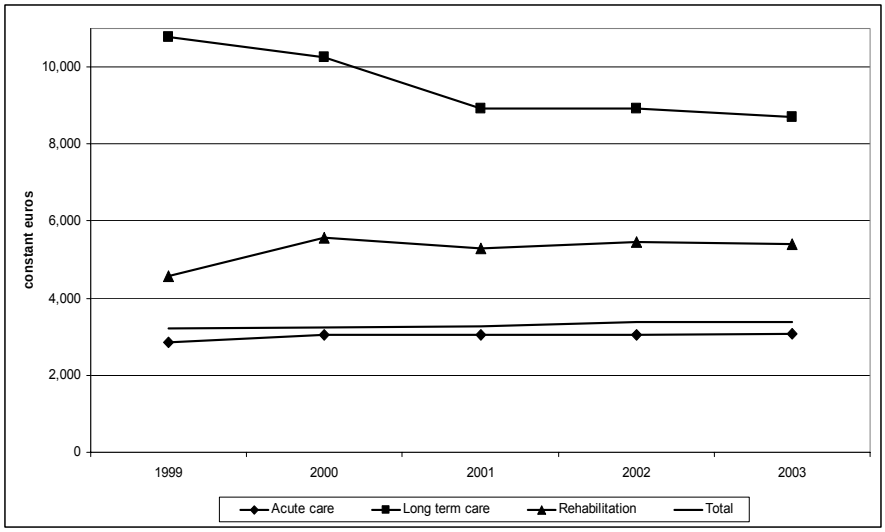
Figure 1 Average cost of hospitalization for mental disorders by region (current euros), 2003



ISTAT 2003

The percentage cost of these treatments is 83.9%, 9.4% and 6.7% respectively. Long-term and rehabilitation treatments are clearly more expensive: the average cost is €9,500 for the former and almost €6,000 for the latter, in contrast with €3,400 for acute care admissions. In constant values (with the year 2000 as reference year), the average costs for acute term care and rehabilitation have increased over time (from €2,800 to €3,066 and from €4,575 to €5,410 respectively from 1999 to 2003). In contrast, the average cost for long-term care treatments dropped from €10,781 in 1999 to €8,694 in 2003. (Figure 2)

Figure 2 Average cost of hospitalization for mental disorders by type of care (constant euros), 1999-2003



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Data regarding community and residential costs for persons with disability are presented in Table 3.

Table 3 Disability Area: costs for community and individual social services. Total Italy, 2003 (totals and percentages)

TYPE OF EXPENSE	Expense	Percentage of expense on total macro area	Percentage of expense on total area	Percentage of expense on Italy total
INTERVENTION AND SERVICES				
Activities of professional social services	36,532,709	7.6	3.6	0.7
Social Integration:	28,408,691	5.9	2.8	0.5
Interventions for the social integration of subjects at social risk	-	-	-	-
Recreational, social and cultural activities	-	-	-	-
Other	-	-	-	-
Total for social integration	28,408,691	5.9	2.8	0.5
Interventions and services for the working market inclusion of people with disabilities				
Scholastic associate-educational support	150,586,671	31.5	14.7	2.9
Socio-educative territorial/domiciliary support	25,149,050	5.3	2.5	0.5
Support for the working market inclusion	31,813,263	6.6	3.1	0.6

TYPE OF EXPENSE	Expense	Percentage of expense on total macro area	Percentage of expense on total area	Percentage of expense on Italy total
Other	8,252,740	1.7	0.8	0.2
Total Educational interventions and services for the working market inclusion of people with disabilities	215,801,724	45.1	21.1	4.2
Domiciliary care:				
Social Domiciliary care	91,895,045	19.2	9.0	1.8
Socio-health domiciliary care	7,953,735	1.7	0.8	0.2
Proximity services (buonvicinato)	374,650	0.1	0.0	0.0
Telecare	447,592	0.1	0.0	0.0
Vouchers, checks for health/social care	10,538,083	2.2	1.0	0.2
Meals distributions/ Laundry home service	868,833	0.2	0.1	0.0
Other	5,441,471	1.1	0.5	0.1
Total domiciliary care	117,519,409	24.6	11.5	2.3
Support services:				
Catering	2,782,778	0.6	0.3	0.1
Social transport	77,566,828	16.2	7.6	1.5
Total for support services	80,349,606	16.8	7.9	1.5
Total for interventions and services	478,612,139	100.0	46.8	9.2
TRANSFERS IN MONEY				
Transfers in money for the payment of participations and services:				
Payment for goods or meals	606,747	0.3	0.1	0.0
Contributions for services	20,546,328	9.3	2.0	0.4
Economic contributions for health services	5,290,742	2.4	0.5	0.1
Money for day centres	23,489,722	10.7	2.3	0.5
Money for other semi-residential services	8,437,637	3.8	0.8	0.2
Money for residential services	82,162,306	37.3	8.0	1.6
Economic contribution for transport services	9,634,036	4.4	0.9	0.2

TYPE OF EXPENSE	Expense	Percentage of expense on total macro area	Percentage of expense on total area	Percentage of expense on Italy total
Economic contribution entitled as a loan (honour lend)	148,110	0.1	0.0	0.0
Economic contribution for lodging	2,374,671	1.1	0.2	0.0
Economic contribution for inclusion in the working market	12,353,087	5.6	1.2	0.2
Economic contribution for the integration in the family yield	15,479,918	7.0	1.5	0.3
Economic contribution for family support	1,956,528	0.9	0.2	0.0
General contributions to social associations	10,146,671	4.6	1.0	0.2
Transfers to municipal companies for tariff facilities on the transports	12,854,525	5.8	1.3	0.2
Other	14,551,084	6.6	1.4	0.3
Total of money transfers for the payment of intervention and services	220,032,112	100.0	21.5	4.2
SETTINGS				
Day or semi residential settings:				
Day Centre	169,409,804	52.3	16.6	3.3
Summer day centre	1,807,541	0.6	0.2	0.0
Leisure centre/laboratories	17,842,306	5.5	1.7	0.3
Social integration centres	9,633,077	3.0	0.9	0.2
Other	9,452,600	2.9	0.9	0.2
Total day semi residential settings	208,145,328	64.3	20.4	4.0
Community residential settings:				
Residential structures	106,220,483	32.8	10.4	2.0
Summer or winter centres	6,516,706	2.0	0.6	0.1
Other	3,059,634	0.9	0.3	0.1
Total community and residential settings	115,796,823	35.7	11.3	2.2
Total settings	323,942,151	100.0	31.7	6.2
Total Disability	**1,022,586,402**		**100.0**	**19.7**

ISTAT. 2003

10. Issues

Regionalisation is a relevant issue in Italy as regions and municipalities play an important role in health and social services provision. However, data collection and terminology homogeneity has not been a problem due to the Istat help.

National elections and changes into the Ministries have caused a delayment in contacts establisment along this project and therefore in the collection of the data.

11. Acknowledgements

Thanks to the ISTAT for their collaboration in the writing of this report and for providing data about prevalence, costs and services. Thanks to the Disabilitá in cifre project for providing an easy access to relevant data about services for people with disability. Thanks also to the PROGRESS study for providing relevant data on mental health services.

12. Information sources on disability used to compile the template and commentary, including people who were interviewed

Disabilitá in cifre. Relevant data about disability: services, prevalence, helps, etc. http://www.disabilitaincifre.it/

Italian Statistical Institute. Statistical information about disability in Italy. http://www.istat.it/

Ministry of Social Solidarity. Disability Area. http://www.solidarietasociale.gov.it/

Disabili.com. Thematic web page that provides information for people with disability in Italy. http://www.disabili.com/

Interviews:

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ISTAT (Rome April 2007)

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EPCAT (Apr Torino 2007) G Tibaldi

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Giovanni De Girolamo

Alessandro Solipaca. Italian Statistical Institute. ISTAT

Luigi D'Alonzo

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Appendix 1: Detailed information, collected as part of the Phase 2 case studies, on three of the regions within

Robert Hayward
Tizard Centre, University of Kent.

The three regions selected illustrate the North-South differences in terms of types and levels of services. Emilia-Romagna and Veneto are situated in the North-East of the country, while Campania is in the South. Only relatively limited information and data (particularly in English) is available and accessible for the northern regions, particularly Veneto, which produces some on-line statistics and description of disability services. Much of the information provided is in the form of broad statistics on publicly provided services. There is very little published material on the private sector, particularly on services provided by the church-based organisations which are particularly influential in the south. Information on Campania is either non-existent or inaccessible (even in Italian). Even by the standards of limited information available, Campania compares poorly on most major economic, health and social care indicators: it has generally higher rates of unemployment (at all ages), lower incomes, poorer health than the northern region (Istat, 2001). Comparisons of selected services by region reveal the extent of the disparities between north and south (All data from ISTAT, 2001, valid at 31/12/01):

Residenza Sanitaria Assistenziale (RSA) (residential homes, health/social care), numbers/percentage of total

Veneto	**528**	**6.5%**
Emilia-Romagna	1211	**14.8%**
Campania	332	**4.1%**
Italy	**8122**	**100%**

Campania has a smaller number and percentage of residential care homes overall (but larger numbers in large institutions and cared for within the family settings)

Places at RSA per 100,000

Veneto	**7.89**
Emilia-Romagna	**8.71**
Campania	**2.09**
Italy	**5.87**

Distribution of RSAs (%)

	Children	**adults**	**older people**
Veneto	13.4	28.2	**35.0**
Emilia-Romagna	7.9	54.0	**2.1**
Campania	38.6	21.7	**18.1**
Italy	**15.9**	**33.1**	**27.1**

Campania has twice the percentage of children than the national average in residential care, but fewer elderly (possibly reflecting reduced life expectancy in the south, larger numbers of older people in big institutions). Veneto and Emilia-Romagna have no institutions for children.

Percentage of institutions for:

	children	**older adults**
Veneto	0.0	**0.9**
Emilia-Romagna	0.0	**28.0**
Campania	16.7	**8.0**
Italy	**100**	**100**

RSAs adults with disabilities (social care/social rehabilitation, low care)

Veneto	**8.8%**
Emilia-Romagna	**16.8%**
Campania	**0.1%**
Italy	**7.5%**

Campania has few residential facilities for low care needs compared to the other regions and Italy as a whole.

Emilia-Romagna

Emilia-Romagna

Emilia-Romagna is the 5-6th largest region in Italy (territory/population). The capital is Bologna. It has a population of approximately 4,187,000 people. It is one of the most developed regions of Italy. Emilia-Romagna has no large institutions for people with intellectual disabilities, it only provides community-based services: socio-rehabilitative

residential centres (SSRCs), group homes (GH) and supported living flats (*residenza protetta*). The number and distribution of services and service users is indicated in the tables below:

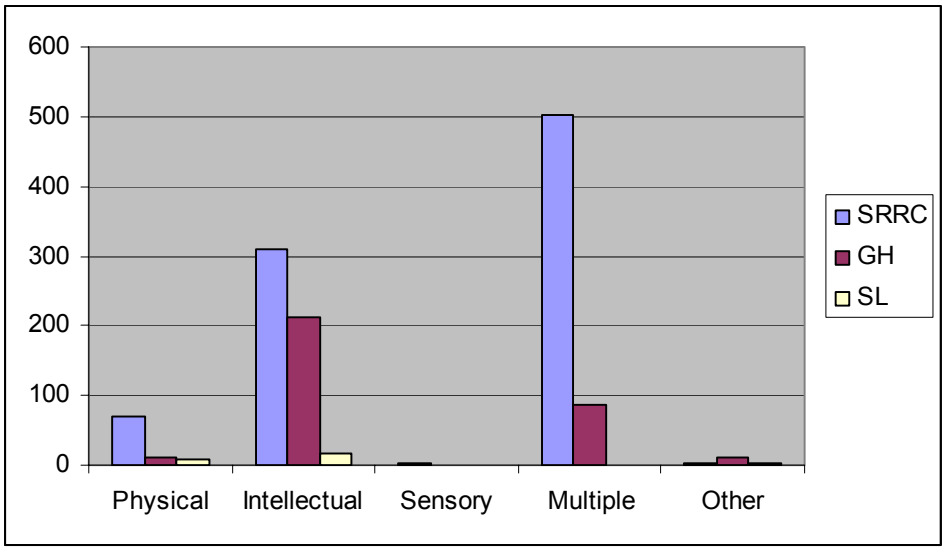
Number and distribution of services, places and service users according to types of residential service for people with disabilities 31/12/ 2004

	services		places		service users	
	number	%	number	%	number	%
SRRC	68	51,91%	1010	70,29%	887	71,82%
GH	59	45,04%	372	25,89%	321	25,99%
SL	4	3,05%	55	3,83%	27	2,19%
total	131	100,00%	1437	100,00%	1235	100,00%

Source: SIPS 2004

	Physical	Intellectual	Sensory	Multiple	Other	Total
SRRC	69	309	4	503	2	887
GH	10	213		87	11	321
SL	8	17			2	27
All res. Serv.	87	539	4	590	15	1235

Source: SIPS 2004



SRRC = social rehabilitation centres (1,125 fte staff)
GH = group home (371 fte staff)
SL = supported living (201 fte staff)

The majority of the total expenditure is accounted for services for the elderly (77.5%). Disability services (including day services) have second largest share (11.4%) and domiciliary services (6.4%). The average cost/day/user was EUR 123 for social rehabilitation centres, EUR 109 for group homes and EUR 80.4 for supported living.

Social rehabilitation centres are the 2nd most expensive service after residential schools for children. The average daily cost of nursing homes for the elderly (RSA) was EUR 100.7.

Distribution of services according to the size of their yearly budget, 2004

	less than EUR 100,000	100,000-200,000	200-300,000	300-500,000	500,000-1,000,000	1-2,000,000	more than 2,000,000
SRRC	9%	3%	18%	29%	34%	3%	4%
GH	20%	34%	27%	15%	3%		
SL	50%				50%		
All residential	15%	17%	21%	24%	19%	2%	2%
All social services	37%	18%	10%	11%	12%	8%	4%

Costs of services are met from different budgets, usually a combination of health and social care, together with direct payments (as described).

Table - Example of cost apportioning in Emilia-Romagna region

	(SSN) NHS percentage of payment (Health Care)	Percentage of payment of the person, their family or the Council (Social Care)
Day Centre - diagnosis and therapeutic treatments	100%	
Day Centre - rehabilitation, education and activities of socialisation, respite to families	67.5%	32.5%
Residential Homes combined with therapeutic treatments, rehabilitation and socialisation	50%	50%
Residential Homes with a high level of health needs of the clients	70%	30%
Residential Home (Comunità Alloggio) low level of health needs	30%	70%

Mental Health Services in Emilia-Romagna

Persons in residential care by average size

Tipologia di struttura	Media dei posti letto per tipologia distruttura	Totale dei postiletto per tipologia distruttura
RTI	17.86	250
RTP	15.00	225
RSR	13.31	519
Comunità Alloggio	14.88	253
Gruppo Appartamento	6.98	335
Altro	15.14	106

Source: DGS, 2006
RTI = residenze psichiatriche a trattamento intensivo (24 hour, max 30 days stay)
RTP = residenze psichiatriche a trattamento protatto (12 hour staff, max 180 days, rehabilitation)
RSR = residenze psichiatriche a trattamento socio-rehabilitavo (6 hour staff)
CA = residential home, low needs, can vary in size 20-100
GA = group home usually up to 6 persons

Numero di strutture suddivise per tipologie all'interno dei DSM della Regione Emilia-Romagna

Tipologia strutture residenziali / Aziende USL	R.T.I.	R.T.P.	R.S.R.	Comunità alloggio	Gruppi Appartamento	Altro	Totale
Piacenza	1	5	0	0	3	0	9
Parma	3	0	0	5	8	0	16
Reggio-Emilia	1	0	1	2	2	5	11
Modena	3	3	5	3	8	0	22
Bologna	3	4	4	3	6	1	21
Imola	0	0	8	0	1	0	9
Ferrara	3	0	0	0	0	0	3
Ravenna	0	1	8	0	6	0	15
Forlì	1	0	7	3	2	0	13
Cesena	0	0	5	1	5	1	12
Rimini	0	1	1	7	0	0	9
Totali R.E.R.	**15**	**14**	**39**	**24**	**41**	**7**	**140**

Source: DGS, 2006

Number of persons/type residential care by ASL (2000)

Posti letto per tipologia strutture residenziali / Aziende USL	R.T.I.	R.T.P.	R.S.R.	Comunità alloggio	Gruppi Appartamento	Altro	Totale
Piacenza	50	88	0	0	20	0	158
Parma	49	0	0	98	74	0	221
Reggio-Emilia	12	0	22	28	19	75	156
Modena	30	30	47	22	44	0	173
Bologna	47	70	45	38	35	25	260
Imola	0	0	99	0	7	0	106
Ferrara	62	0	0	0	0	0	62
Ravenna	0	9	111	0	43	0	163
Forlì	0	11	118	56	18	0	203
Cesena	0	0	48	11	29	6	94
Rimini	0	17	29	0	46	0	92
Totali R.E.R.	**250**	**225**	**519**	**253**	**335**	**106**	**1688**

Source: DGS, 2006

Numbers (%) by type of service, 2004

	RTI	RTP	RSR	CA	GA	Altro
Nessuno	14.3	13.3	21.0	23.5	25.0	14.3
1 – 2	7.1	26.7	39.5	29.4	56.2	14.3
3-5	0.0	6.7	26.3	17.6	12.5	14.3
6-9	7.1	13.3	7.9	17.7	4.2	28.6
10 +	71.5	40.0	5.3	11.8	2.1	28.5

Source: DGS, 2006

Personnel in mental health services (professions)

Professionisti presenti nelle strutture	**Operatori**	**Operatori a Tempo Pieno**	**% di op. tempo pieno su op. totali**
Psichiatri	110	18	16.36
Psicologi	85	27	31.76
Terapisti riabilitazione psichiatrica	21	4	19.05
Infermieri	480	375	78.13
Educatori professionali	277	202	72.92
Assistenti Sociali	55	9	16.36
Personale tipo OTA,OSA	457	355	77.68
Altro personale qualificato	106	78	73.58

Altro personale non qualificato	113	88	77.88
Totale	1704	1156	67.84

Source: DGS, 2006

Part-time workers account for nearly two thirds of the workforce, the largest number to be found in the nursing and allied professions and in staff without formal qualifications, suggesting that many of the health care workers will be women fitting work with family and other commitments. Over 70% of all staff in residential care are part-time workers.

Numbers of staff in mental health services (residential)

Distribuzione del personale all'interno delle strutture	Operatori	Rapporto op. numero di strutture %	Operatori a Tempo Pieno	Rapporto op. TP numero di strutture %	% di op.tempo pieno su op. tot
RTI	260	18.57	203	14.50	78.08
RTP	246	16.40	186	12.40	75.61
RSR	522	13.38	365	9.36	69.92
Comunità Alloggio	231	13.59	136	8.00	58.87
Gruppi Appartamento	343	7.15	193	4.11	56.27
Altro	102	14.7	73	10.43	71.57

Veneto

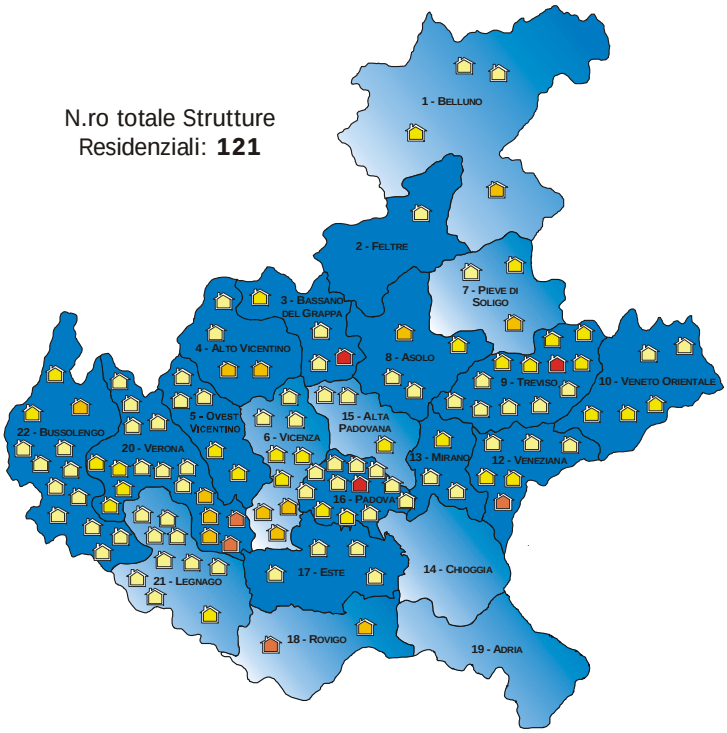
Veneto is the 8th largest and 5th most populated region of Italy. It has 7 provinces and the capital is Venice. The number of inhabitants is approximately 4,738,000. Veneto is one of the most industrialised regions of Italy with a strong economy. In Veneto there is a network of residential and semi-residential services that works in an integrated system of competences, responsibilities and resources both public and private. In the public sector competences are given to *Communi* (Councils) for the social aspect of support needed, whereas for health needs *Aziende* are responsible. In this region there are 22 *Aziende* responsible for all the health services in the territory plus the local hospitals. Within the Veneto Region every *Aziende* has to present every 3 years a Local Disability Plan (*Piano Locale per la Disabilità)* where they have to describe in details all the services, projects and network of support that are going to be developed to support people with disabilities and their families. There is an emphasis on inclusive services that maintain people in their homes and services that offer respite are the main areas of support that are being planned at the moment.

Many day centres and residential homes are run by Associations and Cooperatives whose members are relatives and friends of people with a disability.

Veneto has a mixed structure - small-scale community-based residential services are present together with large institutions (accommodating 400+). Altogether there are 121 residential services accommodating 2,680 persons with disabilities. The average size is 25, however the size of services ranges from 587 to 3 residents.

REGIONE VENETO

Distribuzione territoriale delle Strutture Residenziali classificate per numero di persone con disabilità accolte. Dati al 31/12/2005



Numero persone con disabilità accolte

Fino a 10 | da 11 e 20 | Tra 21 e 50 | da 51e 90 | Oltre 90

The distribution of services and residents according to size of service

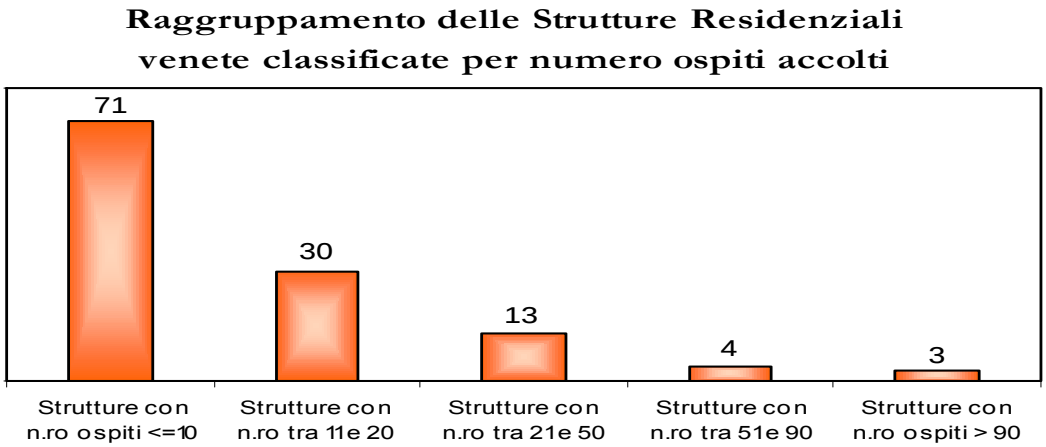
	1-10	11-20	21-50	51-90	91 -	total
services	71	30	13	4	3	121
% services	59%	25%	11%	3%	2%	100%
users	411	441	394	263	1171	2680
% users	15%	16%	15%	10%	44%	100%

1984 (Law 8) and 1989 (Law 22) defined the standards of services both in terms of structural characteristics and in terms of organisation, professionals and modality based on the realisation to develop a network of home, community-based and residential facilities to respond to the needs of patients and their families in the hope of achieving better social status and quality of life.

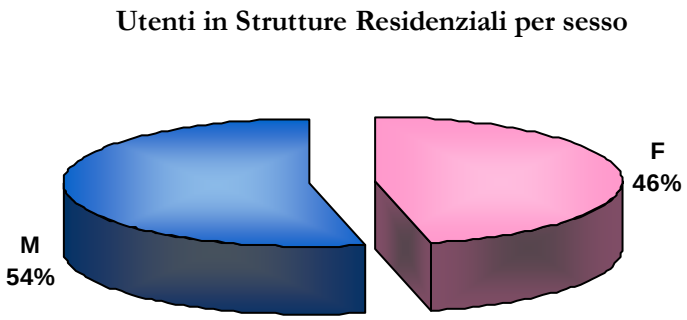
There are no figures on the distribution of service users by type of disability, only whether they have "certificate of disability" introduced by the subsequent Law 104/1992 which promoted the development of services for people with disabilities and their families and has resulted in a network of daytime and residential services organised as an integrated system. Nearly 50% of service users have certificate of

serious disability, 9% have certificate of disability and the remaining 41% have no certificate because the majority of them were living in institutions prior to 1992. People with disabilities contribute to the payment of their place in residential homes using a maximum of 80% of their pensions/income. If they are not able to provide to the payment themselves, their families have to. If they do not have any family, the Council will meet the expense.

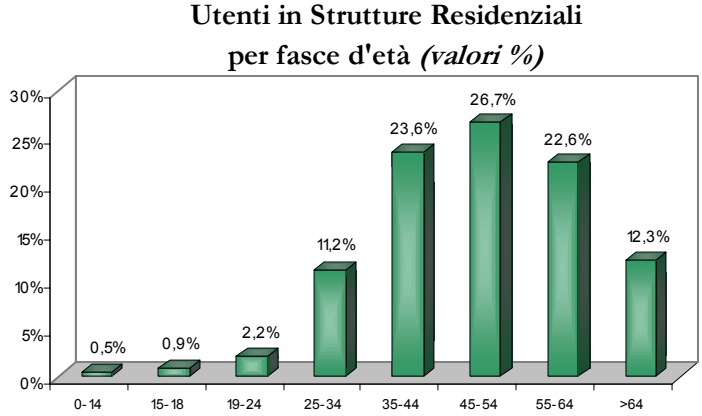
Residential Homes in Veneto classified by number of clients



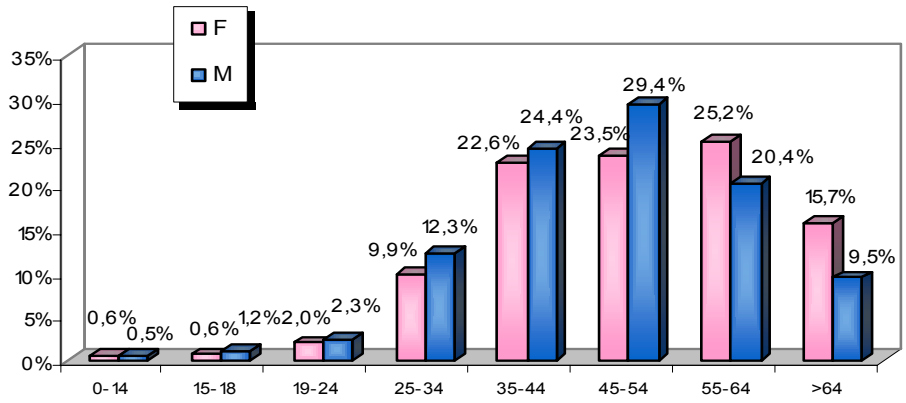
Percentage of people in Residential Homes by the end of 2005 by gender



Percentage of people with a disability in Residential Homes at the end of 2005 by age



Percentage of people in residential Homes by the end of 2005 by age and gender



Organisation of social care in Veneto

Domiciliare	Territoriale	Residenziali
S.A.D. (home-based services)	C.E.O.D. (Centre Education and Occupation Daytime)	G.F. (Group homes)
A.P. (pastoral aid)	S.I.I.S. (Service Integrated Scholastic and Social)	C.A. (Communita allogio – appartments/homes)
	S.I.L. (Service Integration & Work)	R.S.A. (Residenza Sanitaria Assistita)

CEOD is a major part of the organisational set-up that was developed to give continuity of education to people with severe disabilities (young and old) who required assistance to fulfil education. CEOD is an effective means in contrast to inappropriate hospital care in protecting the rights of people with disabilities.
Law 104/1992 called for social integration of persons with handicaps and CEOD, developed under earlier legislation, was seen as a vehicle that could maintain an individual's autonomy by offering support to users and families to avoid the risk of institutionalisation:

- Organised daily structures
- Guaranteed qualified assistance that satisfied both basic needs of individuals with mental disabilities and those with psychiatric disorders.
- Maintained level of autonomy to promote physical and mental well-being

Mental health care

In the province before 1978, most of mental health care was hospital-based – in 1968 a new hospital was built on the outskirts of Verona. Verona was one of the first academic departments to accept proposals for CMHS for a geographically defined area (South Verona) and a psychiatric case register was established that linked the CMHS with a research unit. There is some evidence that dichotomy exists in Verona

– South Verona had a more community-based service compared to the north, which had hospital-based system of care (29%:57%) (Tansella et al., 1998). From 1982 there were no new admissions to the hospital which was converted to a long-stay institution for elderly, people with learning disabilities (adults) etc. Part of the structure was converted to supported apartments where staff are available 24 hours/day. Three (residential care) sheltered apartments were created near the hospital – one "on call" only, one offering 6 hours cover per day and the other 24 hours cover each day. The sheltered apartments were staffed by *educatori* (rehab therapists) and nurses on shift. The 24 hour apartment has 10 persons the others have 4 persons in each. 15 beds were established in a psychiatric ward in the general hospital servicing 450,000 people. There are also 2 private clinics providing residential care for a larger catchments area with about 80-100 in each. The NHS provides care by agreement in these clinics. The sheltered apartments are mix funded (voluntary organisati0ons, co-op non-profits), but nurses provided by SSN.

Central to care provision is the family. Financial support is provided to the patient: a disability pension of €240/month is paid. Municipal social workers provide financial support and voluntary organisation personnel may give individual personal care (social, not health care). The main source of care is the CMHC which provide day care, rehabilitation and activities. There are workshops in the centre and meals are provided. Psychiatric services for children *neuropsichiatria infantile* up to the age of 18 are available which also assist in transition from one facility to another.

Veneto region has 22 health districts – within which psychiatry has to compete with other specialisms. Hospitals have adopted diagnostic related groups which include psychiatry. Private clinics and sheltered apartments are paid daily based on DRG and number of days used. Sheltered apartments are always full, and it is a problem to find accommodation therefore people may stay in acute wards (for longer than necessary) and turn to social services (and have to compete with other people for resources).

Private organisations also are active in the health and social care sector providing homes or hostels that take persons with mental health problems, former private hotels providing care for learning difficulties and houses for elderly and poor.
CTRP = structure for rehabilitation, mental health (nurses and "small hospitals").

Campania

Is situated in Southern Italy, its capital is Napoli. It is one of the most densely populated regions, with the 2nd highest number of population (5.8 million people). Campania has 5 provinces. It is one of the poorest regions of Italy

Italy is characterised at the national level by a framework of poor social rights and 'familism' where a principle of the Italian welfare state is that the family and kinship

network has the core responsibility in supporting the individual, protecting him/her from socio-economic risks (Saraceno, 1994). Regarding social care, the state has only residual tasks, with the aim of ensuring some economic transfers for persons with disabilities. In Italy the relationship between social services and citizens is traditionally marked by two main characteristics: first, the orientation for welfare services is to locate citizens in the position of simple passive recipients; and secondly to establish the relevance of narrow prefixed categories of 'needs' (Saraceno, 2002). Nevertheless, regional differences should be taken into consideration especially differences which are particularly evident in Italy, with regard to the north–south divide. Even in a context of weak institutionalisation of rights, the regions of the north, Veneto and Emilia-Romagna stand out for their wealthy endowment of social services, with innovative practices in the field of home care and offering territorial services as an alternative to institutionalisation (e.g. *centri diurni integrati*, integrated daytime centres).

The region of Campania, on the other hand, shows the features of a marginalised system of services: a severe lack of resources and massive recourse to the family. Secondly, it must be stressed that since the second half of the 1990s, the adoption of certain measures on a national scale has encouraged an impulse for change, introducing a universalistic perspective on social rights – although with some uncertainties and problems – and giving the greatest importance to the promotion of an active role for the user-citizen. However, the measures consist of a non-legally binding regulatory framework, leaving room for regional practices with differing implementation. Moreover, after the introduction of these measures, a change of national government and a transformation in the broader political context have favoured policies oriented at privatisation. Several different processes introducing market regulative criteria and strengthening the private sector and the family care have occurred in several different ways according to the various regional contexts, particularly in the two Regions. This is exemplified by the adoption of legislation for social welfare where there are clear differences in regional policy legislation between regions of the north and those of the south (the information presented below is taken from a more extensive table clearly demonstrating regional differences).

In Italy, differentiated health models are also encountered in the health sector, with a general and gradual tendency towards de-hospitalisation, which is still, however, battling to establish itself in most areas of the country. Some public hospital services remain, centred on the presence of medium-large public hospitals (mainly in the Central-Northern regions), but the southern regions are dominated by the public hospital model, but with a significantly inferior capacity.

In Campania, the regional plan governing the guidelines for reform and improvement of social and medical services (2002) has three basic characteristics. First, it offers an open and flexible approach to planning, limiting itself to sketching a framework that establishes priorities and objectives, and identifies criteria and operative structures that are consistent with such criteria. However, this leaves significant autonomy to other institutional parties and, in particular, to local agencies. The second characteristic is related to the weight given to diversification within the plan - not only is economic support provided for, but it also calls for services, both home-based and territorial, and projects that can both work in favour of innovation in the local arena which, paradoxically promotes the *status quo* in the sense that the existing local agencies (often private or church run) can simply continue to provide additional

services. The third characteristic is that the plan explicitly targets the strengthening of the integration between health care and social care services.

From an already high level of integration between the two sectors, the major objective of the plan move away from highly medicalised services to a more socially-oriented model. In actual fact, in certain municipal areas of Campania, experimental programmes for individualised rehabilitation are currently underway. Such programmes aim to boost autonomy and are hinged upon new forms of arrangement between services and monetary transfers. Public and private organisations both contribute to their planning and management. The 'individualised rehabilitation therapy project' is a socio-medical type of intervention intended for people affected by social disabilities caused by mental health problems or social disadvantage and marginalisation. The project constitutes a part of the strategies in middle-sized urban areas (*aversa*) for reducing committals to large clinics and medical residences. The core concept is to convert the cost of the public expenditure for the residence of non-autonomous people into individual budgets ('care budgets') to be spent on sustaining fundamental capabilities of the beneficiaries in relation to three basic functions: housing, work, and socialisation. In other words, the idea is to translate the cost of a bed in an in-patient institution into a budget, an individual property, which the person can then use to develop his or her living and working capabilities. The care budget, in fact, is co-managed by a non-profit organisation and by public agents (of the municipality and the ASL). The reduction of the level of medical care is incentivised by rewards: the care budget is increased by 10 per cent with each step of decreasing medical intensity (and consequently supporting the social inclusion of the beneficiary).

The care budget contract being piloted in parts of Campania demonstrates:
• partnerships being created between public and private organisations;
• private organisations are involved in the decision making, thus the planning of interventions tends to be characterised by negotiation and collaboration;
• the beneficiaries are involved in the planning of projects and become part of an active rehabilitation process;
• a tendency emerging towards the incremental innovation of institutions, which are learning to find the means to integrate social and health care, financing and provision.

Comparison of service provision between regions

Regionale	Numbers	Ratio per 100,000
Veneto	6380	13.84
Emilia-Romagna	2050	5.05
Campania	1011	1.76

RSAs (for elderly and disabled people) (2003)

Funded through SSN per 100,000 (in hospital)

Regionale	Number	% mi	% older adults	% PSD	% LD
Veneto	771	1.9	6.8	0.4	4.8
Emilia-Romagna	741	0.7	11.7	6.1	No data
Campania	33	0.2	No data	0.4	No data

Number of institutions (all) (2003)

Regionale	Total	Public	Private (accredited)
Veneto	2663	2393	272
Emilia-Romagna	3046	1820	1226
Campania	884	62	822

Social co-operatives providing work and support

Regionale	PSD	MI	TOTAL
Veneto	322	136	458
Emilia-Romagna	299	96	395
Campania	98	15	113

Adoption of legislation for care of the elderly 1972-78

	Institutional care	Community care
Veneto	-	**1975 (nr.72)**
Emilia-Romagna	-	**1975 (nr.27)**
Campania	**-**	_

Source: Rhodes, 1997

Regulatory legislation for the handicapped 1972-78

	Traditional agencies	Rehabilitation services
Veneto	-	**-**
E-R	-	**1973 (nr. 27)**
Campania	**1974 (nr.38)** **1975 (nr. 49)**	**-**

Source: Rhodes, 1997

Legislation for reorganisation and planning of social services 1978-1990

	Reform laws		Regulation and planning of SS	
	1980-85	1985-90	1980-85	**1985-90**
Veneto	1982	-	1984	**1989**
E-R	1985	-	-	**-**
Campania	**-**	**-**	**-**	**-**

Source: Rhodes, 1997

These tables show that in short, northern and central regions, with their relatively strong local governments, stimulate the expansion of a wide range of community services, whilst the opposite pertains for Campania with relatively weak, inefficient local structures, which opts for traditional (more institutional) services delivered by traditional providers such as the public sector and the church. A breakdown of regional expenditure in 1978 revealed that the north and centre spent 48% and 68% on innovative services whilst the corresponding figure for the south was less than 20%.

Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

Latvia

Anja Frindt

Centre for Planning and Evaluation of Social Services,
University of Siegen, Germany

Summary of the available data

Description of Service Types

Type of service	Size Interval (places)	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions	Age of service
Child care centres for orphans - provide the necessary care for orphans and children from 2 years of age deprived of parental care for children with physical and mental development problems up to 4 years of age	100 to 150	.	.	24 hour	Mixed	Mixed (any)	All long term	21 to 50 years
Special ward in Mental Hospital	11 to 30	over 60/65	MH	24 hour	State	State	All long term	100+
Boarding school for blind and visually impaired children (speciālā internātskola neredzīgiem bērniem un bērniem ar redzes traucējumiem)	100 to 150	6-18 or 19	Sensory impairments	24 hour	State	Regional authority/LA/County and state	All long term	100+
Mental Hospitals (Psihiatriska slimnica)	201 +	Over 18/25 (i.e. adults only)	Mixed	24 hour	State	State	Mixed	100+
Boarding schools for deaf and hearing impaired children (speciālās internātskolas nedzirdīgiem un vājdzirdīgiem bērniem)	100 to 150	6-18 or 19	Sensory impairments	24 hour	State	Regional authority/LA/County and state	All long term	100+

Type of service	Size Interval (places)	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions	Age of service
Forensic wards	31 to 50	Over 18/25 (i.e. adults only)	Mixed	24 hour	State	State	Mainly long term	21 to 50 years
Boarding school for children with physical disabilities (speciālās internātskolas bērniem ar kustību traucējumiem)	100 to 150	6-18 or 19	PD	24 hour	State	Regional authority/LA/County and state	All long term	21 to 50 years
Boarding schools for children with language disabilities (speciālās internātskolas bērniem ar valodas attīstības traucējumiem (logopēdiskās internātskolas)	151 to 200	6-18 or 19	Speech impairments	24 hour	State	Regional authority/LA/County and state	All long term	21 to 50 years
Long-term specialized state social care centres and social care institutions for severely mentally handicapped	100 to 150	Over 18/25 (i.e. adults only)	.	24 hour	Mixed	Mixed state/local and private contributions (insurance/private)	All long term	21 to 50 years
Special wards in mental hospitals (Psihiatriska profila nodala vispareja tipa slimnica)	11 to 30	6-18 or 19	Mixed ID with PD, SD, MH, Behavioural and other	24 hour	State	State	Mixed	100+
Mental Hospital for children and adolescents (Bērnu un pusaudžu psihiatriska profila nodaļa vispārējā slimnīcā)	151 to 200	3-18/19	Mixed ID with PD, SD, MH, Behavioural and other	24 hour	State	State	All long term	21 to 50 years

Type of service	Size Interval (places)	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions	Age of service
Specialized children social care institutions - provide care for disabled children with severe mental disorders from age of 4 - 18	100 to 150	.	.	24 hour	Mixed	Mixed (any)	All long term	21 to 50 years
Long-term specialized state social care/rehabilitation centre for adult persons with impaired vision	151 to 200	Over 18/25 (i.e. adults only)	.	24 hour	State	State	All long term	21 to 50 years
Boarding schools for children with mental disabilities (Specialas internatskolas berniem ar garigas attīstības traucējumiem)	100 to 150	6-18 or 19	Mixed ID with PD, SD, MH, Behavioural and other	24 hour	State	Regional authority/LA/County and state	All long term	100+
Group homes	.	.	.	.	.	.	.	.

Data available by service type – breakdown by gender and age and disability (no information was available for size of institution).

Type of institution	Places total	ID	MH	PSD	Mixed/ dual	Other/ unspecified	Male	Female	Children	Younger adults	Older adults
Boarding school for children with physical disabilities (speciālās internātskolas bērniem ar kustību traucējumiem)	242	.	.	242	.	0	116	126	240	2	.
Child care centres for orphans - provide the necessary care for orphans and children from 2 years of age deprived of parental care for children with physical and mental development problems up to 4 years of age	485	430	.	.	.	55	274	211	485	.	.
Boarding school for blind and visually impaired children (speciala internatskola neredzigiem berniem Boarding school for blind and visually impaired children (speciālā internātskola neredzīgiem bērniem un bērniem ar redzes traucējumiem)	155	.	.	155	.	0	84	71	120	35	.
Boarding schools for deaf and hearing impaired children (speciālās internātskolas nedzirdīgiem un vājdzirdīgiem bērniem)	321	.	.	321	.	0	186	135	273	48	.
Boarding schools for children with language disabilities	406	.	.	406	.	0	258	148	388	18	.

Type of institution	Places total	ID	MH	PSD	Mixed/ dual	Other/ unspecified	Male	Female	Children	Younger adults	Older adults
(speciālās internātskolas bērniem ar valodas attīstības traucējumiem (logopēdiskās internātskolas)											
Special wards in mental hospitals (Psihiatriska profila nodala vispareja tipa slimnica)	100	.	.	.	100	.	.	.	100	.	.
Mental Hospital for children and adolescents (Bērnu un pusaudžu psihiatriska profila nodaļa vispārējā slimnīcā)	150	.	.	.	.	.	.	.	150	.	.
Specialized children social care institutions - provide care for disabled children with severe mental disorders from age of 4 - 18	356	352	.	4	.	10	205	151	275	81	.
Boarding schools for children with mental disabilities (Specialas internatskolas berniem ar garigas attīstības traucējumiem)	4515	.	.	.	.	4515	2887	1628	3788	727	.
Mental Hospitals (Psihiatriska slimnica)	2900	.	.	.	2900	.	.	.	.	2900	.
Forensic wards	.	.	.	.	49	.	.	.	.	.	.
Long-term specialized state social care centres and social care institutions for severely mentally handicapped	3370	1600	1612	.	.	158	1721	1649	.	2331	*1039*
Long-term specialized state social care/rehabilitation centre for adult persons with impaired vision	213	23	30	.	.	160	113	100	.	85	*128*

Type of institution	Places total	ID	MH	PSD	Mixed/ dual	Other/ unspecified	Male	Female	Children	Younger adults	Older adults
Group homes	.	.	.	.	.	.	.	.	.	.	.
Special wards in Mental Hospitals	250	.	.	.	250	.	.	.	.	.	*250*
Totals	**13463**	**2405**	**1642**	**1128**	**3299**	**4878**	**5844**	**4219**	**5819**	**6227**	**1417**

Staffing

Service type	No. of staff in service	Managers	Educators /day staff	Day and care	Other (inc. ancillary)	Other (not ancillary)
Boarding school for children with physical disabilities (speciālās internātskolas bērniem ar kustību traucējumiem)	180	32	6	48	15	82
Child care centres for orphans - provide the necessary care for orphans and children from 2 years of age deprived of parental care for children with physical and mental development problems up to 4 years of age	828	135	35	55	86	517
Boarding school for blind and visually impaired children (speciala internatskola neredzigiem berniem Boarding school for blind and visually impaired children (speciālā internātskola neredzīgiem bērniem un bērniem ar redzes traucējumiem)	96	28	5	34	4	30
Boarding schools for deaf and hearing impaired children (speciālās internātskolas nedzirdīgiem un vājdzirdīgiem bērniem)	247	54	11	106	8	70
Boarding schools for children with language disabilities (speciālās internātskolas bērniem ar valodas attīstības traucējumiem (logopēdiskās internātskolas)	219	49	9	67	5	73
Special wards in mental hospitals (Psihiatriska profila nodala vispareja tipa slimnica)	.	.	.	.	.	.
Mental Hospital for children and adolescents (Bērnu un pusaudžu psihiatriska profila nodaļa vispārējā slimnīcā)	.	.	.	.	.	.
Specialized children social care institutions - provide care for disabled children with severe mental disorders from age of 4 - 18	471	126	16	30	40	259
Boarding schools for children with mental	2676	405	139	1161	124	997

Service type	No. of staff in service	Managers	Educators /day staff	Day and care	Other (inc. ancillary)	Other (not ancillary)
disabilities (Specialas internatskolas berniem ar garigas attīstības traucējumiem)						
Mental Hospitals (Psihiatriska slimnica)	.	.	.	.	.	.
Forensic wards	.	.	.	.	.	.
Long-term specialized state social care centres and social care institutions for severely mentally handicapped	1984	523	131	.	258	1072
Long-term specialized state social care/rehabilitation centre for adult persons with impaired vision	132	30	8	.	20	74
Group homes	.	.	.	.	.	.
Special wards in Mental Hospitals	.	.	.	.	.	.
Totals	**6833**	**1382**	**360**	**1501**	**560**	**3174**

Staffing qualifications

Type of service	Total staff	Staff with only primary school qualification or less	Staff with secondary school qualification as highest qualification	Staff with higher qualification	Staff with university degree	Unspecified
Boarding school for children with physical disabilities (specialas internatskolas berniem ar kustibu	180	.	.		32	148
Child care centres for orphans - provide the necessary care for orphans and children deprived form p	828		13	62	60	
Boarding school for blind and visually impaired children (speciala internatskola neredzigiem berniem	96	.	.		28	68
Boarding schools for deaf and hearing impaired children (specialas internatskolas nedzirdigiem un va	247	.	.		53	194
Boarding schools for children with language disabilities (specialas internatskolas berniem ar valoda	219	.	.		49	170
special wards in mental hospitals (Psihiatriska profila nodala vispareja tipa slimnica)	.	.	.	.		
Mental Hospital for children and adolescents (Bernu un pusaudžu psihiatriska profila nodala visparej	.	.	.	.		
Specialized children social care institutions - provide care for disabled children with severe menta	471		31	56	39	345
Boarding schools for children with mental disabilities (Specialas internatskolas berniem ar garigas	2676	.	.		405	
Mental Hospitals (Psihiatriska slimnica)	.	.	.	.		
Forensic wards	.	.	.	.		
Long-term specialized state social care centres are social care institutions for severely mentally h	1984		313	139	71	1461
Long-term specialized state social care centre for adult persons with impaired vision	132		10	16	4	
Group homes	.	.	.	.		
Special ward in Mental Hospital	.	.	.	.		
Total	**6833**		**367**	**273**	**741**	**5452**

Completeness and accuracy of the data

The data presented in the template is based on statistical data and information from the Ministry of Welfare (Department of Social Services and Social Assistance), the Ministry of Health (Mental Health State Agency, Division of the Health Care Organization) and the Ministry of Education and Science (Department of General Education). Interviews with representatives from all mentioned departments have taken place in autumn 2006. Data and information on state social services are collected yearly since 1998 by (State) Social Service Board (Agency under the Domain of the Ministry of Welfare). Information from service providers is put together by region, age and gender. Statistics on mental health care are collected by Mental Health State Agency. Data referring to educational affairs is provided from the Statistical Department under the Ministry of Education. The collected information is yearly based on the last school year and collected each year at September, the 5th. Data on different aspects of school life for example number of children, number of classes, age groups and gender are interrogated.

Statistical data on residential services for disabled people covers all age and disability groups. But there is no differentiation between services for younger and older adults. The statistical data shows that the majority of residents in long-term specialised state social care centre for adults with impaired vision is over 60 years old or is cared for in special wards in mental hospitals for older adults. The collected data covers staff numbers and data on staff training (without psychiatric care). Besides statistical information there were other sources used to write this country report, as listed at the end of this chapter.

It can be summarised that – because of intensive communications with all relevant officials – the presented data is on the most complete and accurate (national) level possible for the year 2005. The existing country report has been authorized by Sandra Garsvane (Senior Expert of Social Service Unit, Department of Social Services and Social Assistance, Ministry of Welfare) and Baiba Sveile (Senior Officer Department of Public Health, Division of Health Care Organization).

Commentary: Latvia

1. Overview

As an emerging independent democracy Latvia is currently undergoing a wide range of political, economic and social reforms. By international standards the system of residential care is under-funded and overly reliant on institutional beds, it still remains centred on large institutions.

Latvia is a young European country and a lot of transition processes can be observed. The Ministry of Welfare of the Republic of Latvia and the Ministry of Health of the Republic of Latvia are both drafting new laws with regard to the system of aids for persons with disabilities. The Ministry of Welfare is working on transforming the responsibility for social care from the state level to local governments. At the moment the whole system is very centralized, state is responsible for the provision of social services to their residents. Besides overlapping between health/psychiatric care and social care is a big discussion topic between the two above mentioned Ministries.

The challenge facing the mental health system in Latvia is how to shift the resources from mental hospitals to community mental health facilities. Mental hospitals still predominant in the mental health system and almost all the financing and staff resources are concentrated in these institutions. Long stay patients make up about 1/3 of all patients.

2. Political and social context

The Republic of Latvia is situated at the eastern shore of the Baltic Sea and has a territory of 64,597 sq km. Latvia has 2.3 million inhabitants in total. 59 % of them are Latvians, 29 % Russians, 4 % Byelorussians, 3 % Ukrainians and 2.5 % Polish people and 1 % Lithuanians. Nearly one third (725,000 people) of the whole population live in the capital Riga. Official language is Latvian, but Russian is widespread. The main religions are Evangelical Lutheran, Roman Catholic and Russian Orthodox. Latvia declared its independence on November the 18th in 1918. It was occupied during First World War and forced to enter the Soviet Union on 21 July 1940. Latvia regained regained independence on 21 August 1991.

2.1 Government organisation and structure

The Republic of Latvia is a parliamentary democracy. Latvia's administrative structure is a central state with limited local autonomy. The Latvian territory is divided into 5 regions: Riga, Vidzeme, Zemgale, Latgale and Kurzeme. The gross domestic product per head was 5,506 Euro in 2005. Since 1 May 2004 Latvia is member of the European Union.

Source: http://europa.eu/abc/maps/members/latvia_de.htm

3. Demographics

Latvia has a population of 2,307,000. The life expectancy is 66 years for men and 76 years for women. So, life expectancy in Latvia is 10 years lower than in western European Countries for men, and almost five years lower for females. Women have a much higher life expectancy than men, like in the other Baltic Countries. The main causes of death in Latvia are diseases of the circulatory system and cancer. Infant mortality is 11 per 1000 for males and for women. Health expenditure as a percentage of GDP was 6.4 in 2003. The total health expenditure per capita was 678 Intl $ in 2003.

4. Health and Social Care System

Social care is divided in social services (government and local authorities are responsible) and social assistance (responsibility of local government). The system of social care in Latvia started in 1991.

Long-term institutionalized care for people with disorders of a mental nature is organized by the Ministry of Welfare and is provided in 33 social care homes for adults and children. There is no clear policy from Ministry of Welfare whether it may also include people with mental health problems. The responsibility to provide home care, day care and group homes for people with disorder of a mental nature, mainly for persons with intellectual disability, has been delegated from Ministry of Welfare to local municipalities. When municipal reform in Latvia is completed by 31.12.2007 responsibility for all state social care homes will be transferred to municipalities.

Psychiatric care is provided under the aegis of the Ministry of Health. Mental Health care is usually hospital based care. There are 9 mental hospitals[24] in Latvia with 115-500 beds. Some of them are acute hospitals, some provide rehabilitation and outpatient facilities, like community day-centre (treatment, rehabilitation, social work, sports) as well. There are also chronically hospitals where patients live and work. These hospitals have a residential function for their patients (presumably for 1/3 of all patients).

4.1 Organisation

Social welfare services for children are mixed pattern – the state or municipalities provide the services, some of them are provided by private providers.

[24] This is the number of hospitals in 2004 according to the template, in 2005 two hospitals were consolidated so that there are now 8 hospitals.

Long-term specialised state social care centres for "severely mentally handicapped" are provided by the state or municipalities, some of them are provided by NGOs. Long-term specialised state social care centre for adult persons with impaired vision is provided by the state.

Local Government Social Service Office shall provide social services and social assistance to their residents and evaluate the needs of persons applying for social care.

Ministry of Health is responsible for regulation and management of health care. Health Compulsory State Agency has agreements with hospitals and outpatient services. Mental health care is part of general health legislation and provided by the state. The Medical Treatment Law provides regulations for the general health system, while specific mental health legislation is under development.

4.2 Financing

Latvian health care is financed by health insurance, which is organized by the Health Compulsory Insurance State Agency.

Mental health care is financed from different sources depending on the type of service provided, health care budget funds psychiatric hospitals and outpatient psychiatric care. Ministry of Welfare budget supports social care homes and day centres for persons with intellectual disabilities. Few municipalities support NGOs to operate community services for the intellectually disabled.

Ministry of Welfare has funded through the Social Services Board together with respective municipalities some community-based services for those with intellectual disabilities including 18 day care centres and 2 group homes.

According to Law on Social Services and Social Assistance Child care centres for orphans are financed from state budget and municipality budget. Specialized child social care institutions are financed from state budget and municipality budget.

Long term specialised state social care centres for severely mentally handicapped adult persons are financed form state or state bought these services. Long-term specialised state social care centre for adult persons with impaired vision are funded from state budget, too.

According to Law on Social Services and Social Assistance social assistance to a client shall be provided on the basis of an evaluation of his or her material resources – income and property, individually providing for the participation of each client in conformity with the Law on Social Security. A person living in a long-term social care institution has the right to a particular sum of money for personal expenses in the following amount:
1) for a person of legal age who has been granted the pension prescribed by law or a state social security benefit, the sum of money remaining at his or her disposal after payment for the long-term social care service may not be less than 15 percent of the amount of the amount of the pension or state social security benefit of this person;
2) for a person of legal age who does not have the right to receive the pension prescribed by law or a state social security benefit, the sum of money to be paid from

the budget of the long-term social care institution shall be 15 percent of the amount of the state social security benefit and
3) for a child from the age of seven years, the sum of money to be paid from the budget of the long-term social care institution shall be 15 percent of the amount of the state social security benefit.

Schools for children with special needs are funded from state budget. In boarding schools everything is funded by the state (pedagogical staff, all books, food and in some cases transportation costs). District authorities divide the budget to specific schools and specific kindergarten according to the number of children attending.

5. Definition, eligibility and diagnosis/assessment

Latvian legislation defines the term "person with a disability" in the Law on People with Disabilities, article 4 as „a person who due to the impairment of the functions of the system of organs caused by diseases, trauma or innate defects, needs additional medical and social assistance, and to whom a disability status has been attributed in the procedure set in this Law and other normative acts". Article 5 defines disability: "the continuous or ceaseless restriction of physical or mental abilities, which is not connected with changes in the human body because of old age and which prevents the integration of a person into the community, as well as completely depriving them of, or partially restricting, their ability to work and to take care of themselves". The Law on People with disabilities is the most important law addressing the rights of persons with disabilities in general. Besides including a definition of disability, it defines three disability groups and the procedure for evaluation of working capacity.

In the Law on Social Services disability is not defined, the term functional disorder is used as it's close to the term disability. A functional disorder is a disorder of a physical or mental nature caused by a disease, trauma or congenital defect which restricts the ability of a person to work, take care of him or herself and makes it difficult for the person and to integrate into society. At the moment the Ministry of Welfare of the Republic of Latvia is preparing a new law on people with disabilities where the term disability will be defined. In a draft version a preliminary definition of "mental disability" is used.

The Ministry of Health speaks of a loss of function and possibility to work due to mental/physical factors. The most widely used term is mental behavioural disorder.

The Law of Education and the Law of General Education state that special education shall be for those who can't follow the mainstream curricula and need additional support/adapted education.

The International Classification of Diseases and Related Health Problems (ICD-10) is used as a standard reference in Latvia. Severity of disability is distinguished in severe (disability group I and II) and moderate (disability group III) disability. The legal interpretation of the term "disability" is very narrow, it's valid only those persons for whom a disability group has been designated by the Medical Commission.

In Latvia there are different procedures for diagnosis and assessment of disability: for educational purposes, for employment purposes and for access to social benefits. The

two last mentioned procedures are carried out by State Commission of Physicians for Health and Work Capacity Examination.

Result of the assessment procedure for adults is assignment to one of three following levels of disability:

I – designated if a person has a very severe restriction of physical or mental abilities, integration into society without permanent assistance is impossible, work and self-care abilities are very restricted;

II – designated if a person has severe restriction of physical or mental abilities, integration without appropriate assistance is impossible, work and self-care abilities are restricted;

III – if a person has moderate restrictions in physical or mental abilities, integration without appropriate assistance is restricted, work and self-care abilities are restricted as well.

Under the domain of the Ministry of Welfare works the State Commission of Physicians for Health and Work Capacity Examination is checking each concrete person having functional impairments and makes a decision about receiving a disability group. Normally local doctor suggests their patients to go to the Commission. Main State Commission is located in Riga, besides there are 18 local Commissions. At the moment there are a lot of planned changes discussed with this Commission. Currently the procedure follows former soviet legacy and will be adapted to EU-Laws, EU-Directions and documents. One of the planned changes is the participation of social workers, occupational therapists and other specialists in the Commission which consists only of doctors by now. Another new idea is the implementation of rehabilitation plans. Ministry of Welfare is checking very carefully if there is a social worker working with clients on this plan. Only persons with disability group I or II are eligible to get a service in an institution, except old people. For receiving a place in a service the local care service evaluates and checks the client for special needs. This information is then forwarded to Social Service Board, which allocates places according to waiting lists.

Ministry of Health estimates that 60-80 percent of the patients in mental hospitals are diagnosed by the Commission.

The assessment procedure for children is carried out by State Pedagogical Commission. There are three levels of disability for children:

A – mild intellectual disabilities (equivalent to F-70, ICD 10),

B – moderate intellectual disability,

C – severe intellectual disability.

When children have problems to follow the curricula their teacher suggests them to be diagnosed, usually that takes place at the end of the school year. The child, their parents and the teacher attend the medical assessment. State Pedagogical Commission gives a recommendation for a special school or special education according to the classified level of mental disability. The recommendation is only a suggestion to parents. Finally they decide which school their child shall attend. Usually parents decide for mainstream school with additional support. A diagnose of the Commission is precondition for studying at a special school.

6. Prevalence of disability

According to the Population and Housing census 2000 there are 2,331,500 inhabitants in Latvia. The Statistics of the Mental Health State Agency counted 64,198 people with registered mental disabilities or behavioural problems in 2003. 14,281 of them were persons with intellectual disability, including 5,547 children.

13,060 people received state social insurance benefit in 2002, 12,187 of them in the event of disability. Additional payments to the family state benefit for a disabled child was received by 8,981 people.

7. Residential Services for people with a disability

7.1 Overview

The process of deinstitutionalisation has been slow in Latvia. The majority of residential care for persons with disabilities is still provided in large institutions. Long term social care is provided in 4 forms: for adults, for adults with mental disabilities, for children and for children with visual impairment. State is responsible for orphans up to 4 years, children with physical disabilities mixed with mental disabilities and children with mental disabilities. Later in the circle of life (care homes for orphans from 4 to 18 years, children with physical disabilities) state and local government share the responsibility. There is one institution (for the whole country) with 200 places for blind persons. In the year 2004 841 children with disabilities have been living in State institutional care and in private and NGO-run children's homes. The lack of community based alternatives to institutional care can also be noticed concerning residential care for adults. Nearly 3600 adults with disabilities were residing in specialised State Social Care homes for adults with mental disabilities and for the elderly. A number of persons live in psychiatric hospitals, which also provide long-term care for patients.

The Ministry of Welfare has developed a national program to increase the scope and number of community-based services available: "Improvement of infrastructure and equipment of social care and social rehabilitation institutions". This program will be implemented with financial support from the European Regional Development Fund. New group homes for persons with disabilities shall be established. This idea was raised in 1995 but local governments weren't interested because of the costs of new buildings, equipment and so on. That's why it was put into legislation that the Ministry of Welfare covers the costs of new group homes for the first year. From the second year on local authority has to pay for this service. At the end of the year 2006 9 group homes shall be established. Besides the Ministry of Welfare is now looking for quality systems and aims to shift responsibility of all 36 state institutions to local governments.

Statistics on state social services are collected yearly since 1998 by (State) Social Service Board. Information from service providers is put together by region, age and gender.

The priority of the Ministry of Health is to develop community health services and the downsizing of large mental hospitals. Mental hospitals will be transformed to residential homes and half-way-houses and day clinics providing rehabilitation flats in community shall be established. There are plans to remove from old hospitals and to

build new ones with more rehabilitation activities. The action plan for the years 2007-2017 foresees to build half-way-houses. Patients should not live in hospitals but in flats, training to go back home and skills for independent living shall be provided in half-way-houses. At the moment this service is provided by NGOs. Policy aims to develop from hospital care to community-care. Smaller community-based services, sheltered workshops and the increase of staff's salary are topics on the agenda, too.

Statistics on mental health care are collected by Mental Health State Agency, situated in one of the mental hospitals. Besides collecting and analysing statistical data this agency make projects, provide an information system and reports and drafted new psychiatric law.

Perspectives of the Ministry of Education are to diminish the number of boarding schools and the number of children attending special schools. Their status should be changed to become more like resource centres like in Scandinavian countries without residential facilities. Staff will work with groups of children, support for parents, children and teachers through specific knowledge and experiences. Some boarding schools will remain because of the situation of the family of the child or for children who can't be integrated into mainstream schools, but number of children in boarding schools will diminish.

Statistical data is provided from statistical department under the Ministry of Education. The collected information is yearly based on the last school year and collected each year at September, the 5th. Data on different aspects of school life for example number of children, number of classes, age groups and gender are interrogated.

7.2 Services for children with a disability

Depending on their age and condition of health children are provided with social care at 2 types of long term child care and upbringing institutions: child care centres for orphans and specialised children social care institutions.

7.2.1 Child care centres for orphans

Child care centres for orphans provide the necessary care for orphans and children deprived from parental care up to 2 years of age and for children with physical and mental development problems up to 4 years of age. This type of service has been provided for 30-70 years in Latvia. In 2004 485 children, mainly intellectual disabled, were provided with 24 hour support in 5 centres, which are still huge institutions.

7.2.2 Specialised children social care institutions

Specialised children social care institutions provide care for disabled children with severe mental disorders form age of 4 years up to 18 years of age. In 3 specialised social care institutions live 356 children.

Table Number of institutions and children placed in institutions, 1 January 2006

	Child care centres for orphans	Specialised children social care institutions
Number of institutions	5	3
Number of children	114 85 115 64 107	84 171 101
Total number of children	485	356

7.2.3 Special education institutions

Under the domain of the Ministry of Education there are 64 special education institutions in Latvia, most of them are boarding schools. Less than 10,000 students – about 3% of the whole school population - attend special schools, the majority of them have a mental disability, in former times called mental retardation. In the schools there can be 1/3 of students who go home after lessons and don't live in the boarding school. Especially in Riga it's widespread to attend a special school and live with their family at home. But the typical percentage of extern students is lower in schools in the countryside. A big problem is public transportation, children who are living 50 or 100 km away from school come to study there. Because of the big distances and sad public transportation possibilities, they have to stay at school during the week, but quite a lot of children came only for lessons. The birth rate in Latvia is falling since the mid of 90's so the schools want to remain students at their own school and develop different services. As result the number of integrated children with disabilities into general education schools has increased. There are seven kinds of special schools in Latvia according to the type of disability:

1 for blind and visually impaired children,
2 for deaf hearing impaired children;
5 for children with social emotional disabilities,
2 for children with language disabilities,
1 for children with learning difficulties,
2 for children with physical disabilities
and 40 schools for children with mental disabilities, all of them provide residential care, usually a five-day-a-week service. Usually children go home every weekend and for vacation. If there is a difficult situation at home they can stay at school but are not obliged to (the same at vacations). Most boarding schools are a 5 day living place. Children are involved in many activities (sport, international activities) much more than in mainstream schools. In soviet times the special schools were more closed, students were not brought into public. This attitude has changed and there are now a lot of opportunities (cultural activities, exhibitions.

7.3 Services for younger and older adults with a disability

There is no differentiation between residential services for younger and those for older adults in Latvia. According to the Law on Social Services and Social Assistance long-term social care and social rehabilitation institution is a social institution which provides a person who cannot take care of himself or herself due to old age or state of

health, as well as orphans and children left without parental care with housing, full care and rehabilitation. Three kinds of service types exist under the aegis of the Ministry of Welfare: long-term specialised social care centres, long-term specialised state social care centres for adults with impaired vision and group homes.

7.3.1 Long-term specialised state social care centres

Long-term specialised state social care centres are social care institutions for severely mentally handicapped adult persons. Latvia has 24 of these institutions with altogether 3370 places. Nearly 500 clients are diagnosed to have organic, including symptomatic, mental disorder, about 1,100 are diagnosed with schizophrenia, schizotypal and delusional disorders and the majority (nearly 50 % of clients) are diagnosed with mental retardation. 24 hour support is provided in long-term specialised social care centres. Different staff provides social rehabilitation and up-bringing establishments. State social care centres exist in Latvia since 30-70 years. There is only 1 "small" institution with 10-30 places, the other ones are much bigger and very large (11: 51-100 places, 7: 101-200 people, 5: 201-500).

7.3.2 Long-term specialised state social care centre for adults with impaired vision

Long-term specialised state social care centre for adults with impaired vision is a social care and rehabilitation institution. The one institution of this type in Latvia 213 places and is 35 years old. The majority of residents is over 60 years old.

7.3.3 Group Homes

8 group homes exist in Latvia.

7.4 People with mental health problems

Inpatient care is provided by the hospital of the mental Health State Agency and 8 mental hospitals with the total number of 3117 beds[25], as well as in 3 psychiatric profile wards with 80 beds (children hospital Gailezers, Rezekne hospital and the hospital of the Prison Administration of the Ministry of Justice).

There are quite a large number of beds used for social patients who are not able to live alone due to their mental health condition, but who, due to the insufficient number of alternative care institutions in the health and social care system, are forced to occupy hospital beds.

The following service types can be differentiated:
1) **special ward in mental hospital** (1 in Latvia): means more acute and short term treatment. Normally children stay 2 – 4 months. If it is not possible for them to go back home they go to:
2) **psychiatric ward in General hospital for children and adolescents**: only 1 in Riga, which is more nice and has more possibilities for clients than the other facilities. Level of qualification of staff is high: psychologists and psychotherapists are working there.

[25] This data refers to the year 2004 according to the template, newer data from 2005 states, that two hospitals were consolidated, so there are now 7 mental hospitals with 2897 beds.

3) **mental hospital for children**: There is one mental hospital for children, where chronically ill children are treated and can get education/school.
Adults are treated in:
4) **mental hospital**: there are 7 in Latvia, which exists since 150 years and provide treatment for adults with mental retardation, organic mental disorders, major depression etc.
5) **forensic ward**: This one ward with 50 places was established 7 years ago.
There is no big difference between services for older and younger adults.
6) **special wards in mental hospitals for older adults:** are located on a different place of the hospital than the other facilities. 7 of these special wards for older adults exists in Latvia for people aged 60+.

About half of the above mentioned facilities were organizationally integrated with mental health outpatient facilities. Mental hospitals focused on the treating the adult population: only 9 % of mental hospitals beds were reserved for children and adolescents. The most frequent diagnosis in mental hospitals is schizophrenia, schizotypal and delusional disorders (42 %) and other disorders (36 %). The average number of days spent in mental hospitals was 67. Concerning the length of stay 66 % of patients spent less than one year, 14 % of patients spend 1-4 years, 11 % of patients spend 5-10 years, and 9 % of patients spent more than 10 years in mental hospitals.

8. Other relevant information on residential services

Private Provision: There are just a few private providers in the field of mental health care. It is not popular to people and often there is no possibility to pay for such kind of service. Normally people are asking for help in local governments which provide the services.

NGOs provide private flats and day-centres-activities, but only for little patients. So their activities do not have an important impact. There are a lot of good examples and projects, but they are not part of the regular system. Still less NGOs are working in Latvia. An increase can be seen only in private psychiatric sector, for people who are able to pay for this service for private psychotherapy and private psychiatrists.

With regard to the educational field there is no private sector. Quite a lot of NGOs try to help boarding schools. They visit schools, talk to children, support teacher and make the environment more open in that respect.

9. Staffing

Ministry of Welfare has plans to employ from 2008 on in each institution social workers with higher education. At the moment the situation concerning staff is very poor. Often staff doesn't have enough qualifications, courses are paid from European money. There is one programme for professional social workers. State pays that they can get higher education. In soviet times staff had no special education. Sometimes untrained social service staff is good professionals, but they need to get more theoretical knowledge attending programmes for local service staff to get higher education. Directors of institutions are obliged to have higher education degrees from 2003 on. This degree should not obligatory be social education as the director of the institution is a manager. The general situation concerning staff is getting better, it's obligatory to have special courses for few times during 1 year. All staff who works

directly with clients in institutions needs to participate in special courses (for example psychology, social work and rehabilitation, work with clients with disabilities). These special courses for 8 /16 or 24 hours a year were established in 2003. Jobs in social service institutions are not regarded as attractive. In the country side it's the only possibility to get a job with a normal salary. Salary is not good, but was increased in 2006.

Ministry of Health also states that there is not enough staff in some regions. This problem doesn't occur in the centre in Riga, but in the countryside. Especially social workers, psychiatrists and occupation therapists) are missing. General plan is to increase the salaries. Normally in mental hospitals doctors, social workers and psychologists have a university degree, nurses have more and more a college degree, nurses assistant have basic education and courses in hospitals, specialists and therapists (art, sport) and educators have mostly a university degree, but no special degree in mental health. Staff should do some training to get a certification for example special courses in psychiatry, social work. Child psychiatrists are missing and a lot of qualified staff leaves the Latvia to work in England or Ireland. Director of a mental hospital is a psychiatrist who tries to make second education in economy, project providing or organisation studies.

According to Law on General Education and Law on Education, teachers should have a higher education degree (university degree or teacher training college degree). Normally the staff at boarding schools consists of psychologist, social teacher, medical staff (at least 2 nurses), ancillary staff (sometimes responsible for heating and water), secretary and two different pedagogical staff groups (subject teachers and those who work with the students after the lessons- care teachers, organise all after lessons activity, homework etc.). All staff who works directly with the children has to have a higher education degree (university – bachelor or teacher training college degree) and quite a lot have masters or even a doctor degree. A teacher training programme on special education is provided by the Ministry of Education. Teachers' salary is quite low and common attitude to school and teachers is bad. A lack of teachers in schools is a big problem, especially in natural sciences and languages. To be a teacher in Latvia is not regarded as attractive, it's not a prestigious job. That's why a lot of young teachers try to find another job or migrate to our countries.

10. Costs

Costs for services differ from institution to institution and are dependant on region. For example services located in Riga are more expensive than in the other regions. Age of the building of the institution and number and qualification of staff are other important factors which influence the costs. Budgets of services are checked by Social Service Board for every institution individually yearly in advance, which means a huge administrative work. For example average costs in specialised children social care institution are 475 Lats (676 Euro) per month, covering prices from 389 Lats (554 Euro) to 557 Lats (793 Euro). Costs for long-term specialised state social care institutions for severely mentally handicapped adult persons differ between 170 Lats (242 Euro) to 307 Lats (437 Euro) per month, the average place costs 190 Lats (270 Euro).

Concerning the costs of hospital care there are agreements between hospital and state health insurance agency according to bed days. There are little different prices in the

regions. On average one bed day is 9-15 Lats (between 13 and 22 Euros). Payments are made yearly in advance. Budgets have increased year by year because prices go up for nearly everything – gas, medication, salary of staff and inflation.

Costs of a place in a boarding school are calculated according to the minimum wage in 2001 which has changed during the last years. The price for a place doesn't depend on the type of the school but on the calculated sum of money one child needs. According to calculation from the year 2001 this sum should not be less than 89 lats per month (128 Euro). But today this money only covers the maintenance. Budgets increases because of the rise in salaries of teachers and other staff and of different other costs (electricity, heating). From the next year on (2007) European Structural Fund gives money to the infrastructure of special schools including boarding schools.

11. Issues

11.1 Ethnicity

A high percentage of Latvian population are Russian people, in the district Latgale lives quite a lot of Russian population. Russian language is widespread. Apart from that ethnicity does not appear to be a major issue in Latvia. Available statistics do not distinguish or provide information on ethnic groupings.

11.2 Gender

Regarding the life expectancy in Latvia women tend to live much longer than man. Nevertheless there are long waiting lists especially for males in institutions, sometimes up to 2 years.

11.3 Regional/geography

During the past years social services has become more and more similar to each other and offer more and more the same level. In the eastern part of Latvia are no good facilities, but this is changing. Institutions are now in almost all regions and in all big cities. Programmes financed by EU money aim to overcome regional variations and improve the quality of services.

Concerning mental hospitals there are no great regional variations, too. In some regions is a bigger part of chronically patients, in Riga are mainly acute patients treated. In some parts of Latvia are rehabilitation measures and sheltered workshops available, in others not. About two-thirds of psychiatric beds in the country were located in or near Riga, such a distribution of beds prevented access for rural users.

Special schools are scattered over all regions of Latvia. The bigger ones and the special schools for deaf children, blind children and children with hearing impairments are located in Riga.

12. Acknowledgements

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13. Information sources on disability used to compile the template and commentary, including people who were interviewed

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Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

Lithuania

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Summary of the available data

Description of service types.

Type of service		Size Interval (places)	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions	Age of service
1	Institutions providing professional rehabilitation services	11 to 30	16/18/25 - 60/65 (adults but not older adults)	PD and Sensory/other	24 hour	State	State	Short to medium term (up to 2 years if specified)	0 to 20 years
2	Care home for older people	31 to 50	Over 18/25 (i.e. adults only)	Elderly infirm/mentally ill/dementia	24 hour	Mixed	Mixed state/local and private contributions (insurance/private)	All long term	.
3	Residential nursery	100 to 150	0-5 years	Mixed	24 hour	Local authority/municipality/county	State	All long term	.
4	Comprehensive schools, boarding schools and centres of special education which prosecuted child care	100 to 150	0 - 25	Mixed	24 hour	Local authority/municipality/county	State	All long term	.
5	Care home for children and young people with disabilities (pension)	201 +	3 into adulthood (60/65)	ID only	24 hour	Local authority/municipality/county	Mixed state/local and private contributions (insurance/private)	All long term	.
6	Care home for people with disabilities	201 +	Over 18/25 (i.e.	Mixed	24 hour	Mixed	Mixed state/local and private contributions	All long term	.

	Type of service	Size Interval (places)	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions	Age of service
	(including group homes and independent living homes)		adults only)				(insurance/private)		
7	Rehabilitation hospital	201 +	All ages (0 to death)	Mixed	24 hour	Local authority/municipality/county	State	Mixed	.
8	Mental hospital	201 +	All ages (0 to death)	MH	24 hour	Local authority/municipality/county	State	All long term	.

Data available by service type – size of service and disability groups.

Type of institution	Places total	Under 30 places	Over 30 places	Size unspecified	ID	MH	PSD	Elderly/ dementia	Mixed/ dual	Other/ unspecified
Residential nursery	450	.	450	0	.	.	.	.	450	0
Comprehensive schools, boarding schools and centres of special education which prosecuted child care	4897	108	4789	0	.	.	.	.	4897	0
Care home for children and young people with disabilities (pension)	735	.	732	3	.	.	.	.	732	3
Institutions providing professional rehabilitation services	30	30	.	0	.	.	30	.	.	0
Care home for people with disabilities (including group homes and independent living homes)	5416	42	5364	10	.	.	.	.	5416	0
Rehabilitation hospital	8268	.	775	7493	.	.	775	.	.	7493
Mental hospital	25668	.	2814	22854	.	2814	.	.	.	22854
Care home for older people	5117	906	4210	1	.	.	.	.	2735	2382
TOTALS	**50581**	**1086**	**19134**	**30361**		**2814**	**805**		**14230**	**32732**

Data available by service type – breakdown by gender and age.

Type of institution	Places total	Male	Female	Gender unspecified	Children	Younger adults	Older adults	Age unspecified
Residential nursery	450	253	174	23	427	.	.	23
Comprehensive schools, boarding schools and centres of special education which prosecuted child care	4897	2638	1822	437	3735	725	.	437
Care home for children and young people with disabilities (pension)	735	414	321	0	254	481	.	0
Institutions providing professional rehabilitation services	30	11	2	17	0	13	0	17
Care home for people with disabilities (including group homes and independent living homes)	5416	2936	2476	4	0	3894	1518	4
Rehabilitation hospital	8268	3570	4089	609	609	4186	3473	0
Mental hospital	25668	14239	10666	763	783	21809	3096	-20
Care home for older people	5117	1754	3173	190	.	.	.	5117
TOTALS	**50581**	**25815**	**22723**	**2043**	**5808**	**31108**	**8087**	**5578**

Staffing

Service type	Total staff	Managers	Educators/ day staff	Day and care staff	Clinical staff	Other (inc. ancillary)	Other (not ancillary)	Qualifications: primary school only	All other qualifications
Residential nursery	675	169	18	91	.	119	278	.	.
Comprehensive schools, boarding schools and centres of special education which prosecuted child care	3367	95	154	1540	.	152	1426	.	.
Care home for children and young people with disabilities (pension)	685	288	13	102	.	110	172	.	.
Institutions providing professional rehabilitation services	45	10	0	0	.	25	0	.	.
Care home for people with disabilities (including group homes and independent living homes)	2777	1229	65	54	.	375	1054	.	.
Rehabilitation hospital	580	271	.	.	.	45	.	264	.
Mental hospital	3263	1175	.	.	.	320	.	1166	.
Care home for older people	909	3	111	.	.	325	1047	.	.
Totals	**12301**	**3240**	**361**	**1787**		**1471**	**3977**	**1430**	

Completeness and accuracy of the data

The data presented in the template refers to the year 2005 and is based on statistical data and information from the Ministry of Social Security and Labour (Department of the Disabled), Government of the Republic of Lithuania (Department of Statistics) and Ministry of Health Care (Lithuanian Health Information Centre).

Concerning the accuracy of data we have to take into account, that there is a possibility that some institutions which where founded by NGO, different religious groups, private funds or other organisations and did not supply statistics to authorized institutions were not included in the information given. Information about health services is included bearing in mind that in rehabilitation and mental hospitals and hospices services are provided to a variety of people, not just to persons with disabilities. There is no data available how many of the people receiving services in these institutions are disabled. The differentiation between services for younger and older adults was not easy, as usually services are for both groups. Accordingly, data about age of clients, rehabilitation and mental hospitals were put under "adult services" and hospices under "older services" (although rehabilitation hospitals provide services for almost equal number of persons in both categories). Excluded from the template are 17 mental and psychosomatic units, 22 rehabilitation units, 33 hospice units in multi-profile hospitals where clients or staff can not be defined. There is no information from 6 hospices which where closed during the year 2005.

It is important to note that in some services – residential nurseries and care homes for older people – approximately 30 - 50 percent of persons had disabilities. In other institutions there were from 81 – 100 % disabled people: 81 % in comprehensive schools, boarding schools and centres of special education which prosecuted child care and provided social services as well as accommodation; 99 % in care homes for people with disabilities; 100 % in care homes for children and young people with disabilities.

The collected data covers staff numbers as well. Concerning the training of staff, data can be presented partly for direct care staff and education day-care workers. Besides statistical information there were other sources used to write this country report, as listed at the end of this chapter.
It can be summarised that the presented data is on the most complete and accurate (national) level possible for the year 2005.

Commentary: Lithuania

1. Overview

All information included in this template was given by official Lithuanian institutions for the year 2005. There is a possibility that some institutions which where founded by NGO, different religious groups, private funds or other organisations and did not supply statistics to authorized institutions were not included in the information given.

Information about health services is included bearing in mind that in rehabilitation and mental hospitals and hospices services are provided to a variety of people, not just to persons with disabilities. There is no data available how many disabled people received services in these institutions. Also it was not easy to put it in the list of services as it is not defined if these services are for adults or for older people as usually it is for both. So according to data about age of clients, rehabilitation and mental hospitals were put under "adult services" and hospice under "older services" (although rehabilitation hospitals provide Services for almost equal number of persons in both categories). Excluded from the template are 17 mental and psychosomatic units, 22 rehabilitation units, 33 hospice units in multi-profile hospitals where clients or staff can not be defined. There is no information from 6 hospices which where closed during the year 2005. It is important to note that in some services – residential nurseries and care homes for older people – accordingly 30 or 50 percent of persons were with disabilities. In other institutions there were from 81 – 100 % disabled people: 81 % in comprehensive schools, boarding schools and centres of special education which prosecuted child care and provided social services as well as accommodation; 99 % in care homes for people with disabilities; 100 % in care homes for children and young people with disabilities.

2. Political and social context

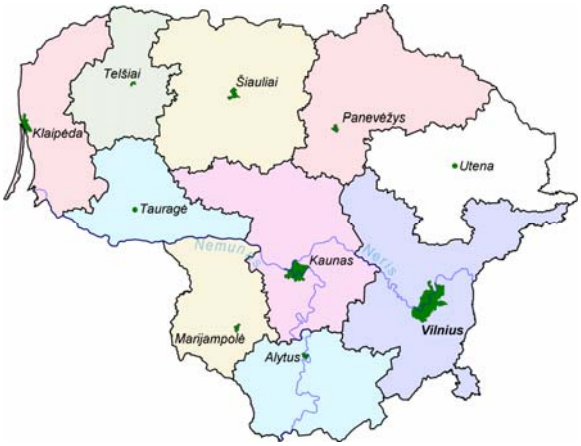
Lithuania is situated on the eastern shore of the Baltic Sea with a population at the beginning of year 2006, of 3, 403,000 people (which is 218,000 less than in the beginning of year 1995). 46.7 % of them are men and 53.3 % are women. About two thirds of Lithuanians live in the cities and one third in the countryside. The official language is Lithuanian. Lithuanian population according to nationalities (2001): Lithuanians 83.45 %; Polish 6.74 %; Russians 6.31 %; Belarusian 1.23 %; Others 2.27 %. Lithuania regained its independence on 11th March 1990. Since 01 May 2004 Lithuania has been a member of the European Union (together with Estonia, Latvia and etc) and on 29 March 2004 Lithuania joined NATO.

2.1 Government organisation and structure

The Republic of Lithuania is multiparty parliamentary democracy.

Lithuania is divided into 10 administrative units - districts (Alytus, Kaunas, Klaipeda, Marijampole, Panevezys, Siauliai, Taurage, Telsiai, Utena, Vilnius), which are divided into 60 municipalities.

Districts in Lithuania:[26]



3. Demographics

In Lithuania life expectancy is 66 years for men and 78 years for women, so women have a much higher life expectancy than men. Health expenditure as a percentage of GDP was 6.6 in 2003. Total health expenditure per capita was 754 Intl $ in 2003. Child mortality is 10 per 1000 for males and 9 per 1000 for women.

- **Challenges of emigration.** According to the data of the Department of Statistics, from 1990 to 2005 about 334 thousand Lithuanian residents had emigrated, and alone in year 2005 yet emigrated 15.6 thousand. Majority of them had emigrated to United Kingdom (4.2 thousand), Ireland (2.1 thousand), USA (2.0 thousand), Germany (1.5 thousand), Russian Federation (1.1 thousand) and Spain (0.8 thousand). It is estimated, that intensive emigration should continue at least until year 2010. According the Department of Statistics research results from 2001 to 2005 from Lithuania there had unofficially left about 70 thousand people, together with those who had declared their departure this number ups to 126 thousand people.

4. Health and Social Care System

Since regaining independence much work was done in the development of health and social care system of Lithuania.

According the law of social services the main social care services management institutions are:
1) the Ministry of Social Security and Labour
2) county governors
3) municipalities and
4) the Social Services Monitoring Department under the Ministry of Social Security and Labour.
The management of social services shall cover the planning and organisation of social services, division of competence, assessment, monitoring and control of the quality of social services at state and municipal levels.

[26] Source: http://upload.wikimedia.org/wikipedia/commons/3/32/Lietuvos_apskritys.png

Jurisdiction of the Ministry of Social Security and Labour
The Ministry of Social Security and Labour shall implement the state social services policy.

Jurisdiction of a County Governor
A county governor shall implement the state social services policy in a county:
1) establish, reorganise and liquidate regional social services establishments as well as ensure their functioning;
2) draw up and implement county social services programmes and projects.
The social services establishments whose founder or member is a county governor (hereinafter referred to as a "county governor's social services establishment") shall provide the social services which are not required by residents of every municipal territory of the county.

Jurisdiction of a Municipality
A municipality shall be in charge of the ensuring of provision of social services to residents of its territory by planning and organising social services and controlling the quality of social services of general interest and social attendance.
A municipality shall organise social services for persons (families):
1) organise the establishment of a person's (family's) need for social services;
2) according to a person's (family's) established need for social services, grant the social services to the person (family);
3) assess the financial possibilities of a person (family) to pay for social services and determine the amount to be paid by the person (family) for the social services;
4) in accordance with the procedure laid down by the legal acts regulating public procurement, purchase social services for residents of its territory;
5) where necessary, in accordance with the procedure laid down by the legal acts regulating the management, use and disposal of state-owned and municipal property, transfer the premises owned by the municipality to social services establishments on the basis of loan for use to temporarily manage and use free of charge;
6) establish, reorganise and liquidate social services establishments as well as ensure their functioning;
7) select the families which can be foster families and supervise them;
8) draw up and implement municipal social services programmes and projects.

Competence of the Social Services Monitoring Department
The Social Services Monitoring Department shall assess, monitor and control the quality of social services.

4.1 Organisation

4.1.1 Organisational Structure of Health Care

Institutions of the National Health Care System (NHCS) provide personal health care and public health care services and carry out pharmaceutical activities. They are public, budgetary and private.

Levels of NHCS activity organisation:

- Municipal;
- County;
- National.

Primary (primary health care). Primary health care services are available to the entire population of Lithuania and are oriented towards the main health problems of patients. Primary individual and public health care is organised by municipal executive institutions. First of all, a patient applies to the family physician, who decides what kind of a help s/he needs. The family physician decides when a patient needs to consult a specialist. Patient funds pay for family physician services. More is paid for health care of the rural population. Applicable legal acts establish that each individual may freely choose a primary health care institution and family physician (internist or paediatrician) that is closest to his or her place or residence or most convenient.

In Lithuania primary personal health care services are provided by outpatient personal health care institutions that have a licence to engage in primary health care activities:

- medical stations;
- primary health care centres;
- ambulatories;
- polyclinics;
- family physicians' offices;
- mental health centres.

Primary outpatient personal health care services provided in Lithuania:

- non-specialised qualified services of personal health care provided in accordance with the requirements of medical norms of the family physician and general practice and community nurses;
- dental care and treatment of personal health care;
- mental health care services (mental health care and treatment of addictive disorders of adults, children and adolescents);
- promotional primary outpatient personal health care services;
- outpatient individual health care services according to preventive programmes
- support treatment and nursing services.
- Currently the number of private primary health care institutions (PHCI) where one or more family physicians work is rapidly increasing. Private PHCI make agreements with patient funds, therefore family physician services are free of charge.
- Secondary (secondary health care)_and tertiary (tertiary health care). Municipal, county institutions and institutions subordinate to the Ministry of Health provide secondary and tertiary personal health care services which are divided into outpatient and inpatient services.
-

4.1.2 Organisational Structure of Social Care

Social services in Lithuania are divided into social services of general interest and special social services. Special social services shall be provided to a person (family) in respect where social services of general interest are insufficient to develop or to compensate for the abilities to independently care for his private (family) life and to participate in society.

The following services shall be regarded as special services:
1) social attendance;

2) social care.

Social attendance means the totality of the services aimed at providing to a person (family) complex assistance not requiring permanent attendance by specialists, e.g. a*ssistance at home, development and maintenance of social skills, temporary lodging as well as other services* shall be regarded as social attendance.

Social care means the totality of the services aimed at providing to a person (family) complex assistance requiring permanent attendance by specialists. According to duration, social care is divided into *day, short-term and long-term care*.

Social services of general interest and social attendance is provided by the social services establishments which are engaged in the provision of social services and whose social services meet the requirements set forth by legal acts for the social services of general interest and social attendance.

Social care is provided by the social services establishments which are engaged in the provision of social services, whose social care complies with social care norms and which hold a licence to provide social care.

Social care is provided by the foster families which meet the requirements set forth to them by legal acts, where the social care provided by them complies with social care norms.

4.2 Financing

4.2.1 Financing of health care

In Lithuania the Compulsory Health Insurance Fund (CHIF) is the main source of health care funding. According the Ministry of Health of the Republic of Lithuania in 2007 it is planned 3,6 billion LTL for total expenditure for health care (the increased by 26 percent). Compulsory health insurance is transacted by the Compulsory Health Insurance Council, the State Patients' Fund under the Ministry of Health and territorial patients' funds.

The Law on Health Insurance (1996) provides two types of health insurance – compulsory and additional (voluntary) insurance. Funds collected from compulsory health insurance are allocated for maintenance and improvement of the quality of health care services as well as for reimbursement of costs of rendered health care services, medicines and medical aids. The basic costs of medicines acquired for outpatient treatment are reimbursed by 100, 90, 80 and 50 per cent. Not all medicines but only those included into the list prepared by the Ministry of Health are reimbursed. Children under 7 years of age and disabled persons fewer than 18 years of age are reimbursed 90 per cent of the total basic cost of treatment at sanatoria.

For persons not covered with compulsory health insurance only the basic medical aid is ensured. Such persons should pay for other services according to the procedure established by the Ministry of Health.

The largest part of revenue of the fund's budget – 48.4 percent – made deductions from income tax of companies, institutions and organisations and natural persons

engaged in individual activities, whereas state budget payments and appropriations constituted a 24.2 percent and compulsory health insurance contributions of employees - 17.3 percent.

The amount to be paid for social services shall be established taking into consideration the type of the social services provided to a person (family) and the financial possibilities of the person (family) to pay for the social services.

4.2.2 Financing of social care

Amount to Be Paid for Special Social Services.

The law on Social services foreseen that the amount to be paid by a person for *social attendance* may not exceed 20 per cent of the person's income. Where social attendance is provided to a family, the amount to be paid may not exceed 20 per cent of the family's income. The amount to be paid by a person for *short-term social care* may not exceed 80 per cent of the person's *income*. The amount to be paid for *long-term social care* shall be established taking into consideration a person's *income and property*. The amount to be paid by an adult for long-term social care may not exceed 80 per cent of the person's income, where the value of the person's property is lower than the ratio of property value as established by a municipality of his place of residence. Where the value of an adult's property exceeds the ratio of property value as established by a municipality of his place of residence, the amount to be paid per month by the adult for long-term social care shall increase by one per cent calculated in respect of the property value exceeding the ratio. The amount to be paid for long-term social care in respect of a child with a disability may not exceed 80 per cent of his income. Social care for a child deprived of parental care and child at social risk shall be provided free of charge.

Financing of social services.

Social services are financed from funds of the state and municipal budgets, funds of social services establishments, EU structural funds, foreign foundations, sponsorship (donations), person's (family's) payments for social services and other funds. State and municipal budgets allocate the funds required for the provision of social services, implementation of social services programmes and projects, and financing of investments in the development of social services (construction, renovation, development of human resources, introduction of progressive and innovative social services, etc.).

5. Definition, eligibility and diagnosis/assessment

For a long time in Lithuania there had been concept "invalid", which is still quite alive. However, during the last decades a lot has been done in the field of the social integration of disabled people and towards formulating a non-discriminating definition of a person with disability.

After rebuilding independence, Lithuania not only started economical and governmental reforms, but also started to strengthen social policy. All the governments of rebuilt Lithuania paid a lot of attention to the affairs of people with disabilities. Yet until the acceptance of UN Standard Regulations on Equal Opportunities for the Disabled (1993) there was accepted a Law on Social Integration of the Disabled (1992) and the first National Programme of Rehabilitation for the

Disabled for Year 1992–2002 (1992), and there was established a Council on the Affairs of the Disabled near the Government of the Republic of Lithuania. These quite modern actions were followed by a preparation and acceptance of many other normative documents, including the ones that ensured a wide scope of benefits for disabled people. In 1998 there was accepted a Law on Special Education and a lot of was done in the field of children assessment: there was created a system of pedagogic – psychological agencies. And in 2004 there was prepared and accepted a Law on social Integration of the Disabled, as well as there were accepted three important after-law documents: the Order of Disability Assessment for Children, Criteria and Regulations of Workability Assessment, and Regulations of Special Needs Assessment. Yet in 2002 there was accepted the new National Programme of Social Integration of People with Disabilities for Year 2003 – 2012. Since July of 2005, Commissions of Social and Medical Expertise were reformed into Disability and Working Capacities Assessment Agencies. Other documents significant for the disabled are: the Law on Social Services (1995), the Catalogue of Social Services (2000, latest version 2006) and the Description of Principles and Order of Assessing the Need for Social Services (2004). One more important step in the field of supporting disabled people's employment is a Law on Social Enterprises (2004).

In 2005, when the Law on Social Integration came into force, there was legally acknowledged a new concept of disability, which was concentrated on person's remained capabilities, rather than the disability. This concept defines disability as "a long-term worsening of health condition, diminished participation in social life and lessened opportunities for activity, which are caused by an interaction between person's body structural or functional disorder and unfavourable environmental factors". According to the new law, person's workability is assessed not only with regards to his health condition, as it used to be, but also by taking into account the entirety of vocational and functional factors and circumstances that influence person's workability (the Ministry of Social Security and Labour, 2005). The new law abandons disability groups and assesses not person's disability, but the level of his working capacities.

This concept is related with compensation of lost workability and people's with disabilities activation. However, the definitions (Lithuanian as well) still imply a certain contradiction, which in life practice actualizes through a conflict of the two tendencies: on the one part such definition orients towards the compensation of lost income, on the other part – towards activating the integration (employment).

From this it can be seen that only the concept of disability is changing, but also there are implemented significant legal and practical steps towards improving and reforming the existing order.

The most important general legislation creating the basis for disability policy in Lithuania is:

- the Law on Equal Opportunities 2003
- the Law on the Social Integration of People with Disabilities 2004 (hereafter, Law on Social Integration 2004) *(entered into force 1 July 2005);*
- the Law on Social Integration 1998
- the Law on Mental Health Care 1995

In Lithuania exists the following procedures for the diagnosis and assessment: for working capacities and disability levels and for special needs.

- For special needs. Special needs and its level are assessed following main field of activities for people with disabilities: daily living and personal live, education, vocational fields and live of society.

The assessment of child's special education needs is implemented by the Commission of special education or (and) Pedagogical psychological office.

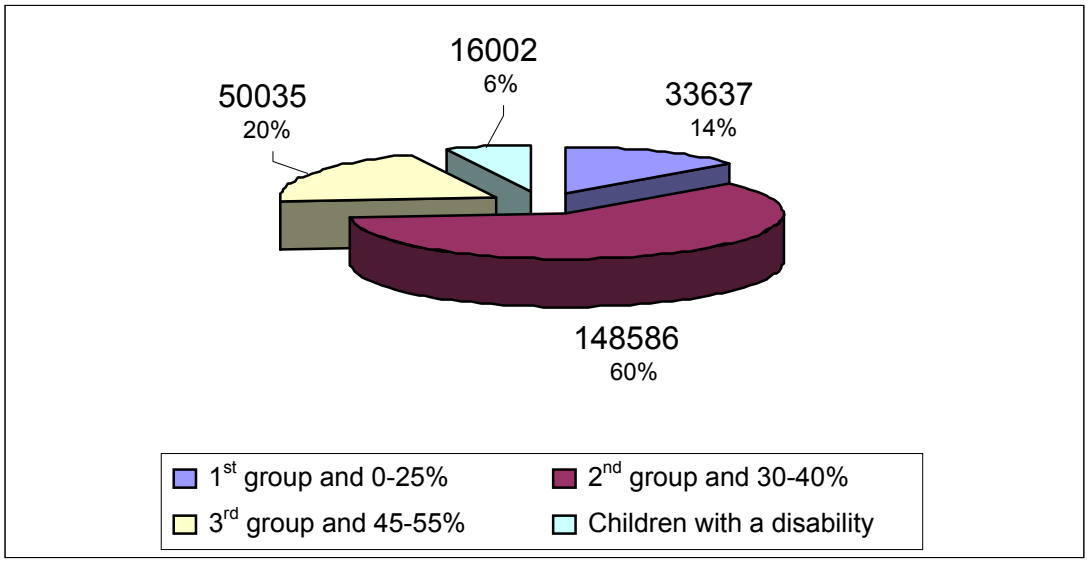
- For working capacities and disability level. Disability and Working Capacities Assessment Agency, which has 11 units in all Lithuania is responsible for assessment of level of disability, level of working capacities, need for vocational rehabilitation, work character and conditions for people with disabilities etc. The disability level can be of three types: severe, moderate and mild, and is assessed for people until 18 years old. The level of working capacities is assessed for people from 18 years old till the retirement age. The level of working capacities is estimated in intervals of 5 percents, which means if a person is estimated to have 0-25 % working capacities, s/he will be considered as not capable of working; if working capacities are 30-55 %, then a person will be considered as partially capable of working; and if work capability is 60-100 %, then a person will be considered as capable of working. The level of working capacities is assessed by the commission of specialists according the documents provided by the family physician, vocational rehabilitation and other specialists.

6. Prevalence of disability

In Lithuania it is difficult to carry out a detailed analysis of the situation of people with disabilities because of inaccurate, insufficient and untimely statistical information. One of the sources to find information about their number and distribution according to disability groups is *a list of people who are entitled to workability loss allowance*. According to the Ministry's of Social Security and Labour data, in 2005 in Lithuania there lived 248,260 people, who were receiving these allowances/pensions and about 2 thousand people who were not entitled to any workability loss/disability pension, and this makes about 7 % of all population.

The number of people with disabilities in Lithuania matches the data of UN, which claim that people with disabilities make up about 10% of the whole world's population. The picture below illustrates that the biggest part of people with disabilities comprises people with a 30-40 % workability level or 2nd group of disability, this means 148,586 people and makes up about 60 % of all the disabled. People with the most severe disabilities, whose workability level is 0-25 % or have 1st group of disability, make up 14 % of all the disabled. People with disabilities whose workability level is 45-55 % or have 3rd group of disability, in 2005 made 20 % of all the disabled, which is 50,035. Children with disabilities under 18 years old made 6 % of all the disabled, which means 16,002.

People with disabilities according to type of disability, workability level and disability level in 2005



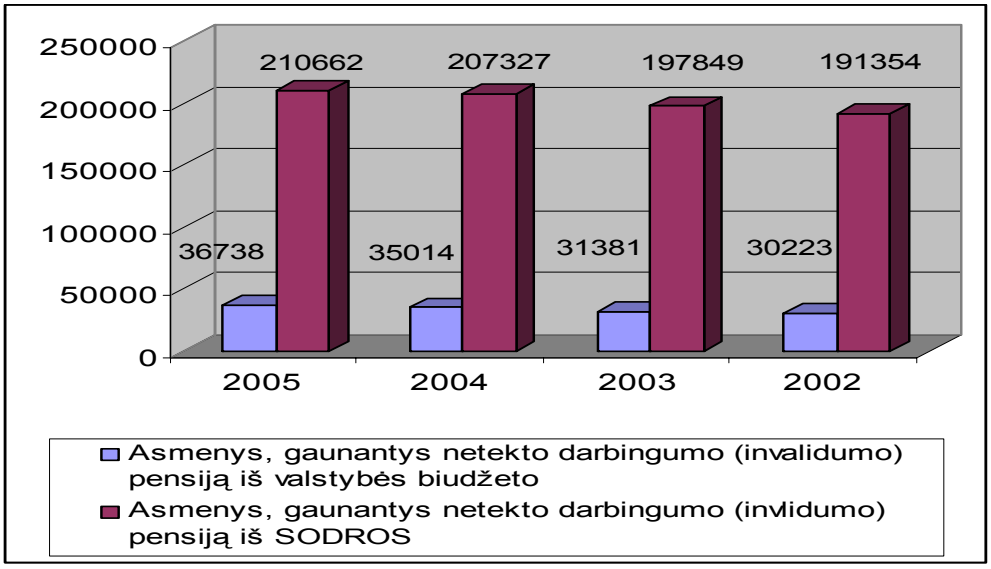
Source: Ministry of Social Security and Labour

The process of society's aging also contributes to an increasing number of people with disabilities – the more elderly people are the larger proportion they make in a total number of people with disabilities. According to the data of the Ministry of Social Security and Labour data, about 36 % of the disabled are people in pension age. People of working age who have a disability group, made 58 %, children with disabilities – about 6 % of all the disabled. This means, that only slightly more than a half of all the disabled are potential workers, who would benefit from participating in programmes for inclusion into labour market.

Often children get a disability group due to disorders of nervous system and sensation organs. Older people most often become disabled due to cardio-vascular system's diseases (in 2004 they made 29 %), skeleton-muscles diseases (19 %) and malignant tumours (13 %).

The data in the illustration below show, that a number of new disabled people is increasing only slightly. When comparing the increase in number of children with disabilities in 2005 and 2004, it can be seen that in 2005 a number of children with disabilities decreased by 0.7 %. A number of people, whose workability level is 45-55 % or have 3rd group of disability, also had increased during 2005.

Number of people receiving SODRA's and workability loss (disability) pensions in 2002 -2005.



Person's receiving workability loss (disability) pensions from state budget

Person's receiving workability loss (disability) pensions SODRA's budget

Source: Ministry of social Security and Labour

A number of people whose work capability level was 0-25 % or had 1st group of disability, had increased by 2.9 %. In 2005, the number of disabled people had increased the least, which is only 1.9 % more than in 2004, meanwhile in 2004 this number increased by 6.2 % when comparing with 2003.

When a disabled person has his workability level/disability group assessed, he becomes entitled to a workability loss (disability) pension. For those who are insured by national social insurance this pension is given from the funds of National Social Insurance Fund (further SODRA), for those who are not insured by national social insurance this pension is given from the state budget funds (support and social pensions). As the picture below shows, the changes in number of people who receive supported disability pensions are only slight, and comparing with year 2002, the number of them had increased by 6,515 people and then it made 36,738.

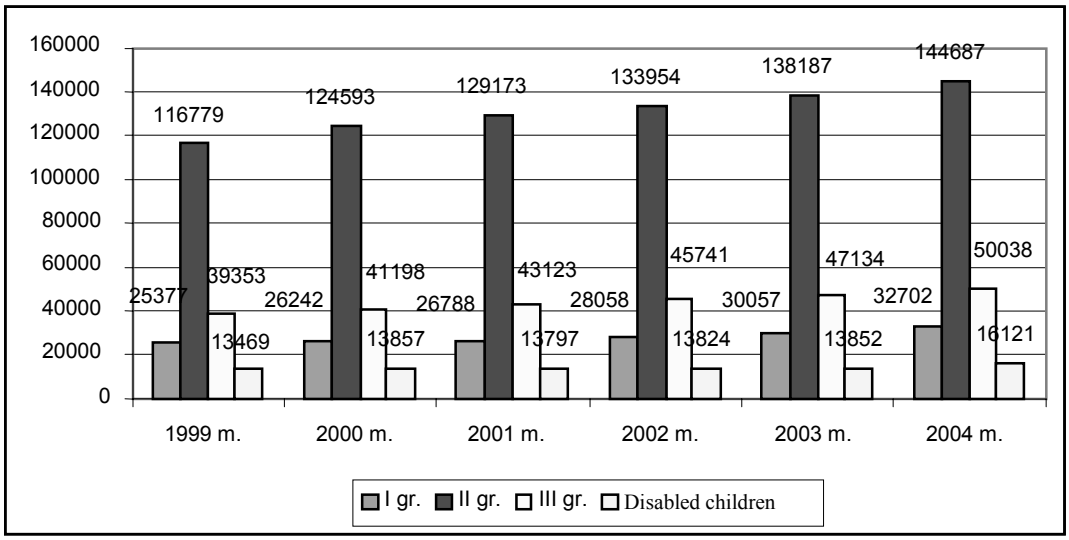
This can be due to the fact, that, according to a change in the Law on Social Integration of the Disabled, since 2004, April the 1st, children have their disability assessed not until 16, but until 18 years old. However, this cannot be said about people who receive SODRA's disability pensions. A number of those people increases yearly, when comparing year 2005 and 2002, it can be seen that in 2005 there were 19,308 people more than in 2002. An increasing number of people in this category is caused by high labour market's requirements and prolonged pension age. When comparing the data of 2005 and 2004, it can be noticed, that a number of people receiving SODRA's workability loss (disability) pensions increased only slightly, which is by 1.9 %.

The current system of financial support and benefits does not promote people with disabilities to start working and often causes a situation, when people seek to receive

the status of a person with disability in order to improve their financial situation or use the benefits. As it seen in picture above, a number of people receiving SODRA's workability loss pensions is continuously increasing and in year 2005 there were 25.6 % more of them than in 1999.

Recently has been increasing a number of people who become disabled because of various diseases. Especially rapidly grows a number of work age people who become disabled. This is not only because of deteriorated health condition, but also because of economical and social problems, like unemployment, weakly developed system of vocational rehabilitation and very developed system of social benefits and allowances. However, the main reason causing disability is severe health disorder. Diagram 6 shows, that during the time of 1999 – 2004, a number of people with disabilities had increased in each disability group. The rates of growth are rather similar – during the period from 1999 to 2004, a number of people with 1st group disability had grown by 22 %, people with 2nd group disability – by 19 % and people with 3rd disability group – by 21 %. Slightly less increased a number of children with disabilities – from 1999 to 2004 it had increased only by 16 %.

The trends of changes in number of people with disabilities according to disability groups in Lithuania during 1999-2004



Source: Ministry of social Security and Labour

According to the data of Disability and Workability Assessment Agency, in 2005, 22,3 thousand people in their work age were for the first time acknowledged as disabled. In comparison with 2004, in 2005 there were 5 % more of these people and for 1000 people of work age there were 10 people with disabilities. Women made 47 % of all the people who were acknowledged as disabled for the first time. Elderly people most often become disabled because of cardio-vascular system's disorders (in 2004 – 29 %), skeleton-muscles system's disorders (19 %) and malignant tumours (13 %).

There is an obvious trend of growing number of disabled people, which grows not only because of growing number of ill people, but also because of social and economical problems. And this means that it is more comfortable to be a disabled person, who receives allowances, benefits and support, rather than to work, because

work prevents from a lot of disability benefits and does not provide sufficient income for living. In this case, when thinking about development of disabled people's participation in labour market, it is important to think of ways how work would provide more than what a person gets from being unemployed.

7. Residential Services for people with a disability

7.1 Overview

Over the last decades many changes were implemented in social and health care. By policy makers it was understood that state care institutions are too large and do not conform to the modern concept of social care, that it operate in remote areas and some of them are established in old and unsuitable buildings whose renovation would require large investments. That's why it was aimed to reduce the number of institutional services by assessing the actual need and providing home help or community-based (day care) services which are more effective, less expensive and ensure greater independence for people.

The majority of state care institutions are overcrowded, they have up to 550 residents and the living premises and living conditions often do not meet basic safety and health requirements. This is why no new county care institutions are planned and the existing ones are being restructured by reducing the number of residents and improving their living conditions.

The similar changes are implemented in health care sector. As there are growing number of people with mental problems the aim of health care ministry is to develop the number of flexible ambulatory services for children and adults with mental health problems. It is planned gradually to integrate psychiatric residential services to general profile hospitals closing specialised hospitals.

7.2 Services for children with a disability

It is important to note that child with disabilities can be person until 21 years old. In Lithuania there are 3 types of institutions providing residential services for children with disabilities:

1. Care home for children and young people with disabilities (pension). There are 4 such pensions in Lithuania in which children and youth with mainly intellectual disabilities get services. The number of places in each varies from 57 to 255. Typical number of places is around 210-255 (applies to 3 institutions, in the remaining one -57 places).
2. Residential nursery. There are 5 residential nurseries in Lithuania. The number of places in each varies from 65 to 105. The target group of these institutions are children with different health and development problems. Typical number of places of service is around 100-105 (applies to 3 institutions out of 5, in the rest - 65 and 80).
3. Comprehensive schools, boarding schools and centres of special education which implement child care and provide social services as well as accommodation. There are 50 such type of institutions in Lithuania. It provides services for children with hearing, aphasia, vision, intellectual, physical/motion and other disorders. The number of places in each varies from 9 *to* 184. In 29 institutions the number of places is <100, in the rest 21 - from 101 to 184.

In all earlier mentioned institutions there are provided 24 hours care for children. Mainly these institutions are financed by state budget, only care home for children and young people with disabilities are partly paid by individuals.

The table below shows that there was the decrease of need for children and youth settlement in care home since 2001. As well the percentage of fulfilled settlement was decreasing.

The need for residential care services for people with disabilities

Applications for children and youth settlement to care home for people with disabilities	2001	2002	2003	2004	2005
Received	62	42	41	24	37
Fulfilled	60	41	37	23	30
% of fulfilled applications	97	98	90	96	81
Applications for adults settlement to care home for people with disabilities					
Received	...	870	939	891	813
Fulfilled	...	502	532	536	499
% of fulfilled applications	...	58	57	60	61

Source: Department of Statistics

7.3 Services for younger adults with a disability

In Lithuania there are 4 types of institutions providing residential services for adult people with disabilities:

1. Care home for people with disabilities (including group homes and independent living homes). There are 27 such institutions in Lithuania. In 6 of it the number of places is below 100, in 8 - from 101 to 200, in 13 - from 201 to 500, in 1 - over 500. The target group – people with different problems - intellectual, physical disabilities and mental health problems.
2. Rehabilitation hospital. There are 4 such institutions in Lithuania. In 1 of it the number of places is - from 51 to 100 (70 places), in 1 - from 101 to 200 (090 paces), in 2 of them - from 201 to 500 (215 and 300 places). Different physical disabilities and mental/behavioural disorders (in one hospital).
3. Mental hospital. There are 11 such institutions in Lithuania. In 1 of it the number of places is from 31 to 50, in 2 - from 51 to 100, in 2 - from 101 to 200, in 5 - from 201 to 500, in 1 - from 501 to 1000. They provide care for persons with mental health problems.
4. Institutions providing vocational rehabilitation services**.** There is 1 vocational rehabilitation centre in Lithuania. Number of places - 30. The services are provided to people with physical disabilities (movement and visual impairments). This kind of service started in 2005 in Lithuania, in 2006 there were already 5 institutions providing such kind of service.

From the table above it is seen that since 2001 it is relatively stable demand for residential services.

7.4 Services for older adults

In Lithuania there are 2 types of residential institutions meant for elderly people with disabilities:

1. Care home for older people. There are 97 such institutions in Lithuania. In 3 of it the number of places is below 10, in 41 - from 10 to 30, in 30 - from 31 to 50, in 11 - from 51 to 100, in 6 - from 101 to 200, in 6 - from 201 to 500. The target group - elderly people with physical (71 %), mental and intellectual disabilities, different health problems, who need permanent care and nursing and can not live independently.
2. Hospice. There are 59 such institutions in Lithuania. In 25 of it the number of places is from 10 to 30, in 20 - from 31 to 50, in 9 - from 51 to 100, in 4 - from 101 to 200, in 1 - 286 places. The institutions provide services for elderly people with long term health problems.

All these institutions provide long term services.

7.5 People with mental health problems

All earlier mentioned institutions providing services for adult people are meant to people with mental services as well. Except vocational rehabilitation centre, this provides services only for people with physical disabilities.

8. Other relevant information on residential services

Private provision: Traditionally health care and social care services are provided by state. NGOs are actively participating in the development of services which are community-orientated. During last decade the number of private health care centres was growing. It is important that the staff working in private sector often additionally work in the institutions funded by the state.

9. Staffing

In Lithuania requirements for health and social care professionals are regulated by law. Four universities (Kaunas University of Medicine, Vilnius University, Klaipėda University and Lithuanian Academy of Physical Education) and six colleges prepare health care and pharmacy specialists in Lithuania. University medicine studies last for 6 years, odontology and pharmacy studies for five years and public health, nursing and rehabilitation studies - for 4 years. Duration of residency in medicine studies varies depending on specialty from 3 to 6 years and in odontology studies - from 3 to 4 years. Master‘s programme in public health, nursing and rehabilitation studies last for two years. PhD studies last for 4 years. Non-university studies take from 2 to 3.5 years, depending on a study programme. In Lithuania 10 universities and colleges prepare social workers. Approximately 670 specialists per year graduate from these educational institutions. Bachelor’s programme lasts for four years and Master‘s programme for two years in universities. PhD studies last for four years. In studie’s programmes there possibilities to specialise in the field of work with youth, community social work and etc. Specialists working in residential sector should have relevant education, qualification or licence to work in residential care institutions. The order of Minister of Social Security and Labour determines the qualification requirements for social workers and their assistants. Typically specialists working directly with people with disabilities should have at least secondary school education. Having a higher education or university diploma is an advantage. There is requirement that day care workers it is required to have at least higher education.

Usually education staff has university diploma. Analogously the order of Minister of Health Care determines the requirements for qualification of medical staff. In health services (rehabilitation, mental hospitals and hospices) doctors and odontologists have university diploma, other clinical staff has higher education or high school diploma in medical education.

10. Issues

10.1 Ethnicity

Although in Lithuania there live people with different nationalities, mainly all residential services are provided in Lithuanian language. It is common that specialists speak Russian language, so often there are no acute problems for Russian speaking people. Concerning secondary schools there are special schools for Russian and Polish people where main language in Russian or Polish.

10.2 Gender

The estimated number of women in residential welfare services for elderly people is very high. This can be explained by the fact that in Lithuania the gap in average life expectancy between men and women is about 12 years. Women tend to live to old age, very often they remain single towards the end of their life and followed by some health problem it is often the cause why they are placed into residential care.

10.3 Age

It is difficult to speak about the age of people staying in residential institutions because of the lack of accurate statistics. There is no statistics about the places in institutions for certain age groups as usually there is one age group category which applies for those who need particular residential services. Children in Lithuania are considered from 0 to 18 but children with disabilities can remain at comprehensive school (centre of special education) and receive education services until they are 21.

10.4 Regional/geography

Every county and almost each municipality in Lithuania has service providers. But in some regions the network of residential institutions is unevenly developed. Usually a person with disability who needs 24-hour-care goes where a care home is and where a free place exists. This can be far away from their home or family.

11. Acknowledgements

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12. Information sources on disability used to compile the template and commentary, including people who were interviewed

Several letters and telephone call with Mrs. Rasa Kalinauskaite, Department of the Affairs of the Disabled under the Ministry of Social Security and Labour

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Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

Luxembourg

Carole Warnier[1] and Hilde De Keyser[2]

[1] Ministère de la Famille et de l'Intégration, Luxembourg
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Summary of the available data

The tables below summarise the services by provider organisations in Luxembourg.

Description of service types

Service	Size interval	Age group	Disability group served	Level of support provided	Type of provider	Funder	Length of admission	Age of service
Autisme Luxembourg a.s.b.l.	201 places +	0 to 65 years	ASD	24 hour	Voluntary/not-for-profit (over 95%)	Mixed (any)	Mainly long term	21 to 50 years
Päerd's atelier	6 to 10 places	Over 18/25 (i.e. adults only)	ID only	Mixed between units within same type - some provide 24 hr, some less than 10 hrs	Voluntary/not-for-profit (over 95%)	Mixed (any)	Mainly long term	0 to 20 years
CHNP Handicap Mental(Etablissement d'utilité publique)	11 to 30 places	All ages	Mixed ID with PD, SD, MH,Beh and other	24 hour	Voluntary/not-for-profit (over 95%)	Mixed (any)	Mainly long term	0 to 20 years
Fondation Autisme Luxembourg	201 places +	14 + to adulthood (60/65 years)	Beh/Emotional/Social/Learning Difficulties	24 hour	.	Mixed (any)	Mainly long term	.
Association pour la création de foyers pour jeunes a.s.b.l.	6 to 10 places	Over 18/25 (i.e. adults only)	Mixed	24 hour	Voluntary/not-for-profit (over 95%)	Mixed (any)	Mainly long term	100+
Yolande a.s.b.l.	6 to 10 places	0 to 65 years	ASD	24 hour	Voluntary/not-for-profit (over 95%)	Mixed (any)	Mainly long term	0 to 20 years
Eislëcker Heem a.s.b.l	11 to 30 places	0 to 65 years	ID only	Night and weekend support only - people out during day	Voluntary/not-for-profit (over 95%)	Mixed (any)	Mainly long term	21 to 50 years
Fondation A.P.E.M.H.	6 to 10 places	All ages (0 to death)	Mixed ID with PD, SD, MH,Beh and other	Mixed between units within same type - some provide 24 hr, some less than 10 hrs	Voluntary/not-for-profit (over 95%)	Mixed (any)	Mainly long term	21 to 50 years
Fondation Kraïzbierg	6 to 10 places	0 to 65 years	ID only	Night and weekend support only - people out during day	Voluntary/not-for-profit (over 95%)	Mixed (any)	Mainly long term	21 to 50 years
Ligue HMC a.s.b.l.	6 to 10 places	All ages (0 to death)	Mixed ID with PD, SD, MH,Beh and	Mixed between units within same type - some provide 24	Voluntary/not-for-profit (over 95%)	Mixed (any)	Mainly long term	0 to 20 years

Service	Size interval	Age group	Disability group served	Level of support provided	Type of provider	Funder	Length of admission	Age of service
			other	hr, some less than 10 hrs				
Fondation du Tricentenaire	11 to 30 places	All ages (0 to death)	PD and Sensory/other	Mixed between units within same type - some provide 24 hr, some less than 10 hrs	Voluntary/not-for-profit (over 95%)	Mixed (any)	Mainly long term	0 to 20 years

Data available by service type – breakdown by size

NB. No breakdown available by disability.

Type of service	Places total	Under 30 places	Over 30 places
Autisme Luxembourg a.s.b.l.	8	8	.
Päerd's atelier	8	8	.
CHNP Handicap Mental(Etablissement d'utilité publique)	64	12	52
Fondation Autisme Luxembourg	20	20	.
Association pour la création de foyers pour jeunes a.s.b.l.	13	13	.
Yolande a.s.b.l.	181	17	164
Eislëcker Heem a.s.b.l	14	14	.
Fondation A.P.E.M.H.	159	159	.
Fondation Kraïzbierg	119	79	40
Ligue HMC a.s.b.l.	46	46	.
Fondation du Tricentenaire	72	34	38
Total	**704**	**410**	**294**

Data available by service type – breakdown by gender and age

Type of service	Places total	Male	Female	Children	Younger adults	Older adults	Age unspecified
Autisme Luxembourg a.s.b.l.	8	4	4	1	7	0	0
Päerd's atelier	8	8	0	7	1	0	0
CHNP Handicap Mental(Etablissement d'utilité publique)	64	41	23	0	61	3	0
Fondation Autisme Luxembourg	20	13	7	4	16	0	0
Association pour la création de foyers pour jeunes a.s.b.l.	13	10	3	1	12	0	0
Yolande a.s.b.l.	181	92	89	18	121	41	1
Eislëcker Heem a.s.b.l	14	8	6	1	13	0	0
Fondation A.P.E.M.H.	159	85	74	3	126	30	0
Fondation Kraïzbierg	119	67	52	8	97	14	0
Ligue HMC a.s.b.l.	46	25	21	0	42	4	0
Fondation du Tricentenaire	72	42	30	5	62	5	0
Total	**704**	**395**	**309**	**48**	**558**	**97**	**1**

Number of Staff

Numbers given are averages and have been rounded to the nearest whole number.

Type of service	Total staff	Number of care staff/nurses/might include teachers in boarding school	Number of managers or other administrative staff (not care staff)	Number of educators/day staff	Day and care staff (no distinction made)	Number of clinical staff (Drs, therapists, psychologists, etc.)	Number of other staff (mainly ancillary staff)
Autisme Luxembourg a.s.b.l.	7	.	0	.	6	0	0
Päerd's atelier	.	.	.	.	.	.	.
CHNP Handicap Mental(Etablissement d'utilité publique)	.	.	.	.	.	.	.
Fondation Autisme Luxembourg	36	.	2	.	17	6	11
Association pour la création de foyers pour jeunes a.s.b.l.	6	.	1	.	5	0	0.5
Yolande a.s.b.l.	148	.	2	.	76	41	29
Eislëcker Heem a.s.b.l	9	.	0	.	7	0	2
Fondation A.P.E.M.H.	131	.	3	.	96	14	18
Fondation Kraïzbierg	134	.	6	.	69	42	17
Ligue HMC a.s.b.l.	22	.	1	.	18	0	3
Fondation du Tricentenaire	70	.	3	.	32	21	15
Total	**563**	**.**	**18**	**.**	**326**	**124**	**96**

Type of service	Total staff	Staff with only primary school qualification or less	Staff with secondary school qualification as highest qualification	Staff with higher qualification	Staff with university degree	Unspecified
Autisme Luxembourg a.s.b.l.	7	0	0	4	2	1
Päerd's atelier	.	.	.	.	.	
CHNP Handicap Mental(Etablissement d'utilité publique)	.	.	.	.	.	
Fondation Autisme Luxembourg	36	0	0	12	9	16
Association pour la création de foyers pour jeunes a.s.b.l.	6	0	0	3	2	2
Yolande a.s.b.l.	148	0	0	56	33	
Eislëcker Heem a.s.b.l	9	0	0	5	2	2
Fondation A.P.E.M.H.	131	0	0	69	34	29
Fondation Kraïzbierg	134	0	0	67	26	42
Ligue HMC a.s.b.l.	22	0	0	9	9	
Fondation du Tricentenaire	70	0	0	33	18	20
Total	**561**	**0**	**0**	**255**	**134**	**172**

Completeness and accuracy of the data

Service descriptions

Since in Luxembourg no specific services exist for disabled children, teenagers, adults or elder people, and the population is usually mixed, only set of services were identified. The data on service descriptions is almost complete, only for *Päerd's atelier* is information lacking with regard to who provides the service and the typical age of the service.

Size

As far as size is concerned the data are complete

Disability type:

Breakdown of places by disability group is not available.

Age and Gender:

The data concerning age and concerning gender are complete

Staff numbers:

For *paerd's atelier* and *CHNP Handicap mental*, no information is available.

Staff training:

For *paerd's atelier* and *CHNP Handicap mental*, no information is available.

Commentary: Luxembourg

1. Overview

The Grand Duchy of Luxembourg (or Luxemburg) is a small country in the centre of Europe, bordered by France, Germany and Belgium. It is one of the countries sometimes called the Benelux countries and it was one of the founding members of the EU and Nato. Luxembourg is a democracy with a constitutional monarchy, ruled by the Grand Duke (http://en.wikipedia.org/wiki/Luxembourg).

2 Political and social context

2.1 Government organisation and structure

The country is led by the Grand Duke/Duchess and the Cabinet. Members are elected by the people to the Chamber of Deputies and the Prime Minister and Deputy Prime Minister are appointed by the Grand duke from the Chamber of Deputies. They remain responsible for the Chamber and also make up the Cabinet along with several other ministers.

2.2 Disability relevant policy

When it comes to the policy for disabled people within the national government, the **Ministry for the Family and Integration** plays the role of coordinator.

The Ministry for the Family and Integration is responsible for the disabled person policy, the Higher Council for Disabled People, the day and night care services, the training, information, consultation, work, re-education, early assistance and home care for disabled people, for accessibility and for the disabled worker service.

The services that come directly under the responsibility of the Ministry for the Family and for Integration are managed by **private associations** who offer, in principle, several types of activities to a well determined population (see point above).
As regards the care structures for disabled people, the supply of places is determined in line with the demand.

The special education service of the **Ministry for National Education and Vocational Training** is in charge of the organisation of the education of special needs children.
According to **article 1** of the **law of 14 March 1973 creating institutes and services of special education**,

« The State ensures that any child of compulsory school age and who due to his mental, behavioural, sensorial or motor specificities cannot follow ordinary or special schooling and who has special educational needs receives, either the appropriate instruction in a special education centre or institute or the help and individualised support of a special education service within the framework of a preschool education class or a primary education class. The minister for national education is responsible for the educational aspect, the minister for public health for the medical aspect and the minister for the family for the family and social aspect of the special education.

The **Ministry for Transport** is in charge of all questions relating to the transport of the children schooled in special education establishments, centres for professional propedeutic and sheltered workshops.

The **Ministry for Health** is responsible for the re-education services, of people affected by a mental illness and dependence (drug addiction) : homes, work structures, services under contract and home care services.

The **Ministry for Social Security** is in charge of insurance.

The **Ministry for Labour and Employment** is competent for the management of the sheltered workshop structures and for certain questions linked to the status of the disabled worker. The Disabled Assessment and Resettlement Panel of the Department for Employment guides disabled workers towards the ordinary job market or towards the sheltered workshops.

For further information about the various ministries, please consult the Web sites :
www.gouvernement.lu
www.etat.lu

3. Demographics

The total population of the Grand Duchy of Luxembourg stands at 459 500 inhabitants, 76 600 of whom live in the capital. More than 181 800 foreigners represent 29.6% of the total population. (Source : Statec, January 2006). The national language is Luxembourgish and the administrative languages are French, German and Luxembourgish.

4. Health and Social Care System

The concept of « social security » covers a range of schemes designed to redress the consequences of various events described as “social risks”. These schemes are reflected in social security policies, which, to achieve their aims, take concrete form in legally structured social security systems.

The social security policies and systems have precise objectives, namely that of protecting to a sufficient degree, any person against a certain number of eventualities that are likely to reduce or put a stop to their activity, incur additional costs, leave them in need as a survivor or reduce them to a state of dependence.

The institutions that make up the country’s social protection system can be divided up into seven types of bodies according to the nature of the risk or of the need covered :

- the health insurance bodies,
- the dependence insurance bodies,
- the pension insurance bodies,
- the accident insurance bodies,
- the national family benefits fund,
- the employment bodies
- the social assistance bodies.

We can identify three sources of funding of benefits : the public powers, the employers and the protected people.
The levies to cover expenses are collected according to two types of mechanisms: charges and contributions of the public authorities. The charges are mainly payable by the employers and the protected people. They are based on professional income and are calculated via a uniform charge rate, regardless of the individual situation of those concerned (age, sex, family situation, health). The contribution of the public powers is mainly based on general tax revenue.

4.1 Organisation

As a general rule, the providers of assistance and care are :

- associations,
- foundations
- or public establishments.

They are financed by

- the participation of users
- and the support of various branches of social security subsidies/state aids.

According to the respective fields of action the cases come under the competence of the Ministry for the Family and Integration, Women, Youth, the Ministry of Health or the Ministry for Labour and Employment.

The activities proposed by the managers of structures generally come under the law of 8 September 1998 governing relations between the State and the bodies working in the social, family and therapeutic fields (ASFT),

According to **article 1** of the **law of 8 September 1998 governing relations between the State and the bodies working in the social, family and therapeutic fields (ASFT)**,

« No one may, whether as a principal or accessory and in return for payment, undertake or exercise in a non-occasional manner any of the activities listed below in the social, socio-educational, medico-social or therapeutic field, unless they hold written ***approval****, in line with their respective competencies, either from the Minister for the Family, or the Minister for Women, or from the Minister for Youth or from the Minister for Health. The activities subject to approval, as long as they are not the subject of another legal provision, are the following in favour of all categories of people :*

- *the day and/or night-time care of over three people at the same time ;*
- *the provision of consultation services, aid, care, assistance, guidance, social training, animation or professional guidance.*

The approval is obligatory both for natural persons and for legal entities under private and public law.
A Grand-Ducal regulation may stipulate the activities listed under paragraph 1, it may provide for a joint approval of the aforementioned ministers for the activities that come under the competence of more than one minister ».

According to **article 3** of the **grand ducal regulation of 23 April 2004 relating to the governmental approval to be granted to managers of services for disabled people** and enforcing the law of 8 September 1998 regulating relations between the State and bodies working in the social, family and therapeutic fields,

« The types of services in question (...) are the following :

Early childhood assistance service
It targets all services that offer early treatment for young children with special needs as well as support for the family concerned. The aim is to limit the effects of a deficiency or offset late development through functional re-education, educational stimulation, socio-educational guidance and support for the family.

Home care service
It targets any service that offers, within the family environment, care and/or material and psychological assistance to disabled people and their families. The aim is to promote the home care of disabled people.

Homes
This targets any service that offers accommodation and/or multidisciplinary professional care to more than three people suffering from a disability. The aim is to ensure that disable people receive professional care according to a global and coherent approach by supplying them, on the one hand, with assistance and care within the meaning of the law of 19 June 1998 introducing dependency insurance and, on the other hand, a socio-educational care adapted to their needs and individual expectations.

Training service
This targets any service that offers vocational training to over thee disabled people who have passed compulsory school age. The aim is to give them general and/or professional knowledge preparing them for a subsequent working life.

Employment service or « sheltered workshop »
This targets any service, created and managed for a social and economic body, that allows people registered as disabled workers and guided by the disabled assessment and resettlement panel towards the sheltered work environment to exercise within an economic production unit a salaried professional activity in conditions adapted to their needs and expectations. The employment service or « sheltered workshop » employs disabled workers who are guided by the aforementioned panel towards the sheltered working environment and who, due to their limited working capacities, are not capable at the time of their professional assessment or reassessment, of coping with the demands and constraints of the ordinary labour market.

The purpose of the employment service or « sheltered workshop » is the following :
- *to offer disabled people a valorisation of their skills, continuous training, adapted jobs and working conditions and occupational insertion measures to the ordinary job market ;*
- *to promote the access of disabled workers to the ordinary job market;*
- *to promote the access of disabled workers to the ordinary job market and organise their professional support and monitoring;*
- *to organise socio-educational and therapeutic activities in favour of disabled workers who, due to their invalidity and/or their age, cannot be continuously employed for production activities;*
- *to set up a production at market value and a commercial approach that allows its marketing.*

Day activities service
This targets any service that offers day activities to over three people suffering from a severe disability or a multiple disability. In addition to the allowances and care within the meaning of the law of 19 June 1998 introducing dependency insurance, the service ensures socio-educational and therapeutic support through varied activities that are adapted to the needs and individual expectations of disabled people. The service offers day care to disabled people who, because of their deficiency and/or their age, cannot continuously follow a professional training or a job. The aim is to provide professional and multidisciplinary care to disabled people and to support the families caring for a disabled person.

Information, consultation and meeting service
This targets any service that offers information, consultation, animation and meeting services to disabled people and their families. The aim is to promote the full participation of the disabled people and to prevent their isolation and their social exclusion. "

4.2 Financing

The managing bodies that have signed a **contract** with the Ministry for the Family and for Integration receive financial support from the Ministry of the Family and Integration.

The **law of 8 September 1998 regulating relations between the State and the bodies working in the social, family and therapeutic fields** lays down in its **article 11** :

*« The **State** is authorised to grant **financial support** for the exercise of the activities laid down in article 1, as well as for the related investments. The financial support can take the form of a **subsidy or** a **financial participation** which is granted on the condition :*

a. that the beneficiary accepts to sign with the State a contract that determines :
   1. the benefits to be granted and the terms and conditions of financial management to be observed by the beneficiary ;
   2. the type of financial participation of the State ;
   3. the methods of information, control and sanction open to the State in relation to the duties of the beneficiary defined under 1)
   4. the terms and conditions of cooperation between the contracting parties, without however affecting management, which is the responsibility of the beneficiary ;
b. that the beneficiary keeps the accounts according to the requirements of the State ;
c. that the projected activities meet effective needs observed by the Government in council.

For the care homes/day care centres, there is another source of funding :
Dependence insurance applies for situations of dependence recognised by it. It covers all or part of the pension cost defined within the framework of an agreement between the State and the manager. If necessary and according to individual cases, the State ensures, through a bilateral contract, a daily participation per user cared for, whose amount is invoiced according to the criteria defined in the contract.
For certain other services, there may or may not be a participation in the costs by the users, otherwise the costs are covered within the framework of a bilateral agreement (contract) between the State and the managers concerned.

5. Definition, eligibility and diagnosis/assessment

In Luxembourg, the most commonly used term is « personnes handicapées » (disabled people). This term refers to people suffering from a physical, mental, sensorial or/and psychic deficiency.
As far as mental disability is concerned, we make a distinction between three degrees of disability: light, medium and severe/heavy mental disability.
Another term used in Luxembourg to talk of a "mental disability" is "intellectual deficiency".

To determine the presence of a disability in a given person, doctors often follow the criteria of the international statistical classification of diseases and related health problems – the ICD.

In Luxembourg, a distinction is made between:
- tests during pregnancy,
- tests during infancy,
- diagnosis centres.

Tests during pregnancy :
In Luxembourg, pregnant women are monitored during their pregnancy by a doctor who is a specialist in gynaecology-obstetrics. These medical visits make it possible to inform the pregnant women about the eventual risks to be avoided and to establish an early diagnosis of any prenatal and perinatal anomaly.
During the pregnancy, a minimum of 5 medical examinations must be performed by a doctor specialised in gynaecology-obstetrics as well as a dental examination. Failure to respect these conditions lead to the loss of the maternity benefits (prenatal benefit, birth benefit and postnatal benefit).

There are various methods to analyse the risks of Down's Syndrome or other diseases. Amniocentesis is recommended to women over the age of 35 and for other cases of "high-risk pregnancies".
The triple test (blood test) performed around the 16th week of pregnancy, gives indications that will make it possible to identify high-risk pregnancies, those with a greater risk of giving birth to a baby suffering from Down's Syndrome, trisonomy 18 or spina bifida.

Tests during infancy :
After the birth of a child, several medical tests are performed to determine the health and development of the child.

- To be eligible for the postnatal benefit, the parent or any other person who has custody must submit the child to two perinatal examinations and four subsequent examinations up until the age of two years. These examinations must be performed either by a paediatrician or by a doctor specialised in internal medicine, or by a general practitioner. The perinatal examinations may only be performed by a paediatrician.
- The early detection, the re-education and the rehabilitation of the visual function by the Orthoptic and Pleoptic Service : systematic detection at national level allowing a continuous monitoring of toddlers and school aged children.

The detection, prevention, treatment and correction of problems that may arise in the field of communication by the Audiophonological services : in the field of neonatal audiometric detection, a screening by acoustic oto-emission (OEA) is available to all babies born in Luxembourg within 48 hours of birth. A series of audiometric detection examinations are offered to children aged two and a half years within the framework of the "BILAN 30", and to 5 year old children within the framework of school audiometry testing. The "BILAN 30" detection is designed for children aged 30 months and sets out to detect communication problems, pathological lateness in language and spoken development and hearing problems.

The early childhood support services and the diagnosis centres.

Often a disability is diagnosed and evaluated in one of the many health services. The timing of diagnosis always depends on the type of disability.

If the child is showing signs of developmental problems, he is guided towards an early childhood support service such as :

- The SIPO : this service offers assistance to children between the ages of 0 and 6 who show signs of developmental problems, who have a disability or behavioural problems, and provides advice to the families and entourage. This service carries out evaluations and development diagnoses.
- Hëllef fir de Puppelchen : this service offers physiotherapy, ergotherapy, early education, orthophony, medical and psychological consultations for children between the ages of 0 and 4 who are late developers, who have behavioural problems, a disability or an orthopaedic problem.
- Le Service de Rééducation Précoce (The Early Re-education Service) : the mission of this service is to detect and re-educate infants and small children (aged between 0 and 4) who suffer from the following problem(s) : motor problems ; sensorial problems : learning and fine motricity problems, swallowing, communication and language problems, behavioural problems, late development. It also organises the monitoring of the cognition, neuromotricity and psychosocial behaviour of children that were born prematurely.

The diagnosis centres :

- The Service Médico Thérapeutique d'Evaluation et de Coordination du Centre Hospitalier Luxembourg (CHL) : This service is the only one in the country to ensure a global and continuous approach to the medical treatment and re-education needs of the disabled. It is aimed at children as well as adults suffering from a confirmed disability or significant developmental problems. The medical team ensures continuity through the various life stages, starting with the neonatal period, then through early re-education and schooling (ordinary or special) and finally in the socioprofessional integration centres and the special care centres. The medical activity includes functional, reeducational, paedopsychiatric and psychotherapeutic diagnosis. The aim then is to determine the treatments to be implemented, to evaluate and supervise the re-education, to adapt the technical aids, etc.
  http://www.chl.lu/html/maternite/mat/eval_reduc_fonct.html

- The paedopsychiatric service of the CHL : The pluridisciplinary paedopsychiatric team of the CHL proposes an evaluation of the child's development when there is a suspicion of autism after being alerted by the parents themselves or by professionals from the medico-social or educational network. A diagnosis using standardised observation and interview tools makes it possible to evaluate the difficulties, skills and relational needs of the child in order to determine the appropriate treatment. An individualised treatment plan includes behavioural, exchange and development treatment and media treatments, individual or in a group, for the child combined with family guidance. This service detects 12 to 15 new cases of children showing signs of autism and serious communication and relational troubles every year.

- The Fondation Autisme Luxembourg proposes diagnosis evaluations for all people with suspected autism at the request of the person themselves, of their family or their guardian. The objectives of the procedure are the following: to determine whether the evaluated person is suffering from autism and if necessary, with what degree of severity; to draw up a skills assessment of the person; to offer concrete and individualised educational channels and to help the parents to set them up as quickly as possible; to carry out a medical examination; to meet the various people working with the person in order to adapt and coordinate as effectively as possible the treatment. For those who so wish, the Foundation organises reassessments of the skills of the person on an annual basis in order to track their progress and readjust the support programme set up.
  http://www.fal.lu/

- Le Rehazenter : The aim of the centre is to create and manage a specialised hospital establishment in charge of providing stationary and ambulatory care in the treatment, functional re-education and rehabilitation of victims of accidents.
  http://www.reha.lu/

6.3 Prevalence

There are no figures/statistics available relating to the total number of disabled people in Luxembourg.

- During the school year 2006/2007, 375 pupils were educated in a Special Education Centre, the « Centre d'éducation différenciée » (CED) which accepts children with special needs, 146 pupils were enrolled in a specialised institute and 89 pupils followed a training course in a public professional propedeutic centre (CPP).
  In total, **610** pupils with special needs were enrolled in a CED, CPP or specialised institute in 2006/2007.
  Furthermore, **800** special needs pupils were enrolled in a nursery, primary or post primary school and were followed by the peripatetic remedial teaching service (the Service ré-éducatif ambulatoire),

- The law of 12 September 2003 relating to disabled people introduced an allowance in favour of disabled people whose working capacity is affected by

at least 30%. People who are registered as disabled workers receive an allowance for disabled workers. People who are registered as severely disabled are eligible for an allowance for severely disabled people.

On 31 December 2006, **4562** people had been registered as disabled workers since the entry into force of the amended law of 12 November 1991 relating to disabled workers.
3175 people with a physical disability, 809 people with a mental disability, 308 people with a sensorial disability and 207 people with a psychic disability.

The allowance for severely disabled person is granted to people whose state of health is such that any type of labour is counter-indicated or whose working skills are so limited that it is impossible to adapt a workplace in an ordinary or sheltered workplace to their needs.
On 31.12.2006, **697** people were eligible for the allowance for severely disabled people.

- On 31 December 2006 **697** people were living in care homes for disabled people, 347 women (49.8%) and 350 men (50.2%).
  The age category and the type of disability varies according to the different care homes, but in general we can say that all types of disabilities as well as all age categories are represented in these homes.
  On 31 December 2006, the care homes had 46 people (6.6%) aged between 0 and 19, 201 people (28.8%) between the ages of 20 and 39, 194 people (27.8%) between the ages of 40 and 49, 155 people (22.2%) between the ages of 50 and 59, 98 people (14%) between the ages of 60 and 79 and 4 people (0.6%) over the age of 80.

- In 2005, **1414** children (<18 years) were eligible for the additional special benefit for disabled people.
  The additional special benefit is payable until the age of 18 when the child suffers from an illness or a disability leading to a permanent physical or mental disability of over 50% compared with a normal child of the same age.
  The additional special benefit is continued after the age of 18 when the child, because of his chronic illness or disability, is not in a position to provide for himself. This condition is presumed to be fulfilled when the child has no personal revenues (professional or replacement) that are equal or higher than the guaranteed minimum income.

7. Residential Services for people with a disability

The types of services available of people with a disability are included in the tables at the beginning of this report.

9. Staffing

Staffing information is available as presented in the tables above, although only by type of post and not be level of training/qualification.

12. Acknowledgements

Jean-Claude Muller, Ministry of Family and Integration

13. Information sources on disability used to compile the template and commentary, including people who were interviewed

Annual report (2006) of the Ministry of Family and Integration

Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

Malta

Robert Hayward

University of Kent, UK

Summary of available data

Description of service types

Type of service	Size interval	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions	Age of service
Hospital: Mental institution (Mount Carmel)	201 places +	Over 18/25 (i.e. adults only)	Mixed	24 hour	State	State	Mainly long term	100+
Hospital: St Vincente de Paule Residence	201 places +	Over 18/25 (i.e. adults only)	Elderly infirm/mentally ill/dementia	24 hour	State	State	All long term	100+
Residential homes (government supported) TOTAL NUMBERS	31 to 50 places	16/18/25 to 60/65 (adults but not older adults)	More than one disability group served (no main group) but not mixed	24 hour	State	Benefits/social security	All long term	0 to 20 years
Community Nursing Homes (government run)	201 places +	over 60/65	Elderly infirm/mentally ill/dementia	Per day only - no night time cover	State	Mixed state/local and private contributions (insurance/private)	All long term	.
Community nursing homes (Church/private)	201 places +	over 60/65	Elderly infirm/mentally ill/dementia	Mixed depending on need	Mixed	Mixed (any)	All long term	21 to 50 years

Data available by service type – breakdown by size and disability

Type of institution	Places total	Under 30 places	Over 30 places	Size unspecified	ID	MH	PSD	Elderly/ dementia	Mixed/ dual	Other/ unspecified
Hospital: Mental institution (Mount Carmel)	424	.	424	0	64	299	.	60	.	61
Residential homes (government supported)	42	42	.	0	.	.	.	.	.	.
Residential homes (private/faith)	176	46	120	10	135	15	.	.	10	16
Hospital: SVPR	1040	.	1040	0	.	.	.	1040	.	.
Community Nursing Homes (government run)	619	.	.	.	.	.	.	619	.	.
Community nursing homes (Church/private)	973	.	.	.	.	.	.	973	.	.
TOTAL	**3274**	**88**	**1584**	**10**	**199**	**314**		**2692**	**10**	**77**

Data available by service type – breakdown by gender and age

Type of institution	Places total	Male	Female	Gender unspecified	Children	Younger adults	Older adults	Adults over 18	Age unspecified
Hospital: Mental institution (Mount Carmel)	424	.	.	.	.	.	.	.	364
Residential homes (government supported)	42	27	15	0	0	42	0	.	0
Residential homes (private/faith)	176	.	.	.	.	.	.	176	0
Hospital: SVPR	1040	328	712	1040	0	73	967	.	1040
Community Nursing Homes (government run)	619	.	.	.	.	.	.	.	0
Community nursing homes (Church/private)	973	.	.	.	.	.	973	.	973
TOTAL	**3274**	**355**	**727**	**1040**	**0**	**115**	**1940**	**176**	**1649**

Completeness and accuracy of data

Data description:
(1) National Statistics Office - time series data on population and housing includes data by place of residence, long-term illness and disability.
(2) National Commission for People with Disabilities (KNPD) – register of persons with disability (special ID card) with disability organised in terms of locality, gender, age and different categories of disability.

Problems in collating data
1. Difficulty in establishing good cooperation – there was a poor response from a range of contacts in the Ministry of Health, Elderly and Community Living (main responsible authority), NSO, NGO sector, health sector. Where contacts were established, data provision was scanty or unreliable. Attempts to contact directly managers of care establishments were not met with success. KNPD were the most reliable source of information on residential care services.
2. NGOs, church-based and umbrella organisations providing residential care generally do not hold statistical data. Even so, there was little response to requests for assistance, even at unit level.

Completeness & quality
1. NSO produce computerised time series data on various statistical themes derived from the last national census (2005). Few statistics on residential care collected – only high level data available.
2. KNPD produces data derived from a register. The material is organised in such a way that no information is available at institutional level – numbers from geographical districts/regions are aggregated for national level statistics.
3. Church-based institutions collect some data at unit level only, most of this refers to current occupancy levels with little reference to type of disability.
4. Independent NGOs do not appear to collect data of use to this project, there is no data available of relevance although general information from published reports (where they exist) has been included in the commentary.
5. No information on staffing exists except at unit level – this information (provided at face-to-face interview) has been included as notes to the template or commentary where verified. Electronic data is available on registration, but it is mostly macro-economic material – with little detail or information on residential care. This material is mostly in the form of summative tables. Data sets can be purchased (from NSO), but it is costly to do so.

A listing of all residential care establishments has been collated and it has been possible to obtain or calculate data on the approximate numbers of persons in residential care for ID & PSD. One large residential home and one large hospital account for the largest number of people in residential care. Some information also exists from 2003 KNPD survey of services and benefits which includes some information on specialist education (mostly non-residential), and residential care in smaller NGOs (numbers by gender, age, locality). There is also data on numbers by impairment, but there is a significant degree of double counting where individuals have more than one disability. *Appogg*, the Foundation for Social Welfare, has data on the numbers of residential homes (children) and residents, but no information as to disability. Data on people with mental health problems exists at unit level, but only as

bed numbers (except where in other residential care).The Ministry of Health (Dept of Elderly) have some data on 22 residential homes (including 12 church-based).

Accuracy & reliability

Apart from census and register information from 2005, other sources are likely to be from several years earlier. There is no information on private provision (except for 1998 figures for numbers of retirement homes for the elderly (?) disabled). A good account of the development of disability services exists, although no statistics or other data are provided to support the description.

Commentary: Malta

1. Overview

The Maltese islands are a group of three islands in the Mediterranean 60 miles south of Sicily. Malta's GDP is about a half of the EU average (European Commission, 2003). Until the mid-1950s the Maltese economy was based on subsistence farming with meant that many people lived in relative poverty, which, coupled with associated factors meant that impairments were widespread (Camilleri, 2006). Unemployment is about 6.5%. Strong family structures, linked with Christian traditions have provided the impetus for family and faith-led care for the "sick" and "less fortunate". In the 1890s the first charitable institutions provided care based on religious and moral grounds for people with social problems. The 1945 polio epidemic which affected large numbers of children caused the Maltese to consider concepts such as rehabilitation over care, although from the end of WW2 to the nineties, disabled people were treated under an empirical, positivist medical model. Between 1945-1973 the first NGO for disabled people was formed, the first residential home for severely disabled run by the Catholic Church was established and legislation was enacted (the 1969 Employment (Handicapped Persons) Act). The population (in 2003) was around 400,000 people with a rapidly ageing population. Average life expectancy for men is 74.3 and women, 80.2. About 13% is over 65 and there are an estimated 2,600 suffering from dementia (RCP, 2006). Care of the elderly is still based on family looking after relatives, but increasingly people are being placed in residential care either in privately funded homes, some government community residences or in the government St Vincente de Paule Residence, built in Victorian times as a workhouse. Mount Carmel Hospital, another Victorian hospital, has some 400 beds catering for a mixture of long-stay patients (including intellectual, physical and mental disabilities) and some assessment wards. Other residential care is provided privately in residential homes of varying quality and price or by church-based or voluntary organisations.

People with disabilities

Age Distribution	Persons with Disability (% distribution)	Entire Population (% distribution)	Age cohort Persons With disability within Population cohort (%)
School age (0-14)	916 (14.5)	20.4	1.2
Early working (15-29)	862 (13.6)	21.9	1.0
Interim working (30-44)	1161 (18.3)	20.8	1.5
Late working (44-59)	1108 (17.5)	20.2	1.4
Early retirement (60-74)	1414 (22.3)	12.0	3.1
Late retirement (75+)	871(13.7)	4.8	4.7
Average age (years)	45.8	36.2	

Source: National Disability Survey 1999

2. Health and social care system

2.1 Organisation

The Maltese government provides a comprehensive health service to all Maltese residents funded from general taxation. Services are free at the point of delivery, although there is some "means-testing" to qualify for certain services, for example, free pharmaceuticals. Some people with certain chronic conditions are able to receive free treatment irrespective of their financial means. The Ministry of Health, the Elderly and Community Care (Ministeru tas-Sahha, I-Anzjani u I-Kura tal Komunita') is responsible for providing health care services and the necessary monitoring and control mechanism to promote and contribute to the well-being of elderly people and community care. Primary care is provided mainly through eight health centres and GP and nursing services are supplemented by specialist services accessed at specialised clinics. There is a thriving private sector operated by many of the same personnel working in primary care settings. Secondary and tertiary care is provided at a number of public hospitals, the principle one being the new replacement for St Lukes. There are also three private hospitals with 168 beds.

Social care falls under the Ministry for the Family and Social Solidarity (Ministeru ghall-Familja u Solidarjeta' Socjali) which is responsible for the supervision of benefits paid by the social security department and for the provision of personal social services and support to individuals, organisations and communities in providing for vulnerable groups. The National Commission for Persons with Disability falls under the direct responsibility of the Permanent Secretary. Sedqa, Sapport (adult residential care) and Appogg (child protection) fall under the auspices of the Foundation of Social Welfare Services who are also accountable to the permanent secretary. Residential services became Sapport's core service with the aim of enabling disabled persons to live as independently as possible within small apartments and houses.

In Malta, everyone over the age of 16 and who has not reached retirement has to be insured (unless exempted by law). This compulsory contribution covers the risks of old age, death, invalidity, industrial injury, occupational disease and for pensions and supplementary benefits. It also covers childrens' allowance, social assistance and services under the health scheme. All cash benefits are administered by the Social Security Department through 24 district offices (22 in Malta and 2 in Gozo). There is no obligatory health insurance and there is a free NHS covering the resident population.

The Ministry of Health, the Elderly and Community Care is responsible to provide health care services and the necessary monitoring and control mechanism, to actively promote and contribute to the well-being of the elderly people and community care. It is the main government department with responsibility for residential care for persons with disabilities.

2.2 National Commission for Persons with a Disability (KNPD)

Activity in the field of disability is co-ordinated by the Kummissjoni Nazzjonali Persuni b'Dizabilita' which is a government funded organisation. The aims of KNPD were to crate a national focal point on disability; advise the government on disability

issues; provide a direct link to NGOs and to involve disabled people. The commission keeps a register of persons with a disability organised in terms of locality, gender, age, and category of disability. These statistics are published on its website. Registered persons get a Special Identity Card which carries certain entitlements.

2.2 Financing

In Malta there is no obligatory health insurance, but all workers pay a weekly National Insurance Contribution that finances welfare services in general. Some people purchase health insurance on a voluntary basis in order to make use of services of practioners and specialists operating in the private sector. In 1998, the government spent 9.6% of its budget on health care (Lm 51.3 million) (Ministry of health, 2006), although a precise estimate of the proportion spent on different services is difficult to calculate partly because, for example, some services are provided by secondary care staff on a part-time basis.

3. Prevalence of disability

Figures for the prevalence of disability are hard to find. Approximately 12% of the population have some form of disability – this figure is partially derived from the numbers of persons applying for the special identity card for disabled people (8402 in 2006).

4. Residential services for people with disabilities

The description of the services is based on communications from contacts within Malta, including contacts at the institutions themselves in some cases.

4.1 Services for children with disabilities

There are no residential facilities for disabled children who may attend one of five special educational schools or a special unit for persons with severe impairments (the Sannat Unit). What constitutes "disability" has not been clearly defined in the existing literature (in English). The official leaving age for special schools is 19. All of the special schools are described as being either architecturally unsuitable, underused or poorly staffed and are due for re-structuring to develop them into resource centres.

4.2 Services for adults with a disability

4.2.1 Hospitals

St Vincente de Paule Residence

Administered by the Ministry for Health, the Elderly and Community Care, the SVPR is a large institution that is over 100 years old and is situated to the south and west of Valletta in a rural area on the urban fringe. There are over 1000 mostly elderly persons who are living there on a long-term basis 90% of whom are aged over 60 (65 adults under 60, 1245 over 60; Ministry for Health, 2006). Most of the residents are elderly infirm, but they also include people with long-term mental health problems who are elderly, some people with behavioural/social problems and some individuals with intellectual disabilities (no further details available). There is a long waiting list for admission, necessitating some people remaining in accommodation that is inappropriate or not geared to their needs. SVPR has been a traditional employer of

local people and there are some issues including over-employment and increasing overheads of large ageing institutions that are impacting on the desire to maintain the institution.

SVPR: Age/gender breakdown

Age range	Female	Male	Total
0-4			
5-9			
10-14			
15-19			
20-24			
25-29	1		1
30-34		1	1
35-39	1	1	2
40-44	1	2	3
45-49	2	4	6
50-54	18	8	18
55-59	13	12	25
60-64	14	17	31
65-69	24	18	42
70-74	64	38	102
75-79	108	59	167
80-84	195	70	265
85-89	155	61	216
90-94	84	29	113
95-99	34	7	41
100-105	6	1	7
	712	328	1040+

Mount Carmel Hospital

Built over 150 years ago using the model of the Wakefield Asylum, it currently provides care to approximately 400 persons with mostly mental disabilities (long-term mental health and developmental disabilities).

There are three wards for persons with intellectual disabilities:

Male 8	(average numbers in 2006	= 19)
Juvenile	(" " "	= 17)
Female 8	(	= 28)
Total		= 64
There are 2 "geriatric wards"		= 60
A forensic facility		= 25
Chronic wards for mentally ill		= 250 (+/-)
2 long-stay hostels 24 hour care mi		= 24
Total		= 424 (as at 11/04/07)

The wards are staffed by 4 “nurses” by day and 2 at night, working across three shifts. There are approximately 240 nursing staff and aids (134 male, 107 female) and the trained staff are general nurses (not psychiatric trained). There is no staff trained in the care of people with ID. People with physical disabilities receive “good unqualified care”. Some work is currently being out-sourced (in the hostels and new community-based care).

Mount Carmel Hospital is over a century old and outdated both in respect of its architectural standing but also in the development of modern techniques relating to patient care. Neglect of the infrastructure and the environment exists which renders the hospital barely fit for human habitation. Many places in the hospital are silent witnesses of gross neglect, bareness and cheerlessness with bureaucratic organisation of work schedules with bizarre consequences especially on the patients who are forced to live according to the institutional time and not to their personal time. The archaic ‘custodial care’ approach still preponderates with the result that the hospital has maintained its asylum characteristics: the chronically institutionalised patients reside in closed, sex segregated wards and enjoy little attention and are offered few or no possibilities of rehabilitation. Patient turnover is very low with poor differentiation of the patient population within wards. The hospital has little autonomy in the field of human resource management, financial policy and daily development policy. Modern management structures are absent resulting in a lack of autonomy, accountability or responsibility for resource utilisation, performance, outcomes and quality of care. There is a considerable lack of trained human resources, a striking lack of communication, deliberation and co-ordination at all levels, both in the field of policy making as well as in the field of patient care. Multidisciplinary teams are relatively underdeveloped and there are hardly any specialised care units.

Recent psychiatric services are being planned for a shift to the community and the opening of a community home. The analysis of the patients' census recently carried out within Mount Carmel Hospital, reveals that there are about 149 patients who are suitable for such accommodation. At this moment, this figure is still a rough estimate and further research and preparation is required. Assuming that each hostel will cater for 20 clients, 8 such hostels need to be provided over the coming years. Persons with mental retardation but without psychiatric problems are still misplaced in general psychiatric wards. The two existing long-stay hostels are run in partnership with NGOs and located in buildings owned by the hospital. Current issues include transition costs (to accommodate moves from hospital) and additional costs associated with high dependency to provide for better individual care. The principle of money moving with the patient is acknowledged but for implementation it is dependent on whole wards closing. It is hoped that 15 persons (with ID) will move from Mt Carmel and transitional and capital expenditure will follow the patient if a ward closes. Recurrent direct costs will go with the patients.

Local epidemiological data on psychiatric morbidity is not available, necessitating reference to international data to estimate the psychiatric disease burden in the local community. Mental illness and health related psychosocial problems make significant demands on health and social services. In Malta, it is estimated that about 15% of public health care users are suffering from mental health problems.

Zammit Clapp
A specialised geriatric hospital with 60 beds for elderly physically and mentally infirm mostly long-stay. No further details available.

Gozo General Hospital
Has 100 psychiatric and geriatric beds, some of which are long-stay, although statistics are unavailable.

4.2.3 Government provision in the community

Agenzija Sapport
The Ministry for Social Policy established the Agency SAPPORT in 2001 within the Foundation of Social Services with the aim of providing residential and professional services within the community for people with disabilities and their families. Sapport runs five residential homes, and one (Cospicua) is under construction, all of which are mixed gender and age range (young, older adults) with different types of disabilities. Each home has at least one staff member with a degree or diploma in nursing, social work or similar.

Kirkop & Fgura are 24 hour staffed, for persons with intellectual disabilities; the latter is for "challenging behaviour". Both are new apartments in an apartment block of 6. **Mtarfa** is a purpose-built detached bungalow for people with ID and autism with challenging behaviour. **Vajrita** is housed in a small holiday complex (over 50 years old) which has been refurbished to provide accommodation over two floors and has 6 flatlets for 1-3 persons on one floor and 6 with 12 residents on another. 9 persons have challenging behaviour and 1 has physical disabilities.

Total staff is about 98 (34 males, 64 females) with full-time care workers numbering 43. Every member of staff has to undertake a basic care course and should have 2 'O' levels. Each team has a superior and a professional support worker (who are graduates of psychology, social work, physiotherapy or similar). The work is relatively undifferentiated with "everybody expected to do everything".

Table: Sapport residences (breakdown by number, age, gender and staffing

Residence	Number	Ages	Males	Females	Staff (f/p)
Mtarfa	6	22-46	4	2	23 (11/12)
Vajrita I	15	25-52	9	6	28 (12/16)
Vajrita II	14	26-63	8	6	21 (12/9)
Fgura	3	26-34	2	1	13 (5/8)
Kirkop	4	25-40	4	0	8 (3/5)
	(42)				(93)

4.2.4 NGO/private/faith-based provision
There are a large number of NGOs active in this sphere (including Down's Children Association, Society for Deaf Children and Youths, Muscular Dystrophy Group etc.), but few providing residential care.

Dar-tal-providenza
Church-based residential home for 120 residents with ID and multiple disabilities based in an isolated former navy training camp. The camp was handed over in 1967 and refurbished in the following two years. It is staffed by nuns from the

Congregation of the Sisters of St Joan Antide Thouret who provide pastoral care alongside professional staff such as physiotherapists, 24 hours a day, seven days a week. There is also a small house at Zerniq providing care to 4-6 persons with unspecified disabilities.

Fondazzioni Wens

Dar-il-wens is a residential home for 6 persons with ID offering minimal support. There is also a small house for 3 persons with more support.

Nazareth Foundation

Two homes run by catholic priests accommodating 10 persons with a mixture of physical and sensory disabilities and ID.

Richmond Fellowship of Malta

Residential services at Villa Chelsea an old, refurbished building, for 15 persons with "mental problems". Mt Carmel is also running two projects in partnership with the RF.

Arka Foundation

6 persons in residential home. Mixed disabilities.

4.4 Other provision

1. Community nursing homes for the elderly independent run by the government (only limited information available.) The service exists to provide a physically safe environment to elderly persons and persons with a disability who can no longer cope in their own homes. Residents must be over 60 (except if other forms of disability are present). The bedrooms in these residential homes are equipped with an en-suite kitchenette. These homes are alternatively described as "residential care" or "nursing homes", though there is little other additional information available, it is apparent that they are "communal" in that some facilities (toilets, bathrooms) are shared and they also have a Nurse Call system for emergencies. There is no information available on staffing or care provided, but it is suggested that because of relative independence, that support may be minimal. There is no further information with regard to size. In 2005 there were 619 persons in this form of care (and this number has been included in the template data), (Ministry of Health, 2006).

2. Private/church-based homes for elderly severely disabled (limited information only). These are different establishments from those recorded on the template for persons with ID, PSD under the age of 65. They are mostly faith-based homes, usually staffed by a mix of sisters/nuns and support workers drawn from nearby population. It is assumed, (if the figures below are accurate), that these are, in the main, generally quite large establishments with over 20 persons and in some, over 50 persons resident. Anecdotal information suggests that some of these are annexes to buildings used for other religious purposes, many are relatively older buildings (over 50 years) converted to present day use. The total numbers have been added to the template.

Example: RETIREMENT HOMES FOR THE ELDERLY

Type	homes	residents	f/t staff	p/t staff
Church run	12	469	149	95
Religious run	5	186	74	7
Privately run	5	318	83	148
Total	22	973	306	250

Source: Central Office of Statistics (1999)

3. According to the Central Office of Statistics (1999), there were 22 non-governmental retirement homes for the elderly catering for 973 residents. Over half were church-run (469 persons), 5 managed by religious orders (186 persons) and 5 managed by private enterprise (318 residents). Staffing for the 22 homes encompassed 306 full-time workers and 250 part-time workers. The ratio of full-time workers to residents varies from 2.7:1 (religious –run), 3.3:1 (church) to 5.6 (private enterprise). The income for non-government homes is derived mainly from residents' contributions (94.5% in private homes).

5. Issues

Many services are aimed at providing more humane care to people with disabilities, based on the evidence of the poor material state of the existing large institutions. Some professionals in the field believe that smaller, more modern institutions (rather than more individualised, personalised care) will provide the solution. For example, St Lukes Hospital – the former general hospital, (now being replaced by the new University Hospital), is currently an empty building and is being proposed to be used as a big residential home operated by KNPD (the costs associated with economies of scale being used as the basis for the decision).

6. Informational sources

6.1 Data source(s)

National Statistics Office – electronic/tables (StatDB) (www.nso.gov.mt, accessed 12/03/07)
KNPD Annual Report (2005), (www.knpd.mt, accessed 12/03/07)
Services & Benefits to Persons with Disabilities (2003), KNPD.
National Disability Survey (2003), KNPD.
Lifestyle Survey (2003), NSO.
Census of Population and Housing Annual Report (2005), NSO.

6.2 Verification of information

On-site visit to Malta and meetings with sources 10-13 April 2007.
Alfred Bezzina, National Council for Persons with a Disability (KNPD), 11/04/2007, 12/04/07; Joe Rapinette, St Vincente de Paule Residence, 12/04/2007 ; Agnes Bezzina, Agenzija Sapport, 12/04/2007; Angie Farrugia, Agenzija Sapport, 12/04/2007; Ethel Felice, Mount Carmel Hospital, 12/04/2007; Monica Gaglioni, Mount Carmel Hospital, 12/04/2007; May Caruana, Mount Carmel Hospital, 12/04/2007; Tony Mifsud, Mount Carmel Hospital, 12/04/2007.

7. Acknowledgements

Alfred Bezzina (KNPD)

8. References

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Central Office of Statistics (1999) News Release 59/99. www.magnet.mt/home/cos (Accessed 10/11/2006)

Ministry of Health, the Elderly and Community (2006) Residential Homes for the Elderly. www.sahha.gov.mt/pages.aspx?page=250 (Accessed 04/05/2006)

Ministry of Health, the Elderly and Community (2006) St Vincente de Paule Residence. www.sahha.gov.mt/pages.aspx?page=253 (Accessed 04/05/2006)

Royal College of Psychiatrists (2006) Supporting and promoting dementia services in Malta. www.rcpsych.ac.uk/college/faculties/oldage/international (Accessed 10/11/2006)

Appendix 1: Malta a "typical" case scenario

Maria is a 22 year old woman with severe learning disabilities who also presents some behavioural problems. Maria is unable to live on her own without constant care. Until her mother died recently, she lived in the family home, receiving some supports from the municipality. There is no other immediate family.

Given that Maria has been living at home until now, and bearing in mind the nature of her disabilities, what would have been her likely pattern of education and care to this point?

MOST PROBABLY SHE WILL BE ATTENDING A DAY CENTRE NOW RUN BY AGENZIJA SAPPORT. HER FAMILY, IF THEY HAVE ASKED, WOULD HAVE BENEFITED FROM A WEEK OR TWO WEEKS A YEAR OF RESPITE CARE I.E MARIA WILL BE ABLE TO SPEND SUCH TIME AT A RESIDENTIAL RESPITE CARE CENTRE (THE FAMILY HAS TO PAY A SUBSIDISED FEE), SHE IS ENTITLED TO A DISABILITY PENSION WHICH IS AROUND 60% OF MALTA'S NATIONAL MINIMUM WAGE AND POSSIBLY HER FAMILY IS RECEIVING A FEW HOURS OF HOME/CARING SUPPORT EITHER FROM THE DEPARTMENT OF THE ELDERLY OR FROM AGENZIJA SAPPORT.

Who would have provided and paid for these services? How would have this been decided and by whom?

NATIONAL GOVERNMENT FUNDS COMPLETELY DAY SERVICES FOR ADULTS WITH DISABILITIES.
RESPITE CARE SERVICES IS PROVIDED BY A NGO WHICH IS FUNDED TO A LARGE EXTENT (AROUND 80-90%)BY NATIONAL GOVERNMENT DISABILITY PENSION IS FUNDED BY NATIONAL GOVERNMENT AGENZIJA SAPPORT AND THE DEPARTMENT OF THE ELDERLY ARE GOVERNMENT RUN AND BY AND LARGE PROVIDE THEIR SERVICES FREE OF CHARGE.

What is the most likely outcome for Maria now? (What, realistically, might Maria expect from health or social welfare services?). What input might Maria or her advocate/representative have in this process?

SHE WILL BE ASSESSED BY AGENZIJA SAPPORT TO PROVIDE HER WITH THE NECESSARY SUPPORT EITHER TO CONTINUE LIVE IN THE COMMUNITY OR ELSE IN A SMALL COMMUNITY HOME. HOWEVER THIS AGENCY HAS A WAITING LIST. IF THIS FAILS SHE WILL HAVE TO BE INSTITUTIONIZED PROBABLY AT AN INSTITUTION CATERING ELDERLY PEOPLE (ST VINCENT DE PAULE).

Who would typically be responsible for providing services? (ie. what department, which professions would be involved, who would be responsible for determining or managing care and how might this be paid for?)

AGENZIJA SAPPORT WILL AS A RULE PROVIDE THE SERVICES INVOLVING SUPPORT WORKERS WHO UNDERGO AN INHOUSE TRAINING. THEY ARE SUPPORTED AND SUPERVISED BY A SMALL TEAM OF PROFESSIONALS MAINLY CONSISTING OF PSYCHOLOGY GRADUATES AND SOCIAL WORKERS.

What factors might influence her pathway or access to services? (for example, entering residential care provided by a church-based organisation versus a state-run facility, or residential care home over nursing home, or day support rather than educational or work facilities). How is one type of service chosen over another? How is this decided and by whom?

AT PRESENT THE ONLY SERVICES PROVIDED IN SIMILAR CIRCUMSTANCES IS BY AGENZIJA SAPPORT. THERE IS A POSSIBILITY THAT THE FAMILY WILL FINANCE A CARE PACKAGE THEMSELVES WHICH WILL GENERALY BE ONE OF TWO POSSIBILITIES:
A) RESIDENTIAL SERVICE IN A PRIVATELY RUN INSITUTION CATERING MAINLY FOR ELDERLY PEOPLE
B) RECRUIT A FOREIGN LIVE-IN PERSONAL ASSISTANT.

Without going into too much detail, and given the limited information, what can you tell me about the likely next stage in Maria's life and the likely people to be involved, and the way decisions such as patterns of service and funding might be made? A brief and direct answer, without going into too much detail will suffice as long as any complexities or barriers are briefly mentioned.

IT IS HOPED THAT AGENCY SUPPORT WILL BE GIVEN THE EXTRA RESOURCES TO CONTINUE PROVIDING SERVICES IN THE COMMUNITY SO THAT PEOPLE WITH DISABILITY CONTINUE TO LIVE IN THEIR FAMILY OR IN SMALL HOMES IN THE COMMUNITY. THE NATIONAL COMMISSION PERSONS WITH DISABILITY WILL CONTINUE WORKING FOR THIS TO MATERIALISE AND IT WILL DO ITS UTMOST SO THAT THIS POLICY IS NOT REVERSED WITH THE DEVELOPMENT OF A NEW LARGE INSTITUTION FOR PERSONS WITH DISABILITY.

(Information provided by Alfred Bezzina)

Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

The Netherlands

Anja Declercq[1], Melanie Demaerschalk[1], Hilde De Keyser[2]

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Summary of the available data

The tables below summarise the descriptions of the services included in the template.

Description of services

Type of service	Size interval	Age group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admission
gezinsvervangende tehuizen (family replacing homes for the physically impaired)	.	.	PD	24 hour	Voluntary/not-for-profit (over 95%)	State	All long term
gezinsvervangende tehuizen (family replacing homes for the mentally impaired)	less than 6 places	Over 18/25 (i.e. adults only)	ID only	24 hour	Voluntary/not-for-profit (over 95%)	State	All long term
kindergezinsvervangende tehuizen (family replacing homes for mentally impaired children)	6 to 10 places	0 - 18/19 years	ID only	24 hour	Voluntary/not-for-profit (over 95%)	Regional authority/LA/County and state	All long term
algemene instellingen voor verstandelijke gehandicaptenzorg (general institution for people with intellectual disabilities)	6 to 10 places	Over 18/25 (i.e. adults only)	ID only	24 hour	Voluntary/not-for-profit (over 95%)	State	All long term
kindergezinsvervangende tehuizen (family replacing homes for physically impaired children)	6 to 10 places	0 to 25 years	ID only	24 hour	Voluntary/not-for-profit (over 95%)	Regional authority/LA/County and state	All long term
orthopedagogische centra (orthopedagogic centers)	6 to 10 places	3 into adulthood (60/65 years)	ID only	24 hour	Voluntary/not-for-profit (over 95%)	State	All long term

Type of service	Size interval	Age group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admission
kleine woonvormen (small living forms)	6 to 10 places	Over 18/25 (i.e. adults only)	PD	24 hour	Voluntary/not-for-profit (over 95%)	State	All long term
instellingen voor visueel gehandicapten (institutions for the vision impaired)	11 to 30 places	.	Sensory impairments	24 hour	Voluntary/not-for-profit (over 95%)	State	All long term
instellingen voor auditief gehandicapten (institutions for the auditive impaired)	11 to 30 places	.	Sensory impairments	24 hour	Voluntary/not-for-profit (over 95%)	State	All long term
grote woonvormen (large living forms)	51 to 99 places	.	PD	24 hour	Voluntary/not-for-profit (over 95%)	State	All long term

Data available by service type – breakdown by size

N.B. no breakdown by disability group available

Type of service	Places total	Under 30 places	Over 30 places	Size not known
kindergezinsvervangende tehuizen (family replacing homes for mentally impaired children)	490	490	.	.
kindergezinsvervangende tehuizen (family replacing homes for physically impaired children)	584	584	.	0
Living forms for people with multple disabilities (for staffing data only)	.	.	.	.
gezinsvervangende tehuizen (family replacing homes for the physically impaired)	2,455	.	.	.
gezinsvervangende tehuizen (family replacing homes for the mentally impaired)	18,272	18,089	.	183
algemene instellingen voor verstandelijke gehandicaptenzorg (general institution for people with intellectual disabilities)	36,079	35,718	.	361
orthopedagogische centra (orthopedagogic centers)	2,745	2,745	.	0
kleine woonvormen (small living forms)	1,841	1,823	.	18
instellingen voor visueel gehandicapten (institutions for the vision impaired)	269	.	.	.
instellingen voor auditief gehandicapten (institutions for the auditive impaired)	621	.	.	.
grote woonvormen (large living forms)	788	.	.	.
Total	**64,144**	**59,450**		**561**

Data available by service type – breakdown by gender and age

Type of service	Places total	Male	Female	Gender not known	Children	Younger adults	Older adults	Adults over 18	Age not known
kindergezinsvervangende tehuizen (family replacing homes for mentally impaired children)	490	.	.	490	376	114	.	.	.
kindergezinsvervangende tehuizen (family replacing homes for physically impaired children)	584	.	.	584	470	102	.	.	12
Living forms for people with multple disabilities (for staffing data only)	.	.	.	.	.	.	.	.	.
gezinsvervangende tehuizen (family replacing homes for the physically impaired)	2455	.	.	2455	.	.	.	.	2455
gezinsvervangende tehuizen (family replacing homes for the mentally impaired)	18272	.	.	18272	.	16627	1644	.	1
algemene instellingen voor verstandelijke gehandicaptenzorg (general institution for people with intellectual disabilities)	36079	20565	15514	0	3969	29224	2886	.	0
orthopedagogische centra (orthopedagogic centers)	2745	1702	1043	0	2333	412	.	.	0
kleine woonvormen (small living forms)	1841	.	.	1841	.	1712	92	.	37
instellingen voor visueel gehandicapten (institutions for the vision impaired)	269	.	.	269	.	.	.	.	269
instellingen voor auditief gehandicapten (institutions for the auditive impaired)	621	.	.	621	.	.	.	.	621
grote woonvormen (large living forms)	788	.	.	788	.	.	.	.	788
Total	**64144**	**22267**	**16557**	**25320**	**7148**	**48191**	**4622**		**4183**

Staffing and staff qualifications

Type of service	Total staff	Staff with only primary school qualification or less	Staff with secondary school qualification as highest qualification	Staff with higher qualification	Staff with university degree	In service training only	Unspecified
kindergezinsvervangende tehuizen (family replacing homes for mentally impaired children)	.	.	.	.	.	.	
kindergezinsvervangende tehuizen (family replacing homes for physically impaired children)	.	.	.	.	.	.	
Living forms for people with multple disabilities (for staffing data only)	8649	548	1656	325	4774	1346	0
gezinsvervangende tehuizen (family replacing homes for the physically impaired)	3543	180	1383	22	1102	856	856
gezinsvervangende tehuizen (family replacing homes for the mentally impaired)	71505	4257	12024	9206	29743	12572	16275
algemene instellingen voor verstandelijke gehandicaptenzorg (general institution for people with intellectual disabilities)	.	.	.	.	.	.	
orthopedagogische centra (orthopedagogic centers)	.	.	.	.	.	.	
kleine woonvormen (small living forms)	.	.	.	.	.	.	
instellingen voor visueel gehandicapten (institutions for the vision impaired)	2238	450	193	157	1077	361	361
instellingen voor auditief gehandicapten (institutions for the auditive impaired)	.	.	.	.	.	.	
grote woonvormen (large living forms)	.	.	.	.	.	.	
Total	**85935**	**5435**	**15256**	**9710**	**36696**	**15135**	**18838**

Completeness and accuracy of the data

On children services there is no information available about the typical age of the services.

Adult services: for '*instellingen voor visueel gehandicapten*, *instellingen voor auditief gehandicapten*, *gezinsvervangende tehuizen* and *grote woonvormen'*, (services for visual and auditif disabled, homes which „replace" a family and large homes) no data is available on which age group they provide services to. Information about the typical age of the services is absent for all organizations.

Older services: no division is made for people below and above 60, thus services for the elderly are included in adult services.

Size: For "*instellingen voor visueel gehandicapten*, *instellingen voor auditief gehandicapten*, *gezinsvervangende tehuizen* and *grote woonvormen"* (see explination above), no data is available concerning the number of places.

Disability type: For Intellectual disability, Dementia, Autism, Mixed and Dual diagnosis, no data is available. For "*grote woonvormen"*, no information about disability is provided.

Age: For "*instellingen voor visueel gehandicapten*, *instellingen voor auditief gehandicapten*, *gezinsvervangende tehuizen* and *grote woonvormen"*, no age-specific data is available.

Gender: Gender specific data is only available for "*algemene instellingen voor verstandelijke gehandicaptenzorg* and *orthopedagogische centra"* (general services for people with intellectual disabilities and orthopedagogic centers)

Staff numbers: No information on staff numbers is available for "*kindergezinsvervangende tehuizen, algemene instellingen voor verstandelijke gehandicaptenzorg, kleine woonvormen* and *grote woonvormen*"

Staff training: There is no information whatsoever available about staff training.

Commentary: The Netherlands

1. Political and social context

1.1 Government organisation and structure

The Netherlands is a constitutional monarchy and a parliamentary democracy. The head of state is Queen Beatrix, who has an important role during the formation of a government and appoints the prime minister.

Dutch politics and governance are characterized by a common strife for broad consensus on important issues, within both the political community and society as a whole.

Currently the Netherlands consist of twelve administrative regions (provinces) which are each ruled by a Governor.

1.2 Disability relevant policy

The principal foundation of Dutch government's policy on people with a physical, mental or sensory disability is that they have the same rights and duties as anyone else.

The Ministry of Health, Welfare and Sport encourages people with disabilities to be as independent as possible. They must be able to use the same facilities as anyone else.

Those citizens who are not able to exercise their rights are supported by a legal representative.

In the past, people with disabilities were often regarded as medically unfit. Services and aids were provided on that basis. The current policy is not to shut them away in institutions, but to give them a place in the community.

In 2002, parliament unanimously approved a bill on the equal treatment of disabled and chronically ill people, prohibiting discrimination against them in the field of employment, training and transport. This law, the Equal Treatment on the Grounds of Disability or Chronic Illness Act, came into force December 2003.

Over the last twenty years the Dutch policies in the disability field focused very much on integration and inclusion. Person centeredness, empowerment and equal opportunities became very important in the new plans and legislation. One of the important new developments in the 1990’s was the ban to build new residential facilities. This ban together with private initiatives started a movement towards smaller group houses and community houses in the Netherlands. Mostly people with mild and moderate disabilities profit from these developments. People with profound and multiple disabilities are still living in residential facilities. But the residential settings will keep also because of a shortage of places in the community houses. Waiting lists for places in supported living do still exist in the Netherlands. In theory people can choose the kind of support they want, through a personal budget. Also

slow administrative processes complicate the free choice of support for people with disabilities. (Stoelinga & Zomerplaag, 2002)

2. Demographics

The Netherlands is the most densely populated country in Europe. 16,491,461 people are living on an area of 41,526 km².

3. Health and Social Care System

In national legislation there are several acts which are of importance for people with disabilities.

The Care Insurance for Everybody Act provides that every citizen pays a contribution and everybody can choose his or her insurance. Most costs are covered by the insurance and if wanted additional contribution for additional functions are possible.

The Act for Special Long-term Costs or AWBZ gives special functions for people with long term needs and chronicle illness. It is based on contributions paid by employees and employers and it provides the basis for many services for people with disabilities, such as personal budgets, homes, activity centres, special treatment. The amount of contribution depends on personal income.

Acts on income replacement compensate the lack of income for younger people with disabilities and lay down the rules for disability-related payments for people who are not able to work due to long-term illness or disability.

A new act is being introduced: WMO, which provides for local governments to implement measures that promote the social inclusion of residents. As a result local government will take over many tasks from other acts and responsibilities that are now on national level.

3.1 Organisation

Services are provided by private initiatives: foundations with governing bodies, responsibility to government and insurance, working according to several acts on governance, influence of staff and clients, quality, professional requirements.

3.2 Financing

Organisations have an agreement with the insurance (AWBZ erkend en uitvoering) about the production every year, money comes from the central office of the AWBZ. A person who gets a personal budget can purchase the care and support needed. He or she will receive the money from the insurance. Total yearly budget and increasing or decreasing needed decided by the minister and parliament.

In the Netherlands the government is funding both the system of personal budgets and the movement towards the „safe“ choice of living in a „sheltered world“[27]

[27] IDRESNET working papers, March 2003

4. Definition, eligibility and diagnosis/assessment

After the birth of a child with a disability early-intervention teams support both the child and the family. An organisation (called MEE) with an office in each region supports the family and informs them about the different possibilities as there are technical aids, adaptation, school, transport, personalised budgets and all the other questions a family can have. For some children rehabilitation centres specialised in rehabilitation methods are needed and will be available.

In order to receive specialised support (schooling, housing, and in a later stage work...) an assessment will be done by the Centre for assessment assessing the needs and wishes of a person and the available support-possibilities. The way of supporting a child with a disability depends also on the wishes of the parents and the strength of the family.

The target group a person belongs to, and thus the indication for which kind of care a person is entitled to, is given on the basis of IQ-tests and/or clinical observation. This indication is given independently from the funders and the providers of care.

Subsequently the individual needs of a person with intellectual disabilities are mapped out. The indication advice consists of a description of the type of care and the amount of care that is needed, and the way parents or legal guardians would like the care to be funded (in kind or in the form of a personal budget with which the person can purchase care). With this indication advice the person with intellectual disabilities can go to the organisation that funds care. These organisations are obliged to allocate the care that is needed (LCIG, 2001)

5. Prevalence of disability

5.1 Issues of definition

ICF is used more and more; for people who need care and support a system of assessment on the basis of functions is developed; assessment take place by an independent body. More and more disability is seen in connection with the society.
In practice different definitions are used within both the disability sector and the medical sector.

5.2 Numbers/rates available

Exact figures on the number of people are not available and therefore the following graph is base on estimations of the “Sociaal en Cultureel Planbureau (SCP)”

Table 1: Estimation of number of people with disability according to kind of disability

Type of disability	Number of persons
light intellectual(2002)	49,700
Severe intellectual (2002)	53,600
Severe physical(2002)	512,000
Visual impairment(2000)	158,000
Hearing impairment (2000)	29,000
Talking difficulties (2000)	71,000

Source: De Klerk, 2000; De Klerk, 2002

The number of people with intellectual disabilities has been growing over the last 20 years. This is not due to the fact more people with an intellectual disability are born but due to a better care system and therefore longer life-expectancies for people with disabilities (see Klerk 2000).

6. Residential Services for people with a disability

There are different service provision options for people with disabilities:

1. Parents can receive support at home when taking care of their child with a disability.

2. Semi-residential settings or the so called daycentres where people are supported during the day-time.

3. Residential settings exist in all sizes and forms in the Netherlands. There are group homes, community homes, large settings etc. The type of care they provide depends on the need of the service-users. Some people receive 24hours/day care while others receive support when needed (e.g. only in the mornings and the evenings). At this moment in the Netherlands a scale with 4 levels is used to classify the intensity of support needed for a specific service user: 'intermittent', 'limited', 'extensive', 'pervasive' support.

Table 2: Living- and daycentres in 2004 (provisional figures)

	Capacity	Places taken[b]
Intramural services		
Service for intellectual disabled	36,594	35,810
Service for intellectual disabled youth	2,690	2,585
Service for people with hearing impairments	1,022	648
Service for people with visual impairments	568	259
So called "big" living places	788	759
'Semi-mural'/supported living		
Gezinsvervangende tehuizen (VG) homes which replace a family for the visual impaired	18,276	17,666
Gezinsvervangende tehuizen (LG) homes which replace family for the physical impaired	2,875	2,806
Gezinsvervangende tehuizen (ZG) homes which replace a home for the sensorial impaired	170	167
Daycentres		
Daycentres for elderly people (VG)		11,711
Children - care (VG)		3,453
Activity-centres (LG)		1,985

(Source: CTG/ZAio)

[b] Where we had no data we made a calculation.

7. Issues

Decentralisation from Central act and execution to the local government, step by step approach, quality of services, community based settings as important direction, critics

of parents about the chosen direction, new system of payment by functions and weight of the care and support needed, bench-marking.

8. Acknowledgements

Mineke Hardeman

9. Information sources on disability used to compile the template and commentary, including people who were interviewed

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Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

Poland

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Summary of the available data

Description of service types.

Type of service	Size interval (places)	Age group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions
Pomoc Spoleczna domy i zaklady dla dzieci i mlodziezy niepelnosprawnych intelektualnie	51 to 99	0-18/19	ID only	24 hour	Mixed	Mixed (any)	All long term
Social Welfare homes for mentally retarded adults	100 to 150	Service for over 18s but some children do live there	ID only	24 hour	Mixed	Mixed (any)	All long term
Specjalne osrodki szkolno-wychowawcze	51 to 99	6-18 or 19	ID only	24 hour	State	.	.
Social Welfare homes for chronically mentally ill	100 to 150	Service for over 18s but some children	MH	24 hour	Mixed	Mixed (any)	All long term
Specjalne osrodki wychowawcze	51 to 99	6-18 or 19	ID only	24 hour	State	.	.
Social Welfare homes for physically handicapped	100 to 150	Service for over 18s but some children	.	24 hour	Mixed	Mixed (any)	All long term

Data available by service type – size of service and disability groups (N.B. no breakdown was available by size).

Type of service	Places total	ID	MH	PSD	Elderly/ dementia	Mixed/ dual	Other/ unspecified
Pomoc Spoleczna domy i zaklady dla dzieci i mlodziezy niepelnosprawnych intelektualnie	8097	.	.	.	.	.	.
Specjalne osrodki szkolno-wychowawcze	28534	15460	.	3900	.	2349	6825
Specjalne osrodki wychowawcze	2970	1834	.	147	.	237	752
Social Welfare homes for mentally retarded adults	15239	.	.	.	.	.	.
Social Welfare homes for chronically mentally ill	17782	.	.	.	.	.	.
Social Welfare homes for physically handicapped	1119	.	.	.	.	.	.
TOTALS	**73741**	**17294**		**4047**		**2586**	**7577**

Data available by service type – breakdown by gender and age.

Type of service	Places total	Male	Female	Gender unspecified	Children	Younger adults	Older adults	Age unspecified
Pomoc Spoleczna domy i zaklady dla dzieci i mlodziezy niepelnosprawnych intelektualnie	8097	4411	3606	80	1668	6199	150	80
Specjalne osrodki szkolno-wychowawcze	28534	.	.	.	.	.	.	28534
Specjalne osrodki wychowawcze	2970	.	.	.	.	.	.	2970
Social Welfare homes for mentally retarded adults	15239	8177	6844	218	220	11623	3178	218
Social Welfare homes for chronically mentally ill	17782	9582	8044	156	19	11048	6559	156
Social Welfare homes for physically handicapped	1119	541	571	7	50	451	611	7
TOTALS	**73741**	**22711**	**19065**	**461**	**1957**	**29321**	**10498**	**31965**

Staffing

There is no information on staff available other than that presented in the relevant section of the following commentary.

Completeness and accuracy of the data

The information for this chapter was provided by the Department of Social Assistance and Integration, Ministry of Labour and Social Policy, and the Polish Central Statistical Office (CSO). Data is for 2005 and covers both children and adults with relatively complete data on age and almost complete data on gender. However, data on disability is limited and no data is included for services providing for people with mental health needs.

There are no additional sources of data which allow an assessment of accuracy other than the account of

Commentary: Poland

1. Overview

The Republic of Poland is situated in Eastern Europe. It is bounded to the north by the Baltic Sea and an enclave of the Russian Federation; to the north-east by Lithuania; to the east by Belarus; to the south-east by Ukraine; to the west by Germany; and to the south by the Czech Republic and Slovakia.

2. Political and social context

After decades of communist rule, by 1988 Poland had reached an impasse; the economy was collapsing and the government was discredited, unable to run the country. Round Table talks in April 1989 legalised Solidarity and instituted political reforms.

A fundamental reform of the state administration entered into force in January 1999. Powers have been devolved to three levels of self-government at regional (voivodships), county (poviats) and commune (gminas) levels and the number of voivodships has been reduced from 49 to 16. This was significant in helping to prepare Poland for entry into the EU, with its emphasis on regional self-government.

2.1 Government organisation and structure

Today Poland is a multi-party democracy in which all citizens 18 years of age and older have the right to vote and to cast secret ballots. Executive power is shared by the Prime Minister, the Council of Ministers and to a lesser extent the President. Parliament has legislative powers and powers to appoint and control the government.

Following the administrative reform of the state and amended Act on professional and social rehabilitation and employment of disabled persons, the majority of tasks related to professional and social rehabilitation were entrusted to local governments (voivodship). The State Fund for Rehabilitation of Disabled Persons (PFRON) allocates funds to voivodship and poviat-level local governments.

2.2 Disability relevant policy

The Social Welfare Act of 1990 made it possible for those purchasing welfare services to develop contracts with services other than state agencies. A range of non-profit agencies developed to provide care, rehabilitation and educational support for disabled people.
The Local Administration Reform Act of 1999 decentralized power, creating new levels of local administration (provincial and regional), which are responsible for services for disabled people.

The Act on Social Welfare, 12 March 2004, provides guidelines for the operation and development of the care centres for disabled persons, describes this as the responsibility of the district and specifies national financial support for care centres.
Regulation of the Minister of Labour and Social Policy on social welfare homes, 15 September 2000.

3. Demographics

Poland is the largest and most populous state in Central Europe, with a population, in 1996, of approximately 38 million. The capital of Poland is Warszawa, commonly known as Warsaw. It is situated in the east of the country and has an estimated population of 1,628,500 (as at 31/12/1996). The next largest city in Poland is Łodz, which has an estimated population of 818,000 and is situated in the centre of the country, closely followed by Krakow and Wroclaw, which each have an estimated population of 740,700 and 640,600 and are situated in the south of Poland.

4. Health and Social Care System

Poland has a comprehensive health care system which is available to Polish Nationals and foreigners who have been given residence status there. Each voivod has a number of district health centres which provide a full range of treatment including mental health care. Psychiatrists and physiologists undertake counselling both for the public funded welfare system and privately. There is a private health care system, although it is expensive. Some of the large state companies have their own medical centres, including mental health care.

It is recognized that people with disabilities may require special consideration in relation to health care provision. Article 68 of the Polish Constitution specifically states that public authorities must ensure "special health care" for "handicapped people." Specialist health care for people with intellectual disabilities is, however, predominantly limited to institutional care for those who also have a mental illness and/or challenging behaviour. Primary and secondary services are accessed via the general health care system.

4.1 Organisation

The Ministry of Labour and Social Policy (MPS) is the ministry under which disability falls. Under the ministry is the Government Plenipotentiary for Disabled People which supervises execution of tasks specified by the relevant government Act. The advisory body to the Plenipotentiary is the National Consultation Council for Disabled Persons. The Plenipotentiary does not collect or process information about residential services. The Department for Social Assistance and Integration, also under MPS, is responsible for this area of social policy. The Central Statistical Office (CSO) compiles statistics on disability, included in its yearbooks.

The creation of the ministry made care and rehabilitation (especially the social and vocational aspects) the focus for central, regional and local authorities. Partly due to public opinion, and partly due to the influence of models of care and rehabilitation coming to Poland from Western Europe, new standards of providing care and rehabilitation services for all disabled people were developed.

4.2 Financing

Funding for service provision is administered by the state. Resources for the implementation of tasks are transferred to the lower administrative levels in the forms of grants and subsidies.

The State Fund for Rehabilitation of Disabled Persons (PFRON) is the state's targeted fund established on 1 July 1991. PFRON funds are allocated to: 1) voivodship and

poviat-level local governments, to finance specific tasks, and 2) entities performing tasks assigned by the Fund or other tasks under the Act. The Fund's resources are used to establish new and retain existing jobs for the disabled, to fund social rehabilitation of such persons, and co-finance tasks under governmental programs. At least 65% of the Fund's revenues are channelled into employment and vocational rehabilitation.

5. Definition, eligibility and diagnosis/assessment

The first official definition was published in the Polish Parliament Resolution from 1. August 1997. The disabled were defined as persons *whose physical or mental state constantly or temporary impedes, restricts or prevents them from leading everyday life, taking advantage of education work and taking up social roles according to the legal and common norms.* The Act on vocational and social rehabilitation and employment of disabled persons from 27 August 1997 defines disability as: *Temporary or permanent state of being unable to fulfil social roles, caused by permanent or temporary impairment of body functions. Such state in particular makes the person incapable of work.*

In Poland the term disability is used as a general term for all types of disabilities. However, for intellectual disability the term "mental retardation" is more common. For intellectual disability, there are different procedures for diagnosis and assessment for educational purposes (for children), for employment (for adults), and access to social benefits (adults and children). For educational purposes, children are diagnosed with one of four levels of intellectual disability: mild, moderate, severe, and profound. Legal disability status can only be awarded for those with disabilities of at least a moderate level. There is lack of specific data on people with intellectual disabilities.

6. Prevalence of disability

According to the 2002 Population and Housing Census, the number of disabled people reached 5.5 million, constituting 14.3% of the total population. Approximately 12 percent (11.7) had legal confirmation of disability, while 2.6% of the population only declared biological disability (these persons did not have legal confirmation of disability). Thus, in 2002 one in seven Poles was a disabled person (Nowak, 2004). The number of disabled persons increased by more than 1.7 million between 1988 and 2002, by 46.1%, largely due to the process of ageing of the population. Women constitute the majority of the disabled (52.9%) (Nowak, 2004). Nearly 60% of the disabled are retirement age.

7. Residential Services for people with a disability

7.1 Overview

The type of help offered to persons who require long term care is residence in a social care centre. Social care centres are around the clock permanent living establishments. The provide services for needs such as: assisted living, care, support, and educational needs. The Department for Social Assistance and Integration oversees residential facilities (social welfare homes) for persons with disability. Their organization is regulated by the Act on Social Welfare, 12 March 2004 and by Regulation of the Minister of Labour and Social Policy on social welfare homes, 15 September 2000.

There are six kinds of social care centres in Poland:

- For children and young persons with intellectual disabilities (up to 30 years old; however, in particular situations people can remain after age 30, for example if they have difficulty adapting to changes in environment)
- For adults with intellectual disabilities
- For old persons
- For persons with chronic diseases
- For persons with chronic mental illness
- For persons with physical disability

According to the welfare act, the operation and development of the care centres is the responsibility of the district and is accompanied by national financial support. Regional or specialized care centres can be operated by local governments of the voivodship. Territorial self-governing bodies can create a commission to operate a care centre, giving grants or financial backing to NGOs, religious organizations, foundations, etc. Care centres must obtain a license.

7.2 Services for children with a disability

According to the CSO, as of 31 Dec 2004, 3908 children and young people up to age 18 lived in stationary social welfare facilities. All of these facilities appeared to have a small proportion of residents up to age 18. The majority of children (1853) were in homes for intellectually impaired children and young people. (CSO, "Basic data on health services in 2004").

There are 104 social care homes/facilities for children and young people with intellectual disability, with 8097 places, 8017 residents. As noted above, residents 18 and younger comprise only part of the population (1853) of these facilities, the largest proportion of this population being 19-40 (4594).

Forty facilities are in the public sector; 64 in private sector. Although it was not possible to obtain the "typical size" of these facilities, based on a list of facilities by voivodship with the number of facilities and number of places, an estimate of the typical size is 50-100 places, although there are probably 3-4 with capacity of slightly more than 100. Most facilities seemed to be very near capacity (CSO, "Stationary social welfare facilities: long-term care by voivodship in 2005").

There are also residential institutions under the Ministry of Education: **special education care centres** (specjalne osrodki szkolno-wychowawcze) and **education centers** (specjalne osrodki wychowawcze). These units are for children with various kinds of disability. In 2005 there were 395 special education care centres and 51 education care centres, accommodating more than 31,000 children. Children with intellectual disabilities are the largest proportion of children at both types of facilities. These public institutions consist of a boarding school and an on-site special school (or schools) where both boarders and non-boarders are educated. Education care centres differ from special education care centres in that they are purely care institutions and do not include a school (although their wards must also fulfil the compulsory education requirement). Although children with mild intellectual disabilities comprise the largest group of children placed in these centres, concern was expressed in the EUMAP report "Rights of People with Intellectual Disabilities: Access to Education and Employment" (2005) that too many children are placed there simply because they are from disadvantaged families. A difficult financial situation can mean that

residence of children in special education care centres serves as a form of social support for the family. The report argues that disability should not be a reason for limiting the right of a child to live in their family, concluding that "Only the need to provide really advanced professional care can be a justification for placing a child in an institution" (p. 79). The report also notes that some centres have serious financial problems and are not able to offer sufficient and adequate accommodation. Most of the homes inspected for the report were large, old buildings, often in bad condition with numerous architectural barriers. Accommodation was usually intended for 70-120 children. It was not able to determine the typical size of these facilities from the CSO data.

7.3 Services for younger adults with a disability

As noted above a fairly large number of individuals over age 18 reside in the social care homes for children and youth (6415). This represents less than 10% of the institutionalized adult population.

In 2005 there were 179 **social care homes and facilities for "adults mentally retarded**" with capacity of 15,239 (15,095 residents) according to the CSO. The majority of these (143) are in the public sector. Based on the number of places divided by number of facilities in each voivodship, estimated typical capacity is 100.

There are 241 **social care homes and facilities for individuals who are chronically ill with somatic disorders**, with 25,466 places and 24,317 residents. Most of these (197) are in the public sector.

There are 174 **social care homes and facilities for individuals who are chronically mentally ill**, with 17,782 places and 17,626 residents. The majority (145) are public sector. Estimated capacity of most is 100, although there are some that appear to have capacity of 200.

There are 13 **homes/facilities for physically handicapped individuals**, with 1119 places and 1112 residents. Seven are public, 6 are private.

7.4 Services for older adults

There are 15,695 individuals residing in **social care homes for old persons**.

8. Other relevant information on residential services

Otrebski (2000) noted that while some group homes and supported living had been developed in Poland, this could not be viewed as a "clear tendency" towards deinstitutionalization.

9. Staffing

According to standards established by the Welfare Act, therapeutic and care staff index employed full time in different types of care centres are as follows:
a) care centre for elderly people—not less than 0.4 per resident
b) care centre for people with chronic diseases—not less than 0.6 per resident
c) care centre for people with chronic mental disease—not less than 0.5 per resident
d) care centre for adult mentally handicapped people—not less than 0.6 per resident

e) care centre for children and youth mentally handicapped—not less than 0.6 per resident
f) care centre for physically handicapped people—not less than 0.5 per resident

There were 50,684 persons employed in social welfare homes (31 Dec. 2005). The categories of workers and number in category are as follows (roughly translated):

Kierujacy jednostkami organizacyjnymi (managers)	931
Dzialalnosci opiekunczo-terapeutycznej (therapeutic workers)	24,408
Dzialalnosci medyczno-rehabilitacyjnej (medical-rehabilitation)	8,615
Dzialalnosci administracyjnej (administrative)	4,480
Gospodarczy (housekeeping and service)	12,250

10. Costs

Since 1999, operation of care centres has been the sole responsibility of poviats and is financially backed by the federal government.

Care centres operated by the gminas are their sole responsibility; care centres operated by the poviat are their sole responsibility and are financially backed by the federal government; regional centres can be self-financed or financially backed by the federal government. Stays in the care centres are paid as follows:

- A person referred to the care centre is the first one to pay the costs up to 70% of his/her income, no more than the full cost of living
- When payment made by the resident does not cover costs of living, the family of the referred person pays if the financial situation allows them to do so
- The gmina from which the person is referred to the care centre makes up the difference

The amount of payment for stay in the care centre is to be determined by administrative decision while decisions concerning the amount of payments made by other entities are not decided on. Payments made by family members are determined by agreement. The family pays the amount of money to the gmina who then forwards it to the poviat to supplement payments up to the average cost of living.

The percent of residents paying all costs of stay is 2-4%.

11. Acknowledgements

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12. Information sources on disability used to compile the template and commentary, including people who were interviewed

Statistical data received from:
Aneta Wojciechowska, Ministry of Labour and Social Policy, Department of Social Assistance and Integration Aneta.Wojciechowska@mpl.gov.pl

Polish Central Statistical Office

Other:
Information on Special Education Care Centres sent by
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"Wydzial Uslug Pomocy Spolecznej DPiIS MPiPS" (Report on Social Welfare Homes) Sent by Ewa Chylek (on behalf of Mrs. Jolanta Lukasik), Ministry of Labour and Social Policy, Department of Social Assistance and Integration
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Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

Portugal

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Summary of the available data

Descriptions of service types

Type of service	Size interval	Age group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admission	Age of service
Lar de Apoio para jovens e crianças com deficiência (Support home for children with disability)	11 to 30 places	0 - 18/19 years	.	24 hour	All (over 95%) private	Regional authority/LA/ County and state	Mixed	0 to 20 years
Centro de Reabilitaçao Psicopedagogica de crianças e jovens (Ordens Religiosas) (Rehabilitation centres for children and youngsters)	201 places +	3-18/19 years	Mixed ID with PD, SD, MH, Beh and other	24 hour	Voluntary/not-for-profit (over 95%)	State	All long term	0 to 20 years
Centro de Recuperaçao de Menores (Recuperation centre)	100 to 150 places	3-18/19 years	Mixed ID with PD, SD, MH, Beh and other	24 hour	Voluntary/not-for-profit (over 95%)	State	All long term	0 to 20 years
Colégio de Educação Especial com Residência (Residential School)	.	6-18 or 19 years	ID only	24 hour	All (over 95%) private	All private/insurance	All long term	0 to 20 years
Residência Autónoma para Pessoas com Deficiência (Autonomous Residential Home for people with a disability)	6 to 10 places	16/18/25 to 60/65 (adults but not older adults)	Mixed	Less than 10 hrs per week	Voluntary/not-for-profit (over 95%)	Regional authority/LA/ County and state	Mixed	21 to 50 years
Lar Residencial para Pessoas com Deficiência (Residential Home for people with a disability)	11 to 30 places	16/18/25 to 60/65 (adults but not older adults)	Mixed	24 hour	Voluntary/not-for-profit (over 95%)	Regional authority/LA/ County and state	Mixed	21 to 50 years

Type of service	Size interval	Age group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admission	Age of service
Unidade de Vida Apoiada para Doentes Mentais (Supported Residential unit for mental disorders)	11 to 30 places	16/18/25 to 60/65 (adults but not older adults)	Mixed	24 hour	Voluntary/not-for-profit (over 95%)	Regional authority/LA/ County and state	All long term	21 to 50 years
Centro Psicogeriátrico (Ordens religiosas) (Psychogeriatric centre)	51 to 99 places	over 60/65	Elderly infirm/mentally ill/dementia	24 hour	Voluntary/not-for-profit (over 95%)	State	All long term	50 - 100 years
Santas Casas (Residential settings for elderly people)	151 to 200 places	over 60/65	Elderly infirm/mentally ill/dementia	24 hour	Voluntary/not-for-profit (over 95%)	Mixed (any)	All long term	50 - 100 years
Lar de Idosos (Residential setting for elderly)	.	over 60/65	Elderly infirm/mentally ill/dementia	24 hour	Voluntary/not-for-profit (over 95%)	Mixed benefits and state/LA contributions	All long term	50 - 100 years

Data available by service type – breakdown by size and disability

Type of service	Places total	Under 30 places	Over 30 places	Size unspecified	ID	MH	PSD	Elderly/ dementia	Mixed/ dual	Other/ Unspecified
Colégio de Educação Especial com Residência (Residential School)	.	.	.	.	.	.	.	.	.	.
Lar de Apoio para jovens e crianças com deficiência (Support home for children with disability)	642	642	.	0	.	.	.	.	642	0
Centro de Recuperaçao de Menores (Recuperation centre)	120	.	120	0	120	.	.	.	.	0
Centro de Reabilitaçao Psicopedagogica de crianças e jovens (Ordens Religiosas) (Rehabilitation centre for children and youngsters)	240	.	240	0	240	.	.	.	.	0
Residência Autónoma para Pessoas com Deficiência (Autonomous Residential Home for people with a disability)	.	.	.	.	.	.	.	.	.	.
Lar Residencial para Pessoas com Deficiência (Residential Home for people with a disability)	3,592	3,592	.	0	.	.	.	.	3,592	0
Unidade de Vida Apoiada para Doentes Mentais (Supported Residential unit for mental disorders)	94	94	.	0	.	94	.	.	.	0
Unidade de Vida Autonoma para Doentes Mentais (sheltered residential unit for mental disorders	99	99	.	0	.	99	.	.	.	0
Psychiatric hospital for mental disorders	1,707	.	1,707	0	.	1,707	.	.	.	0
Psychiatric social institutions from religious orders	4,612	.	4,612	0	.	.	.	.	3,880	732
Residential unit for psychiatric patients with legal problems	269	.	269	0	.	269	.	.	.	0
Rehabilitation centre for psychiatric patients	47	.	47	0	.	47	.	.	.	0
Lar de Idosos (Residential setting for elderly)	1,336	.	1,336	0	.	.	.	.	.	.
Centro Psicogeriátrico (Ordens religiosas) (Psychogeriatric centre)	222	.	222	0	.	.	.	.	222	0
Santas Casas (Residential settings for elderly people)	4,715	.	.	.	.	.	.	.	.	.
Total	**17,695**	**4,427**	**8,553**	**0**	**360**	**2,216**			**8,336**	**732**

Data available by service type – breakdown by gender and age

Type of service	Places total	Male	Female	Gender unspecified	Children	Younger adults	Older adults	Adults over 18	Age not unspecified
Colégio de Educação Especial com Residência (Residential School)	.	.	.	.	.	.	.	.	.
Lar de Apoio para jovens e crianças com deficiência (Support home for children with disability)	642	.	.	.	642	.	.	.	0
Centro de Recuperaçao de Menores (Recuperation centre)	120	0	120	0	120	.	.	.	0
Centro de Reabilitaçao Psicopedagogica de crianças e jovens (Ordens Religiosas) (Rehabilitation centre for children and youngsters)	240	0	240	0	240	.	.	.	0
Residência Autónoma para Pessoas com Deficiência (Autonomous Residential Home for people with a disability)	.	.	.	.	.	.	.	1,707	.
Lar Residencial para Pessoas com Deficiência (Residential Home for people with a disability)	3,592	.	.	.	.	3,294	.	.	298
Unidade de Vida Apoiada para Doentes Mentais (Supported Residential unit for mental disorders)	94	.	.	.	.	94	.	.	0
Unidade de Vida Autonoma para Doentes Mentais (sheltered residential unit for mental disorders	99	.	.	.	.	99	.	.	0
Psychiatric hospital for mental disorders	1,707	.	.	.	.	.	.	.	1,707
Psychiatric social institutions from religious orders	4,612	1,625	2,255	732	.	.	.	3,880	732
Residential unit for psychiatric patients with legal problems	269	.	.	.	.	.	.	.	269
Rehabilitation centre for psychiatric patients	47	.	.	.	.	.	.	.	47
Lar de Idosos (Residential setting for elderly)	1,336	.	.	.	.	.	.	.	1,336
Centro Psicogeriátrico (Ordens religiosas) (Psychogeriatric centre)	222	52	170	0	.	.	222	.	0
Santas Casas (Residential settings for elderly people)	4,715	.	.	.	.	.	.	.	4,715
Total	**17,695**	**1,677**	**2,785**	**732**	**1,002**	**3,487**	**222**	**5,587**	**9,104**

Staffing

Information on staffing only available for 3 service types.

Type of service	Total staff	Care staff/nurses/ might include teachers in boarding school	Managers or other administrative staff (not care staff)	Educators/daystaff	Day and care staff (no distinction made)	Clinical staff (Drs, therapists, psychologists, etc.)	Other staff (mainly ancillary staff)	Other staff (excluding ancillary staff)
Psychiatric hospital for mental disorders	874	616	.	.	.	258	.	.
Psychiatric social institutions from religious orders	2,052	521	.	151	.	231	.	1,149
Rehabilitation centre for psychiatric patients	32	24	.	8	.	.	.	.
Total	**2,958**	**1,161**		**159**		**489**		**1,149**

Completeness and accuracy of the data

Availability and reliability of information about services in Portugal follows different pathways depending on whether we are interested on mental health services or social services. Data about mental health residential services are more complete. In many cases the borders between these two areas are quite confusing, as occurs in other countries. Residential services are provided by health public sectors, ngos, private non profit institutions, charities, municipalities, etc. However there is not an available catalogue accounting for all types of services, nor a national survey that put together services characteristics, number of places or data about residents.

List of services
The lists of services have been produced collating information available in different sources. Mental health services included in the lists have been obtained from a national chart of mental health services edited by the Ministry of Health. However alternative residences and services depending on charities are not included in a clear way. Social services and overall services for intellectual disability are not clearly assigned to mental health services or social services. We are not able to provide information about the number of places of two types of services: Colégio de Educação Especial com Residência (Residential School) and Residência Autónoma para Pessoas com Deficiência (Autonomous Residential Home for people with disabilities).

Size of services
This is a reliable data as there are laws and norms that specify the required size for every type of service. We have checked the size of services in a broad web search and all of them follow the normative.

Disability type
Numbers in this section for mental health services are accurate as these services are specific. However social services for mixed disabilities and services for elderly do not provide number of places for different types of disability. We have included the numbers in the "mixed" category.

Age and gender
It is difficult to provide data about sex and gender of residents. Disaggregated numbers are not available and several services provide care for adults and older adults. Although services have been divided into services for adults and services for older adults depending on their aims there is a number of places that are used by different age groups.

Staff training and staff numbers
Staff numbers are only available for mental health services. Social services do not provide information about staff.

Costs
Detailed data about costs for social services is included in this report. However data about mental health services is not available.

Commentary: Portugal

1. Overview

Portugal is a democratic republic ruled by the constitution of 1976 with Lisbon, the nation's largest city, as its capital. The four main governing components are the president of the republic, the assembly of the republic, the government, and the courts. The constitution grants the complete separation of powers among legislative, executive, and judicial branches. The administrative system comprises 18 districts and 2 autonomous regions (Azores & Madeira).

2 Political and social context

2.1 Government organisation and structure

The president, who is elected to a five-year term, has a supervising, nonexecutive role. The Assembly of the Republic is a unicameral parliament composed of 230 deputies elected for four-year terms. The government is headed by the prime minister, who chooses the Council of Ministers, comprising all the ministers and the respective state secretaries. The courts are organized into categories, including judicial, administrative, and fiscal. The supreme courts are the courts of last appeal. A thirteen-member constitutional court oversees the constitutionality of legislation.

Portugal has an administrative structure of 308 municipalities (Portuguese singular/plural: concelho/concelhos), which are subdivided into more than 4,000 parishes (freguesia/freguesias). Municipalities are grouped for administrative purposes into superior units. For continental Portugal the municipalities are gathered in 18 Districts, while the Islands have a Regional Government directly above them. Thus, the largest unit of classification is the one established since 1976 into either mainland Portugal (Portugal Continental) or the autonomous regions of Portugal (Azores and Madeira).

Portugal joined the European Union in 1986 and started a process of modernization within the framework of a stable environment. It has achieved a healthy level of growth. Successive governments have implemented reforms and privatized many state-controlled firms and liberalized key areas of the economy. Portugal was one of the founding countries of the Euro in 1999.

The Global Competitiveness Report for 2005, published by the World Economic Forum, places Portugal on the 22nd position, ahead of countries like Spain, Ireland, France, Belgium and Hong Kong.

A research about standard of living by Economist Intelligence Unit or EIU Quality-of-life Survey places Portugal as the 20th country with best quality of life in the world.

2.2 Disability relevant policy

The Portuguese legislation is notoriously shaped by international guidelines and directives, such as UN Standard Rules on Equalisation of Opportunities for Persons with Disabilities, the Recommendation nº R (92) 6 of the Committee of Ministers of the Council of Europe on a coherent policy for people with disabilities, the European

Social Charter, also of the European Council, and the Treaty of Amsterdam. The national legal system reflects an evident determination to implement a global policy on rehabilitation, including towards such end the following areas: health, education, social security, employment, vocational training, transportation, housing, sports and culture.

According to the law n. 17/2000 of 8 August, the purpose of the Portuguese Social Security System includes the right to the social protection and the development and adaptability of its rules to the conditions and contingencies of social, economic and demographic order. This law launches the basis of the new social security system in Portugal. However, it has not been implemented yet, being the social security legislation previous to the approbation of this law still in effect.

The main general principles on which the system is based are the following: universality, equality, social equity, positive discrimination, solidarity, social inclusion, acquired rights maintenance, public responsibility, complementarity, legal guarantee, unity, efficiency, decentralisation, participation and information. The sub-system on the family protection covers: Family charges, Disability and Dependency

Article 71 of the Constitution of the Portuguese Republic determines that citizens with disabilities “enjoy the rights and are subjected to the obligations contained in the Constitution, with the exception of the exercise or compliance with those for which they are incapacitated”

The Constitution also stipulates that the State should develop a national policy for prevention, treatment, re-education and integration in relation to disabled people. Moreover, it should act to make society aware of its duties of respect for and solidarity with disabled people, and should ensure that they fully enjoy their rights, without prejudice to the rights and duties of the parents or guardians”.

Item number 3 states, “the State supports citizens with disability”.

The Portuguese legislation has been organised taking into account the elimination or attenuation of the social, economic and cultural inequalities in order to ensure juridical-material equality, or the reaffirmation or confirmation of the principle of equality. This principle concludes by prohibiting both the illegitimate advantages and disadvantages, in the attribution of rights or in imposition of obligations or responsibilities.

The comprehensive law of 1989 (Law n. 9/89, of May 2 - Frame Law on Prevention, Rehabilitation and Integration of People with Disabilities) defines the national policy on rehabilitation. It aims at promoting and ensuring the exercise of the Constitutional rights in the areas of disability prevention, treatment, rehabilitation and equal opportunity.

Article 4, nº 6, states that equality of opportunities "... imposes that all the discrimination due to disability are eliminated, and that the physical environment, social and health services, education and work, cultural and social life in general become accessible to all".

This law lays out the policy aims concerning health, education, social security, vocational training, employment, transport, accessibility, information, housing and public buildings, fiscal matters, culture, sport and recreation, in order to achieve equal opportunity through attention to individual needs, and by eliminating social, cultural and physical barriers to integration. The rehabilitation policy obeys to the principles of universality, wholeness, integration, co-ordination, equal opportunity, participation, information and solidarity.

Compliance with these principles guarantees people with disabilities equality of rights and opportunities, as long as the objectives of sectorial policies are undertaken in the fields of prevention, medical-functional rehabilitation, education, social security, vocational rehabilitation, employment, transportation, housing, accessibility, information, finance, culture, sports and recreation, as defined in the present law.

In order to get an Invalidity Pension and to be eligible to use different types of services for being disabled a medical diagnosis of a condition followed by a medical certification of the invalidity is needed (this applies to physical or mental permanent incapacity).

In 1997, the National Council for Rehabilitation and Integration of People with Disabilities (Decree-Law 225/97, of August 27), existing since 1977 as a body of the National Secretariat for Rehabilitation, became an advisory body of the Minister of Labour and Solidarity for the definition and execution of the policies on rehabilitation and integration of people with disabilities, directly dependent on the Minister. This Council's mission is to enable the participation of public services, social partners and associative movements in the areas of prevention, rehabilitation and integration of people with disabilities in the definition of the national policies on rehabilitation.

The SNRIPD -Secretariado Nacional para a Reabilitação e Integração das Pessoas com Deficiência (National Secretary for the Rehabilitation and Inclusion of People with disability) depends on the Ministry of Work and Social Solidarity and aims to define national policy for rehabilitation, residential living, prevention and inclusion of people with disabilities. They also provide information about programs, activities and statistic information at their webpage.

3. Demographics

The country is fairly homogeneous linguistically and religiously. Native Portuguese are ethnically Caucasian with mixed immigrant population from previous Portuguese colonies.

In the 2001 census, the population was 10,356,117, of which 51.7% was female. By the end of 2003, legal immigrants represented about 5% of the population, and the largest communities were from Brazil, Ukraine, Romania, Cape Verde, Angola, Russia, Guinea-Bissau and Moldova with other immigrants from parts of Latin America and Eastern Europe. The great majority of Portuguese are Roman Catholic. The biggest metropolitan areas are Lisbon, Porto, Braga, Coimbra, Setúbal and Aveiro.

Portugal, long a country of emigration, has now become a country of net immigration, and not just from the former Indian and African colonies. Today, many Eastern

Europeans (especially Ukrainians, Moldavians, Romanians and Russians), as well as Brazilians, are making Portugal their home. There is a rapidly growing community of Chinese and a notable number of Macanese, who are descendants of Chinese and Portuguese settlers, with some Malays and Indians.

Key data

- Area - 92,142 km2
- Population – 10.536.000 (2004)
- Active population - 5,523 thousand (2004)
- Gross Domestic Product - 135,035 Eur (2004)
- Gross Domestic Product per capita – 18,465 Eur (2005) listed country number 34.

4. Health and Social Care System

4.1 Organisation

Social Welfare in Portugal depends on the Ministry for Labour and Social Solidarity. The Ministry was created in 1916 as Ministry for Labour and Social Welfare. Now it is called Ministério do Trabalho e da Solidariedade Social (MTSS)

Duties performed by the MTSS include definition, orientation and practice of the politics of labour and employment, professional training, social security and social insertion, as well the rehabilitation of disabled people. The politics of MTSS are putting into action through integrated services under the direct administration of State, organisms under superintendence and tutelage as well consulting organisms.

The "Social Action System" (Sistema de Acçao Social) implemented by public, private and non-profit organisations aims to prevent and to look for a solution for deprivation situations and socio-economic disparity in dependency, disability and social exclusion/vulnerability as well as for the community integration and promotion of people and their empowerment.

The government-run social security system provides old-age, disability, sickness, and unemployment benefits, family allowances, and health and medical care. The system is funded by payroll contributions from employers and employees. The government subsidizes social pensions for those persons not employed. Retirement is set at age 50 for miners, age 55 for fishermen and seamen, and age 65 for other professions. Medical benefits are provided to all residents, and cash sickness and maternity benefits are provided to employees. Maternity benefits of 100% of earnings and benefits are paid for 120 days for all employed persons. Paternity and adoption benefits are also available. There is a income based family allowance, a special education allowance, and a funeral grant.

Under the solidarity and social security system, benefits in kind, especially those intended to support disabled people, come under social welfare. Support of this kind

in practice enables people to use a network of equipment and services and provides the resources that they need to do so. For instance: permanent care homes; care homes for people with permanent or temporary disabilities aged over 16; day centres; temporary foster homes for disabled infants and children aged 6 to 16. Attendance of an establishment depends, among other conditions, on the nature and extent of the disability. Financing is paid directly by the state to the host establishment, following the conclusion of an individual agreement. Beneficiaries pay an amount towards costs calculated on the basis of their family income. Complete information about the services provided for disabled people, elderly, young and children, etc can be found in the document: "Carta Social. Rede de Serviços e Equipamento 2005". http://www.dgeep.mtss.gov.pt/estudos/cartasocial.php This document is a complete working paper that provides statistics about the use of social services and a lists of the different type of social services serving different populations.

NHS psychiatric and mental health care is organised around the following areas: adults' mental health, infant and childhood mental health, alcohol rehabilitation and drugs rehabilitation. There are high socio-economic and regional inequities in access to health care and funding in Portugal.

The Ministry of Health is also responsible for the long term care or Continuous care of people with disability. A recent resolution from the Council of Ministries (Resolução do Conselho de Ministros n.º 84/2005) claimed for a reorganisation of the National Health System in order to be able to provide health care to the ageing population, the disabled population and in general to all the citizens with a severe loss of autonomy. This resolution promotes the integration of the health and social security dimensions. Based on this resolution a National Policy for the Creation of a Network of Continuous Care Services have been developed. Different pilot services have been set up and objectives have been established in order to complete the network within ten years (2006-2016). Continuous care services for ageing and disabled include the creation of nearly 17,000 new places/beds for rehabilitation, continues care, promotion of autonomy and recovery. New services include units for autonomy recuperation and medium stance and rehabilitation: UNIDADES DE CONVALESCENÇA UNIDADES DE INTERNAMENTO DE MÉDIA DURAÇÃO E REABILITAÇÃO; Units for Long and Continues Care: UNIDADES DE INTERNAMENTO DE LONGA DURAÇÃO E MANUTENÇÃO and Palliative Care Units: UNIDADES DE CUIDADOS PALIATIVOS.

4.2 Financing

The Portuguese health care system is based on a tax funded NHS that is expected to provide universal access to health care, nearly free at the point of use. Given historical developments, provision and/or funding of mental health care is the joint responsibility of two Ministries, the Ministry of Health and the Ministry of Labour and Social Security. The legal framework that defines the state responsibilities for care funded or provided by the two ministries highly differs, which implies a split in the health and social care systems in mental health. This split between health and social care has been a factor contributing for high variations in local supply, and as currently designed, this split seems to be operating as a barrier to appropriate deinstitutionalisation of mental health care.

The legal framework for mental health care under the responsibility of the Ministry of Health is characterized by universal coverage, financial access nearly free at the point of use, and by provision dominated by the public sector. The public-private mix in provision varies for types of services, and the presence of the private sector in mental health care is higher than for most NHS services (for example, psychiatric inpatient care is mostly provided by the private not-for-profit sector). A central feature of the Portuguese NHS is the gate keeping system, with an entry to the system through primary care (that is dominated by public GPs for general consultations). Nonetheless, the Portuguese NHS has been centred on hospital care and has shown crucial difficulties in shifting care towards primary care settings (which implies problems of prevention, recognition and access to mental health care).

Social Security (i.e. social care) is characterized by universal coverage but financial access depending on socio-economic conditions/means-tested. The principle of subsidiarity applies to services provided through Social Security System, and no clear system of entitlement has been defined. There is no tradition of state provision of mental health social care services and the main providers are in the social sector (through Private Institutions of Social Security (IPSS) and the Holy Houses of the Poor ("Misericórdias")). Access depends highly on local availability of services, on local services of social security, and traditionally there has been a reliance on family care to support community services (although this is changing).

Within the NHS, the following payment systems have applied for mental health treatments:

- For inpatient care in psychiatric hospitals, a fixed rate per day of stay has been applied (with an adjustment for outliers)
- For acute inpatient care in general and specialised non-psychiatric hospitals, payments have been made at diagnostic related group rates (DRG), with the exception for readmissions (where fixed per day of stay prices apply)
- For day hospital and external consultations, payments are made per act.

Nevertheless, retrospective reimbursement has applied in practice to financing systems given that hospital deficits have not been punished. Overall, the financing system has been linked to production and has not accounted for need, and resource allocation methods and payments systems have not been promoting cost containment and efficient behaviour. Payments systems in the Social Security sector are legally defined by type of services (Oliveira, 2003), as a capitation payment or a fee for service, depending on the types of services. There has been a low spending in mental health for Portugal, and available figures on mental health spending are underestimated, as they do not account for the public spending under the social solidarity sector, for the family burden, and for other components, for which disentangling is difficult (e.g., such as difficulty in accounting for the private sector, and difficulty in computing spending mental health spending in the primary care setting). Many indicators show that given the level of resources invested, Portugal underperforms in the OECD and/or EU context.

5. Definition, eligibility and diagnosis/assessment

In Portugal, the general definition of the term "disability" is set out in the Framework Law on prevention and rehabilitation of disabled persons (Law 9/89 of 2 May 1989).

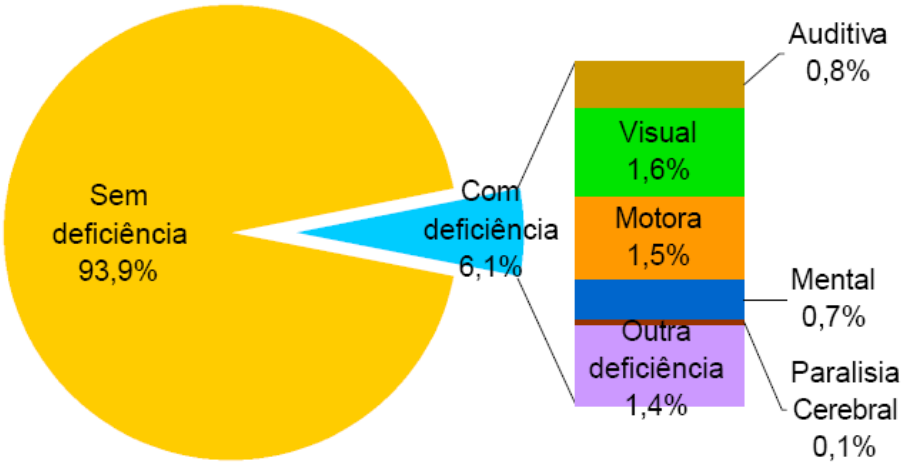
Under this law, people who, as a result of a congenital or acquired loss or abnormality of psychological, intellectual, physiological or anatomical structure or function, are in a disadvantaged situation as regards the performance of an activity considered normal taking account of age, gender and prevailing social and cultural factors, are considered to be disabled. For social security purposes, the legal provisions regulating disabled people's eligibility for benefits have used this definition. Entitlement to benefits is not shaped by the various forms of disability; it is guaranteed when there is a proven situation of disability in keeping with the above definition.

6. Prevalence of disability

The most updated statistics about people with disability in Portugal are from February 2002 (www.ine.pt) and data were obtained from a national census. According to this, the number of people with disability at Portugal reached 634,408 of which 333,911 were males and 300,497 were females representing a total 6.1% of the Portuguese population. However, previous statistics from 1997 put the number of people with a disability at 905,488 which represented 9.16% of total population. It seems clear that some sort of methodological issue may be the responsible for this great difference at disability number. This question should be further clarified as it is difficult to estimate the exact number of people with disability at Portugal. See figures 1, 2 and 3.

According to data from the 2001 census visual disability was the most frequent in the Portuguese population followed by mobility disabilities, any other disability, hearing disability, mental disability and cerebral palsy.

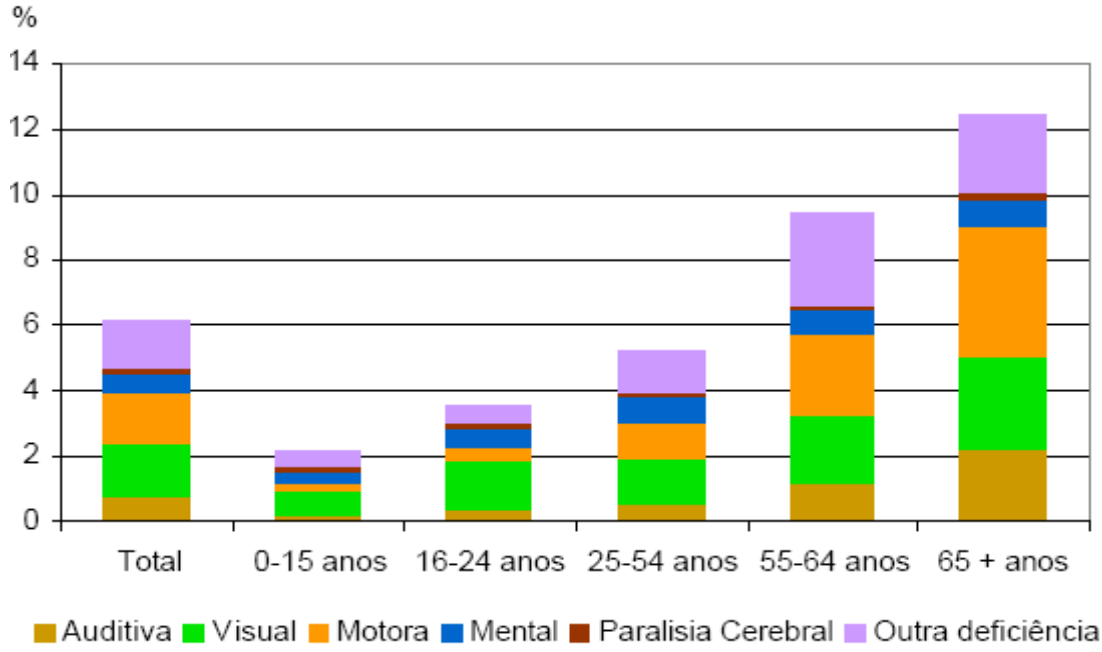
Figure 1 Population with and without disability and type of disability



Source: INE 2002

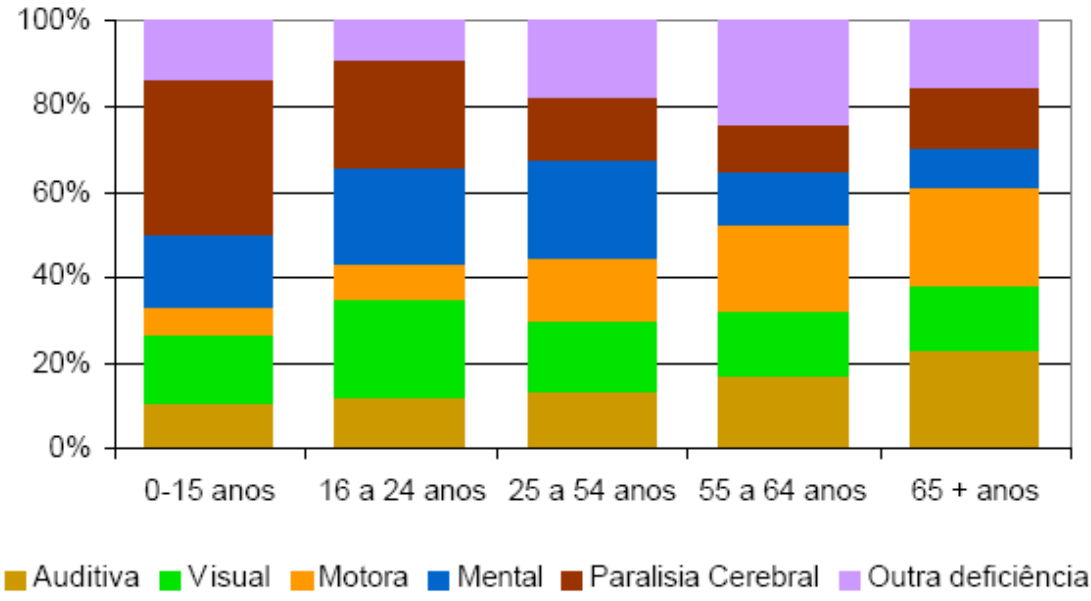
The higher rates of disability appear within the old adult population as it could be expected. About 12% of the population over 65 years have some kind of disability.

Figure 2 Type of disability per age range



Source: INE 2002

Figure 3 Type of disability distribution per range of age



INE 2002

7. Residential Services for people with a disability

7.1 Overview

Residential care for people with disabilities in Portugal is organized and funded by the Ministry of Health for people with mental health problems, physical rehabilitation needs and in some cases intellectual disabilities and the Ministry of Work and Social Solidarity for children with disabilities (mainly intellectual) and adults and old adults with disabilities. Charity organisations and private non-profitable sectors play an important role in service delivery. The set of services comprises residential settings staffed 24 hours, supported living, hospital care, educational residential centres and a whole range of services for mental health care. Detailed data on type of services, number of places and services characteristics are scarce.

7.2 Services for children with a disability

"Lar de Apoio para jovens e crianças com deficiência" (Support home for children with disability): Residential settings serving children with disability between 0 and 18 years old. The typical age is 6 to 16 years old. Normally, children in these institutions have more than one disability: mixed disability. There are in total 642 places. These institutions provide between 15 and 20 places to children with disability and provide educational support and help to families. The care is 24 hour support for long and short term care. These residential facilities are mainly private (non profit). The typical size of these institutions is between 10 and 30 places.

"Unidade de Saúde Mental para crianças em Hospitais Gerais" (Mental health unit for children at general hospital): in total there are 24 places all for less than 10 persons. This service serves children between 0 and 18 years old. These institutions provide 34 places in each institution. There are 113 persons working in these Residential Facilities: 38 are care staff, 15 are education and day care staff, 60 are clinical staff. This kind of facility is public, with 24 hour support and acute treatment. This service type is not included in the template on the basis that it is short-term rather than long-term care.

"Centro de Reabilitaçao Psicopedagogica de crianças e jovens (Ordens Religiosas)" (Rehabilitation centre for children and youngsters): Residential centres for mild and severe intellectual disabilities, motor problems and cerebral palsy, multiple disabilities and other problems related to psychiatric disorders for children and youngsters of both sexes. There are 240 places in these institutions and all of them are in institutions with 201-500 places. They are private Institutions (100% non-profit) and provide 24 hour care support for long term. All places (240) are occupied by children with intellectual disability. All the places are for children between 3 and 18 years old.

"Centro de Recuperaçao de Menores" (Recuperation centre for children and youngsters)": Residential setting for health care with treatment and rehabilitation for children and younger with mental disability and other problems related to mental health. All the places (120) are for children with intellectual disability and for institutions with 101 to 200 people. The children in these institutions are between 3 and 18 years old. These Institutions are private and provide long-term care and 24 hour support. All places are for female children.

"Colégio de Educação Especial com Residência" (Residential School): For children with disability between 6 and 18 years old. Service users are typically aged between 7-17 years. The children in these institutions have psychical disability. These institutions provide educational support. The care is 24 hour support for long-term. These residential facilities are private. No data is available about the number of places in these institutions.

7.3 Services for younger adults with a disability

"Lar Residencial para Pessoas com Deficiência" (Residential Home for people with a disability): The typical number of places in these type of service is between 12 and 24. The age group served is usually from 16 to 60 years old and the typical age of these services is from 19 to 59 years old. There are 3,592 places for persons with a disability in these facilities. The places are mixed and different types of disabilities can be admitted. The **"Lar Residencial para Pessoas com Deficiência"** provides 24 hour support for long and short–term care and there are mainly private institutions. There are 3,592 places in these institutions for institutions with 10 to 30 people.

"Residência Autónoma para Pessoas com Deficiência" (Autonomous Residential Home for people with a disability): They are apartments or houses for people with disability who are able to live alone. They are visited by care staff every day or night and the places are 5 to 7 in each house or apartment. People with 16 to 60 can live in these settings. These houses or apartment provide long and short term care and mainly are private institutions. The exact number of places in this type of service is not available.

"Unidade de Vida Apoiada para Doentes Mentais" (Supported Residential unit for mental disorders): in total there are 94 places for people with a disability: all for mental health. The typical number of places is 20 and the age group served is between 18 and 65 years old. The majority of places are for people from 19 to 59 years old. These institutions provide 24h support care, usually on a long-term basis. These institutions are mainly private non-profit. All the places "**Unidade de Vida Apoiada para Doentes Mentais"** are for 10 to 30 people.

"Unidade de Vida Protegida para Doentes Mentais" (Sheltered Residential unit for mental disorders): Residential setting to promote the autonomy of adults with severe psychiatric problems with chronic evolution. The aim is the rehabilitation and social inclusion of service users. The typical number of places is between 5 and 7 places. The age group served is usually from 18 to 60 years old. There are 99 places for persons with disability in these facilities: all the places are for people with mental health problems and for institutions with less than 10 people. These institutions provide long-term and 12 hour support only. These institutions usually are private non-profit.

"Unidade de Vida Autónoma para Doentes Mentais (Autonomous Residential unit for mental disorders)": Residential facilities for adults with severe psychiatric problems, but stable and good autonomic capacity that allow their inclusion in training programs and in sheltered or normal work. The typical number of places is between 5 and 7 places. The age group served is usually from 18 to 60 years old and the typical age of these services is from 19 to 59 years old. There are 29 places for persons with disability in these facilities, all for mental health. The **"Unidade de**

Vida Autónoma para Doentes Mentais" provides 12 hour support for long-term care, with care staff visits every day . They used to be private institutions. The 29 places used to be for people between 19 and 59 years old and these places are all in institutions with less than 10 places.

"Unidade en Hospitais Gerais para Saúde Mental" (Mental health units at general hospitals): These institutions are for people with mental health problems who are aged between 18-60, usually are 19 to 59 years old. They have 15 to 50 places and each one have between 31 and 50 people. These institutions provide 24 hour support and are public. There are in total 1,010 places in this type of residential service. This service type is not included in the template on the basis that it is short-term rather than long-term care.

"Casa de Saúde (Ordens religiosas)" (Psychiatric clinics depending on Religious Orders): For adults with mixed disability aged between 18-60 years. Typical services include acute and chronic psychiatric settings, psychogeriatric units, and psychiatric rehabilitation services. The typical age is 19 to 59 years old. These institutions provide between 150 and 500 places to adults with a disability. The care is 24 hour support for long and short term. These residential facilities are private (non-profit). There are 4,612 places in the "**Casa de Saúde**" in Portugal. Although there are no exact figures, it is estimated that there are at least 1,625 places for males and 2,255 for females. Personnel working in these institutions include also the personnel for the "Medical Rehabilitation Hospital" and the Psychogeriatric Centres given that they are different services but depend also from the same religious orders and they provide aggregated data for all their services. These services are staffed by a total of 521 direct care staff, 151 education or day care staff, 231 clinical staff and 1,149 other staff.

"Unidade de Psiquiatria Forense" (Residential unit for psychiatric patients with legal problems): For adults and older adults between 18 and 80 years old with psychiatric disorders and legal problems**.** The typical age is 19 to 80 years old. These institutions provide between 30 and 85 places to adults and older adults with mental health problems and also provide legal support. The care is 24 hour support for long and short term. These Residential facilities are funded by the State. There are 269 places in the "**Unidade de Psiquiatria Forense**" in Portugal, all in large institutions with 101 to 200 places.

"Centro Psiquiátrico de Recuperaçao" (Recuperation Centre for psychiatric patients): Institutions for people with mental health problems, between 18 and 60 years old. There are 47 places and all are in institutions with 31 to 50 places. They provide 24 hour support and long-term care too. They are public residential facilities. There are 32 persons working there: 24 are care staff and 8 are clinical staff.

"Hospital para Reabilitação Física" (Medical Rehabilitation Hospital): These institutions provide residential services for children, adults and older adults with a physical disability in need of care provision for rehabilitation. They provide 24 hour support, short-term care and they are private (non profit). There are 93 places in total in this type of service.

7.4 Services for older adults

"Lar de idosos" (Residential setting for elderly people)": provides accommodation and health and social care for elderly. Although they are not specific for people with a disability they can include a number of places reserved for people with disability or non-autonomous persons: Services with less that 20%, or 20-40%, 40-60%, and more than 80% of places reserved for people with disability. Typical age of residents is above 65 years. Places are publicly funded and there are a total of 1,336 specialised places for non-autonomous/dependent elderly under the Social welfare system.

"Centro Psicogeriátrico" (Ordens religiosas) (Psychogeriatric centre): is a residential service for elderly people with mental health problems and degenerating illnesses. These institutions have 50 to 80 places and are for older adults, aged 65 years or over. They provide 24 hour support on a long-term basis. They are private and have 222 places in Portugal: 52 males and 170 females and all the places are in institutions with 51 to 100 people.

"Santas Casas" (Residential setting for elderly, Religious orders): These services provide support, continuous care, day centres, etc. for elderly people. There are no exact figures about the number of places in this type of service. The data we present are partial and is an extract of the National Survey conducted by the Misericoridias – the religious order that runs these services. According to this study there are 4,715 places for severely affected or non-autonomous persons at these settings. There are no data regarding services size, gender of service users or staffing.

8. Other relevant information on residential services

The change of mental health care in Portugal has followed several principles that are common to other countries, like Italy and Spain (Direcçao Geral da Saude, 1995). The mental health care reform was initiated in 1985 and after 1990, when the Ministry of Health changed it was suspended until recent years (Direcçao Geral da Saude, 1999). Deinstitutionalisation is a political objective in Portuguese health policy, and there have been policies to implement deinstitutionalisation. There has been a decrease in public psychiatrics beds, as well as a change in the pattern of care in public psychiatric hospitals, with a decreased length of stay, and an increase in discharges and external consultations; and there has been a move towards transferring service users into general hospitals (and away from psychiatric NHS hospitals). Nonetheless, despite the decrease in the number of public psychiatric beds, evidence points for an increase in the number of psychiatric beds in the private sector (mostly not for profit), which raises questions on the extent of deinstitutionalisation and on the presence of re-institutionalisation. In addition, there have been difficulties to deinstitutionalise mental health care given the lack of alternative community services, as well as slowness to implement deinstitutionalisation. There is little information on the creation and level of community services, as well as a lack of local studies. Few routinely collected data is available in this area. Analysis has indicated that there are some opportunities to shift care away from hospitals, but there are also many barriers to deinstitutionalise mental health care while creating community services and improving access to services to the poorest. In particular, there is a critical need to improve available information on community services and on services provided by the private sector, to improve planning systems (to be linked with need), to develop transparent payment systems that create appropriate incentives to the private sector, in

special in areas with low supply of services, and to define entitlements for populations.

Number of psychiatric beds and patterns of discharge in psychiatric facilities, general hospitals and social care homes

On the one hand there has been a decrease in public psychiatric beds in psychiatric and non-psychiatric hospitals, but on the other hand, available evidence points for an increase in psychiatric beds in the social sector. For public hospitals, the length of stay has decrease in the last 10 years, while discharges have increased. There is lack of data to fully analyse trends in beds and discharges, because there is little information on supply and utilisation of mental health facilities in the private sector (including the social sector) and there is very little information on the provision of community services and services funded by the Ministry of Social Security (funded both at the central and local level).

There is evidence on effective deinstitutionalisation in the public sector, as there was a decrease on the number of NHS psychiatric beds in the last 10 years. The decrease in public beds is explained mainly by reductions in capacity, but also by closures of public psychiatric hospitals, by transfers of psychiatric hospitals to the social (private) sector, and to a smaller extent, by a decrease in psychiatric beds in non psychiatric hospitals. Since 1995 there was a maintenance of beds for alcohol and drugs rehabilitation, and also a decrease in NHS beds for psychiatric rehabilitation.

For NHS psychiatric services, there has been a decrease in beds, a reduction in the length of stay and an increase in admissions in psychiatric hospitals and in psychiatric services of non-psychiatric hospitals.

In 1996 most psychiatric beds were in the private not for profit sector. There is no routinely available information on beds and utilisation indicators for the social sector that would allow for accurate time trend analysis. There is only a 1996 publication that contains all the institutions with psychiatric activity. However, data from the 2004 referral network for mental health includes the numbers of beds for some large institutions, and even if it does not account for all institutions, it shows that there has been an increase in the number of psychiatric beds in the private not for profit sector (in comparison to 1996 data. This finding raises questions on the extent of deinstitutionalisation given the increase in capacity in the social sector, which is higher than the decrease in public psychiatric beds.

9. Costs

In the following table (Table 1) data on annual costs per type of setting and population for the Ministry of Work and Social Solidarity are provided. The annual costs for social residential settings for people with mental health problems is 1,040,798.69€, the residential services for people with disability reach a total of 37,764,153.77€.

Detailed data about mental health residential services costs will be presented in the WHO-AIMS Portugal report that will be available soon in the following address: http://www.who.int/mental_health/who_aims_country_reports/en/index.html

Table 1 Total annual costs for social residential services for elderly, disabled and mental health population

Population	Financed services	Source of financing		2005
Elderly	Private non profit Institutions	Programmed budget	Residential setting for elderly	2.151.050,13
		Current budget	Residential setting for elderly	169.841.968,57
			Complement for residential setting for elderly	1.800.111,50
			Residence for elderly	895.213,42
	Integrated settings	Running costs	Disabled Elderly	15.878.023,17
Disabled			Invalidity and rehabilitation	6.323.783,38
	Private non profit Institutions	Programmed budget	Residential Home	618.850,68
		Current budget	Residential Home	30.821.519,71
Mental Health	Private non profit Institutions	Programmed budget	Unidade de Vida Apoiada	
			Unidade de Vida Protegida	29.642,30
			Unidade de Vida Autónoma	1.387,90
		Current budget	Unidade de Vida Apoiada	420.673,18
			Unidade de Vida Protegida	561.787,43
			Unidade de Vida Autónoma	27.307,88

SIF/SAP Ministry of Work and Social Solidarity2006

According to the "As Misericórdias Portuguesas na assistência aos idosos" a study from the Observatory of severe dependents, a place for an elderly person within a hospital setting can reach 1610€ per month. However a place in a community residence for a person with high dependency and complex needs, reaches about 722€ per month. Regarding mental health treatment at psychiatric units depending of general hospitals the cost per day and patient admitted is around 114€ being the average cost per patient discharged 4,136€.

10. Issues

Diversity in the service provision in Portugal has settled different sources of information that overlap each other. Some of them are not available or just do not exist.

11. Acknowledgements

Thanks to the *Secretariado Nacional para a Reabilitação e Integração das Pessoas com Deficiência* in Lisbon for their help in the data collection and for providing updated information about services and costs.

12. Information sources on disability used to compile the template and commentary, including people who were interviewed

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Ministry of Health http://www.dgs.pt/

Government of Portugal http://www.portugal.gov.pt/

SNRIPD -Secretariado Nacional para a Reabilitação e Integração das Pessoas com Deficiência http://www.snripd.pt/

Mental Health Economics European Network. MHEEN. http://www.mheen.org/

Irmãs Hospitaleiras do Sagrado Coração de Jesus. http://www.ihscj.pt/

Contacts and Interviews:

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Prof. Mónica Oliveira. Instituto Superior Técnico. Departamento de Engenharia e Gestão.

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Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

Romania

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Summary of the available data

Description of service types.

Type of service	Size interval	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions	Age of service
Internat-scoala profesionala speciala (Special boarding vocational school)	.	14 + to adulthood (60/65 years)	.	24 hour	.	.	.	.
Internat-centru scolar special (Special boarding school centre)	.	3 to adulthood (60/65)	.	.	.	.	.	.
Shelter Homes (LP)	.	20 to 30	.	.	State	.	.	.
Unitate sanitara/sectie de spital (Sanitary unit/hospital section)	.	.	.	.	.	.	.	.
Complexele de servicii comunitare pentru. persoanele cu handicap (Community services complexes for persons with handicaps)	.	20 to 30	.	.	State	.	All long term	.
Psychiatric Hospitals	.	.	.	.	State	.	.	.
Family-type homes	6 to 10 places	3-18/19	.	24 hour	.	.	.	.
Centre de recuperare si reabilitare neuropsihiatrica (Neuropsychiatric recovery and rehabilitation centre)	100 to 150 places	All ages (0 to death)	.	.	State	Mixed (any)	.	.
Placement centres for	201	All ages	ID only	24 hour	Local	.	.	.

Type of service	Size interval	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions	Age of service
the rehabilitation and recuperation of children with medium or severe handicap	places +	(0 to death)			authority/municipality/county			
Centre de ingrijire si asistenta (Care and assistance centers) CIA	100 to 150 places	Over 18/25 (i.e. adults only)	Mixed	24 hour	State	Mixed (any)	All long term	21 to 50 years
Centru de primire a copilului in urgenta (Urgent receival center of children)	.	.	.	.	.	.	.	.
Centru maternal (Maternal centre)	.	.	.	.	.	.	.	.
Centre de ingrijire prin terapie ocupationala (Integration centers for occupational therapy) CITO	100 to 150 places	Over 18/25 (i.e. adults only)	ID only	24 hour	State	Mixed (any)	All long term	.
Placement centres for children with sight deficiencies	201 places +	3 into adulthood (60/65)	Sensory impairments	24 hour	Local authority/municipality/county	.	.	.
Centre de recuperare si reabilitare personae cu handicap (Recovery and rehabilitation centres) CRRPH	100 to 150 places	All ages (0 to death)	Mixed	24 hour	State	Mixed (any)	All long term	.
Placement centres for children with auditory deficiencies	201 places +	0 - 11	Sensory impairments	24 hour	Local authority/municipality/county	.	.	.
Centre pilot de	100 to	0 to 65	.	.	State	Mixed (any)	.	.

Type of service	Size interval	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions	Age of service
recuperare si reabilitare personae cu handicap (Pilot centres for recovery and rehabilitation)	150 places							

Data available by service type – size of service and disability groups.

N.B. No data available for children's services.

Type of institution	Places total	Under 30 places	Over 30 places	Size not unspecified	ID	MH	PSD	Elderly/ dementia	Mixed/ dual	Other/ unspecified
Shelter Homes (LP)	26	26	.	0	10	16	.	.	.	0
Complexele de servicii comunitare pentru persoanele cu handicap (Community services complexes for handicapped persons)	39	.	.	.	.	.	.	.	.	.
Psychiatric Hospitals	12210	.	10975	1235	.	.	.	.	.	.
Centre de recuperare si reabilitare neuropsihiatrica (Neuropsychiatric recovery and rehabilitation centre)	5515	27	5489	1	2462	2007	56	.	494	496
Centre de ingrijire si asistenta (Care and assistance centres) CIA	7689	77	7612	0	2083	1542	867	.	485	2712
Centre de ingrijire prin terapie ocupationala (Integration centres for occupational therapy) CITO	4573	54	1564	2955	952	3308	142	.	171	0
Centre de recuperare si reabilitare personae cu handicap (Recovery and rehabilitation centres) CRRPH	2344	30	2318	4	1377	505	54	.	271	137
Centre pilot de recuperare si reabilitare personae cu handicap (Pilot centres for recovery and rehabilitation)	387	.	390	3	156	185	1	.	36	9
TOTAL	**32783**	**214**	**28348**	**4182**	**7040**	**7563**	**1120**		**1457**	**3354**

Data available by service type – breakdown by age (no breakdown by gender was available and no data available for children's services)

Type of institution	Places total	Children	Younger adults	Older adults	Adults over 18	Age unspecified
Shelter Homes (LP)	26	.	.	.	.	26
Complexele de servicii comunitare pentu persoanele cu handicap (Community services complexes for handicapped persons)	39	.	19	20	.	0
Psychiatric Hospitals	12210	.	26	.	.	12184
Centre de recuperare si reabilitare neuropsihiatrica (Neuropsychiatric recovery and rehabilitation centre)	5515	137	4769	609	.	0
Centre de ingrijire si asistenta (Care and assistance centres) CIA	7689	60	3186	4443	.	0
Centre de ingrijire prin terapie ocupationala (Integration centers for occupational therapy) CITO	4573	46	1493	79	.	2955
Centre de recuperare si reabilitare personae cu handicap (Recovery and rehabilitation centers) CRRPH	2344	177	1913	254	.	0
Centre pilot de recuperare si reabilitare personae cu handicap (Pilot centres for recovery and rehabilitation)	387	191	196	0	.	0
TOTALS	**32783**	**611**	**11602**	**5405**		**15165**

Staffing

There is no information available for staffing of residential care facilities.

Completeness and accuracy of the data

The data for residential facilities for adults with disabilities is very good due to the excellent cooperation and organization of the National Authority for Persons with Handicaps (ANPH) under the Ministry of Social Solidarity and Family. At the time of the visit to the ANPH Office for Methodology, Standardization and Authorizing in August, 2006, they were able to produce data tables and pie charts to answer my questions. They also provided the *National Strategy 2006-2013 on social protection, integration and social inclusion of disabled people* (ANPH, 2005). Meetings were also held with the Director and the Scientific Secretary of the National Institute for Fighting Social Exclusion of Persons with Handicap, a research institute that is under ANPH. As a result, the template is fairly complete for adults, with the exception of information about staff level of training.

Meetings were also held with the Child Rights Monitoring Director and several other individuals from the National Authority for the Protection of Children (ANPCA), but with much less success. They provided no data at all. In response to repeated requests, one contact prepared a descriptive report, but there are few numbers in it. As a result, the template is lacking information on facilities for children with disabilities. Although informed that they would send the data requested for the template, this was never received. The only recent statistical data located for children with disabilities is from the ANPCA website (www.copii.ro): Table A.10, "Number of disabled children (from public and private centres, professional foster caregivers, extended families, biological families) monitored by specialized public services for child protection." Data on the following aspects of residential facilities for children with disabilities was not made available; however, it seems likely that this data does in fact exist:

- Size of facilities
- Proportion of children with specific disabilities in each type of facility
- Staff members in each type of facility
- Staff training

At the time of the visit to Romania (August 2006), the Ministry of Health was in some disarray. No response was received to email messages or letters sent by post to this ministry, and individuals from the other ministries were unable to provide a contact in the Ministry of Health. All of the information used in the template is from the website, although communication from one contact implied that of the 16,700 psychiatric beds, 4800 were for chronic patients, and that there are 38 mental hospitals and 75 psychiatric sections in general hospitals.

Commentary: Romania

1.Overview

Located in Southeast Europe, Romania is south of the Ukraine, east of Hungary and Serbia, north of Bulgaria, and its eastern border is the Black Sea. The population is approximately 22,300,500 and is 89.5% Romanian, 6.6% Hungarian, and 2.5% Roma.

2. Political and social context

The post-war Soviet occupation of Romania led to the formation of a Communist "people's republic" in 1947 and the abdication of the king. The decades-long rule of dictator Nicolae Ceausescu, who took power in 1965, and his Securitate police state became increasingly oppressive and draconian through the 1980s. Ceausescu was overthrown and executed in late 1989. Former Communists dominated the government until 1996 when they were swept from power. Romania joined NATO in 2004 and the EU in 2007.

2.1 Government organisation and structure

The Government of Romania is the executive branch of Romania. It is headed by the Prime-Minister, and consists of the Ministries, the institutions subordinated to it, and the 42 Prefectures (the representative of the Government in the territory (county)).

2.2 Disability relevant policy

The Romanian government approved the National Strategy for the Special Protection and Social Integration of People with Disabilities in Romania on 31 October 2002. This National Strategy was based on the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities. In order to develop an Action Plan for the implementation of the National Strategy, the European Commission financed a Twinning Light project: “Finalisation of the Romanian National Strategy for Persons with Disabilities and Elaboration of the Action Plan for the period 2001-2005.” A Draft Action Plan was finalized in March 2003 and approved by the government. The Plan indicated that special attention would be given to closure of large old style “camin spitals” by developing alternative social services and small scale residential care. The current *National Strategy 2006-2013* (ANPH, 2005) provides guidelines on social protection, integration and social inclusion of disabled people.

3. Demographics

The July 2007 population estimate of Romania was 22,276,056. 89.5% of the population is Romanian, 6.6% Hungarian, 2% Roma and the remainder Ukrainian, German, Russian, Turk, other.

4. Health and Social Care System

Social care is separated from health care. The Ministry of Health and the National House of Health Insurance are responsible for regulating and implementing health policies.

Psychiatric facilities are under the Ministry of Health. The Ministerul Muncii, Solidarității Sociale şi Familiei (MMSSF—Ministry of Work, Social Solidarity and Family), and increasingly, local authorities, are responsible for social care. MMSSF is the government ministry under which protection and services for individuals with disability are provided.

4.1 Organisation

Protection and services for children are under the National Authority for Child Protection and Adoption (ANPCA). ANPCA was created by Government Emergency Order no. 12/2001 as the specialized body of the Romanian government providing coordination in the field of children's rights protection. Government strategy for protection of children includes institutionalized children and special needs children.

Protection and services for adults are under the National Authority for Protection of Persons with Handicap (ANPH). The Authoritatea Națională pentru Personele cu Handicap - ANPH (National Authority for People with Handicaps; www.anph.ro) - is also under the Minister Muncil, Solidarității Sociale şi Familiei (www.mmssf.ro). It is the specialized body of the central public administration which coordinates activities related to the special protection and promoting of the rights of people with disabilities. It develops policies and standards, monitors enforcement of regulations and controls the special protection activities for people with disabilities. ANPH has within its structure the Superior Assessment Commission for adults with disabilities which make decisions in order to settle appeals against certificates establishing the degree of disability issued by the county commissions or the commissions of the districts of Bucharest. The ANPH has eight regional offices responsible for overseeing the implementation of disability policy. The National Institute for the Prevention and Combating of Social Exclusion of People with Disabilities is also under ANPH.

4.1.1 Special protection institutions coordinated by the National Authority for Disabled Persons, on March 31, 2006

Type of Institution	**Number**	**# of beneficiaries**
Care & Assistance Centres	82	7,689
Integration centres for Occupational Therapy	12	1,618
Disabled persons recovery and rehab pilot centres	5	387
Neuropsychiatry recovery & rehab centres	32	5,515
Disabled persons recovery & rehab centres	18	2,344
Sheltered Houses	2	26
Crisis Centres*	1	14
Community Services complexes for persons with Disabilities	1	39
Total	157	17,959

4.2 Financing

The protection system for people with disabilities is financed from the state budget, local budgets, donations and sponsorships, grant funds, contributions of people with disabilities and/or their families/legal representatives.

5. Definition, eligibility and diagnosis/assessment

The Romanian Constitution refers to the protection of "handicapped people," and the word "handicap" is used in official law and policy. There is no specific definition of intellectual disabilities used in legislation.

There are separate procedures for the diagnosis of disability in children and adults. The procedure for diagnosing children involves two bodies: the local Service for the Complex Evaluation of the Child, which initially assesses the child, and the Child Protection Commission, which issues a certificate on the level of disability based on the Service's recommendation. This certificate determines eligibility for social welfare benefits.

For adults, the Medical Expert Commissions for People with Handicap, based in each county or district, make an assessment on the level of disability. These are conducted annually, and they determine continued eligibility for social welfare benefits and establish the capacity to work.

Diagnosis procedures for intellectual disability for both children and adults use four-level classification systems in line with ICD-10.

6. Prevalence of disability

Various institutions collect statistical information on the basis of different criteria. ANPH data indicate in 2002 people with disabilities represented 5.2% of the population. Of the registered disabled population, in 2002 approximately 55,000 people (4.9%) had severe disabilities in need of 24 hour intensive care (ANPH, 2005).

6.1 Issues of definition

The Romanian child is 0-18 years of age. Disability levels are classified according to the IQ levels specified in ICD-10: mild, moderate, severe, and profound. Order 725/01.10.2002, jointly elaborated by the Ministry of Health and the National Authority for Child Protection and Adoption, establishes three structural and functional categories that are used in determining the level of intellectual disability in children: *mild* intellectual disability, "intellectual disability without another association," and *moderate*, and *severe* and *profound* intellectual disability. A second order from about the same time sets out similar classifications for the diagnosis of adults with intellectual disabilities.

Site visits by MDRI (Mental Disability Rights International) investigators in 2006 found a disparate pattern of children and babies being labelled with "severe disabilities." According to their report (MDRI, 2006), "The phrase apparently can be used whenever it is administratively convenient, and it is often applied to children with little or no disability" (p. 3).

6.2 Issues of measurement

There is no way to know exactly how many children with disabilities are born in Romania each year. Children with disabilities are not counted in government statistics unless they obtain an official disability certificate from the County Commission for Child Protection. Most often this occurs when a child reaches school age in order to qualify for special schools and services. Consequently, children with disabilities under the age of six or seven are rarely counted. Abandoned children, who lack a birth certificate, are also missing from official disability statistics as they are legally "non-existent" (MDRI, 2006).

6.3 Numbers/rates available

Table A.10, "Number of disabled children (from public and private centres, professional foster caregivers, extended families, biological families) monitored by specialized public services for child protection," shows 68,805 children certified as having a handicap at 31 December 2004 (www.copii.ro).

ANPH had oversight of 17, 959 disabled persons as of March 31, 2006. Of these, 17, 605 were adults and 354 were children. The Office of Methodology, Standardization and Authorizing, ANPH, compiles data on residential services for individuals over age three with disabilities.

7. Residential Services for people with a disability

7.1 Overview

Institutional care represented the most frequent form of health and social care for people with disabilities under communism. People with severe disabilities were placed in establishments which were supposed to provide medical care, therapy, and social care. However, the environment in such institutions was neither therapeutic nor beneficial and under internal and international pressure, some establishments, especially for children with disabilities, were closed down.

At the beginning of the 1990s, due to incapacity of the state to respond adequately to the previously hidden needs and to new ones brought by socioeconomic changes, and due to very limited resources spent inefficiently in the public sector, the private sector took over some of the care responsibilities from the state, with Western support. Although non-existent under communism, the NGO sector has flourished since the early 90s and proposed various models inspired by Western systems trying on the one hand to improve living conditions in the public institutions, especially for children and people with disabilities, and on the other hand to create alternatives to institutions. Home care services for elderly appeared also as a NGO, not-for-profit initiative.

ANPH is working to compile a list of services for individuals with disabilities sponsored by NGOs and other organizations.

7.2 Services for children with a disability

As in the other Soviet bloc countries, the state rather than the family was seen as responsible for children with disabilities. A network of large institutions was developed and families were encouraged to give their children into the care of the state. Romania ratified the UN Convention of the Rights of the Child in 1990; new legislation in 1997 started the long and difficult process of reform. A turning point was 2001 when child welfare became a government priority. The main emphasis was changing the priority from institutional to family care, and by 2005 over 170 large children's institutions had been closed down.

Until 2000, the centres for children with disabilities were under the Ministry of Education, the Ministry of Health, or the National Authority for People with Handicaps. The Ministry of Education had oversight of the special boarding schools where children with a simple degree of handicap with special educational needs were housed. The former "camine spital" where children with handicaps were housed were under the former State Secretariat for Disabled Persons. The Ministry of Health had oversight of centres where there were mainly children with social and medical problems. In 2000 these centres were taken over by the General Directorates for the Protection of Children's Rights, the majority being closed down or reorganized by the creation of family-type centres. The ones that are still functioning have been reorganized into apartment-type modules.

The classic placement centres for children had capacity of 100-300. In 2002, 34 classic centres for children with disabilities were functioning. I was told during the August 2006 interview that there were 12-13 large institutions remaining. The majority of classic and modulated residential centres of family-type homes (8-12 places) have been reorganized into complexes of services and, along with day care centres for recuperation and rehabilitation, counselling centres for children and parents and other services for children with disabilities, are offering services for children in the natural family or extended family, in foster families (children with mild disability), or with professional maternal assistants (e.g., a baby born with a disability will have this type of care). (There are maternal centres in the residential system.)

According to information provided by ANPCA at the time of interview, residential services for children with handicap/disabilities consist of the following types:

- Placement centres for the rehabilitation and recuperation of children with medium to severe handicap (neuro-psycho-motor disability)
- Placement centres for children with HIV/AIDS
- Placement centres for children with sight deficiencies
- Placement for children with auditory deficiencies

Children are mixed, boys and girls of different ages, without regard to ethnic, religious or other criteria. Table A.10, "Number of disabled children (from public and private centres, professional foster caregivers, extended families, biological families) monitored by specialized public services for child protection," shows that at 31 December 2004, of the 68,805 children certified as having a handicap:

- 5909 were in public placement centres
- 604 were in private placement centres
- 2344 were at a professional foster caregiver (public)
- 67 were at a professional foster caregiver (private)

(www.copii.ro).

As regards types of disabilities, mainly there are centres for children with neuro-psycho-motor disabilities (simple-medium), HIV/AIDS, sight and auditory deficiencies.

Residential-type services can be established by authorities of the local public administration or by decision of some accredited private organization. The sources of financing for residential services for children with disabilities are:

- The state budget
- The local budget
- Private funds

Statistics for 31 December 2004 indicate that 5,344 children with handicap have been integrated into mass education, and 11,929 children are in special education. 8,343 children are beneficiaries of alternative services (day care, treatment centres). I was not able to ascertain whether special boarding schools still function.

Certainly the number of children institutionalized in Romania has been drastically reduced. A number of alternative services have been implemented, principally foster caregivers. ANPCA has organized public tenders to encourage participation of NGOs in several programs of national interest. Some of these involve provision of care in family-type homes for children with severe handicaps.

7.2.1 Reform

A recent (2006) report on the website of the National Authority for the Protection of Child's Rights ("The Story of a Reform Process," available at www.copii.ro) describes reform of the child protection system in Romania and highlights the phenomenal drop in the number of children in residential institutions. The brochure includes a page with the heading, "Children less than 3 years old … should not be placed in residential care without a parent," taken from an article in the British Medical Journal. What is omitted in the page heading is the phrase, "with or without disability." (The quote in its entirety is in the text of the page.) Although Romania's Law 272 bans placement of children age 2 and younger in residential institutions, the law does not extend protection to babies with disabilities. Article 60, paragraph 2 states:

> As an exception to the provision stipulated under paragraph (1) [that is it forbidden to place a child less than 2 years old in a residential service], the placement in a residential service of the child who has not yet reached the age of 2 years old may only occur in the case in which the child has a severe disability and is dependent on specialized residential care services.

The report indicates that doctors still encourage parents to give up a baby born with a disability. Despite reports of the creation of an extensive "maternal assistance program" to provide substitute family (foster) placement for many children once left in orphanages and a family support program to assist families of children with disabilities, MDRI found that the array of services described by authorities do not always exist in practice.

MDRI released its report, "Hidden Suffering: Romania's Segregation and Abuse of Infants and Children with Disabilities," May 10, 2006, 3 months before I visited Romania. According to the report, "Much of the reform in Romania merely transferred children with disabilities from large to small institutions" (p. 2). Because the report had just been released there was distrust on the part of the people with whom I met, and I am sure this had an impact on the information I was given. The individuals with ANPCA were adamant, for example, that the "camine scoala pentru debil mintal" (school-type hostels for mentally defective children) no longer existed. I was told that ANPCA took over the camine in 1997 and transformed them.

7.3 Services for younger adults with a disability

There were 17,959 individuals with disabilities accommodated in 157 ANPH facilities as of 31 March 2006 (see table). Of these, 354 are children, the majority of whom (271) have severe handicap, "neuropsychic" (113) or "associated" (101). The majority of adults (7,174) have mental handicap, neuropsychic (4,506), "social" (2,584) or "associated" (1,411) and degree of handicap is classified as severe or accentuated.

The following special protection institutions are coordinated by ANPH:

- Care and assistance centres (CIA)—Centre de ingrijire si asisenta
- Disabled persons recovery and rehabilitation pilot centres (CP)—Centre pilot de recuperare si reabilitare personae cu handicap
- Integration centres for occupational therapy (CITO)—Centre de integrare prin terapie ocupationala
- Neuropsychiatric recovery and rehabilitation centres (CRRN)—Centre de recuperare si reabilitare neuropsihiatrica
- Disabled persons recovery and rehabilitation centres (CRRPH)—Centre de recuperare si reabilitare personae cu handicap
- Residential Centers for rehabilitation and recuperation (CSCPH)—Centre rezidentiale de recuperare si reabilitare personae cu handicap
- Shelter houses (LP)
- Crisis centres (CC)

The typical number of places depends but there is agreement that the optimum number of residents is around 50. About half are 40 years old; about 30% are new and some are very new. The following website includes photos from a number of centres: http://atlas.ici.ro/disability_old/DocumenteSSPH/ANPH/raport/anexe/anexa13.html.

I am not sure the crisis centres still exist. I was told that they had closed, due to lack of funding from the NGOs that started them.

7.4 Services for older adults

The majority of institutionalized individuals age 65 and older with disabilities reside in Care and Assistance Centres (CIA). There are more women than men in this population.

Care centres for adults are overcrowded, with long waiting lists, especially for the growing numbers of elderly people in need of long-term support (Roth and Dobre, 2005). The care homes for the elderly have been transferred under the responsibility of local authorities in the larger process of decentralization of social services. This means that local councils have to provide funds for the functioning of these units. Only a limited number of homes remain under the authority of the Ministry of Work, Social Solidarity and Family. According to research on Workforce in Care services (Roth and Dobre, 2005), the "process of decentralization is at the same time a process of fragmentation, both in ensuring the standards and in the collection of statistical data related to the residents of elderly homes" (p. 6). In response to attempts by the NGO sector to draw the attention of authorities to the poor and lonely elderly and to convince them to start up public funded services of home care, MMSSF opened the possibility of public funding for home care. Many local authorities, in partnership with local NGOs, have begun to provide home-care services. However, providers' estimates indicate that the formal system covers only a small part of the needs of the population (maybe 10%). The rest are relying on informal networks or do not receive the needed care at all (Roth and Dobre, 2005).

8. Other relevant information on residential services

The Future

Much has changed in Romania in recent years with regard to the situation of individuals with disabilities. The *National Strategy 2006-2013 on social protection, integration and social inclusion of disabled people* (2005) is subtitled, "Equal opportunities for persons with handicap: towards a non-discriminatory society." There are many aspects of this plan, but some that are most relevant to this report include the following:

- Planning the transition of the disabled child from the child protection system to the disabled adult protection system, based on his/her individual needs
- Preventing the institutionalization of people with disabilities
- Coordinating the transformation of existing institutions from passive hospitalization and medical and social surveillance units into institutions having an active policy regarding the social integration of people with disabilities
- Restructuring/closing down institutions where minimal quality standards are not implemented
- Creating conditions for development of alternative family-type services
- Diversifying the financing sources for programs and projects, increasing funds allocated for programs and projects aimed at improving living conditions of peopled with disabilities, including identifying and managing the financing sources required for the process of restructuring/closing down of the institutions and the creation of alternative family-type services

Roth and Dobre (2005) were surprised by the great number of non-profit organizations which have struggled in the last 15 years to change the strongly institutionalized and centralized Romanian care system "to become patient centered, rights centered, and high quality" (p. 13).

9. Staffing

Categories of personnel in Residential Services for Children 0-18 include:

- Specialty personnel—psychologists, social workers, psychopedagogues, physicians (general medicine, pediatric specialists, neurological specialists, psychiatrists, recuperation specialists (balneo-physio-kineotherapy), nurses, specialized educators
- Administrative personnel
- Care personnel—nurses, supervisor
- Auxiliary personnel

Typical staffing of ANPH facilities includes physicians, psychologists, medical assistants, hygiene assistants, pharmaceutics assistants, social assistants, medical nurses, hospital attendants, pedagogues, auxiliary staff, individuals specializing in ergo-, kineto- and physiotherapeutics among others. Those involved in direct care have the lowest level of education and training; administrative and auxiliary staff generally have high school education; medical and rehab staff have studied at university.

Roth and Dobre (2005) conclude that "Regarding the number of medical staff involved in socio-medical services in Romania, no data are available. Generally, it is quite difficult to evaluate the workforce in socio-medical services as the data about the workforce in the care sector is limited and fragmented, barely available at the national level for specific sectors, mainly due to the fragmentation of the social services system run by local authorities" (p. 8). They note a long-term staff deficit in institutions providing residential care for people with disabilities. Part of this problem is due to low salaries in Romania which contributes to emigration of the workforce to western countries.

10. Costs

International funds for Romania's social sector have decreased, so in the past few years NGOs have tried to obtain more funding from internal resources. Some have been successful in obtaining funding from companies or individuals, but many NGOs do not consider fund raising to be a reliable financial resource for Romania, especially in the area of care for handicapped and elderly people, where individual donors are less active. Some NGOs try to encourage not only sponsors, but also clients to contribute financially to the cost of their care. The desire to comply with Europe's common regulations in order to be admitted to the EU created a favourable climate for changing the care sector and developing some financial mechanisms to decentralize and deinstitutionalize care, by creating a system of financing home care.

According to case studies analyzed by researchers (Roth and Dobre, 2005), organizations such as Caritas (and many others) have taken over the financial burden from both the state and the served individuals. Because the hired caregivers are working in difficult conditions, these organizations "have developed a system of motivating their staff otherwise as by financial means: good quality training periods, supervision, international exchanges, technical devices (office cars, access to ICT, including mobile phones)" (Roth and Dobre, 2005, p. 16).

11. Issues

It was not possible to obtain information regarding institutionalization of Roma.

12. Acknowledgements

Monica Stanciu, Chief, and Nicolae Dicu, Office of Methodology, Standardization and Authorizing, ANPH
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Catalin Bucinschi, Director, NIFSEPH

13. Information sources on disability used to compile the template and commentary, including people who were interviewed

Monica Stanciu, Chief, and Nicolae Dicu, Office of Methodology, Standardization and Authorizing, ANPH (interview)
Aurelia Bandila, Scientific Secretary of The National Institute for Fighting Social Exclusion of the Persons with Handicap (NIFSEPH) (interview)
Catalin Bucinschi, Director, NIFSEPH (interview)
Institutul National de Statistica
Andreea Neacsu, Advisor, Child Rights Monitoring Direction, ANPCA
Ali Cranta, ANPCA

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Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

Slovakia

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Summary of available data

Description of service types.

N.B. older people's services included in the descriptions here but were not included in the analysis in the report unless it was clear that the people who lived there also had a disability.

Type of service	Size Interval (places)	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions	Age of service
Geriatric facility (Gerontopsychiatricke Oddelenie)	.	over 60/65	Mixed	24 hour	State	All private/insurance	All long term	50 - 100 years
Children psychiatric hospital (Detska psychiatricka nemocnica DPL)	.	0 - 18/19	MH	24 hour	State	All private/insurance	All long term	.
Residential kindergarten for children with disabilities (Materska skola internatna pre deti s postihnutim)	less than 6	3-18/19	More than one disability group served (no main group) but not mixed	24 hour	State	Mixed state/local and private contributions (insurance/private)	All long term	.
Nursing care service facility (Zariadenie opatrovatelskej sluzby)	11 to 30	over 60/65	Mixed	Mixed pattern within institutions (internat, externat, demi-internat)	Mixed	Mixed state/local and private contributions (insurance/private)	All long term	50 - 100 years
Sheltered housing facility (Zariadenie chraneneho byvania)	11 to 30	16/18/25 to 60/65 (adults but not older adults)	Mixed	Mixed pattern within institutions (internat, externat, demi-internat)	Mixed	Mixed (any)	All long term	21 to 50 years
Rehabilitation centre for	11 to 30	3 to 25	Mixed	Mixed	Mixed	Mixed (any)	All long term	0 to 20 years

Type of service	Size Interval (places)	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions	Age of service
children (Rehabilitacne centrum pre deti)				depending on need				
Rehabilitation centre (Rehabilitacne centrum)	31 to 50	16/18/25 to 60/65 (adults but not older adults)	Mixed	Mixed pattern within institutions (internat, externat, demi-internat)	Mixed	Mixed (any)	All long term	21 to 50 years
Social service home for children (Domov socialnych sluzieb pre deti)	51 to 99	3 - 25	Mixed	Mixed depending on need	Mixed	Mixed (any)	All long term	.
Social service home for children and adults (Domov socialnych sluzieb pre deti a dospelych)	51 to 99	3 into adulthood (60/65 years)	Mixed	Mixed depending on need	Mixed	Mixed (any)	All long term	.
Combined pensioners and social services home for adults (Domov dôchodcov kombinovaný s domovom sociálnych služieb pre dospelých)	100 to 150	Over 18/25 (i.e. adults only)	Mixed	Mixed pattern within institutions (internat, externat, demi-internat)	Mixed	Mixed state/local and private contributions (insurance/private)	All long term	50 - 100 years
Pensioners' home	100 to 150	over 60/65	Mixed	Mixed pattern within institutions (internat, externat, demi-internat)	Mixed	Mixed state/local and private contributions (insurance/private)	All long term	50 - 100 years
Social service home for adults (Domov	151 to 200	Over 18/25	Mixed	Mixed pattern within	Mixed	Mixed (any)	All long term	21 to 50 years

Type of service	Size Interval (places)	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions	Age of service
socialnych sluzieb pre dospelych)		(i.e. adults only)		institutions (internat, externat, demi-internat)				

Data available by service type – size of service and disability groups.

Type of institution	Places total	Under 30 places	Over 30 places	Size unspecified	ID	MH	PSD	Elderly/ dementia	Mixed/ dual	Other/ unspecified
Children psychiatric hospital (Detska psychiatricka nemocnica DPL)	.	.	.	.	.	.	.	.	.	.
Residential kindergarten for children with disabilities (Materska skola internatna pre deti s postihnutim)	134	62	.	72	.	.	99	.	.	35
Rehabilitation centre for children (Rehabilitacne centrum pre deti)	62	.	.	.	.	.	.	.	62	0
Social service home for children (Domov socialnych sluzieb pre deti)	1465	338	1127	0	.	.	417	.	908	140
Social service home for children and adults (Domov socialnych sluzieb pre deti a dospelych)	1999	162	1837	0	.	.	21	.	1398	580
Psychiatric hospitals, wards (Psychiatricke oddelenie - ward, Psychiatricka klinika - hospital)	.	.	.	.	.	.	.	.	.	.
Sheltered housing facility (Zariadenie chraneneho byvania)	130	92	38	0	.	.	.	.	46	84
Rehabilitation centre (Rehabilitacne centrum)	202	62	140	0	.	.	.	.	152	50
Social service home for adults (Domov socialnych sluzieb pre dospelych)	8260	.	.	.	.	.	556	.	3019	4685
Geriatric facility (Gerontopsychiatricke Oddelenie)	.	.	.	.	.	.	.	.	.	.

Type of institution	Places total	Under 30 places	Over 30 places	Size unspecified	ID	MH	PSD	Elderly/ dementia	Mixed/ dual	Other/ unspecified
Nursing care service facility (Zariadenie opatrovatelskej sluzby)	664	584	80	0	.	.	.	.	.	.
Combined social services home pensioners and adults (Domov dôchodcov kombinovaný s domovom sociálnych služieb pre dospelých)	4957	195	4762	0	.	.	.	.	.	.
Pensioners' home	4399	220	4179	0	.	.	.	.	.	.
TOTAL	**22272**	**1715**	**12163**	**72**			**1093**		**5585**	**5574**

Data available by service type – breakdown by gender and age.

Type of institution	Places total	Male	Female	Gender unspecified	Children	Younger adults	Older adults	Adults over 18	Age unspecified
Children psychiatric hospital (Detska psychiatricka nemocnica DPL)	.	.	.	.	.	.	.	.	.
Residential kindergarten for children with disabilities (Materska skola internatna pre deti s postihnutim)	134	71	63	0	.	.	.	.	134
Rehabilitation centre for children (Rehabilitacne centrum pre deti)	62	20	42	0	28	34	.	.	0
Social service home for children (Domov socialnych sluzieb pre deti)	1465	820	641	4	1108	353	.	.	4
Social service home for children and adults (Domov socialnych sluzieb pre deti a dospelych)	1999	1026	946	27	464	1391	117	.	27
Psychiatric hospitals, wards (Psychiatricke oddelenie - ward, Psychiatricka klinika - hospital)	0	.	.	.	.	.	.	.	0
Sheltered housing facility (Zariadenie chraneneho byvania)	130	85	45	0	0	126	4	.	0
Rehabilitation centre (Rehabilitacne centrum)	202	101	96	5	0	188	9	.	5
Social service home for adults (Domov socialnych sluzieb pre dospelych)	8260	3463	2753	2044	0	4402	1806	.	2052
Geriatric facility (Gerontopsychiatricke Oddelenie)	0	.	.	.	.	.	.	.	0

Type of institution	Places total	Male	Female	Gender unspecified	Children	Younger adults	Older adults	Adults over 18	Age unspecified
Nursing care service facility (Zariadenie opatrovatelskej sluzby)	664	268	396	0	0	18	646	.	0
Combined social services home pensioners and adults (Domov dôchodcov kombinovaný s domovom sociálnych služieb pre dospelých)	4957	1756	2720	481	0	609	3867	.	481
Pensioners' home	4399	1338	2494	567	0	1050	2782	.	567
TOTAL	**22272**	**8948**	**10196**	**3128**	**1600**	**8171**	**9231**		**3270**

Staffing data:

Type of service	Total Number of staff in each type of service	Number care staff/nurses/ might include teachers in boarding school	Number managers or other administrative staff (not care staff)	Number clinical staff (Drs, therapists, psychologists etc)	Number of other staff (mainly ancillary staff)	Staff qualifications: Primary or less	Staff qualifications: Secondary	Staff: Higher Ed.	Staff: degree level
Children psychiatric hospital (Detska psychiatricka nemocnica DPL)	.	.	.	.	.	.	.	.	.
Residential kindergarten for children with disabilities (Materska skola internatna pre deti s postihnutim)	.	.	.	.	.	.	.	.	.
Rehabilitation centre for children (Rehabilitacne centrum pre deti)	7	.	.	.	.	.	5	1	1
Social service home for children (Domov socialnych sluzieb pre deti)	633	247	73	177	136	10	223	12	2
Social service home for children and adults (Domov socialnych sluzieb pre deti a dospelych)	1262	475	168	328	291	19	430	22	4
Psychiatric hospitals, wards (Psychiatricke oddelenie - ward,	.	.	.	.	.	.	.	.	.

Type of service	Total Number of staff in each type of service	Number care staff/nurses/ might include teachers in boarding school	Number managers or other administrative staff (not care staff)	Number clinical staff (Drs, therapists, psychologists etc)	Number of other staff (mainly ancillary staff)	Staff qualifications: Primary or less	Staff qualifications: Secondary	Staff: Higher Ed.	Staff: degree level
Psychiatricka klinika - hospital)									
Sheltered housing facility (Zariadenie chraneneho byvania)	22	2	3	17	.	.	1	1	.
Rehabilitation centre (Rehabilitacne centrum)	36	15	7	12	2	0	10	4	1
Social service home for adults (Domov socialnych sluzieb pre dospelych)	3016	1286	337	452	941	48	1161	69	8
Geriatric facility (Gerontopsychiatricke Oddelenie)	.	.	.	.	.	.	.	.	.
Nursing care service facility (Zariadenie opatrovatelskej sluzby)	240	126	36	16	62	4	114	6	2
Combined pensioners and adult social services home (Domov dôchodcov kombinovaný s domovom sociálnych služieb pre dospelých)	2148	1002	207	201	738	15	927	53	7
Pensioners' home	1826	742	211	179	694	19	683	35	5
TOTAL	**9190**	**3895**	**1042**	**1382**	**2864**	**115**	**3554**	**203**	**30**

Staff qualifications

Type of service	Total staff	Staff with only primary school qualification or less	Staff with secondary school qualification as highest qualification	Staff with higher qualification	Staff with university degree	Unspecified
Children psychiatric hospital (Detska psychiatricka nemocnica DPL)	.					
Residential kindergarten for children with disabilities (Materska skola internatna pre deti s postih	.					
Rehabilitation centre for children (Rehabilitacne centrum pre deti)	7	.	5	1	1	0
Social service home for children (Domov socialnych sluzieb pre deti)	633	10	223	12	2	386
Social service home for children and adults (Domov socialnych sluzieb pre deti a dospelych)	1262	19	430	22	4	787
Psychiatric hospitals, wards (Psychiatricke oddelenie - ward, Psychiatricka klinika - hospital)	.	.	.	.	.	
Sheltered housing facility (Zariadenie chraneneho byvania)	22	.	1	1	.	20
Rehabilitation centre (Rehabilitacne centrum)	36	0	10	4	1	21
Social service home for adults (Domov socialnych sluzieb pre dospelych)	3016	48	1161	69	8	1730
Geriatric facility (Gerontopsychiatricke Oddelenie)	.	.	.	.	.	
Nursing care service facility (Zariadenie opatrovatelskej sluzby)	240	4	114	6	2	114
Domov dôchodcov kombinovaný s domovom sociálnych služieb pre dospelých	2148	15	927	53	7	1146
Pensioners' home	1826	19	683	35	5	
Total	**9190**	**115**	**3554**	**203**	**30**	**5288**

Completeness and accuracy of the data

The data presented in the template refers to the year 2005 and is based on statistical data and information from the Ministry of Labour, Social Affairs and Family (Department of Integration of Persons with Disabilities and Social Services), the Ministry of Health (Department of Health Care, Department of Psychiatry) and the Ministry of Education and Science. Interviews with representatives from all mentioned departments have taken place in February 2007. Data and information from the Ministry of Labour, Social Affairs and Family on Social Services is based on information of Slovakian self-governing regions (Bratislava, Trnava, Nitra, Trenčín, Banská Bystrica, Žilina, Prešov, Košice). Statistical data and information from the Ministry of Health is collected by the Institution of Health Information and Statistics.

As the criteria and categories set in the template are not surveyed in Slovakia in that way, it was not possible to get all data from official sources. For that reason, regional authorities with responsibility for social service provision (following decentralisation) were asked to provide the requested data. Data on 290 social service facilities out of the total of 775 facilities can be presented. 557 facilities out of the total number of 775 social services provide services for persons with disability (can be seen on the name of the service). In total there were 36,615 persons living in institutions in the year 2005 (including social care homes for children, crisis centres, centres for rehabilitation and refuge centres), 23,975 of them were disabled. The presented data on 290 services does not cover all services for persons with disabilities, but gives a typical insight:

Pensioners' homes:	194 in total, data from 48
Sheltered housing – pensioners' homes:	14 in total, data from 9
Social service homes for adults:	142 in total, data from 79
Social service home for children:	65 in total, data from 28
Sheltered housing facilities:	11 in total, data from 9
Rehabilitation centres:	17 in total, data from 7 + 3 (for children)
Nursing service facilities:	91 in total, data from 34.

The group of citizens with disabilities is not recorded and monitored separately within the system of healthcare services, i.e., it is not possible to selectively give the healthcare establishments in which health care is provided exclusively or predominantly to persons with disabilities. For this reason, it is not possible to give precise statistics how many persons were or are being provided with healthcare services in the Slovak Republic.

Existing statistical data on residential services for disabled people covers all age groups. Concerning the group of disability no exact data is available, only on combination of disabilities. The collected data partly covers staff numbers and staff training. Staff numbers are not available for services under the domain of the Ministry of Education. Data on staff training is not available for psychiatric care and services under the Ministry of Education. Besides statistical information there were other sources used to write this country report, as listed at the end of this chapter.

It can be summarised that - because of intensive communications with all relevant officials – the presented data is on the most complete and accurate (national) level

possible for the year 2005. The existing country report has been authorized by Eva Zaujecova (Ministry of Labour, Social Affairs and Family), Eva Palova (Ministry of Health) and Jana Juraskova (Ministry of Education).

Commentary: Slovakia

1. Overview

The Republic of Slovakia has a territory of 49,030 sq km. Slovakia has 5.4 million inhabitants in total. 85.7 % of them Slovaks, 10.6 % Hungarians, 1.6 % Roma, 1.1 % Czechs, 0.6 % Russians and Ukrainians and 0.4 % others. On 01.01.1993 Slovak Republic was established after the partition of the Czech-Slovak Federal Republic.

2. Political and social context

2.1 Government organisation and structure

The Republic of Slovakia is a parliamentary democracy and consists of eight self-governing regions: Bratislava, Trnava, Nitra, Trenčín, Banská Bystrica, Žilina, Prešov and Košice. The gross domestic product per head was 6,111 Euro in 2004. Since 29 March 2004 Slovakia is member of the NATO. In the same year, on 1 May the country became member of the European Union.

Source: http://europa.eu/abc/maps/members/slovakia_en.htm

3. Demographics

Slovakia has a population of 5,379,455. The life expectancy is 70 years for men and 78 years for women. Infant mortality is 9 per 1000 for males and 8 per 1000 for women. Health expenditure as a percentage of GDP was 5.9 in 2003. The total health expenditure per capita was 777 Intl $ in 2003.

4. Health and Social Care System

Social services as specialised activities are designed to address social hardship (the state, in which the citizen is unable to secure daily living activities, care of his household, protection and exercise of his rights and legally protected interests, or the contact with the social environment owing, in particular, to age, unfavourable health state, social maladjustment, or loss of employment). It involves the provision of in-kind (non-cash) benefits. Social services provision is governed by the Act No. 195/1998 Coll. on the social assistance approved by the National Council of the SR on 19 May 1998 and coming into force on 1 July 1998.

From the aspect of basic categorisation of social services we can distinguish out-patient social services and institutional social services. Institutional social services are

represented by social service facilities. Pursuant to the Act on the social assistance, social service facilities include:
- pensioners' home,
- sheltered housing – pensioners home,
- nursing service facility,
- social service home,
- sheltered housing facility,
- single parent home,
- nursing service station,
- asylum,
- rehabilitation centre,
- pensioners' club,
- pensioners' canteen,
- personal hygiene centre,
- laundry.

The Inspectorate at the Ministry of Labour, Social Affairs and Family is responsible for the quality control and supervision of social services.

Psychiatric care is provided under the aegis of the Ministry of Health. The Constitution of the Slovak Republic guarantees the right of every citizen to health protection and free health care based on health insurance, which is funded on principles of solidarity, non-profitability and plurality. New types of health care facilities are introduced, e.g. day-care facilities or nursing care homes. Inpatient care includes hospitals and specialised institutes (e.g. psychiatric). Community care services include long-term inpatient care, day care centres and social services for the chronically ill, the elderly and other groups with special needs. Many of hospitals and institutes were transferred to municipalities and under mixed ownership. Ministry of Health maintains a wide scope of competence, which covers development of policy and drafting of legislation on health care and health protection, health care provision in public inpatient facilities, price regulation, supervision etc. Health insurance companies are private entities. Health insurance is financed from public resources collected on a mandatory basis and redistributed on the basis of the solidarity principle. 85 % of citizens are covered by health insurance. The General Health Care Law includes a section which deals with psychiatry, mainly with involuntarily admissions. Besides there is no special mental health law in Slovakia. Mental Health Care is usually hospital based care. There were 5 psychiatric hospitals, 5 psychiatric long-term care facilities, 32 psychiatric wards of hospitals in 2004.

4.1 Organisation

Within the continuing public administration reform, at 1 July 2002 and at 1 January 2003, respectively, (through the Act No.416/2001 on the transfer of certain competences from state administration authorities to municipalities and upper-tier territorial units) and at 1 January 2004 (through the Act No. 453/2003 Coll. on the state administration authorities in the field of social affairs, family and employment services and on amendment of certain acts) social services were decentralised to local authorities under their self-governing responsibility.

Municipalities and self-governing regions, as self-government authorities, provide social services on the basis of the split competences laid down by statute (§ 71 and §

71a of the Act on the social assistance). The Act on the social assistance stipulates legal conditions for the provision of particular types of social services, as well as the material scope of the necessary care that represents the standard. The legal entitlement to the provision of selected kinds of social services is decided through administrative proceedings, if the social service provider is a public administration authority or a social service facility established by it, having a legal capacity. The Act on the social assistance also makes provision for a possibility to have valid decisions on matters of social services provision reviewed by court (§ 98 of the Act on social assistance).

Following completion of the decentralisation process in social service provision to self-governing regions, the role of the Government, or the Ministry of Labour, Social Affairs and Family (MoLSAF) as the central body of state administration in the SR in the area of social assistance, is focused on the preparation of legislation having national force, which is binding for both, municipalities and regional authorities in performing their self-governing functions in the area of social services. Municipalities or self-governing regions decide about the way of setting reimbursement rates, the amounts of reimbursement, and the form of payment for social services provided and any particulars on social service provision by generally binding regulations adopted for their territorial constituencies. MoLSAF undertakes state supervision over provision of social services, particularly the observance of basic human rights and freedoms of citizens in social service provision (§ 66 letter k, and § 69a to 69c of the Social Assistance Act). Besides these tasks the MoLSAF elaborates concepts to approve social services, implements EU-laws, organises further education of staff and defines standards for the qualification of staff.

Social service home for children, social service home for children and adults, social service home for adults, sheltered housing facilities, rehabilitation centres, nursing care service facility, pensioner's home combined with social service home for adults and pensioners homes are provided by public administration body (regional authority), local authority or not-for-profit organisation,

Services related to school issues (residential kindergarten for children with disabilities, primary school for pupils with disabilities, special needs primary school for children with disabilities, secondary school for children with disabilities) and services related to health care (children psychiatric hospital, children psychiatric out-patient-office, psychiatric hospitals, geriatric facilities) are provided mostly by the state.

4.2 Financing

The financing system of social services has changed with the decentralisation process. From 01.07.2002 till 01.01.2005 all expenses of social services without receipts were financed through earmarked subsidies from the state (Ministry of Finance). Since 01.01.2005 social services are paid through taxes on investment income on community level (fiscal policy of decentralization). The process of decentralisation is finished, but 79 institutions and services under the domain of the municipalities still get money from the Ministry of Finance as a transitional solution.
The "Program on Transformation of Social Services" with a budget of 14 Million Euro aimed to improve the quality of life of clients had been the most important issue during the last years. The MoLSAF took a credit of 6 Million Euro to restructure social services and increase the quality of life of clients. Between 2003 and 2006 the

money was spent for 23 projects and institutions, chosen by the MoLSAF. Besides other things two new services for supported living for persons with slight mental disabilities and two services especially for people with autism were created, hippotherapy was introduced (at 1 psychiatric hospital), architectural barriers were removed, dormitories were changed into smaller units, therapy rooms were set up, leisure time facilities had been installed. So this first big program of improvement had helped to establish new facilities which hasn't been there before or had been in a weak condition. At the moment the focus is on building measurements for example insulation and heating, maybe with money from the European Structural Fond from 2007 to 2013. But in general a negligent amount of money was assigned for social services serving to people with mental disabilities despite the fact that some of the social facilities for psychiatric patients are in a terrible condition.

Social service provision is funded from the national budget, municipal budget, self-government region budget and the fees for services paid by citizens and persons having maintenance obligations in respect of these citizens (if it involves a public provider), and from receipts at agreed price paid for the social service (if it involves a private provider). Social services are also paid from gifts of legal entities and natural persons.

In the case of public providers, financial affordability of social service provision is guaranteed for the beneficiary by a statutory legal protection of the citizen against payment for social services that would be unreasonable in terms of his/her income, property and family circumstances. It involves a guaranty of income balance after paying for the social service, laid down in relation to the amounts of subsistence minimum, which are subject to annual adjustment (valorisation). For example 20% of subsistence minimum is guarantied in facilities where is yearly care is provided, 50% of subsistence minimum is guarantied in facilities where weekly care is provided and 75% of subsistence minimum is guarantied in facilities where daily care is provided.

Most social services are funded according to founder: public funding (regional or local authority), financial contribution for the service of a not-for-profit organisation (regional authority or municipality) + co-financing on the part of the clients (remittance for providing the service).

Services for children related to school issues (residential kindergarten for children with disabilities, primary school for pupils with disabilities, special needs primary school for children with disabilities, secondary school for children with disabilities) are funded by a normative per pupil to be determined and provided by the state to both state and non state facilities. A parents' fee is possible (only in non state institutions) as well as funding through sponsor contribution. The yearly amount per pupil financed from the state is around 735 €. For children with special needs the yearly amounts are higher, e.g. for pupils with hearing impairment around 1295 € or for children with autism 5880 €.

Services related to health care (children psychiatric hospital, psychiatric hospitals and geriatric facilities) are funded by public health insurance or direct payment from the client.

5. Definition, eligibility and diagnosis/assessment

Slovakian legislation defines "disability" in two different ways. The law Nr. 461/2004 on Social Security speaks of invalidity if a person's decline of ability to work is from 40 to 100 percent. These persons are eligible for invalid pensions.
The Social Assistance Act Nr. 195/1998 uses the terms citizen with unfavourable health condition and citizens with severe disability. The extent of malfunction of these persons is more than 50 percent by comparison with healthy people of the same gender, age and circumstances. The person's degree to cope with daily life activities is restricted. All people who are living in residential facilities are grouped under this category. After passing an individual assessment of nursing and care people with unfavourable health condition and/or severe disability can apply for subsidies, services or a disability card (to get benefits by public transportation, taxes or cultural events). The Social Assistance Act defines exactly which medical and social preconditions have to be fulfilled to get access to the different kind of services.

Other definitions of disability are used in the field of health care and education, which refer more or less to the definitions used in social care.

The General School Law Nr. 29/1984 (with 18 amendments) uses the term pupils with special educational needs. In § 3 the different kinds of special needs are listed as below: mental retardation, hearing impairment, visually impairment, physically impairment, week health condition, communication impairment, autism, learning difficulties, behavioural difficulties, psycho-social development difficulties and highly gifted. Children with special needs should get education according to their individual abilities. Special forms of education as well as forms of integration are defined by law.
In Slovakia there are different procedures for diagnosis and assessment of disability: for educational purposes, for employment purposes and for access to social benefits. The two last mentioned are carried out by Special Assessment Teams under the domain of the Ministry of Labour, Social Affairs and Family.

Besides including a definition of disability the Social Assistance Act defines the procedure for diagnosis and assessment of disability. If a person applies for the official disability status the purpose of the application has to be clear (subsidies, social services or a disability card to get benefits by public transportation, taxes or cultural events). The assessment team is part of the state administration. Doctors and social workers assess the individual needs of the person in four fields: mobility/orientation, communication, self-supply and increased expenses (caused by the handicap). There are 46 assessment teams in whole Slovakia, who decide about receiving a disability status. If a person does not agree with the decision of the assessment team two steps of appeals are possible. First step is to take appeal on regional state department of labour, social affairs and family and the second is court. Precondition to get a residential social service is that the requirements of the individual can't be fulfilled at home. Experts assess the individual needs: 1. on medical topics and 2. on why the person is not possible to get along at home and in which fields of daily life supervision and support are necessary.

The assessment procedure for children is carried out by Special Education Support Teams. There exist about 90 of these teams in Slovakia, some by public and some by private providers. They diagnose special needs for children and youth and are

specialised for different types of disability. The Special Education Support Team can consist of special teachers, psychologists, social workers and therapists. They give recommendations which curricula the child should follow according to the classified special needs. The recommendation is only a suggestion to parents. Finally they decide which type of education – special school or special class in mainstream school or individual integration in mainstream class - their child shall attend. Another task of the Special Education Support Teams is to give advice to teachers how to promote children adequately to their special needs.

The International Classification of Diseases and Related Health Problems (ICD-10) is used as a standard reference in Slovakia.

6. Prevalence of disability

Slovakia has 5.4 million inhabitants in total. According to data from the Statistical Office at the end of the year 2004, social service facilities had altogether 35,531 residents. Out of the total number of residents 23,028 were disabled.

According to the Law on Social Security there are in total 182,838 people with status of invalidity (decline in ability to work in December 2006). 80,032 of them with a decline in their ability to work from 41-70 percent (group 1) and 102,806 with a decline in ability to work from 71-100 percent (group 2).

7. Residential Services for people with a disability

7.1 Overview

The majority of residential care for persons with disabilities is still provided in large institutions in Slovakia. Long term social care is provided in 3 different forms: for children (social service home for children, rehabilitation centre for children), for younger adults (social services home for adults, rehabilitation centre for adults, sheltered housing facilities) and for older adults (pensioners home, pensioners home combined with social service home for adults, nursing care services facility). The lack of community based alternatives to institutional care can be noticed throughout all age groups.

Ministry of Labour, Social Affairs and Family has developed the program "National Programme for Development of Living Conditions of Citizens with Disability in All Sphere of Life". It was approved by the Slovak Government in 2001 to improve the quality of life for persons with disabilities.

A big problem is the increasing number of older people with high support needs, e.g. there are no special facilities for people suffering from Alzheimer. At the moment they are mixed up with people with mental disabilities and people with autism.

The Statistical Office collects data on social services from documents of local authorities every year. As already mentioned above, the selected data does not cover all residential services for persons with disabilities (23,975 of in total 36,615 persons in social services are disabled, data is provided for 290 social services out of 557 providing care for persons with disabilities) but gives a typical insight.

Persons with mental health problems are treated in psychiatric hospitals or wards (one psychiatric hospital for children, psychiatric hospitals/wards for adults and geriatric facilities). Priority of Ministry of Health is to develop community health services but these services are not covered by the plan of Ministry of Health for the years 2005-2010. At the moment there is no community based psychiatry, no sheltered workshop no sheltered living (only provided by 1 NGO), no early intervention service, no crisis intervention centres, although the number of psychiatric patients is increasing regularly every year. Statistics on mental health care are collected by the Institution of Health Information and Statistics under the Ministry of Health in a good quality.

Schools and residential Kindergartens are provided for children and youth with special needs. The information on these kind of services is collected by the Statistical Department under the Ministry of Education yearly. It's based on the last school year and collected each year at September, the 15th. The latest data covers for the first time the individual integration, too.

7.2 Services for children with a disability

Care in a social service facility for children may be provided from the childbirth until the completion of compulsory school attendance or completion of education in the event of further preparation for vocation, but no longer than until the age of 25 years. Prior to the placement in a social service home, children with mental and behavioural disorders are ensured special needs educational, psychological, medical and social diagnostics. Children are provided with social care at 2 types of long term child care and upbringing institutions: social service home for children and social service home for children and adults.

7.2.1 Social services home for children

Data is provided for 28 institutions with 1465 places in total (out of the total number of 65 institutions with 2961 places), divided into social service homes for children with sensory and/or physical impairment (417 places), social service home for children with mental and behavioural disorders (136) and combination of these (908). The typical number of places is 50-100, serving the age group from 3 to 25 years.

7.2.2 Social service home for children and adults

There are 34 facilities with 1999 places in total, divided into social services homes for people with mental or behavioural disorders (553 places), sensory impairment (5 places), physical impairment (16 places) and or combination of these (1398 places). The typical number of places is 50-100, serving people from age 3+. During the last years there have been attempts to restructure the big residential facilities for children to more family orientated living facilities. Legal basis for social service homes for children is not the Social Assistance Act.

7.2.3 Rehabilitation centres for children

Besides there exist 3 Rehabilitation centres for children with 62 places. This service is mixed one with day, week or year-round stays for children with mental or behavioural disorders, sensory impairment, physical impairment and or combination of these, serving the age group from 3 to 25 years.

7.2.4 Residential Kindergarten for children with disabilities

Under the domain of the Ministry of Education there are several services for children with special needs. Educational care for children with special needs has more than 50 year history in Slovakia.

These are either kindergartens designed for the upbringing of children of pre-school age (3 to 6 years) with mental disability, or hearing or visual impairment or classes for children with disabilities in the mainstream kindergartens. They are specialised in one kind of disability (there are special kindergartens for children with hearing disabilities, vision disabilities, communication disabilities and mental disabilities). Residential special needs kindergartens offer care for children throughout the working week (5 days a week) including nights. They are set up by Regional School Authorities but can also be set up as non-state facilities. Teachers must satisfy qualification requirements in the discipline of the special needs pedagogy. In the Slovak Republic there are 35 special needs kindergartens of which 17 are residential.

7.2.5 Primary schools for pupils with disabilities (10) and special needs primary schools (44)

In Slovakia there are special schools and classes for pupils with educational special needs as follows:

- Schools for pupils with hearing impairment
- Schools for pupils with vision impairment
- Schools for pupils with physical disabilities
- Schools for pupils with mental and hearing or vision or physical disability
- Schools for pupils with communication disabilities
- Schools for pupils with mental disabilities
- Schools for pupils with autism
- Schools for pupils with intellectual giftedness
- Classes (not schools) for pupils with behavioural disabilities
- Classes for pupils with learning disabilities
- Schools for pupils with behavioural problems in residential care (pupils with serious problems, which play truant, abuses drugs and make thefts)
- Schools in hospitals
- Schools in social service residences.

Primary schools serve the age group from 6 to 15 years (first to ninth grade). Pupils are provided with special needs educational care. Forms and methods of teaching accommodate the disability's special needs. Classes are smaller than in mainstream schools. Some schools - mostly designed for pupils with severe disabilities (type a, b, c, d, e and k) – provide residential care. They are established by the Regional School Authorities but they can also be set up by private providers. Teachers must satisfy the qualification requirements in the discipline of special needs pedagogy. In total there are 31 schools for disabled children of which 14 are residential.

7.2.6 Secondary schools for pupils with disabilities

These schools offer special needs educational care for pupils with hearing disabilities, vision disabilities, physical disabilities, mixed disabilities, mental disabilities, intellectual gifted and for pupils with behavioural problems in two to four grades.

They are established by the Regional School Authorities but they can also be set up as private ones. Teachers must satisfy the qualification requirements in the discipline of special needs pedagogy. Secondary schools for physically, visually or hearing-impaired are established as grammar schools, secondary vocational schools, a conservatory and secondary apprentice schools. A special system of secondary schools, namely an apprentice school and practical instruction is set up for the mentally disabled (for more severely mentally disabled). There are 57 schools in total, serving the age group from 15 to 18/19 years.

There are two types of school integration in Slovakia: one is the classic individual integration, where the pupil can (depends on finances) get a pedagogical assistant (free of charge) and follows the mainstream curricula. The other possibility is to attend a special class in a mainstream school led by a special teacher. Today more and more pupils are integrated into mainstream schools. The trend is towards integration, although a lot of teachers share the opinion that integration is not the best way for each child because of insufficient conditions (finances, qualification, special equipment, number of pupils in class). So teachers face a lot of problems by implementing this idea.

Statistical data on the number of children attending services under the Domain of the Ministry of Education for the year 2006:

Residential Kindergarten:	1,153
Special classes in Kindergarten:	288
Individual integrated in Kiga:	642
Special schools:	19,917
Special classes:	6,992
Individual integrated:	13,074[28]

7.3 Services for younger adults with a disability

7.3.1 Social service home for adults

Social service home for adults can provide care to persons with physical impairment, mental disorders and behavioural disorders, with sensory impairments or a combination of disabilities. Care in a social service facility for adults may be provided from the completion of compulsory school attendance, completion of education or further preparation for a vocation and to other adult persons with disabilities from the age of 25 years. As all service types based on the Social Assistance Act, social service home provide the necessary care comprising provision of meals, housing and maintenance. In addition other care is provided that includes upbringing, counselling, leisure activities, cultural activity, occupational therapy, recreational activity, rehabilitation activity and conditions are created for work. There are 142 facilities with 10,839 places in total in Slovakia. Data covers 79 facilities with 6,260 places. These facilities are divided following the type of disability in social service homes for adults with physical impairment, social service home for adults with combined disabilities, social service homes for adults with sensory impairment and social service home for adults with mental and behavioural disorders.

[28] Source: Information from the Ministry of Education

7.3.2 Sheltered housing facilities

Sheltered housing facilities offer housing and supervision to persons with disabilities or mental difficulties who are capable of independent living with some help from another person. There are 11 facilities with 192 places in total, data covers 9 facilities with 130 places, serving the age group from 25 to 60 years.

7.3.3 Rehabilitation centres

In Rehabilitation centres person with severe disabilities who are in need of restoring the highest attainable individual degree of personal development and physical capacity are rendered rehabilitation to activate the inner capacities of the person to overcome personal and social consequences of a severe disability, the necessary care (meals, housing, maintenance) and the counselling. The provided data covers 17 facilities with 202 places in total. Most clients are between 25 and 60 years old.

7.4 Services for older adults

7.4.1 Pensioner's home

Pensioner's homes provide care to citizens who are in receipt of an old-age pension and who owing to their unfavourable health condition need constant care that can't be provided by either the family or the nursing care service. The pensioners' home as a social service facility is not directly designed for persons with disabilities but, in majority of cases, residents suffer from the diseases or disabilities that are associated with older age. A pensioners' home provides the necessary care comprising meals, housing and maintenance. Additionally other support is provided, including counselling, leisure activities, cultural activity and rehabilitation activity, while participation in community life is being encouraged. There are 194 facilities in total offering 13,277 places. Data can be provided for 48 facilities with 4399 places. Typical number of places in each institution is around 100 people, from 60 years up.

7.4.2 Pensioner's home combined with social service home for adults

Pensioner's home combined with social service home for adults combine both services. Data is provided for 48 of these combined facilities with 4,957 places in total, so the majority of these institutions are very big ones.

7.4.3 Nursing care service facility

Nursing care service facility provide the necessary care comprising meals, housing and maintenance to a person who subject to the referral of a health facility (or physician) depends on being provided with help in daily life. 91 nursing care facilities with 16,664 places for older people age 60 and older exist in Slovakia. Typical insight gives the 34 nursing care service facilities with 664 places listed in the template.

7.5 Services for people with mental health problems

An older WHO –Paper (2001) criticizes the poor state of financing of mental health care, inadequate education and training of professionals in the field and stigmatization of the mentally ill in society. The transformation beginning in the year 1989 brought numerous changes to the entire health care system. Before the changes psychiatry was mostly biologically orientated, some psychiatric institutions had been placed in old castles far away from urban centres. Mental health care reform was planned in 1990

and 1991 and served as basis for the mental health programme approved in 1997. Every region with 100,000 to 150,000 inhabitants should have inpatient and outpatient mental health care services, restructure the number the profile of beds by closing beds in mental hospitals and opening new wards in general hospitals and develop outpatient services, e.g. day centres, rehabilitation facilities, sheltered workshops, sheltered housing. The reforms were interfered by economic difficulties.

Under the domain of the Ministry of Health there is one ***children psychiatric hospital*** with 90 beds, serving children with mental diseases or disorders from age 0 to 18. Children are treated between 3 to 6 months and stay in small wards with 20-30 beds that are newly rebuilt. School and swimming-pool is part of the facility.

Inpatient psychiatric care for adults is provided in ***Psychiatric hospitals, long-term psychiatric facilities and wards or university departments (3) in general hospitals.*** There were 5 psychiatric hospitals, 5 long-term care facilities, 32 psychiatric wards/departments of hospitals, 7 centres for therapy of drug dependences and 2 anti-alcoholic interception stations in 2004 with 4507 beds in total. This corresponds to 1.8 beds (acute and chronic) per 100,000 inhabitants (in 2001). 90 % of the wards are part of general hospitals, so treatment is not such a big stigma. Concerning acute psychiatric treatment it can be stated that nearly 90 % of the patients are treated for the first time in that year (2005) and the average length of stay is 19 to 20 days. Chronic patients are treated in long-term facilities, where the average length of stay is 47 days.

Older people with mental health problems are cared for in ***Geriatric facilities*** with 779 beds. Three regions out of eight do not have a facility for psycho-geriatric care and it is even not planned for the next 5 years. Another problem is the provision of service for elderly people with dementia, which need a specialised facility and specialised staff (combining psychiatric and geriatric knowledge). Repeated requests for these facilities have been declined in past (and present as well) constantly.
Specialised day care facilities are lacking in the field of mental health. There is no community based psychiatry, no sheltered workshop or rehabilitation service for psychiatric patients (with 2 exceptions), no sheltered living, no early intervention service, no crisis intervention centre and no day-hospital for people with mental health problems. So the perspectives are to build up community based psychiatric facilities. But there are no allocated financial aids for this kind of services neither at the Ministry of Health nor in the community. Trained staff is lacking as well.

8. Other relevant information on residential services

Private Provision: In comparison with other Eastern European States (e.g. the Baltic States) private provision of services is a common thing in Slovakia, in social care as well in the field of education or health care. Private sellers have to be registered by regional authority and to fulfil legal conditions (§ 72 - § 83 of the Act on the social assistance).

For example the owner-type of social services is as follows:
Self-administration: 56.4 % of places
local authority 19.3 %
church 4.8 %
other legal persons 7.5 %
natural persons 2.3 %.

In the field of psychiatry there are 10 NGOs working without support from official bodies.

9. Staffing

The topic of staffing is regulated by different laws in Slovakia. Before the fall of the wall a lot of medical staff had been working in social services. This situation is now changing, following the motto "from patient to citizen". Services shall be a substitute for home, not for hospital. More social workers and all kind of therapists enter the field of social services. It's possible to study social work in Slovakia since 1990. But jobs in institutions are not regarded as attractive, the wages are low (420 Euro on average) and the image is bad. Law no. 249/1992 and law no 552/2003/04 contain requirements for work in public areas as well as scale of charges, level of qualification and other issues. Not only the formal education is decisive, but also the highest job level held. The director of an institution is obliged to have a higher education degree. Director, head sister and social worker also have to fulfil special qualification conditions, so they have to take a special course and introduce a project for increasing quality of provided social service.

The following table contains the ***Number of employees in social service facilities*:**

Employee category		Registered number of employees at end of period under review (natural persons)	of which women	Total wages and salaries (000 SKK)
Total employees of social service facilities		**12,168**	**10,486**	**1, 811, 861**
v tom	professional and administrative staff	1,212	947	262,689
	educators	224	188	38,831
	assistant educators	367	332	54,610
	health care giving staff	2,207	2,141	390,668
	assistant health care staff	1,871	1,700	228,407
	employees performing social agenda	390	368	63,551
	employees executing social work	183	162	31,655
	ergotherapists	259	207	40,568
	psychologists	31	27	5,527
	special needs teachers	91	67	15,509

	institutional doctors	6	2	638
	professional nursing care staff	858	784	106,580
	craft workers, manual or manipulation workers	2,973	2,167	371,550
	catering operations staff	1,496	1,394	201,078

Source: MoLSAF SR statement

The work profile of a „social worker carrying out social work", for which first- and second- level higher education qualifications are required, has been put in place in the social service facilities only from 1 April 2001, when the Act No. 313/2001 Coll. on the public service and the Government Regulation No.111 issuing catalogues of work activities in public service and their amendments went into force. (From 1 January 2004, the Act No. 552/2003 Coll. on performing of work in public interest, as later amended and the Act No. 553/2003 Coll. On the remuneration of certain employees at performing of work in public interest and on amendment of certain acts, as amended by later regulations, and the Government Regulation No. 341/2004 Coll. establishing catalogues of work activities at performing of work in public interest and on their amendments, went into effect that superseded previous regulations.)

The following is the structure of employees in social service facilities by education:
- 3 % employees with higher education (tertiary),
- 28.4 % employees with complete secondary (advanced level) education
- 68.6 % employees with primary or secondary vocational education.

This is due to the fact that a great majority of employees perform the so-called attending work activities categorised and remunerated according to the work activities catalogue as craft, manual or manipulation work activities with prevailing physical work in the performance of work in the public interest.

Staff qualifications concerning education are fixed by law, too. Special teachers and special educators must have a university degree in special education, educators a high school degree and special courses in the area of special needs. The director should have a university degree in special education and at least 5 years experience of teaching.

A problem concerning the area of psychiatric care is the bad payment of doctors. It is no problem to find qualified staff, but to pay them is difficult. That's why a lot of (young) people go abroad.

10. Costs

The average costs for the social services listed in the template are as follows:
pensioners home: 414 €, co-financing of the client 100-130 €
sheltered housing – pensioners home: 350 €, co-financing of the client 100-130 €
social services home for adult: 457 €, co-financing of the client 115-145 €
social service home for children: 486 €, co-financing of the client 100-130 €
sheltered housing facilities: 229 €, co-financing of the client 100 €
rehabilitation centres: according to needs 294 to 353 €,

nursing services facility: 414 €, co-financing of the client 100-130 €.[29]

The amount of the co-financing of the client depends on the size of the room and the catering and corresponds with the income and property of the individual. Persons with an income from less than 28 € per month do not pay a contribution (conditions for public providers). Costs and contributions been increased during the last years, mainly because of higher prices for energy and water.

The yearly amount for services related to school issues per pupil (financed from the state) is around 735 €. For children with special needs the yearly amounts are higher, e.g. for pupils with hearing impairment around 1295 € or for children with autism 5880 €.

An average bed day costs from 24 to 30 € in a mental hospital (long-term-facility).

11. Issues

11.1 Ethnicity

Available statistics do not distinguish or provide information on ethnic groupings.

11.2 Gender

The majority of Social Service Homes are still segregated institutions for men and women. Institutions for persons with mental disability has been segregated by gender in the past, this is changing slowly. In some services e.g. sheltered housing men and women are living together. As women tend to live longer than men they are overrepresented in pensioner's homes.

11.3 Age

In a social service home for children, care is provided only from the age of 3 years until the completion of 25 years. However, in many cases clients stay there even longer. In pensioner's home, care is provide only from the age entitled for old age pension (women from 53+, men from 60+).

11.4 Regional/geography

Institutions who offer social services are equipped differently. At the moment a monitoring process is going on under the aegis of the MoLSAF till the end of April, to find out where services are missing (e.g. sheltered housing). The Ministry of Health states that the whole area of Slovakia is covered with facilities, but in some rural areas specialists are lacking. There is a tremendous discrepancy between the capital Bratislava and the rest of Slovakia, especially the eastern part where some types of facilities are completely lacking (e.g. Prešov´s region with more than ¾ million of inhabitants has no psycho-geriatric facility neither facility for child psychiatry – neither out-patient nor in-patient).

12. Acknowledgements

Lydia Brichtova
Eva Zaujecova

[29] All prices were given by month and are average costs.

Eva Palova
Jana Juraskova

13. Information sources on disability used to compile the template and commentary, including people who were interviewed

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Statistical information on Social Services based on information of Slovakian self-governing regions (Bratislava, Trnava, Nitra, Trenčín, Banská Bystrica, Žilina, Prešov, Košice) and Supplementary report for the comparative research project "Local services for the disabled people in Europe"

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Country Report

Slovenia

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Summary of available data

Service types and number of places

Type of service	Size interval	Places total
Centres for residential care for adults		*821*
Special units in homes for the elderly		
Social care institutions for training		
Special departments in homes for the elderly		
Social care institutions		
Sheltered workplaces providing institutional care in residential homes and group homes		
Residential institutions for children	51 to 99 places	*1697*
Total		**2518**

No other detailed information is available.

Staffing

No information on staffing is available.

Completeness and accuracy of the data

Actual data for Slovenia can not be provided. Despite intensive efforts to gain the data, constant requests were not answered by the Ministry of Labour, Family and Social Affairs, nor from the National Institute for Education and the Ministry of Health. According to the Statistical Office of Slovenia the requested data could not be provided.

Commentary: Slovenia

1. Overview

Actual data for Slovenia can not be provided, only some figures from older publications. Besides intensive efforts to gain the data, constant requests weren't answered by the Ministry of Labour, Family and Social Affairs, but also from the National Institute for Education and the Ministry of Health. According to the Statistical Office of Slovenia the requested data could not be provided. The EU-Map Report states that there is no national system for the regular and comprehensive collection of statistics on people with intellectual disabilities and data on adults with intellectual disabilities is inconsistent and incomplete. But detailed statistics on children with intellectual disability are available from information on school placements and receipt of social benefits. Figures of Government Institutions differ greatly. Adults with mild intellectual disability are not registered in any official source, as they are considered able to work and are not eligible for social benefits.

2. Political and social context

Slovenia is a small country on the crossing between middle and south-east Europe. Neighbours are Italy in the west, the Adriatic Sea on the southwest, Austria in the north and northwest, Hungary is northeast and Croatia in east and southeast. Slovenia has a territory of 20,273 sq km and has 1,997,004 inhabitants in total. 83.6 % of them are Slovenians, autonomous minorities are Hungarians and Italians, other population groups are Croatians, Serbians/Montenegrins, Macedonians, Bosnians, Albanians, Roma and Germans. Nearly 300,000 people live in the capital Ljubljana. Slovenia proclaimed its own statehood on 25 July 1991. It was the first country to leave the Federal Republic of Yugoslavia.

2.1 Government organisation and structure

The Republic of Slovenia is a parliamentary republic. Slovenia's administrative structure consists of 194 local authorities. The gross domestic product per head was 12,139 Euro in 2003. Since 29 March 2004 Slovenia is member of the NATO, since 1 May 2004 member of the European Union.

Source: http://europa.eu/abc/maps/members/slovenia_de.htm

3. Demographics

Slovenia has a population of nearly 2 million. The life expectancy is 73 years for men and 81 years for women. In total 37 % of deaths were caused by diseases of the circulatory system and 26 % by cancer. Infant mortality is 5 per 1000 for males and 4 per 1000 for females. Health expenditure as a percentage of GDP was 8.8 in 2003. The total health expenditure per capita was 1,669 Intl $ in 2003.

4. Health and Social Care System

4.1 Organisation

Social security for persons with intellectual disability is ensured on a basic level in Slovenia based on several laws. The Law on Social Security for Persons with Intellectual and Physical Disability foresees a disability benefit (for adults over 18 years). The Social Security Act grants a financial support. The Pension and Disability Insurance Law provides social security benefits for family members. The Health Care and Health Insurance Law provides medical treatment free of charge.

The EU – Map Report states that persons who attend social institutions enjoy a higher level of social security than persons with intellectual disability who are under domestic care.

4.2 Financing

Adults in residential care pay part of the costs from their own resources or the resources of parents or relatives. The municipality covers the remainder of the costs.

Prices for institutional care vary significantly between different institutions.

In 1992 a five-year project on direct payments has been initiated by NGO Sklad Silva. Although Slovenian legislation does not cover provision for direct payments, all three municipalities who took part in the project are still running the scheme. Today 13 adults with intellectual disabilities receive direct payments on the basis of an individual plan and yearly revised budget. Another example for direct payments is the programme “Independent Living of Disabled People” realized by the Association for the Theory and Culture of Handicap (YHD).

5. Definition, eligibility and diagnosis/assessment

Status and Rights of people with intellectual disabilities are regulated by:

- The Placement of Children with Special Needs Act 2000
- The Act on the Social Care of Mentally and Physically Disabled Persons 1983
- The Act on the Vocational Rehabilitation and Employment of People with Disabilities 2004.

The first mentioned Placement Act regulates the work of the commissions responsible for diagnosis and placement and provides a definition of intellectual disability. For educational purposes five levels of intellectual disability are diagnosed: borderline, mild, moderate, severe and profound.

The Social Care Act was passed in 1983 and was considered as a breakthrough in securing the social care for people with mental and physical disabilities. Adults (aged

over 18) can appoint for an "invalid status" on the basis of this law. This status enables them to get access to various types of care and guarantees financial support, such as disability allowance and assistance allowance. A big disadvantage of this law is that by receiving the "invalid status" people are automatically determined as incapable of independent life and work. They have the right to receive social security benefits but are not covered by the provisions of the Vocational Rehabilitation Act.

The terms "person with disabilities" and "person with intellectual disability" are not used in Slovenian legislation. The Social Care Act still refers to "invalids" or "mentally retarded persons". Newer laws introduced less stigmatising terms. The Placement Act for example speaks of "children with disturbance in mental development" or "children with special needs". The Placement Act defines "persons with disturbance in mental development" as follows: "person having poor cognitive, verbal, motor and social skills in comparison to the average skill level of a person of the same age, which reflects an unbalanced development between the mental and chronological age of the person".

There are different procedures for the diagnosis and assessment of disabilities according to their purpose. Different procedures exist for educational purposes for children, for employment purposes for adults and for access to social benefits for adults. For educational purposes Placement Commissions for Children with Special Needs under the authority of the National Institute for Education are responsible. They diagnose children with one of five levels of intellectual disabilities (borderline, mild, moderate, severe or profound intellectual disability).

Rehabilitation Commissions are responsible for assessing the working capacity and employability of adults since May 2004. These Expert Commissions work under the authority of the National Employment Service. Adults with moderate, severe or profound intellectual disability receive the "invalid status" under the Social Care Act and are eligible for social benefits. In the assessment the Rehabilitation Commission takes into consideration the severity of a person's disability and their corresponding need for personal assistance.

6. Prevalence of disability

The Population Census from the year 2000 included detailed questions on disability, but does not provide information disaggregated by the type of disability. According to the census there was a total of 103,154 people with disabilities or long-term illness out of a population of approximately 1.73 million, this included 4,874 children with disabilities age 14 and under, most of them (97,929) were living in private households, 5,225 people were living in institutions. This group includes 288 children age 14 or under and 2,291 people age 60 and above.

In the first half of 2002 social benefits for people with disabilities were paid to 4,580 children under 16 and 84,794 people age 16 and over. Approximately 45,000 adults with disabilities were receiving an incapacity pension.

According to data from the Ministry of Labour, 7,242 persons were registered as "invalid" under the Social Care Act in 2002. The Statistical Office recorded 4,258 adults with intellectual disabilities in 2003. Adults with mild intellectual disabilities are not registered in official sources as they are considered able to work and are not

eligible for social benefits. 3,351 children were diagnosed with intellectual disability in 2002.

7. Residential Services for people with a disability

7.1 Overview

According to the EU-Map Report the Statistical Office of Slovenia maintains detailed statistics on the number of people with disabilities assessed each year by the Medical Examination Commission of the Social Security Board. No information is available on the type of disability and is not possible, to distinguish statistically between the different types of disability. The Statistical Office reports that the requested data could not be provided and forwarded our request to the Ministry of Labour, Family and Social Affairs, to Mr. Stefan Kociper, Executive Director Office for Social Affairs. The Country Report from Inclusion Europe and Sozitje states, that institutional care for persons with intellectual disability is relatively well developed, but there are deficiencies in care for persons with profound intellectual disability and for older persons with intellectual disability. Government policy aims to create smaller units and residential communities within central institutions, to support the transition to a more independent life for clients. Priority is given to residential communities, smaller day care centres and day centres. In five institutions for training, work and social welfare for persons with moderate and severe intellectual disability there were 808 children and 819 employees.

The EU-Map Report states, that an important trend towards deinstitutionalisation can be observed with larger institutions opening day centres as an alternative to residential care, especially for children. Children with moderate or profound intellectual disabilities are still referred to residential institutions for educational purposes. Approximately 70% of adults and 90% of children with intellectual disabilities live with their family. The "*National Programme on Social Security by the year 2005*" promoted inclusion and community-based services. Conceptual changes included in this program are to expand the network of social actors and services and to promote a better quality of life for vulnerable groups.

7.2 Services for children with a disability

Most of the children and adults with intellectual disability still live with their families. As all children are obliged to attend school, exclusion nearly does not exist. In the year 1999/2000 62 primary schools provided education with adjusted programs to 2796 pupils with intellectual disability, every year about 30 professors of special education are formed. Detailed statistics on the number of children diagnosed with intellectual disabilities should be available, also disaggregated by level of intellectual disability, under the National Institute for Education. Children and young people with moderate, severe or profound disabilities are cared for in 10 residential institutions providing education, training and work in accordance with legislation on education, health and social security. These institutions include 5 centres for the training and care of children and young people. In total 821 children lived in these residential institutions in the year 2000.

7.3 Services for younger adults with a disability

Adults with intellectual disabilities are placed in several types of residential institutions:

1) Social care institutions for training: Five institutions of this type provide institutional care and prolonged education and training.
2) Centres for residential care of adults: There are 10 of such centres in Slovenia operating together with sheltered workshops.
3) Social care Institutions: Five such institutions provide care and some training programmes for adults with moderate, severe and profound intellectual disabilities.
4) Sheltered workplaces providing institutional care in residential homes and group homes: provide institutional care for 524 people in 11 towns. Besides there are 3 public providers offering this kind of care in 3 towns for 69 people.
5) Group homes: in 1999 there were 23 group homes for 96 residents.

7.4 Services for older adults

1) Special units in homes for the elderly: Three homes care for adults with moderate, severe and profound intellectual disability. Some units are in the same building as the home for the elderly, some are physically segregated.
2) Special departments in homes for the elderly: 7 special departments care for adults with moderate, severe and profound intellectual disability as well as for adults with physical disabilities. 1,697 people resided in these special departments in 2003, including 103 people aged below 39 years.

7.5 Services for people with mental health problems

According to the WHO there is one University Psychiatric Hospital and five regional psychiatric hospitals in Slovenia and about 150 qualified psychiatrists (in 2001). Factors which damage mental health in the country are unemployment, high use of alcohol, ageing of the population and a high level of stigmatization of persons with mental disorders. Despite the strong influence of neighbouring Italy, deinstitutionalisation has not taken place significantly, though the number of psychiatric beds has been reduced to 0.8 per 1000 of the population. Two specialised social institutions provide about 200 beds for patients with chronic psychiatric disorders, eight local homes for older people have departments with psychiatric beds. Adequate complementary services has not been developed in the communities, as result persons with mental disturbance present a major social and family burden. But various community support systems had build up by NGO's. Multidisciplinary teamwork is normal in psychiatric care, working groups are normally led by a doctor. The network of organizations and services outside psychiatry is weak. Matters of concern are the need to extent and supplement training/education programmes to broaden the anti-stigma movement to families and the general public, the need to establish standards for work in NGO's and other services which deal with mental health, priority task is to create and extend the network of services for mental health (WHO 2001).

8. Other relevant information on residential services

Private Provision: All NGOs are organised in a National Board of Disability Organisations. Sozitje for example represents 51 branch organisations, has over 20,000 members and performs a wide range of social programs and has been working in Slovenia for 38 years.

9. Staffing

Professional pedagogical staff is educated at the Faculty of Education at the universities in Ljubljana and Maribor.

10. Information sources on disability used to compile the template and commentary, including people who were interviewed

Ministry of Labour, Family and Social Affairs
Ministry of Health
Institute of Public Health
National Institute for Education
Statistical Office
NGOs: Sent, Sozitje, Centre Draga
University of Ljubljana (all of them contacted)

11. References

German Foreign Office: Länderinformationen: www.auswaertiges-amt.de/diplo/de/Laender/Slowenien.html (Information about Slovenia in german)

Inclusion Europe, Sozitje: Human Rights of Persons with Intellectual Disability. Country Report Slovenia, Brussels and Ljubljana 2002

Map: http://europa.eu/abc/maps/members/slovenia_de.htm

Open Society Institute: Rights of people with Intellectual Disability. Access to education and employment. EUMAP – EU Monitoring and Advocacy Programme, 2005, http://www.eumap.org/topics/inteldis/reports/national/slovenia/id_si.pdf

World Health Organization: Information on demographics: http://www.who.int/countries/svn/en/

World Health Organization: Highlights on Health in Slovenia 2005, o.O. 2006: http://www.euro.who.int/Document/E88408.pdf

Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

Spain

L. Salvador-Carulla, R Martínez-Leal, JA Salinas, M. Poole, Romero A

PSICOST Scientific Association

Summary of the available data

Description of service types

The table below summarises the descriptions of the 16 service types included in the template.

Type of service	Size interval	Age group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admission
Centro residencial para niños con discapacidad	11 to 30 places	0 - 18/19 years	Mixed ID with PD, SD, MH, Beh and other	24 hour	Mixed	Mixed (any)	Mainly long term
Residential Centre for People with Intellectual disability	31 to 50 places	16/18/25 to 60/65 (adults but not older adults)	ID only	24 hour	Mixed	Mixed (any)	All long term
Residential Centre for People with Plurydisability, Mixed disabilities, Other disabilities	25	1.8E-59	.	.	.	.	.
Residential Centre for People with Physical disability	31 to 50 places	16/18/25 to 60/65 (adults but not older adults)	PD	24 hour	Mixed	Mixed (any)	All long term
SM. Unidades Hospitalarias de Rehabilitación /Comunidad Terapeutica	11 to 30 places	16/18/25 to 60/65 (adults but not older adults)	MH	24 hour	State	State	Short to medium term (up to 2 years if specified)
SM. Pisos Tutelados/Viviendas Supervisadas	6 to 10 places	16/18/25 to 60/65 (adults but not older adults)	MH	Mixed depending on need	Mixed	Mixed (any)	Mixed
SM Pensiones/Hostales	11 to 30 places	16/18/25 to 60/65 (adults but not older adults)	MH	Less than 10 hrs per week	Mixed	Mixed (any)	Mixed

SM. Residencias Hogar	11 to 30 places	16/18/25 to 60/65 (adults but not older adults)	MH	24 hour	Mixed	Mixed (any)	All long term
SM. Unidades de Media Estancia	.	16/18/25 to 60/65 (adults but not older adults)	MH	24 hour	State and Local Authority/municipality	Regional authority/LA/County and state	Short to medium term (up to 2 years if specified)
SM. Unidades de Larga Estancia	.	16/18/25 to 60/65 (adults but not older adults)	MH	24 hour	State and Local Authority/municipality	Regional authority/LA/County and state	All long term
Hospital Psiquiátrico	151 to 200 places	Over 18/25 (i.e. adults only)	MH	24 hour	State and Local Authority/municipality	State	All long term
Hospitals for Psychophysic Rehabilitation	11 to 30 places	16/18/25 to 60/65 (adults but not older adults)	PD and Sensory/other	24 hour	State and Local Authority/municipality	State	Mixed
Hospital Nacional de Parapléjicos	201 places +	3 to 25 years	PD and Sensory/other	24 hour	State and Local Authority/municipality	State	Mixed
Elderly homes for people with disability	.	over 60/65	Mixed	24 hour	Mixed	State	Mainly long term
Viviendas Tuteladas – sheltered accommodation for elderly people with a disability	6 to 10 places	over 60/65	Mixed	Per day only - no night time cover	Mixed	State	All long term
Hospitales de Geriatría y/o Larga Estancia	100 to 150 places	over 60/65	PD and Sensory/other	24 hour	State	State	All long term

Data available by service type – breakdown by size and disability

Type of service	Places total	Under 30 places	Over 30 places	Size unspecified	ID	MH	PSD	Elderly/ dementia	Mixed/dual	Other/ unspecified
Centro residencial para niños con discapacidad	0	.	.	.	.	.	.	.	.	.
Residential Centre for People with Intellectual disability	20,376	.	.	.	20,376	.	.	.	.	0
Residential Centre for People with Plurydisability, Mixed disabilities, Other disabilities	1,822	.	.	.	.	.	.	.	1,822	0
Residential Centre for People with Physical disability	3,260	.	.	.	.	.	3,260	.	.	0
SM. Unidades Hospitalarias de Rehabilitación /Comunidad Terapeutica	812	257	555	0	.	812	.	.	21	29
SM. Pisos Tutelados/Viviendas Supervisadas	1,350	1,350	.	0	.	1,350	.	.	.	0
SM Pensiones/Hostales	46	46	.	0	.	46	.	.	.	0
SM. Residencias Hogar	740	740	.	0	.	740	.	.	.	0
SM. Unidades de Media Estancia	2,401	.	.	.	.	.	.	.	.	.
SM. Unidades de Larga Estancia	8,143	.	.	.	.	.	.	.	.	.
Hospital Psiquiátrico	3,624	.	.	.	.	.	.	.	.	.
Hospitals for Psychophysic Rehabilitation	32	32	.	0	.	.	32	.	.	0
Hospital Nacional de Parapléjicos	222	.	222	0	.	.	222	.	.	0
Elderly homes for people with disability	138,354	.	.	.	.	.	.	.	.	.
Viviendas Tuteladas	454	.	.	.	.	.	.	.	.	.
Hospitales de Geriatría y/o Larga Estancia	12,833	.	.	.	.	.	.	.	.	.
Total	**194,469**	**2,425**	**777**	**.**	**20,376**	**2,948**	**3,514**		**1,843**	**29**

Data available by service type – breakdown by age

N.B. No breakdown by gender available.

Type of service	Places total	Children	Younger adults	Older adults	Adults over 18	Age not known
Centro residencial para niños con discapacidad	0	.	.	.	.	0
Residential Centre for People with Intellectual disability	20,376	.	.	.	.	20,376
Residential Centre for People with Plurydisability, Mixed disabilities, Other disabilities	1,822	.	.	.	.	1,822
Residential Centre for People with Physical disability	3,260	.	.	.	.	3,260
SM. Unidades Hospitalarias de Rehabilitación /Comunidad Terapeutica	812	.	.	.	.	812
SM. Pisos Tutelados/Viviendas Supervisadas	1,350	.	.	.	.	1,350
SM Pensiones/Hostales	46	.	.	.	.	46
SM. Residencias Hogar	740	.	.	.	.	740
SM. Unidades de Media Estancia	2,401	.	.	.	.	2,401
SM. Unidades de Larga Estancia	8,143	.	.	.	.	8,143
Hospital Psiquiátrico	3,624	.	.	.	.	3,624
Hospitals for Psychophysic Rehabilitation	32	.	.	.	.	32
Hospital Nacional de Parapléjicos	222	.	.	.	.	222
Elderly homes for people with disability	138,354	.	.	138,354	.	0
Viviendas Tuteladas	454	.	.	.	.	454
Hospitales de Geriatría y/o Larga Estancia	12,833	.	.	12,883	.	0
Total	**194,469**			**149,412**		**43,232**

Staffing

Type of service	Total staff	Care staff/nurses/ might include teachers in boarding school	Managers or other administrative staff (not care staff)	Educators /day staff	Day and care staff (no distinction made)	Clinical staff (Drs, therapists, psychologists, etc.)	Other staff (mainly ancillary staff)	Other staff (excluding ancillary staff)
Centro residencial para niños con discapacidad	.	.	.	.	.	.	.	.
Residential Centre for People with Intellectual disability	.	.	.	.	.	.	.	.
Residential Centre for People with Plurydisability, Mixed disabilities, Other disabilities	4,795	.	.	.	.	.	.	.
Residential Centre for People with Physical disability	.	.	.	.	.	.	.	.
SM. Unidades Hospitalarias de Rehabilitación /Comunidad Terapeutica	1,264	197	.	83	.	539	.	445
SM. Pisos Tutelados/Viviendas Supervisadas	.	.	.	.	.	.	.	.
SM Pensiones/Hostales	.	.	.	.	.	.	.	.
SM. Residencias Hogar	.	.	.	.	.	.	.	.
SM. Unidades de Media Estancia	13,854	7,634	1,378	417		1,568	2,760	97

Type of service	Total staff	Care staff/nurses/ might include teachers in boarding school	Managers or other administrative staff (not care staff)	Educators /day staff	Day and care staff (no distinction made)	Clinical staff (Drs, therapists, psychologists, etc.)	Other staff (mainly ancillary staff)	Other staff (excluding ancillary staff)
SM. Unidades de Larga Estancia								
Hospital Psiquiátrico								
Hospitals for Psychophysic Rehabilitation	.	.	.	.	.	.	.	.
Hospital Nacional de Parapléjicos	.	.	.	.	.	.	.	.
Elderly homes for people with disability	.	.	.	.	.	.	.	.
Viviendas Tuteladas	.	.	.	.	.	.	.	.
Hospitales de Geriatría y/o Larga Estancia	13,893	8,046	1,261	190	.	1,406	2,917	73
Total	33,806	15,877	2,639	690		3,513	5,677	615

Completeness and accuracy of the data

This report collates the most updated and accurate available data regarding residential services for people with disabilities in Spain. However, the report shares the same problems and limitations that the available information sources. For instance, data about disability prevalence in Spain is dated from 1999 and the sampling procedure excluded people living in residencies, institutions or secluded settings such as prisons. Therefore, we do not know the total number of people with disability living in residential settings in Spain.

Type of services
The list of services has been put together taking into account all type of residential services by type of service, type of disability served and all types of providers. We consider the list to be accurate and exhaustive. Although new residential services are being implemented in several regions as residential services for people with intellectual disability and mental health problems, these services are still quite rare in most regions except Cataluña in which we have group it together with Mental Health Hospitals as the National Hospitals Catalogue does. We have also included services that are not usually reported in other studies as monographic hospitals other than mental health hospitals.

Size of services
Collection of data about service size has proven difficult. Total number of places is available but data about size is only detailed for seven different services. This data is not presented in any report and it is only found in types of services with few services included or with a small number of places.

Type of disability
Data for places per type of disability is quite complete as most of the services are specific services for people with certain types of disability and few for mixed disability. Alternative residential settings and Geriatric hospitals for older people with disability are the exception. These services do not provide information about the type of disability of their users.

Age and gender
Data about age and gender are not provided by any institution or agency. There are many annual reports about places and service characteristics but there is not much information about residents or users apart of type of disability. Services for children are all for users under 18 years old and services for elderly are all for users over 65 years old. There is not information about gender at all. We have provided data about age for 3 different Autonomous regions as aggregated data do not exist. These data comes from the DESDE Project database.

Staff number and Staff training
Staff number is not provided for every service. As for age and gender data from 3 Autonomous Region have been collated. There is not individual data as most of the Agencies and institutions provide aggregated data about staff. As data for staff is not available in a detailed way, staff training is an almost impossible data to get.

Costs
Detailed costs are presented according to the most recent published data.

Commentary: Spain

1. Overview

Spain, officially the Kingdom of Spain, is a country located in Southern Europe, with two small enclaves in North Africa (both bordering Morocco). Spain shares land borders with Portugal, France, Andorra, Gibraltar, and Morocco. Spain is a democracy which is organized as a parliamentary monarchy. It is a developed country with the eight-largest economy in the world. Being a State of Autonomous Communities with full competences in health and social services, there is a great variety in terminology used, typology of services, and decentralised databases what makes difficult data collection and in some ways present a confusing picture about national services for people with disability or for any other kind of study.

2. Political and social context

2.1 Government organisation and structure

Spain is a constitutional monarchy, with a hereditary monarch and a bicameral parliament, the Cortes Generales. The executive branch consists of a Council of Ministers presided over by the President of Government (comparable to a prime minister), proposed by the monarch and elected by the National Assembly following legislative elections. The legislative branch is made up of the Congress of Deputies (Congreso de los Diputados) with 350 members, elected by popular vote on block lists by proportional representation to serve four-year terms, and a Senate or Senado with 259 seats of which 208 are directly elected by popular vote and the other 51 appointed by the regional legislatures to also serve four-year terms.

Spain is divided into 17 autonomous communities and 2 autonomous cities - Ceuta and Melilla. These autonomous communities are subdivided into 50 provinces. The lowest administrative division of Spain is the municipality. We use “regional” here as a descriptor for provision at the Autonomous Community level.

Spain is, at present, what is called a State of Autonomies, formally unitary but, in fact, functioning as a highly decentralized Federation of Autonomous Communities (AC); it is regarded by many as the most decentralized nation in Europe; for example, all territories manage their own health and education systems, and other territories (the Basque Country and Navarre) manage their own public finances. The autonomous communities have their own parliaments and regional governments, with broad legislative and executive powers. The “devolution” or transfer of government to ACs followed a different pace in every AC depending on regional policy, the model of administration transfer from the central government, and the agreements between every AC and the national government. At present, ACs are agreeing a new statutes with the central government that provide further autonomy to the ACs. Up to mid 2007, new statutes have been approved or are about to be approved in Catalonia, Valencia, Balearic Islands, Andalusia and Aragon. All other Autonomous Communities will follow this process.

The devolution process has not been accompanied with a parallel development of national agencies or efficient inter-autonomic coordination systems. The lack of advanced coordination agencies and strategies is related to problems in information system across the country. The social services transfer was completed by 1997, and the health service transfer was completed in 2001.

According to the World Bank, Spain's economy is the eighth biggest worldwide and the fifth largest in Europe. As of 2005, the absolute GDP was valued at $1.12 trillion, just behind Italy and ahead of Canada. In 2006 Spain was listed number 25 in the rank of countries sorted by their Gross Domestic Product per Capita.

Spain's mixed economy supports a GDP that on a per capita basis is 90% of that of the four leading West European economies and slightly below the European Union average. Unemployment stood at 7.6% in October 2006, a rate that compares favourably to many other European countries, and which is a marked improvement over rates that exceeded 20% in the early 1990s. Perennial weak points of Spain's economy include high inflation, a large underground economy, low productivity and one of the lowest rates of investment in research and development among developed countries, also an education system slated in OECD reports as one of the worst in Western Europe. Due to the loss of competitiveness, manufacturing jobs are being lost to cheaper workforce countries in Eastern Europe and Asia.

On the brighter side, the Spanish economy is credited for having avoided the virtual zero growth rate of some of its largest partners in the EU. In fact, the country's economy has created more than half of all the new jobs in the European Union over the five years period ending 2005. The Spanish economy has thus been regarded lately as one of the most dynamic within the EU, attracting significant amounts of foreign investment. More recently, the Spanish economy has benefitted greatly from the global real estate boom, with construction representing 16% of GDP and 12% of employment. However, the downside of this has been a corresponding rise in the levels of personal debt; as prospective homeowners struggle to meet asking prices, so the average level of household debt has tripled in less than a decade. Among lower income groups, the median ratio of indebtedness to income was 125% in 2005

2.2 Disability relevant policy

International treaties and international official documents are widely regarded as sources of national laws and norms in Spain (i.e. Rights for people with handicaps, UNO, 1971 and 1975; Article 13 Amsterdam Treaty). In this context, the Madrid Declaration 2002 is considered a key document for future development of policies in this area in Spain.

The Article 139 of the Spanish Constitution states that any Spaniard has equal rights and duties in any part of the Spanish territory. Thus, a person with disability is afforded the same civil rights than any other Spanish citizen. Article 49 says that public administration will carry out a policy of prevention, treatment, rehabilitation and integration of people with physical, sensory and psychological handicap. The administration will provide special care as needed, and will promote special support in order to guarantee the rights these persons are entitled as Spanish citizens.

The Spanish Law for the Social Integration of the Handicapped (Ley de Integración Social de los Minusválidos – LISMI) (7 April 1982, 13/82) provided a national framework for the care of these people. This law has been further developed by the Royal Decree 1997/99. The LISMI objectives have been developed in the "I & II National Action Plan for People with Disability 1997-2002, 2003-2007". A number of Autonomous Communities have issued special laws on this area (for example: Ley 1/1999, de Atención a las Personas con Discapacidad en Andalucía ; Social Services Law of Catalonia –submitted to the Regional Parliament in 2007). Municipalities play also an important role in social care provision, the Law on the Bases of the Local

System of 1985 regulated the powers of the Municipalities, among which "the provision of the Social Services and Social Promotion and Re-insertion" are considered (Chapter III, Article 25, 2K).

Article 49 of the Spanish Constitution states that public administration will carry out a policy of prevention, treatment, rehabilitation and integration of people with physical, sensory and psychological handicap. In 2006, the Spanish Congress passed the law of "Promotion of Personal Autonomy and Care for Persons in Dependence Situation". The "Dependence care system" will start to be implemented during the year 2007 and it will include people needing support from a third person for activities of daily living, being elderly, people with disability, mental health illnesses, etc. A new Agency of Dependency will be started in 2007 to provide care for this population group. At date, different Royal Decrees Laws are being discussed and approved in order to set up the bases and regulate the "Promotion of Personal Autonomy and Care for Persons in Dependence Situation" Law.

Regarding health care, people with disability, as Spanish citizens, are entitled access to free general medical care. However, law enforcements and empowerments have not been sufficiently developed and care gaps do appear in mental health, early care and other relevant areas. The law does not include prevention of disabilities, a topic included in the Law for the Handicapped (LISMI) and the Law of Dependency. Many services for people with disability have been transferred from the health sectors to the social sector. Health care is rights-based while social care is discretionary, except for care for those with severe impairment in activities of daily living (dependent). The extent to which health services provide care and allow access to people with disability differs in each AC. During the last 20 years major regional differences have arisen and inequities certainly do exist (Salvador-Carulla et al, 1999; IDRESNET, 2003).

Law 16/2003, 28th May, for the Cohesion and Quality of the National Health System (SNS) which is still developing and starting to be implemented, establish important measures in the area of dependence, given that for the first time "socio-health care" is mentioned as an answer to severe disability cases and to dependence problems. According to this Law, people eligible to benefit from this type of care will be those "ill people, mainly chronic ones, that because of their special needs may benefit of simultaneous and complementary care from the health and social services in order to increase their autonomy, to decrease their sufferings, to overcome their limitations and to facilitate their social inclusion"(art. 14). The law remarks that the health care will cover: a) long time care, b) convalescence health care and c) rehabilitation for functional recoverable deficits.

Disability Organizations and Institutions

Among others, the most important national Organisations providing information services, advocacy and representing the disability population sector are the Royal Board on Disability, the Spanish National Council of Disabled Representatives and the Information Service on Disability.

The Royal Board on Disability (Real Patronato sobre Discapacidad; http://www.rpd.es/index.html) is a public institution of the Ministry of Labour and Social Affairs. Its mission is to encourage prevention of impairments, rehabilitation and social integration of persons with disabilities, and to facilitate, in these fields, collaboration among entities, associations and private sector. Besides, it aims to provide support to specialists and organizations through studies, research,

documentation and training. The RPD is composed by representatives of the Ministries involved in disability issues and regional governments. Organizations representing disabled persons and their families, scientific institutions and experts, also take part in this institution.

The Spanish National Council of Disabled Representatives, CERMI (http://www.cermi.es/CERMI/ESP/ , exists to represent, defend and act on behalf the Spanish citizens with disabilities (more than 3.5 million) and their families. This disadvantaged group decided to work together through their representative organisations to ensure equal opportunities and full access to fundamental and human rights. CERMI is the Spanish disability movement political platform. CERMI is composed of the main national organisations in the disability field, some sectoral organisations and regional platforms, joining all of them more than 2.500 associations and entities, representing 3.5 million people with disabilities in Spain, 9% of the whole population

The Information Service on Disability (SID) is a public network put in operation by the Ministry of Work and Social Issues and the University of Salamanca for the establishment and development of an information system of state character on disability, via Web, for free and public access. The SID aims to serve as a platform of information dissemination on disability of the impelled sectorial policies from the Spanish Government and, in particular, those developed by the Secretariat of Social Services, Families and Disability, through the Main directorate of Coordination of Sectorial Policies on the Disability, the Institute of Senior Citizens and Social Issues (IMSERSO) and the Real Patronage on Disability. The SID is oriented to the professionals who take part in the scope of the attention to the educational groups, researchers and universities, political, planning and managing people in charge of the different Public Administrations and associative movement, people with disability and their families.

3. Demographics

Spanish population at 2006 was 44.708.964 inhabitants (INE, 2006) contributing to the 9.4% of the EU-25 population. Spain's population density, at 87.8/km² (220/sq. mile), is lower than that of most Western European countries and its distribution along the country is very unequal. In 2005 20.3% of the population was under 20 years old and 17.3% over 60. Life expectancy in 2005 was 77.2 years for men and 83.8 for women. Fertility rate during the period 2000-2004 was 1.27. Following the patterns of the EU, Spanish citizens have less children and later in their lives.

The population of Spain doubled during the twentieth century, due to the spectacular demographic boom by the 60's and early 70's. Then, after the birth rate plunged in the 80's and Spain's population became stalled, a new population increase started based initially in the return of many Spanish who emigrated to other European countries during the 70's and, more recently, it has been boosted by the large figures of foreign immigrants, mostly from Latin America (38.75%), Eastern Europe (16.33%), North Africa (14.99%) and Sub-Saharan Africa (4.08%). Spain presents one of the highest immigration rates in the world (1.5% annually in 2005) and it is followed by the USA the first country in the world receiving the highest number of immigrants. In 2006, 9.27% of Spanish population were immigrants**.**

4. Health and Social Care System

4.1 Organisation

Spain has a public Social Services System aimed at covering social needs and made up of provisions and services of the State Administration, the Administration of the Autonomous Communities (at the regional level) and the Local Corporations (at municipal level). ACs can and do promote new provision of services and benefits for people.

The reforms of the social security system have created a model of protection according to which all Spaniards are guaranteed health care and access to Social Services and protection Benefits for the family and by which pensions are structured on the three following levels:

- the first level of non-contributive attention is for those citizens over 65 years of age or disabled people who are not covered at the contributive level.
- a second level of contributions is that in which pensions depend on previous contributions to the social security system.
- and the third level is of a voluntary character, in which workers freely deposit their savings in pension plans and which may complement the pensions that they receive from the public system.

This protection is extended to Spanish citizens who normally reside and work, study, etc. in Spanish territory, and also to non-resident Spaniards or foreigners with legal residence in the country, if approved. Protection also covers the family of the insured person, pensioners and those who receive temporary financial assistance, those temporarily out of work who nevertheless have medical leave and those who have retired from their field of work but who have a special arrangement with their employer.

The basic services, guaranteed by the Autonomous Social Services Laws, are: Information and Orientation, Home Care, Alternative Accommodation and Prevention and Social Insertion. These services are performed via the Social Services in the Municipalities and constitute the Primary Social Attention Level attending Family, infancy and Youth, Elderly Persons, Women, the Handicapped, Drug Dependants, Ethnic Minorities, Immigrants, Homeless People and Other Sectors and Groups in a situation of need or dropouts.

The Spanish National Agency of Social Services and the Elderly (IMSERSO) the common services of Social Security for the management of technical payments of various types -work security, hygiene, formative action, re-education and rehabilitation of the handicapped and pensioner assistance- appeared with a different name and responsibilities at the beginning of the 1970s and depends on the Ministry of Labour. It was approved by Royal Decree-Law 36/1978, of November 6. The IMSERSO began operating the Social Security System's complementary services and continued to do so until the Royal Decree 530/1985 of April 8, in its third additional article, introduced a fundamental change: it gave IMSERSO some of the functions of the old National Institute of Social Assistance (INAS) which meant that its management activities overlapped the limits of the Social Security System. This integration or universalist direction of IMSERSO was complemented by other subsequent articles: in particular, the Royal Decree 1433/1985 by which the management of the Institute was expanded and for the first time included new groups and new regulatory mechanisms: senior citizens, the physically and mentally

handicapped, refugees and the marginal population. In this way, concurrence of ways and means, representing a launching pad for the universal regulation of social services came about. The obligations and responsibilities of IMSERSO regarding the management of the complementary services of Social Security benefits were transferred, as of January 1, 1991, to the Governments of the Autonomous Communities of Catalunya, Andalucia, Galicia, Valencia, Canary Islands, Basque Country and Navarre. This process of transference finished during 2001.

The IMSERSO has pushed forward research initiatives related to quality assessment, information systems and standard methods for service mapping in Spain. It has also promoted a common research program with the Institute Carlos III and the Ministry of Health starting in 2002. The "Observatorio Nacional de la Discapacidad" (National Disability Observatory) and its satellite office "Servicio de Información sobre la Discapacidad" (SID: http://sid.usal.es), is a dissemination and information centre promoted by the IMSERSO and the University of Salamanca, which is playing an important role in the area.

The IMSERSO, together with Autonomous Regions Social Services, local municipalities Social Services and NGOs are responsible for social residential care for people with disabilities. This type of care includes services for children as residential services for children with disabilities, adult residential services for people with disability and residences for elderly with disability or non-autonomous elderly. They also plan and manage different types of services like sheltered homes, small community residential facilities and social hostels aiming to provide the possibility of carry on with a kind of independent way of living. The IMSERSO still manages several residential centres for people with disability and it has initiated the design and creation of reference centres for chronic mental health disorders, cerebral palsy, Alzheimer reference centres, etc. It has also received responsibilities in the development of policies for the dependency care and it has developed the White Book on Dependency (IMSERSO, 2005a) and the development of the Law for the Promotion of Personal Autonomy and Care for the People on Dependency Situation.
After the return of democracy, the Ministry of Health was reconstructed and the National Institute of Public Health Care (INSALUD) was created, which assumes the managerial functions of public health care and depends on both the Ministry of Health, in all that concerns public health care organization and policy, and the Ministry of Labour and Social Security, in all that concerns patrimonial aspects, budget financing and management and economic control.

The Spanish Health Care system has been shaped by all the public health structures and services, which are formed by the State Administration Health Care Services and those of the Autonomous Communities. Each Autonomous Community forms a Health Care Service integrated by all the centres, services and establishments of the Community, the Diputacion, the City Hall and other intercommunity Territorial Administrations. The principles determining the limitations of the different Health Care areas are geographic, socioeconomic, demographic, cultural and climatological factors; they also depend on existing transportation and communication facilities, as well as the area's health care installations, for each community of 200,000 to 250,000 inhabitants.

The distribution of responsibilities and functions among the different administrative branches is established by the Spanish Constitution, the General Health Care Law, the Local Government Law and the Autonomy Statutes. With respect to these basic

norms, the resolutions of the Constitutional Court regarding the appeals made by the State or the Autonomous Governments with respect to conflicts of overlapping responsibilities must be added, which helps to define more clearly the responsibilities of each.

The Ministry of Health does not have a defined policy on handicaps. Until present year it did not have a national mental health programme, relying on the plans formulated by each Autonomous Community. Although being very similar in their theoretical formulation they are not as similar in their practical application, there are marked differences with regards to funding of resources for psychiatric care among them. There are also marked differences in the care of people with intellectual disability as same Autonomous Community as Cataluña and Madrid are developing their programs for the care of the people with intellectual disability and mental disorder –dual diagnosis-. The National Mental Health Policy has been set up in the document: National Health System's Mental Health Strategies (2007) that aims to establish shared national guidelines for the evaluation, treatment, prevention and promotion of Mental Health Illnesses. National health policies for other physical, sensory or intellectual disabilities do not exist.

The Ministry of Health together with the Autonomous Communities Health Systems, some Regional Institutions and NGOs are responsible for the residential health care for people with disability. Psychiatric Hospitals, Psychiatric Units at General Hospitals, Hospitals for Physical disabilities and Psychogeriatric clinics among others, are services provided by the Health System.

4.2 Financing

In 1982, INSALUD covered 86% of the Spanish population and 31% of hospital beds, which were in the best equipped hospitals in the country. During the first Health Care Reform different directives culminated in the General Law of Public Health Care of 1986. This modification represented the consummation of a change in philosophy, which passed from a system of public health care based on insurance to a public service open to everyone, independent of the amount of the contributions of each of its members. The task of building the National Public Health Law, a number of different bodies had to come to an agreement: public administration -Autonomous Communities, local corporations-, those groups providing the services -doctors, hospital staff, privately contracted people, etc.-. To reach this agreement, the Interterritorial Council of the National Public Health System began functioning in 1987 as a consultative body for the harmonization of health care policies of the State and Autonomous Communities administrations.

The near universalisation of health services -98.9% of the population has the right to receive health service free of charge- together with the growing demands of the population and the generalized incorporation of new technologies have produced a huge increase in health spending. All this means that the National Health System is at present undergoing changes and new assessments.

5. Definition, eligibility and diagnosis/assessment

The Spanish law for the Social Integration for the Handicapped known by its acronym LISMI, provides a legal framework for the definition (Título II, Articulo 7): "A person will be considered as a handicapped when there exists a decrease in the physical, psychological or social abilities as a consequence of a deficit which may be

permanent, and which may have or may have not a congenital basis". The term "Minusvalia" (Handicap) was officially changed to "Disability" in 2006. However "minusvalía" is still used in a number of official documents such as the certificate of entitlement (Certificado de Minusvalia). The term "mental retardation" was changed to "intellectual disability" since the same year. "Intellectual disability" was also adopted by major organisations working in this sector, although the health databases still use "mental retardation" following ICD-9MC or ICD-10 coding systems. Severe Mental Illness has been operationally defined by several ACs including Catalonia and Andalucia. The term "Dependency" has been defined following the European Council Recommendation R(98), 1998; that defines "dependency" like: the condition of a person who, due to a physical, mental or psychological illness or a deficiency of the same type, requires substantial and regular care from another person for performing essential everyday activities".

Health services use the ICD-10 classification. Ministry of Health database use an adaptation of ICD-9 (CIE in Spanish) (CIE9-MC). The IMSERSO) has officially adopted the International Classification of Functioning, Disability and Health (ICF, WHO, 2001) (CIF in Spanish).

The Royal Decree issued on 23 December 1999 (RD 1971/99) defined the procedure for legal recognition and grading of handicaps. It states that: "the legal status of handicapped is provided by the official agencies which are accredited for such task". The Royal Decree enabled the development of a table list for grading all handicaps according to the degree of handicap and a global percentage index of severity. In order to assign a percentage to a particular person, medical and social factors are considered. Its main source is the WHO 1980 classification of impairments, disabilities and handicaps (WHO ICDDH-1980) (In Spanish CIDDM-1980) and a developed adaptation to the CIF. For example, Intellectual Disability is assessed according to IQ level and several areas of functioning. IQ levels define four groups (Borderline functioning, IQ: 70-80/ Mild MR, IQ: 51-69/ Moderate MR, IQ: 35-50 / Severe-profound MR, IQ: less than 35). The areas of functioning assessed are: Language and psychomotor functioning, social and personal autonomy, educational record, occupational past history, and behaviour. This certificate is provided by official assessment agencies deployed in every AC of the Spanish territory: Assessment and Orientation Teams (Equipo de Valoración y Orientación- EVO). The grade and a percentage index of handicap are decided by an official assessment team. This coding is used for entitlement and legal issues. Thus, professional judgment is accepted by the legal system for qualification. The assessment can be reviewed every two years (or more frequently if professionals question it, though this is rare).

After the approval of the "Dependency Law" in 2006, there is a second entitlement to Dependency. The teams responsible of assessing dependency are being designed and organised and the instruments and schedules for dependency evaluation are currently being adapted and tested.

Dependency classification has been divided in three categories in order to establish a graduation to evaluate different dependency situations according to their severity: Moderate dependency –a person that needs help in his/her daily basic activities at least once per day-, Severe dependency – a person that needs help in his/her daily basic activities at least twice or three times per day but does not need the continuous help of a carer- and Great Dependency –a person that need continuous help everyday and the presence of carer 24h per day everyday given the lost of autonomy-.

People with handicaps/dependency are regarded as legally competent unless a judge determines his or her incapacity. This legal decision is included in the Spanish Civil Code (Book 1, Title IX). It should be aimed at protecting the person's rights and not other people's interests or benefits based on the ability of self-drive which is defined as the person's ability of handling and directing his or her own civil rights. Incapacity causes are described in the Article 200 of Law 13/1986, as those physical or psychological deficits or diseases, which prevent the ability of self-direction. The legal procedure is governed by Law 34/1984 (6 August 1984). The provision of incapacity can only be made by a judge following a procedure called "minor trial" and the provision must take into consideration an expert's opinion. The legal provision determines the extent and the limits of incapacity in every individual case. Three different civil status relate to incapacity: prolonged parental tutorship, full tutorship, when it is not assigned to the parents, and partial tutorship when incapability restrains some civil acts and not others (i.e. marriage, heritage, etc). The type of incapacity should be decided by the judge taking into account the severity of intellectual handicap. Hospitalisation and residential care in special institutions is also decided by the judge. A disability general attorney (fiscal) exists in many legal districts in order to handle and monitor these cases. The tutor can give consent on behalf of an adult with incapacity. He or she is also compelled by law to promote the abilities of the person, his or her recovery and the maximum level of insertion in society. Tutorship entities are being promoted at local level. NGOs and local administrations (i.e. municipalities) can assume this role. Incapacity can be reversed through a review process when changes in health or personal status do appear. The legal qualification of handicap and the provision of incapacity are independent and are provided by two different administrations.

The qualification of handicap entitles the person a number of special civil rights in order to compensate the social disadvantages produced by the handicap. The most relevant are fiscal benefits and pensions. From a legal perspective, two different types of provisions and benefits exist in Spain: right-based provisions and discretionary provisions and benefits. Education, health, social security and care for dependency are right-based while other social services are discretionary. Thus, the demand of social security pensions, subsidies and benefits for persons with dependency, or special support services in education are guaranteed while other individual support and social aids such as social funds for NGOs, are not mandatory.

The eligibility for social services, apart from being discretionary and not right-based, social service provision is not guaranteed by a general law as health or education are. The autonomous communities have full responsibility on this area and have issued regional laws regulating social services. All of them mention the handicapped and describe discretionary rights to special social services by this population group. However, most Autonomous Regions have not put forward decrees and norms to provide empowerment and regulate these rights. Local administration also has responsibilities on this topic. Major regional differences do not attain eligibility but provision and access to services.

Health services are guaranteed through the General Law of Health (Ley General de Sanidad). This law also entitles access to rehabilitation care to any handicapped person. However, law enforcements and empowerments have not been sufficiently developed and care gaps do appear in mental health, early care and other relevant areas. The law does not include prevention of handicaps, a topic included in the Law

for the Handicapped (LISMI). To make matters worse, many services for people with disability have been transferred from the health sector to the social sector. As said, health care is right-based while social care is discretionary. The extent to which health services provide care and allow access to people with disability differs in each AC. During the last 20 years major regional differences have risen and inequities certainly do exist.

6. Prevalence of disability

The main sources of information are the National Survey on Disabilities, Deficits and Health States (Encuesta Nacional sobre Discapacidades, Déficits y Estados de Salud; INE e IMSERSO, 1999), the National Health Survey, the Database on People with Disability, the CMBD, as well as other sources of information for specific disabilities such as the FEAPS database or a series of local epidemiological studies. In this report we will focus on the National Survey on Disabilities, Services and Health States.

This sociological study based on home interviews at national level, explored the rate of disabilities grouped by age, condition and type of impaired function. Criteria were drawn from ICDDH-1980, and data can be compared with a previous survey made in 1986. The sampling procedure excluded people living in residencies, institutions or secluded settings such as prisons. According to the 1999 survey, 9% of the Spanish population had some sort of handicap in 1999 (over 3 million people). The main causes were birth related conditions, traffic accidents and chronic diseases.

The prevalence of disabilities is clearly related to age. Thus, more than 32% of people above 65 years have some type of disability. However, disabilities prevalence among the population between 6 and 64 years is nearly 5%. Although the increase in the prevalence rate is constant as the age increase, from 50 years this increase speeds-up considerably (table 1).

Although there are more men than women with disability (58% vs. 42%) this is not true for all the age ranges. Thus between 6 and 44 years, the number of men with disability is a 32% higher than that of women with disability and below 6 years differences are not significant. However, when we consider the population older than 45 years old, the number of women with disability is 60% higher than that of men. When comparing rates for inhabitants, differences between men and women are lower, overall from the 75 years. For instance, in the group formed by people of 85 years and over, for every 100 women with some type of disability, there are only 41 men, but the female disability rate is only a 11% higher than that for men. This is due to the higher number of women in these ranges of age given the greatest death rates for men.

Table 1 Spanish population with disability by gender and age.

	Males	Females	TOTAL
Less than 6 years	24,723	24,853	49,577
6 to 9	15,363	14,420	29,782
10 to 15	20,697	17,804	38,502
16 to 19	28,058	16,232	44,290
20 to 24	36,385	22,663	59,048
25 to 29	48,578	29,697	78,275
30 to 34	64,514	43,117	107,631
35 to 39	60,029	55,142	115,171
40 to 44	61,162	53,918	115,080
45 to 49	66,311	68,764	135,075
50 to 54	74,872	95,962	170,834
55 to 59	96,639	114,323	210,962
60 to 64	141,830	159,512	301,342
65 to 69	161,083	225,255	386,338
70 to 74	168,643	288,626	457,269
75 to 79	172,670	304,256	476,926
80 to 84	120,382	250,319	370,701
85 and more	111,031	270,388	381,418
TOTAL	**1,472,970**	**2,055,251**	**3,528,221**

Source: Survey about Disabilities, Deficiencies y State of Health, 1999.

Regarding the type of deficiencies or illnesses that cause disability, orthopaedic deficiencies are the main cause of disability among the Spanish population (more than a 25% of all the disabilities considered). Visual and hearing deficiencies are responsible for 18% of all registered disabilities. Mental deficiencies and "other deficiencies" (multiple deficiencies and deficiencies not classified otherwise) are responsible each for 11% of disabilities. Visceral disabilities (7%), nervous system disabilities (6%) and language and speaking disabilities (more than 1%) complete the picture (table 2).

Table 2. People with disabilities and prevalence rates according to deficiencies which produced the disabilities, for large group of ages

Deficiencies which produced the disability	***Persons from 6 to 64 years old with disability for each type of deficiency***	***Rate per 1.000 inhabitants from 6 to 64 years***	***Persons with 65 and over for each type of deficiency***	***Rate per 1.000 inhabitants 65 years and over***
Total	**1,405,992**	**45.94**	**2,072,652**	**322.11**
Mental Deficiencies	287,330	9.39	227,542	35.36
Visual Deficiencies	262,815	8.59	567,961	88.27
Hearing Deficiencies	278,652	9.11	542,220	84.27
Language/ speak Deficiencies,	21,812	0.71	31,732	4.93
Orthopaedic Deficiencies	498,397	16.29	757,414	117.72
Nervous System Deficiencies	131,096	4.28	168,330	26.16
Visceral Deficiencies	116,134	3.79	208,717	32.44
Others deficiencies	46,913	1.53	474,704	73.78
Unknown	28,343	0.93	47,492	7.38

Deficiencies which produced the disability	*Persons from 6 to 64 years old with disability for each type of deficiency*	*Rate per 1.000 inhabitants from 6 to 64 years*	*Persons with 65 and over for each type of deficiency*	*Rate per 1.000 inhabitants 65 years and over*
Men	**714,439**	**46.46**	**733,809**	**270.80**
Mental Deficiencies	168,138	10.93	77,451	28.58
Visual Deficiencies	132,368	8.61	205,226	75.74
Hearing Deficiencies	141,729	9.22	227,038	83.79
Languages/speak Deficiencies,	14,371	0.93	17,422	6.43
Orthopaedic Deficiencies	218,100	14.18	208,317	76.88
Nervous System Deficiencies	70,215	4.57	76,787	28.34
Visceral Deficiencies	58,003	3.77	92,710	34.21
Other deficiencies	18,319	1.19	124,578	45.97
Unknown	16,954	1.11	16,777	6.19
Women	**691,553**	**44.97**	**1,338,843**	**359.46**
Mental Deficiencies	119,191	7.75	150,091	40.30
Visual Deficiencies	130,446	8.48	362,735	97.39
Hearing Deficiencies	136,925	8.90	315,181	84.62
Languages/speak Deficiencies,	7,442	0.48	14,310	3.84
Orthopaedic Deficiencies	280,297	18.23	549,096	147.42
Nervous System Deficiencies	60,881	3.96	91,543	24.58
Visceral Deficiencies	58,132	3.78	116,005	31.15
Other deficiencies	28,593	1.86	350,126	94.00
Unknown	11,391	0.74	30,716	8.25

Source: Survey about Disabilities, Deficiencies and State of Health, 1999. Database

7. Residential Services for people with a disability

7.1 Overview

Residential Services for people with disability are provided by the Ministry of Health and the Ministry of Work and Social Services in Spain. In general, services are broadly and equitatively set up around the national territory as Autonomous Regions have competency in health and social services issues. There are specific services for children, younger adults and older adults. Services are also generally aimed to serve a specific disability typology and in general mental health services, physical disabilities and intellectual disabilities are well defined and served in different services. Information about services, places, personnel and costs is not always available or it is not available in an aggregated way mainly due to regionalisation and lack of agreement about terminology.

7.2 Services for children with a disability

"Unidad de Hospitalización Breve Infanto – Juvenil" (Mental Health. Hospital Psychiatric Acute Unit for Children and Youngsters): Facilities for children with mental health disorders and in some cases severe behaviour disorders. 24 hr care is provided in a short-time admission basis. The age group served are children between 0 to 18 years old and these facilities have got 147 places: 30 for centres with less than 10 people and 117 for centres with 10 to 30 people. The typical number of places in these centres is between 10 and 30. All these centres are public and information about

staff is not provided. This service type has not been included in the template data reported above as it is short-term rather than a long-term provision.

"Centro Residencial para niños con discapacidad" (Residential Setting for Children with disability): Centres for children with intellectual, physical and severe behaviour disorders. The typical number of places is 15 and they serve children from 0 to 18. This type of service provides 24 hour support and mainly long –term care, although short-term care and respite care may be provided too. There are public and private (profit-nonprofits state subsidized centres). National data about number of places, staff and so on is not available. We have considered data for three Autonomous Communities in which the DESDE system has been implemented: Madrid, Navarra and Castilla la Mancha. Data about number of places is specific for the type of service, however data about staff include the staffing for other services given that data provided grouped together Residential Facilities for Children and adult with Disability. There are 114 places for children with disability in these 3 Autonomous Communities. The staff (shared with Adult Residential Settings) includes 680 clinical staff, 2873 care staff and 1242 education staff, in total 4795 (only for 3 autonomous regions: Madrid, Navarra and Castilla la Mancha).

7.3 Services for younger adults with a disability

"Centro Residencial para personas con Discapacidad Física" (Residential Centre for People with Physical Disability): These centres provide support to adults with physical disability, with 24 hour support for long – term care. The typical number of places is 34 and the age group served is between 18 to 65 years old. They are public and private and the number of places is 3260. The staff is shared with others services and we can only provide data from 3 Autonomous Regions: Navarra, Madrid and Castilla la Mancha in total 4795, 670 clinical staff, 2873 care staff and 1242 education staff.

"Centro Residencial para Personas con Discapacidad Intelectual" (Residential Centre for People with Intellectual disability): The typical number of places is 35. This type of service is aimed for adults with intellectual disability from 18 to 65 years old. They provide 24 hour support and long-term care and sometimes family respite too. They are public and private. The national number of places for these centres are in total 20,376. National staff data is not available so we again refer to data provided by 3 Autonomous Communities in which the staff is shared with other services: 4795 in total, 680 clinical staff, 2873 care staff and 1242 education staff, in total 4795 (only for 3 autonomous regions: Madrid, Navarra and Castilla la Mancha).

"Centro Residencial para Personas con Pluridiscapacidad, Discapacidades Mixtas y Otras Discapacidades" (Residential Centre for People with Plurydisability, Mixed disabilities, Other disabilities): This type of service is intended for adults with more than one disability, referred as "mixed", from 18 to 60 years old. There are 1822 places and the typical number of places is 25. They provide 24 hour support, long-term care and family respite too. There are public and private facilities. The staff is shared with the other services and there is only data for three autonomous regions (Navarra, Madrid and Castilla la Mancha): 680 clinical staff, 2873 care staff and 1242 education staff, in total 4795.

"Servicios Residenciales Alternativos" (Alternative Residential Settings : supported living, sheltered homes, etc.): There are houses or apartments for adults with intellectual and sensory disability from 18 to 60 who can be autonomous and do

a normal life with some support only some hours per day. The typical number of places in these services is 7. They provide short and long-term care. There are public and private. There are 1994 places: all with less than 10 people, 1847 for intellectual disability and only 9 places for sensory disability. The staff is still shared: 680 clinical staff, 2873 care staff and 1242 education staff, in total 4795. This service type has not been included in the template data reported above as it is short-term rather than a long-term provision.

"Unidad de Hospitalización Breve" (Mental Health. Acute Hospital Unit): There are 4569 places for this type of service, all places are for mental health. Patients served are between 18 and 65 years old and receive 24 hour support and short-term care. The staff in total is 3124: 2403 care staff, 54 education staff, 690 clinical staff and 177 other staff. There is no data about gender of patients. This service type has not been included in the template data reported above as it is short-term rather than a long-term provision.

"Unidades Hospitalarias de Rehabilitación /Comunidad Terapeutica" (Rehabilitation Hospital Units/Therapeutic Communities): This type of service provides rehabilitation and medium-term treatment with 24 hour support, but in many cases there are no free places, therefore medium stance sometimes becomes long term and there are long waiting lists. All the places are for adults with mental health problems between 18 to 65 years old. The typical number of places is between 15 and 30, in total there are 812 places: 257 for centres between 11 to 30 people, 293 for centres with 31 to 50 people, 60 for centres with 51 to 100 people and 202 for centres between 101 and 200 people. They are public and private. The staff: 344 care staff, 83 education staff, 392 clinical staff and 445 "other staff". In total there are 1264 persons working in these centres.

"Pisos Tutelados/Viviendas Supervisadas" (Sheltered accommodations and supervised residences for Meltal Health): Services provided only for mental health problems, for adults between 18 to 65 years old and who do not need 24 hour support. They provide short and long-term care and clinical and care staff overview the inpatients several days per week during some hours per day. They are private and public and only 3 to 12 adults live in these facilities. There are 1350 places in total. No information about staff.

"Pensiones/hostales para Salud Mental" (Pensions/Hostels for Mental Health): The person lives in a hostel or pension in which he/she is independent and the service establish contact with the hostel owner and the attended person in a regular basis. He/she can receive also some support if needed. They provide short and long-term care. This type of service is aimed for adults from 18 to 60 years old. There are 20 to 30 places in each pension/hostel. There are 46 places in total, all for centres with less than 10 people. They are public and private. There is no information about staff.

"Residencias Hogar" (Mental health Homes/Residences): Residences/Homes for mental disorders, for people from 18 to 65 years old, with 15 to 35 places in each one. They provide 24 hour support and long-term care and family respite too. There are public and private with 740 places in total. There is no information about staff.

"SM Unidades de Media Estancia" (Medium-stay Units for Mental Health): Services for adults with mental health problems from 18 to 65 years old. They provide 24 hour support for medium-term care and are public and private. There are 2401

places in total in these centres. There is no data on staff for these Medium Stance Units, only aggregated data for Psychiatric Hospitals, Long Stance Units and Medium Stay Units is provided. Therefore staff data is shared: 7634 care staff, 417 educational staff, 1568 clinical staff, 1378 administrative staff, 2760 ancillary staff and 97 "other staff" (in total 13,854 persons) .

"SM. Unidades de Larga Estancia" (Long-stay Units for Mental Health): Services for adults from 18 to 65 years old and with mental disorders. They provide 24 hour support and long – term care. There are 8143 places in these centres and there are private and public providers. The staff is shared with "Medium-stay Units and Psychiatric Hospitals": 7634 care staff, 417 educational staff, 1568 clinical staff, 1378 administrative staff, 2760 ancillary staff and 97 "other staff" (in total 13,854 persons).

"Hospital Psiquiátrico" (Psychiatric Hospital): These facilities are for adults (18 to 65) and older adults (over 65 years) – psycho-geriatric places-, the typical number of places is 200 and all the places are for mental health. In total there are 3624 places in these facilities. They provide 24 hour support for long-term and they are public and private. The staff is shared with "Medium-stay Units and Long-stay Units": 7634 care staff, 417 educational staff, 1568 clinical staff, 1378 administrative staff, 2760 ancillary staff and 97 "other staff" (in total 13,854 persons) .

"Hospital de Rehabilitación Psicofísica" (Hospitals for Psychophysical Rehabilitation): The typical number of places in these facilities is 15. They are for physical and intellectual disabilities (mixed) and provide 24 hour support. They provide short and long-term support. They are private and public and have got 32 places for centres with 11 to 30 people. Information about staff is not available

"Hospital Nacional de Parapléjicos" (National Hospital for people with paraplegia): These are services for adults with a physical disability who need also psychological support. The group age served is from 18 to 65 years old. They provide 24 hour support and short and long term care. They are public and private and there are 222 places in centres between 201 to 500 people. Information about staff is not available.

7.4 Services for older adults

"Unidad Psicogeriátrica (Psycho geriatric Unit)": For people with more than 65 years old and with mental disorders. In total there are 1825 places: 593 in centres with 31 to 50 people, 528 for centres with 51 to 100 people, 498 for centres with 101 to 200 people and 206 for 200 to 500 people. They are public and private and they provide 24 hour support for short – term care. The staff is shared with "Psychiatric Hospitals" and other Units: 7634 care staff, 417 educational staff, 1568 clinical staff, 1378 administrative staff, 2760 ancillary staff and 97 "other staff" (in total 13854 persons). This service type has not been included in the template data reported above as it is short-term rather than a long-term provision.

"Elderly homes for people with disability": Services oriented to older adults above the age of 65 years. There are 138,354 places: 42,322 places for physical disabilities, 19,910 for cognitive disabilities and 76,122 for mixed disabilities. They provide 24 hour support for long-term care. They have family respite too. There are public and private. Not all of these places are located in specific services for people with disability. Many of them are within institutions oriented to provide a general service

for autonomous elderly, however many of these institutions reserve a determined number of places for elderly persons with disability or non-autonomous.

"Viviendas Tuteladas" (Sheltered Homes for Elderly): Services for people aged 65 years or over and with more than one disability (mixed disability). There are 3 to 10 people in each sheltered house and the clinical staff work and supervise them during some hours every day. They provide long-term care. They are public and private. There are 454 places in total in Spain in this type of service.

"Hospitales de Geriatría y/o Larga Estancia" (Geriatric/Long-stay Hospitals): There are 12,833 places in total in these facilities and the typical number of places in each one is 100. These are services oriented to older adults (over 65 years) with physical and cognitive disabilities. They provide 24 hour support for long-term care. They are usually public. The total number of staff is 13,893: 8046 care staff, 190 educational staff, 1406 clinical staff, 1261 administrative staff, 2917 ancillary staff and 73 other staff.

8. Costs

According to the "White Book of Dependency", there are nearly 20,000 places in residential community facilities for people with disability in a dependency situation. 33.39% of these places are directly financed by public institutions and the remaining 66.61% of the places are private (profit and non profit) state subsidized. However, the cost of the public places makes up 48.02% of the total budget while the state subsidized places account for 51.98% of the total budget. 71.75% of the places are aimed for persons with an intellectual disability, most of the places are state subsidized and account for 68.20% of the total budget. There are 508 residences with a total of 19,895 places and a total annual cost of 349,236,064 €.

Table 3 Residential facilities for persons with disability in dependency situation

	Number	Places	Users	Annual total cost (EUR)
	580	**19,895**	**14,370**	**349,236,064**
Physical Disab.	86	2,670	1,484	52,002,511
Intellectual Disab.	373	14,275	11,737	232,671,439
Sensorial Disab.	0	0	0	0
Mental Disab.	46	425	492	14,383,990
Mixed Disab.	9	295	57	11,566,441
Several deficiencies	34	804	273	11,646,684
Other Disab	25	613	52	15,213,098

Note: Information not available for Illes Balears and Ceuta Autonomous Regions. Data provided here is not totally accurate as centres' managers sometimes cannot provide the required information or are not able to provide disaggregated data for only one of their services.

There are 254 residential centres for people with disabilities. These centres provide 7,478 places in total. Around 85% of these places are private (profit and non profit) state subsidized. Public places are just 15% of the total but they receive 30.64% of the total budget. 81.59% of the places and 60.81 of the resources are destined to persons with intellectual disability followed by mental health and physical disabilities.

Table 4. Residential Facilities for people with disability without dependency

	Number	Places	Users	Annual total cost (EUR)
	254	7478	5116	90,446,653
Physical Disab.	10	590	52	21,755,677
Intellectual Disab.	212	6101	4132	55,003,172
Sensorial Disab.	na	na	54	148,272
Mental Disab.	27	677	872	12,719,788
Mixed Disab.	1	6	6	21,000
Several deficiencies	4	104	na	798,744
Other Disab	0	0	0	0

Note: Information not available for Illes Balears and Ceuta Autonomous Regions. Data provided here is not totally accurate as centres' managers sometimes cannot provide the required information or are not able to provide disaggregated data for only one of their services.

There are 508 alternative residential centres with 3,603 places in total: 39.38% are direct public provision which receive 26.15% of the total budget. 60.62% of the places are private (profit and not profit) state subsidized places and receive 73.85% of the total budget. People with an intellectual disability occupy 51.26% of the places followed by mental health problems (44.32%). Intellectual disability and mental health disabilities consume 93.78% of total resources.

Table 5 Alternative residential settings for people with a disability.

	Number	Places	Users	Annual Total Cost (EUR)
	508	3,603	2,612	28,210,468
Physical Disability	**11**	**88**	**70**	**861,868**
Dependents	3	30	12	311,086
Not dependents	5	42	42	412,293
Intellectual Disability	**277**	**1,847**	**1,928**	**17,767,999**
Dependents	28	219	224	2,632,492
Not dependents	129	967	1,057	10,393,269
Sensory disability	**2**	**9**	**9**	**80,743**
Dependents	2	9	9	80,743
Not dependents	0	0	0	0
Mental health problems	**209**	**1,597**	**582**	**8,688,153**
Dependents	168	1,098	238	6,391,917
Not dependents	25	427	272	1,251,473
Mixed Disability	**2**	**21**	**11**	**674,620**
Dependents	2	21	11	674,620
Not dependents	0	0	0	0
Several deficiencies	**0**	**0**	**0**	**0**
Dependents	0	0	0	0
Not dependents	0	0	0	0
Other Disability	**5**	**29**	**nd**	**nd**
Dependents	nd	nd	nd	nd
Not dependents	nd	nd	nd	nd

Note: Information not available for Illes Balears and Ceuta Autonomous Regions. Data provided here is not totally accurate as centres' managers sometimes cannot provide the required information or are not able to provide disaggregated data for only one of their services.

The Ministry of Health publishes an annual report in which costs for Psychiatric Hospitals and Geriatric/Long Stance Hospitals are detailed. Total costs for Psychiatric Hospitals in 2004 was 554.947.312 € . Then the cost per a psychiatric hospital place in 2004 was 32659 €. Total cost for Geriatric/Long Stance Hospital was 522.929.319 €, then the cost per place in 2004 was 38131 €.

9. Issues

Regionalisation is being considered to be a major problem for data collection, accuracy of databases and information homogeneity. IMSERSO and the Autonomous Governments are well aware of the lack of standardized, detailed and updated information about the different types of centres and/or services for people with disability within the different territories in Spain. A low reliability of information about number of centres per type of disability, number of places and users and information about costs is the consequence of the lack of a single unique national information system. The IMSERSO, aware about these issues, tried to overcame them with several initiatives, but they have not reached the aims proposed. For a long time, national data about services have been only simple lists about centres without structure, coming from webs of the different Public Agencies and from some patients and family associations, from guidelines or annual reports about Management and Memoirs, with no regular updating and guarantee of data reliability.

These simple lists are characterised by the following:

- Absence of a common conceptual framework
- Absence of agreement about the terminology used and the methodology applied.
- They do not allow the comparison of services provided by geographical areas.
- They do not provide adequate basis for planning for the Management Directors
- They hide the cost accounting and, definitely, they hide the evaluation of services provided.

The IMSERSO tried to overcome this situation with two specific strategies:

The first initiative, the Disability Observatory Working group faced the need of available accurate information about typology of centres and number of places of social services in 2000. After an intense debate, they produced a consensus document that was finished in 2002. The document was developed on the basis of four different data collection cards which collected the types of centres and services and the population who used these services and centres, number of services/centres, places and costs. However they did not collect information about individual services or centres. The results of this work were disappointing because there was no agreement about the collected data, the terminology applied was diverse and there was no updating procedure in the applied methodology.

The second initiative was developed by the IMSERSO in collaboration with the University of Cadiz. They supported the DESDE project. DESDE stands for "Schedule for Standardized Description of Services for People with Disabilities". The schedule was supported with two aims: i) to know the type and availability of the different services for people with disability in Spain and ii) to compare them between

each Autonomous Region. This project started in 2002. DESDE is a mapping tree of services for people with disabilities, supported in powerful computer software, which allows compiling an inventory of services for people with disabilities of a particular catchment area. Health services, social services, voluntary and private sector are included. DESDE also records changes over time in the services of a particular catchment area and delineates and compares the structure and range of services for people with disabilities between different catchment areas. DESDE can measure and compare the levels of use of the major types of services for people with disabilities. between different catchments areas. Along this Schedule a Service Tree System has been used for the standardized description of services. This Schedule has four major sections to be completed: "Introductory Questions", "Types of Service Care Mapping Trees", "Service Counting Trees", "Service Inventory". DESDE allows international comparisons, at least within Europe. The DESDE system has been applied in 4 Autonomous Regions: Navarra, Madrid, Castilla-La Mancha and recently in Murcia.

10. Acknowledgements

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11. Information sources on disability used to compile the template and commentary, including people who were interviewed

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Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

Sweden

Robert Hayward

University of Kent, UK

Summary of available data

Descriptions of services

Type of service	Size interval	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admissions
Special accommodation/Residential care (Särskilt boende enl SoL)	less than 6 places	All ages (0 to death)	.	24 hour	Mixed	Regional authority/LA/County and state	All long term
Living in family homes or homes with special service for children and young persons (Boende i familjehem eller i bostad med särskild service)	.	.	.	24 hour	Mixed	Benefits/social security	All long term
Residential arrangements with special service for adults, or other specially -adapted residential arrangements	less than 6 places	Over 18/25 (i.e. adults only)	.	24 hour	Mixed	Regional authority/LA/County and state	All long term

Available data by service type: breakdown by gender and gender

N.B. No breakdown by size or disability. All services in Sweden less than 10 places.

Type of service	Places total	Male	Female	Gender unspecified	Children	Younger adults	Older adults	Adults over 18	Age unspecified
Living in family homes or homes with special service for children and young persons. (Boende i familjehem eller i bostad med särskild service)	2,038	1,289	749	0	1,216	.	.	.	822
Special accommodation/Residential care (Särskilt boende enl SoL)	5,763	3,404	2,359	0	99	.	.	5,664	0
Residential arrangements with special service for adults, or other specially - adapted residential arrangements	21,777	10,961	8,566	2,250	.	19,527	2,250	.	0
TOTAL	**29,578**	**15,654**	**11,674**	**2,250**	**1,315**	**19,527**	**2,250**	**5,664**	**822**

Staffing data

No information available other than global figures in the section in the commentary.

Completeness and accuracy of data

Data description

Electronic: Large tables on PC-Axis accessed by description (contents/quantity), database variables/values (subject area or text enquiry), documents (statistic registers (by subject area). The main problem is obtaining national-level, aggregated data. Data is derived from registers held at municipal level and collated by the national authorities which means that it is problematic to disaggregate figures at a unit level. Administrative data has been used to construct registers from many different sources (which are also used as a basis for sample surveys). Objects in different registers are linked by reference variables to produce a large database with a range of different tables. Socialstyrelsen operates a database, but it is nearly all in Swedish. However, it is necessary to register to access larger data cells and then only certain subject tables available in English - those for health & medical care and social services are in Swedish only. Where collated material exists, it requires further investigation, explanation and verification. Most of the data refers to the annual register census date October 2005 or 2006 as indicated in the template.

Paper: There are a number of publications in both English & Swedish that provide some national figures and context information. Published summary tables for persons affected by the LSS and LASS legislation (i.e. persons with disabilities and those in receipt of residential services or support services) are produced annually by the Socialstyrelsen and have been used to populate the relevant cells in the template. Information on psychiatric disabilities (SALAR), relate to 2004.

Completeness & quality

Register information is of good quality as object sets, definitions and variables are all checked. Psychiatric disability is poor quality and difficult to verify. No staff information is collected, although the qualification levels for the various forms of provision are recorded.

Residential care ID & PSD. From preliminary examination it appears that data for residential services focuses on integrated housing for all disabilities, usually in the form of group accommodation or serviced housing of max of 5 persons, although service housing can also take the form of 5-10 individual flats in one block. At present it is unclear if supported housing takes a “mix” of disabilities and/or a wide age range. Numbers only are available for each type of provision and younger adults inclusion begins at age 23.

Children’s services. There are no reported long-term residential facilities for children, although short term respite placement and some residential care is believed to exist. Educational data sources (special schools) have not been investigated.

Elderly people. Only included in data sets separately where not diagnosed with other existing disabilities, i.e. ID, PSD and age 65+

Specialist services (including psychiatric services) are run on a regional basis and information about psychiatric hospitals appears to be held at this or county level and therefore unobtainable. Information focuses on admission and discharge statistics, diagnostic groups, mean length of stays rather than on individual characteristics, needs or services. Non-profits are increasingly involved in residential service provision, but there is little information accessible.

Commentary: Sweden

1. Overview

Sweden is a monarchy with a parliamentary form of government that boasts a liberal democratic state that has provided effective welfare services since the 1930s that only recently have become affected by global recession and financial constraints. Sweden's generally favourable economic performance has been off-set by the growth of the welfare state which has accelerated in recent years at a rate faster than industrial growth. This has resulted in budgetary deficits and constraints on welfare spending (Wall, 1996). Two main problems are a smaller working population allied to a growing older population. Sweden is amongst the highest-spending states on healthcare, has a high level of beds (12 per 1000), of which 50% are for long-term conditions, 15% are for psychiatric care. In addition there are 7 places per 1000 for elderly in municipally run care, (Swedish Institute, 2006). The standard of living is the highest in Europe with a more even distribution of income and wealth than other European countries, however some social inequality exists evidenced by the incidence of ill-health, especially among immigrants, unemployed persons and lower income groups. People with disabilities are full citizens and as such have the full right to avail welfare services offered to the general public. Special services are supplementary, and can be applied for if an individual's needs are not met by regular services. The cornerstone of Swedish disability policy is the principle that everyone is of equal value and has equal rights.

2. Political and social context

2.1 Government organisation and structure

Sweden has a parliamentary democracy that is unaligned politically and militarily. It is a unitary state where the parliament's (Riksdag) laws apply throughout the territory. In practice there is some flexibility to allow local authorities to interpret framework laws appropriate to the locality. Local government is important – it outspends central government by 2:1 with the major services of health and education being in control of local authorities. Local government plays an important role in the provision of health and social care. There are two basic levels:

- 286 municipalities or communes (each with a minimum population of 8,000)
- 26 counties or regions (including 3 unitary authorities of Gotland, Göteborg and Malmö)

The counties and municipalities all have councils and there are elaborate arrangements for co-ordinating their activities both at a local level, and with the state (at local level). Government has a high legitimacy with 90% turnout in elections. 10% of adults are actively involved in the democratic process, particularly in local government and the provision of health and welfare services.

2.2 Disability relevant policy

Swedish disability policy has taken shape over the past 50 years apace with developments in welfare policy. The association between the two meant that disability policy has been linked to wealth distribution policies, and because social insurance benefits and health and medical care are universal, people with disabilities have not readily slipped through the net of the social security systems. Measures to support

people with disabilities developed in the 19th century with the growth of institutions for different disabilities, the first school for deaf and blind pupils opened in 1809. Following the Second World War, technological and medical progress, together with public initiatives provided new opportunities. In the 1950s rehabilitation became important, strengthened by the labour policies of the 1960s which promoted opportunities to work. By the 1970s, the traditional medical view of disability was superseded by more environmentally relative perspectives where disability was adjudged according to the demands made by the surrounding environment on a person. The existence of institutions was being called into account in the 1960s. Large numbers of people with intellectual disability and other impairments (14,000 places for intellectual disability and 36,000 for psychiatric disorders) were accommodated in these institutions at that time. Legislation is important in modern Sweden in improving living conditions for people with disabilities. The core principles of decentralisation, integration and normalisation emphasise the individuals' freedom of choice and influence. Care, services and education are governed by laws such as the Social Services Act (called SoL), Health & Medical Services Act (HSL), Education Act (SkolL) and supplemented by the LSS. Organisations for the disabled have a strong position in Sweden and their participation in disability policy is regarded as an important component in the democratic process.

3. Demographics

The population was 8.35 million (1985), and is relatively stable at 2.1 children per woman. There is low infant mortality (3.4/1000) and high life expectancy (men 77.1, women, 81.9 in 2005). Cardiovascular conditions account for half of all deaths, and deaths from injuries, alcohol-related diseases and suicide are on the decline, although there is an increase in mental health problems, particularly in the young. Increasing longevity signifies a change in the population structure so that by 2020 a large number of the population will be 80+. In 1998, health care expenditure amounted to 8.4% of GDP (less than the EU average). There are approximately 130,000 people with physical disabilities, of whom 45,000 have severe disabilities. There are no figures for people with intellectual disability. 150,000 people have psychiatric disorders, of whom a significant percentage will experience enduring psychological and social dysfunction. The percentage of persons in June 2000 requesting support from the municipalities was 0.4% (National Board of Health & Welfare, 2004). Whilst Sweden is one of the healthiest nations in the world, increasing rates of sick leave and early retirement may indicate rising morbidity associated with disorders of industrialised countries caused by lifestyle and environment. There is a high incidence of cardio-vascular disease and cancers associated with smoking, drinking and excessive consumption.

4. Health and social care system

4.1 Organisation

Sweden was the last western European state to industrialise in the late 19th and early 20th centuries. Change was rapid and able to accommodate problems seen elsewhere in Western Europe. Up until 19th century embryonic welfare services existed with minimum of state direction with the Church and family providing the majority of help for the poor and sick. Key milestones in the historical development of health and social care were:

1752: national hospital fund made up of donations and indirect taxes set up first hospitals.
1765: local authorities empowered to raise funds and create general hospitals to supplement work of the Church.
1840: Guild system still looking after some needs of the poor and sick, but unable to cope with stresses produced by land reforms and rapid population growth.
1862: local government reform made local authorities responsible for poor relief. Newly created counties responsible for all medical care except for the mentally ill who became the responsibility of the state.
1880s: a period where the belief that social inequities rather than individuals were root causes of problems became highly influential in determining policies.
1932: initiation of social welfare programmes by Social Democratic Party including social insurance, housing education and social services. Incremental growth followed over next 40 years.
1982: Social Services Act strengthened the services of the state, tightened means-testing, and put more onus on individual responsibility.

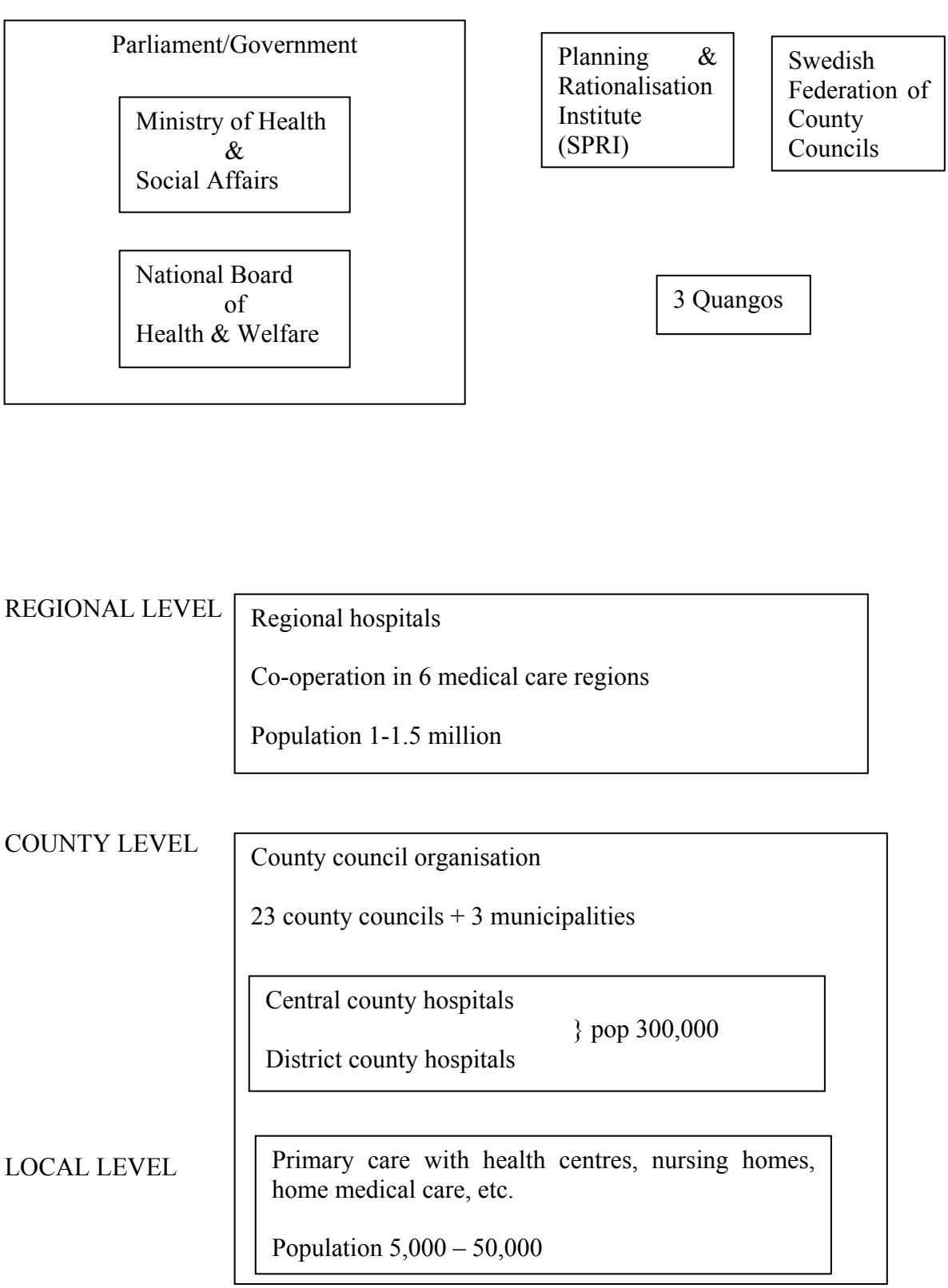
The fundamental responsibility of ensuring good health and social and financial security for people with disabilities is shared by national, regional and local government. Central government is in charge of legislation, general planning and distribution as well as social insurance. Local authorities (municipalities) are responsible for social services, and regional government (county councils) for health care. Municipal social services and county council health and medical services are governed by framework legislation which specifies the frameworks and objectives of activities whilst affording municipalities and county councils the opportunity to interpret the laws to shape their activities according to local guidelines (based on interpretation of local needs/requirements).

4.2 Health care

Primary health care

Organised at a local level and provides a range of services through the primary care districts. Each district has at least one local health care centre and one nursing home for long-term care. School health services are provided by the municipalities. Occupational health services cover 70% of employees. Policy is that as many patients as possible should be cared for in their own homes, so many of the nursing staff provide home care for sick and disabled.

Diagram of structure in Sweden



Secondary health care

Several districts comprise a county and hospital services are mainly organised on a county basis. Usually a county will have one large central county hospital with a range of approx 20 specialities and several smaller district county hospitals with 4 specialities (medicine, surgery, radiology and anaesthetics). Sweden is divided into 6 medical care regions of about 1 million plus persons, comprising several counties with a regional hospital which provides research and teaching. Psychiatric facilities are special purpose, but currently policies of merging care with somatic hospitals and reducing bed numbers is having a profound impact. In 1989 15,000 psychiatric beds, average stay 46 days.

Role of the county councils

Established in mid 19th century to run hospitals for physical diseases, the range of responsibility has increased to cover many aspects of health care, the planning and development of services and health promotion. In 1960s they took over all out-patient services and psychiatric care (previously a government responsibility). The county councils also maintain sensitive information on residents in registers, for example, the In-patient Registry. The National Board of Health & Welfare has a supervisory role.

Role of central government

Although the counties have an important role in the planning and delivery of health and social services, the central government is responsible for overall policy goals in the social welfare field, the key ministry being the Ministry of Health and Social Affairs. The National Board of Health & Welfare (Socialstyrelsen) is the central administrative agency which works with other government bodies responsible for issues related to the disabled and has to co-ordinate, support and promote these issues in their dealings with other authorities. The National Board of Health & Welfare covers county council health and medical services as well as municipal social services.

Other important bodies

The **Office of the Swedish Disability Ombudsman** (Handikappombudsmannen, HO) is a central government agency that monitors the rights and interests of people with disabilities, primarily by combating discrimination.

The **Swedish Handicap Institute** (Hjälpmedelsinstitutet) is a national knowledge centre working with assistive technology and accessibility.

The **Swedish Institute for Special Needs Education** (Specialpedagogiska insitutet) co-ordinates state support in the educational field, advising pre-schools and schools. Handisam is a new organisation to co-ordinate policy.

4.3 Social welfare and residential care

The last three decades in Sweden have been periods during which residential institutions have been dissolved and community based services have been developed. The beginning of this development was marked by the implementation of a new socio-political idea: the normalisation principle, which was introduced in 1946. The realisation of this principle through four Acts of Parliament is concomitant with a shift

between the institutional and the community based tradition of support, with deinstitutionalisation as the logical consequence for development. Nowadays, people with disabilities in Sweden are well aware of their rights to participate in community life (Ericsson, 2002). They are encouraged to use services offered to the general public, which therefore need to be made available for everybody, while special services become supplementary. Officially Sweden no longer has any institutions for people with functional impairments. There are, however, residential arrangements with special service, which are measures regulated in the Act Concerning Support and Services to Persons with Certain Functional Impairments (LSS) as well as the Social Services Act (SoL). In last 3 decades the residential institutions have largely dissolved and community-based services developed. Parliamentary Acts in 1985 and 1993 replaced institutional Acts of 1954, 1967 with community tradition based on concept of citizenship to include persons with ID with a right to participate in community life.

The law and disability

All 286 municipalities have to provide by law, on the first of October each year, information on all people using social care and residential services on that day. Thus a register of persons is constructed, each with a personal number. The register is constructed of three categories: gender, numbers of services used, types of services (across 10 types of service provision under two laws).

The principle laws are called:
(i) LSS - the Act concerning support and services for persons with functional impairments (giving the right to support and services). It defines the people entitles, the services and possibilities of appeal against authorities' decisions. The group of people entitled to services according to LSS are:

- Persons with developmental, intellectual dysfunctions, autism or similar
- Adults with dysfunctions following brain injury
- Physical or psychological difficulties not linked to normal ageing

LSS also defines 10 different services, although some of these services may exclude each other (e.g. residents in special housing offering care services cannot also use personal assistance). All services under LSS must be applied for, but are free of charge, except housing, where there is a rent component.

(ii) LASS – there is a divided financial responsibility for personal assistance. The local municipality pays for needs up to 20 hours per week and the state for needs exceeding that. An assessment is made of basic needs and if passed, entitles the individual to personal assistance to cover the complete need. There are some exceptions when the service can be used (for example if the recipient is in hospital). LASS funding is administered by the national insurance system. Taken together the provide statistics on 10 types of services for each of children, adults and older adults (of which only 4 are entirely residential in nature).

(iii) Other Social Welfare Laws – Social Services Act, 2001 and Health & Medical Services Act, 1982, (SSA)

4.4 Financing

The primary funding for health comes from income tax raised by the county councils at around 13.5% of personal income. These cover just over 60% of total costs, national government provides a further 15%, awarded differentially to counties to compensate for inequities in income levels, and a further 12% is provided for psychiatry (and research). Fees and direct payments account for 4% and 8% from health care insurance (a hypothecated tax).

5. Disability services - descriptions and definitions

1. Counselling and other personal support (*råd och stöd*) (LSS)
The rights to qualified expert help from staff, in addition to their professional skills, have special knowledge of what it is like to live with major functional impairment(s). This support may be provided by different professionals, e.g. a social worker, psychologist, physiotherapist, pre-school consultant, occupational therapist, dietician. Counselling and support is to be a supplement to, and not a replacement for, measures such as rehabilitation and social welfare services.

2. Personal assistance/assistance benefit (*personlig assistans*) (LSS/LASS)
Persons with major functional impairments and an extensive need for support in their daily lives may be entitled to personal assistance from one or more personal assistants. The municipality is financially responsible for those who need assistance for less than 20 hours per week. If a person requires more than 20 hours, they may be entitled to assistance benefit under LASS (in this case the municipality is responsible for the first 20 hours as well.

3. Companion service (*ledsagarservice*) (LSS)
Those not entitled to personal assistance may instead be entitled to a companion service. This companion service is to be a personal service, adapted to individual needs, designed to make it easier for the individual to participate in the life of the community.

4. Personal contact (*kontaktperson*) (LSS)
A personal contact is to be a companion who can help the individual to lead an independent life by reducing social isolation, helping them to take part in recreational activities and providing advice in everyday situations. This support can sometimes be provided by the family (known as support family) or extended family members.

5. Relief service in the home (*avlösarservice i hemmet*) (LSS)
A relief service can be provided on a regular basis as well as for unexpected situations. It is available round-the-clock.

6. Respite care (*korttidsvistelse utanför det egna hemmet*) (LSS)
Short stays away from home are to provide the individual with recreation and a change of scene, while giving relatives a break. A short-term stay can be in a respite home, in another family or in another way, e.g. a stay at a youth camp or a holiday camp.

7.Short period of supervision *(korttidstillsyn för skolungdom över 12 år*). (LSS)

School children over 12 only, who are no longer covered by general child-care service, can receive supervision before and after the school day and during school holidays.

8. Living in family style homes or homes with special service for children and young persons (*boende i familjehem eller i bostad med särskild service*) (LSS)
Children and young persons who cannot live with their parents may be entitled to live with another family or in a home with special service. This is to be a supplement to the parental home, both for children who can live with their parents some of the time, and for those who cannot live with their parents at all.

9. Special accommodation/residential care (adults, specially adapted – *bostad med särskild för vuxna*) (LASS/(SSA)
This can be various arrangements but the most common types are group homes and service homes. The individual may also be entitled to specially adapted housing to which they are referred by the municipality.

10. Daily activities/centres (*dagverksamhet SoL*) (LSS)
People of working age (i.e. not children) who have no gainful employment and are not on a course are entitled to daily activities if they are parts of groups 1 and 2 under the LSS.

6. Prevalence of disability

The total number of individuals who received LSS services on 1st October 2005 is estimated at between 56-58,000 (about 0.6% of the population). Most of those involved, 25,000, received daily activities. Just over 20,400 resided in special homes for adults with disabilities, or other specially adapted homes for adults. 16,700 have support by a contact person, 10,500 counselling and support, 10,500 received a short stay away from home and 9,600 had assigned companions. About 29% of LSS services were provided to children (aged 22 or younger), with about 1000 residing in special housing for children and young people (National Board of Health & Welfare, 2006).

7. Residential services for people with a disability

7.1 Overview

Support to persons with an intellectual disability in Sweden today is characterized by extensive changes. An institutional tradition has previously dominated these services. But this has gradually been dissolved, opening up for the development of a community tradition. The most dramatic part of this change has been the closure of all residential institutions and the shift of responsibility from a regional county organization with special services to local municipality welfare services (European Intellectual Disability Network, 2003). The Socialstyrelsen report that more information on the disabled and the welfare system is required – especially insights into the effect of measures on the individual. The present challenges are therefore concerned with the development of support for persons with an intellectual disability in the municipalities. The task, not an easy one, is now to find the more democratic forms of support, giving a more inclusive role to the persons and their families. Recent state welfare evaluations show that people with disabilities have managed reasonably well due to the LSS legislation, but differences in living conditions persist

despite reforms. Municipal costs continue to escalate and vary greatly between municipalities, partly due to costs for personal assistance, but also due to differing local priorities. The demands for cost savings is having additional effects, for example, municipalities are buying measures from other municipalities and then placing mentally disabled people in residential accommodation a long way from their home town. The concerns about cost reduction have led to recent discussions about the introduction of charges which seem inevitable to many in the field.

7.2 Services for children with a disability

The legal age for children is 18, although the school age is 19. Some people of 20-21 with intellectual disability can be found in schools (depending upon their need). In modern-day Sweden, most children with intellectual disabilities live with their families or in other "foster" type families which receive support through LSS services or the state through social security. There are no institutions for children or young persons with functional impairments. Those children who cannot live in the parental home – either because of extensive medical needs or because they attend a school in another area – can receive help under measures provided by LSS. In October 2004, almost 200 children lived in family homes and 1000 in residential accommodation designed like ordinary home and functioning as much like an ordinary home as possible. A small number of children lived together in a flat or house with round-the-clock support from staff. For visually and auditory impaired there are 4 State residential schools either 5/7 day but not 52 week (they return home for holidays). There is a small group of people who receive their upper secondary school education in specially adapted schools. Their disabilities are so severe they require individually adapted teaching supported by co-ordination for personal care. There are 4 similar schools for people with physical disabilities. As all children with an intellectual disability have the right to education, schools and the education they offer must be organised for this to become a reality. Special schools are no longer recognised, instead the education of children with a disability takes place within the framework of ordinary school system. In addition Folk High Schools offer many opportunities to disabled people on a boarder basis.

7.3 Services for adults with a disability (under the age of 65 in accordance with the Social Services Act (2001:43) and Health & Medical Services Act (1982:763)

Adults with functional impairments who need support and help can have a wide variety of residential arrangements. Some live in their own homes, like most adults, some receive home help services (under the SoL), and some may receive more extensive personal assistance. Each person with a disability decides upon the level of social assistance necessary AND on the individual providing it. Residential arrangements with special service can be group accommodation or service housing located in ordinary housing areas (a block of flats or a house). 80% of people with intellectual disabilities live in residential homes that take two main forms; the first may have 24 hour staff, the latter almost certainly:

1. LSS residential arrangements - comprising an apartment (own key) for one person (bathroom, kitchen, bedroom and one other) located with 4 or 5 apartments in the same building. The flat is the person's private home, and the staff providing service and support must be aware of the person's need for privacy, even though that person

may require comprehensive help. The flats have all the facilities that would be found in ordinary flats. Staff usually occupy a nearby apartment. In October 2004, almost 20,000 people (mostly with intellectual disabilities) lived in residential arrangements with special service.

2. Group accommodation (LSS) – as above, except there may be a maximum of five or six connecting separate flats with an adjacent central source for meals, possibly a shared bathroom with staff on duty 24 hours a day. Old style group homes may have 5 persons sharing one apartment, but most group homes are new build.

Service housing is available to people who want to live more independent lives and usually consists of a separate flat with larger communal areas with staff available 24 hours a day. Under the S0L, the Social Welfare Board in a municipality has to ensure that people who encounter difficulties in their daily lives are provided with meaningful occupations. These measures can be individually based (e.g. daily activities after individual assessment of needs) or the municipality might run an open activity that an individual can opt into. Daily activities under LSS are measures to which people with intellectual disabilities have been entitled to since 1968 and the people using it are usually in receipt of disability pension.

7.4 Services for older adults

Provision is similar to the above, they may have specially adapted residential accommodation – may have own key etc., but share kitchen for meals. The size will always be no larger than 6 persons. Some may have specially adapted residential arrangements: usually a flat provided by the municipality, no staff, but with personal assistance. Some municipalities have group homes for people with Alzheimer's disease.

Elderly people living in residential accommodation are not included on the template unless they are in receipt of other services as well. Under the social welfare law (SAA) there are fewer services for older people or less disabled as the municipalities are not obliged to provide for them unless they require other types of services. Retirement homes had a reduction of long-stay beds from 130,000 (1982) to 98,000 in 1990, and are down from 22 per hundred population to 10.

7.5 People with mental health problems

The existence of institutions began to be called into question in the 1960s. At that time there were about 36,000 in-patient places for people with psychiatric disorders. There has been a decline in the number of beds for psychiatric patients from 12,000 in 1992 to 4,600 in 2004 (SALAR, 2006). There are currently approximately 850 residential services for 8000 patients 9of whom about 77% are long-term residents), an increase of 35% since 1997. Expenditure on psychiatric care = 6.3% of overall costs. Mental health care is part of health and medical care. The basis of mental health care and social services for the mentally ill is that individuals should have the same rights and obligations as other groups in society. The governments focus is for service, support and care to be provided in forms that are as open and normalised as possible. Psychiatry falls under the provisions of the Health and Medical Services Act with supplementary provisions under the Compulsory Mental Care Act (LPT) and the Forensic Medical Care Act (LRV). No detailed figures for detention under these acts

are currently available, although of 550 detained and referred, about half (225) end up in longer-term forensic care (Belfrage, 2000). For people with long term problems, some people are housed in group homes (depending upon the municipality) – there are 2 possibilities according to the two different statutes. There is no division between younger adults/older adults in mental health care settings – just disabled people who have become elderly. People with mental disabilities experience inequality in access to some measures under LSS. Surveys indicate that many municipalities are unable to identify needs and plan measures accordingly – so, for example, those requiring daily activity and support in their own homes are wanting, particularly as the case manager function is being phased out in many municipalities.

8. Other relevant information on residential services

8.1 Age of group homes

Prior to the 1994 law, some municipalities (20-30) had old, small hospitals, "sick homes", which, after Jan 1995, were renovated or re-modelled as group homes or changed into apartments (usually the older style group homes with up to 5 sharing an apartment). All other municipalities had to build group homes, tending to build new apartments; therefore most people are living in housing that is less than 10 years old.

8.2 Private provision

Very few, low numbers (but not included in the template). Usually municipalities will fund the places. No figures exist for number of places at national level – municipalities retain these.

9. Staffing

Few statistics exist on staff in residential care, some information is available in Swedish (National Board for Health and welfare, 2005). The organisation of municipalities carries some information. There are predictions that the supply is declining, and problems in recruitment and training as municipalities no longer provide specialist training (as did the county councils previously). There is high staff turnover and thereby high municipal costs. In 1994 the sick homes had 5000 staff. By 2005, approximately 20,000 people were working in group homes.

10. Issues

10.1 Voluntary sector contribution.

During the 1990s the non-profit sector began to gain greater attention and began to play a more decisive role in important sectors of the social and welfare services, with, by 2000, an estimated half a million people receiving some sort of support through voluntary organisations. This development is expected to continue with an expanded role for NGOs in the welfare system.

10.2 Inequality of access.

There is some geographic variation in the number of people with disabilities and access to services in Sweden. Using mental health care as an example, in large cities, such as Stockholm, Gothenburg and Malmö, the number of psychiatric patients is almost twice as high as in the rest of the country. Around 11,000 adult patients of an estimated total of 43,000 patients nationwide were found in these three cities.

However, there are not sufficient residential facilities in the major cities to meet this need. Consequently, 45% of patients in the major cities need to rely on residential services outside their home community, (National Board of Health & Welfare, 2003).

11. Acknowledgements

Kristina Stig & Ulla Clevnert at the Socialstyrelsen, Stockholm.

12. Principle sources of information

12. 1 Data sources

(i) The *Socialstyrelsen* has prime responsibility for collating data which are contained in on-line and privileged access databases mostly in Swedish. Information is obtained by survey undertaken on 1st October each year and entered into one of a number of registers. Data is held at municipal level and collated by the national authorities. The information is of good quality as object sets, and definitions and variables are all checked. Two main publications are produced each year *Funktionshindrade personer – insatser enligt LSS* and *Funktionshindrade personer* which summarise all published data – the 2006 tables (referring to 2005) have been used.

(ii) Statistics Sweden operate a large database consisting of tables on PC-axis, accessed by description/database variables/document/maps. Statistics Sweden can provide data but are unable to provide comment or it, although it may be possible to purchase larger data sets. Partial access to non-authorised persons.

(iii) The Swedish Association of Local Authorities (SALAR) are involved especially to assist with collation of data on psychiatric disability that is collected and maintained at county level.

(iv) Ministry of Health & Social Affairs DB & publications.

(v) Internal, unpublished documents.

12.2 Verification sources

Meetings 05/12/06, 06/12/06, 07/12/06

Kristina Stig, Socialstyrelsen, Ramlambsvagen 3, S106 30, Stockholm (Kristina.stig@socialstyrelsen.se) (intellectual disabilities, children & adults)

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Marianne Bjorklund, Socialstyrelsen, Ramlambsvagen 3, S106 30, Stockholm (marianne.bjorklund@socialstyrelsen.se) (mental health)

Mathias Tofvesson, Ministry for Health & Social Affairs, Fredsgarten 8, SE103 33, Stockholm (registrator@social.ministry.se) (background)

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Appendix 1 - Sweden a "typical" case scenario

Maria is a 22 year old woman with severe learning disabilities who also presents some behavioural problems. Maria is unable to live on her own without constant care. Until her mother died recently, she lived in the family home, receiving some supports from the municipality. There is no other immediate family.

Given that Maria has been living at home until now, and bearing in mind the nature of her disabilities, what would have been her likely pattern of education and care to this point?

If Maria's mother was working (which most mothers are in Sweden) when she was a little girl she would have been at day-care/nursery school nearby home and together with other children without disabilities living in the same area. Maria perhaps would have had a special assistant. To relive her mother she would probably spend a weekend and some part of summer in a contact-family.
When starting school Maria would attend a special class for children with learning disabilities. The special class would be located in an ordinary school. The class would probably be in a school nearby, but if she has to travel to school she will do by taxi or school-bus. In the afternoon and in summertime she will be in afternoon-care together with other children, both with and without disabilities, up until 12 years of age. After 12 years of age there is normally no afternoon care for children, but if you have a disability you have the right to support in the afternoon and in summertime while your parents are at work. When becoming a teenager Maria will perhaps stay in a respite-home for short-term stay one or two week-ends a month together with 4 or 5 other youngsters with disabilities (instead of staying with the contact-family).

Who would have provided and paid for these services? How would have this been decided and by whom?

For all the support, including school, the municipality is responsible, for decisions and for all the costs.

What is the most likely outcome for Maria now? (What, realistically, might Maria expect from health or social welfare services?). What input might Maria or her advocate/representative have in this process?

Maria and her mother probably have had contact with professionals at a (re)habilitation centre. When Maria got her diagnosis her mother had contact with a doctor, a psychologist, and a social worker. Later on Maria has have support from a pre-school consultant and a speech-therapist. Her mother has had support from the social worker from time to time and Maria was meeting with the psychologist once a week for two years when she was 18-20 years of age. For this support the county council was responsible, both making the decision and for the cost. The county council also is responsible for the health care that she would need.

Who would typically be responsible for providing services? (i.e. what department, which professions would be involved, who would be responsible for determining or managing care and how might this be paid for?)

The municipality is responsible for both deciding about the measures/support that Maria has and the municipality has the cost for the services. The daily activity and the group-home mostly are run by the municipality but it could also be private or be run by an organisation even though the municipality is paying.

What factors might influence her pathway or access to services?(For example, entering residential care provided by a church-based organisation versus a state-run facility, or residential care home over nursing home, or day support rather than educational or work facilities). How is one type of service chosen over another? How is this decided and by whom?

When Maria leaves school (at about 20 years of age) she perhaps will be "working" in daily activities with some activities that she wants to do. She will be at "work" between about 9 to 4 o'clock Monday to Friday. Maria moves to a group-home where she lives together with 4 other young persons with learning disabilities. They all have their own flats next to each other with one room, a small kitchen and a bath-room. They share a living-room in the next flat and there are staff available for services and support 24 hours a day. Maria pays the rent for the flat and she pays for food, her clothes and other things but she doesn't have to pay for the support from staff. Maria has a kind of pension since she was 19 years of age from the Social Insurance Administration.

*Without going into too much detail, and given the limited information, what can you tell me about the likely next stage in Maria's life and the likely people to be involved, and the way decisions such as patterns of service and funding might be made? A brief and direct answer, without going into too much detail will suffice as long as any complexities or barriers are briefly mention*ed.

Maria or her legal guardian has to apply for the service and support she will need and Maria will have a lot of influence over how the support will be arranged.

(Information provided by Ulla Clevnert)

Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

Turkey

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Summary of the available data

Descriptions of service types

The table below summarise the descriptions of the 8 service types included in the template. Please note that the General Hospitals with psychiatric acute units were not included in the analysis presented in the report. In addition, there was no further information available on this service type.

Type of service	Size interval	Age group	Disability group served	Level of support provided	Typical provider	Typical funder	Length of admission	Age of service
Residential Care and Rehabilitation Centres for Children with Disabilities (ozurlu çocuklar için bakim ve rehabilitasyon merkezleri)	51 to 99 places	0 - 18/19 years	ID only	24 hour	.	.	.	0 to 20 years
Rehabilitation Centres for people with visual impairments	11 to 30 places	14 + to adulthood (60/65 years)	Sensory impairments	24 hour	.	.	.	.
Nursing homes and rehabilitation centres for elderly	51 to 99 places	over 60/65	PD	24 hour	Mixed	Mixed (any)	Mainly long term	.
Rehabilitation centres for children with spastics (spastik özürlü çocuklar için rehabilitasyon merkezleri)	51 to 99 places	0 - 18/19 years	PD	24 hour	.	.	.	0 to 20 years
Residential Care and Rehabilitation Centres for people with Intellectual Disabilities	51 to 99 places	14 + to adulthood (60/65 years)	Mixed ID with PD, SD, MH, Beh and other	24 hour	.	.	.	.
General Hospitals with Psychiatric Acute Units for childrens and youngsters	.	.	.	.	.	.	.	.
Residential care and Rehabilitation Centres for people with Physical Disabilities	51 to 99 places	14 + to adulthood (60/65 years)	PD and Sensory/other	24 hour	.	.	.	.
Psychiatric Hospitals	.	.	.	24 hour	.	.	.	.

Data available by service type – breakdown by size and disability

Type of service	Places total	Under 30 places	Over 30 places	Size unspecified	ID	MH	PSD	Elderly/ dementia	Mixed/ dual	Other/ unspecified
Residential Care and Rehabilitation Centres for Children with Disabilities (ozurlu çocuklar için bakim ve rehabilitasyon merkezleri)	1,870	30	1,807	33	1,827	15	28	.	.	0
Rehabilitation centres for children with spastics (spastik özürlü çocuklar için rehabilitasyon merkezleri)	111	.	110	1	68	.	43	.	.	0
Rehabilitation Centres for people with visual impairments	58	26	32	0	.	.	58	.	.	0
Residential Care and Rehabilitation Centres for people with Intellectual Disabilities	1,080	.	1,043	37	865	49	126	.	3	37
Residential care and Rehabilitation Centres for people with Physical Disabilities	179	30	135	14	45	22	112	.	.	0
Psychiatric Hospitals	6,196	.	.	.	.	.	.	.	.	.
Nursing homes and rehabilitation centres for elderly	1505	.	1,505	0	.	.	1,505	.	.	0
Total	**10,999**	**86**	**4,632**	**33**	**2,805**	**86**	**1,872**		**3**	**37**

Type of service	Places total	Male	Female	Gender unspecified	Children	Younger adults	Older adults	Adults over 18	Age unspecified
Residential Care and Rehabilitation Centres for Children with Disabilities (ozurlu çocuklar için bakim ve rehabilitasyon merkezleri)	1,870	1,108	762	0	807	.	.	1063	0
Rehabilitation centres for children with spastics (spastik özürlü çocuklar için rehabilitasyon merkezleri)	111	59	52	0	94	.	.	17	0
Rehabilitation Centres for people with visual impairments	58	37	21	0	5	.	.	53	0
Residential Care and Rehabilitation Centres for people with Intellectual Disabilities	1,080	600	480	0	13	.	.	1030	37
Residential care and Rehabilitation Centres for people with Physical Disabilities	179	100	79	0	73	.	.	106	0
Psychiatric Hospitals	6,196	.	.	6,196	.	.	.	.	6,196
Nursing homes and rehabilitation centres for elderly	1,505	651	854	0	.	.	1,505	.	0
Total	**10,999**	**2,555**	**2,248**	**6,196**	**992**		**1,505**	**2269**	**6,233**

Staffing

Type of service	Total staff	Care staff/nurses/ might include teachers in boarding school	Managers or other administrative staff (not care staff)	Number of educators/ Day staff	Day and care staff (no distinction made)	Clinical staff (Drs, therapists, psychologists, etc.)	Other staff (mainly ancillary staff)	Other staff (excluding ancillary staff)
Residential Care and Rehabilitation Centres for Children with Disabilities (ozurlu çocuklar için bakim ve rehabilitasyon merkezleri)	460	97	45	4	.	113	201	.
Rehabilitation centres for children with spastics (spastik özürlü çocuklar için rehabilitasyon merkezleri)	43	5	6	6	.	22	4	.
Rehabilitation Centres for people with visual impairments	47	9	10	8	.	9	11	.
Residential Care and Rehabilitation Centres for people with Intellectual Disabilities	162	20	20	0	.	60	62	.
Residential care and Rehabilitation Centres for people with Physical Disabilities	47	3	8	1	.	10	25	.
Psychiatric Hospitals	.	.	.	.	.	.	.	.
Nursing homes and rehabilitation centres for elderly	576	70	94	2	.	163	247	.
Total	**1,335**	**56**	**162**	**21**		**502**	**550**	

Completeness and accuracy of the data

Data presented in the template and in this report has been provided by the Ministry of Health and the General Directorate of Social Services and Child Protection Agency. Information is updated for year 2007 and it represents the best available data in Turkey in a national level. We have had access to the raw databases and have obtained the data ourselves so the methodology used have followed the project aims.

Social services provide detailed data about residential service characteristics, resident characteristics and numbers for staff and staff training. However information about mental health residential services is not so complete and only the number of psychiatric beds for different services is available.

Number of places per disability type is also provided for residential social services except services provided to older adults. Theoretically places at residences for the elderly are only for physical and cognitive disability and mental health and behavior disorders are not included. However many residents can develop mental health or behavior problems once they are living in the services. For these cases, data is not available.

Data on costs per type of residential service is not available.

Commentary: Turkey

1. Overview

Turkey, known officially as the Republic of Turkey, is a country that stretches across the Anatolian peninsula in southwest Asia and the Balkan region of south Eastern Europe. Turkey borders eight countries: Bulgaria to the northwest, Greece to the west, Georgia to the northeast, Armenia, Azerbaijan (the Nakhichevan exclave), and Iran to the east, Iraq and Syria to the southeast. It borders the Mediterranean Sea to the south, the Aegean Sea to the west, and the Black Sea to the north. Turkey covers an area of 780,000 square kilometres representing 20 % of the old EU25 total surface.

2. Political and social context

2.1 Government organisation and structure

Turkey is a parliamentary representative democracy and was founded as a republic in 1923. Turkey's constitution governs the legal framework of the country. Executive power is exercised by the Prime Minister and the Council of Ministers that make up the government, while the legislative power is vested in the unicameral parliament, the Grand National Assembly of Turkey. There are 550 members of parliament who are elected for a five-year term by a party-list proportional representation system from 85 electoral districts which represent the 81 administrative provinces of Turkey.

2.2 Disability relevant policy

The Law on Disability (No 5378) adopted in July 2005 brought change and improvement at disability issues. By the Law; discrimination against people with disabilities especially in education and employment is prohibited; inclusion of people with disabilities, their families and relevant NGOs in the policy making mechanisms is accepted as a general principle; international disability classification is accepted; provision of services by the private sector is also adopted; the cooperation with the Ministry of Health is emphasized; conduct of job analysis according to the types of disability and application of the results in preparing relevant education and rehabilitation services is determined; the care services for persons with disabilities can be provided by the natural and legal persons, public institutions and organizations which obtained licence from the SHÇEK; establishment of departments for the disabled in metropolitan municipalities is accepted; and institutional structure of the Administration for Disabled People is strengthened and special education and rehabilitation centres were handed over to the Ministry of National Education. Moreover, services of these centres for all eligible children are being subsidized with the allocation put in the budget of Ministry of Education.

The Law is binding to determine a certain standard in serving disabled people as well as to contribute towards their benefiting from the essential rights and services and to create equal opportunities for disabled people. Being binding of Law on Disability with regard to the arrangements on social life is an indispensable requirement for a State, which has been defined as a Social Law State in its constitution. Through the Law on Disability, the developments made up to date to remove the obstacles to participation in social life; to increase the accessibility of the services for people with disabilities; to make the physical environment accessible for disabled people; to

provide equal opportunities in training and education; to ensure that more disabled people have received from vocational rehabilitation services; to ensure the equality in income for disabled people; to achieve a comprehensive and total understanding on the disability issue and to raise awareness in society.

3. Demographics

According to Turkish Statistical Institute figures, the total population of Turkey which was 71.1 million in 2004 is estimated to reach 76.5 million in 2010 and 84 million in 2020 with a growth rate of 1.5% per year. The western part of the country is more populated and includes the biggest cities: Istanbul, Izmir and Ankara – the capital. Like most European countries, 65 % of the population concentrates in urban areas. The Turkish population is quite young, 29.8% of the population is between 0 and 15 years old. In 2000 the percentage of population over 65 was only 5.7%, lower than the EU average. According to the results of the Study on National Burden of Disease and Cost Effectiveness Survey conducted in 2000, the life expectancy at birth is estimated to be 69.8, 71.9 and 67.7 in general, women and men respectively. According to 2000 Census of Population, the literacy rate was 93.9 for men and 80.6 for women.

Turkey has suffered from unstable economic conditions for much of the last twenty years. Since the early 1980s the previously centrally planned economy has been gradually liberalised. There have been periods of rapid growth interspersed with sudden, mostly short-lived crises, against a background of high inflation (usually in the range of 50-100% annually). However, since the economic crisis of 2001 and the reforms initiated by the finance minister of the time, inflation has fallen to single-digit numbers, investor confidence and foreign investment have soared, and unemployment has fallen. Although the country is a lower middle income group country (based on World Bank 2004 criteria) Turkey has gradually opened up its markets through economic reforms by reducing government controls on foreign trade and investment and the privatisation of publicly-owned industries, and the liberalisation of many sectors to private and foreign participation has continued amid political debate. Nowadays, Turkey has a developing economy and a young, dynamic population.

4. Health and Social Care System

4.1 Organisation

Turkey's health system ranked 70th out of 191 countries according to the World Health Organisation's "World Health Report 2000".

The institutionalisation of health services took place in the first few years of the Republic with the establishment of the Ministry of Health in May 1920 as a separate department responsible for health services. Nowadays health services in Turkey are provided mainly by the Ministry of Health, Universities, the Ministry of Defence, and private physicians and other health professionals. Other public and private hospitals also provide services, but their total capacity is low. Most of these institutions suffer from overcrowding due to problems in the primary care system and the referral system, and thus patients have to wait for hours to see a doctor. The fragmented structure of the agencies which provide health care makes it difficult to ensure effective coordination and delivery of health services (Agartan, 2005) (table 1). As a solution of aforementioned problems, the new Social Security Institution Law that one

of its aims to gather the different health care agencies under one social security umbrella was put into force on 20th of May 2006.

Table 1 Organisations involved in Turkish health care classified by their function

POLICY FORMULATION	
The Parliament	**PROVISION OF HEALTH CARE**
The State Planning Organization	Public
The MoH (Ministry of Health)	The MoH
The Higher Education Council	University Hospitals
The Court of Constitution	The Ministry of Defence
ADMINISTRATIVE JURISDICTION	Private
The MoH	Private Hospitals
Provincial Health Directorates	Foundations
	Minority Hospitals
FINANCE OF HEALTH CARE	Private Practitioners/Specialists
The Ministry of Finance	Outpatient Clinics
SSK (Social Insurance Institution)	Laboratories and Diagnostic Centres
Bağ-Kur (Tradesmen, Craftman and Other Self Employees Social Security Institution)	Pharmacies
GERF	Philanthropic
Private Insurance Companies	Red Crescent
Self Funded Schemes	*Foundations*
International Agencies	

There are 1271 hospitals in total and 831 of the hospitals and 67.4% of the hospital beds are run by the Ministry of Health, 309 of the hospitals and 7.3% of the hospital beds are private, and the remainder are run by other organisations, including other Ministries and Universities (Table 2). For a detailed description about the Health Care System administration and organization see the Turkey Health Report, February 2004 (http://www.mdri.org/projects/turkey/turkey%20final%209-26-05.pdf).

Table 2 Distribution of the Hospitals and Beds by the Type of Institution in Turkey (June 2007)

Name of the Institution	Number of Hospitals	Number of Beds	%
Ministry of Health	831	132.647	67.4
The Ministry of Defence	42	15,900	8.1
University Hospitals	56	29,700	15.1
Municipalities	5	1,138	0.6
Associations and Foundations	20	2,263	1.2
Foreigners	3	232	0.1
Minorities	5	545	0.3
Private	309	14,342	7.3
Total	1,271	196,767	100.0

Source: MINISTRY OF HEALTH 2007

The Ministry of Health is responsible for curative and rehabilitation services for people with mental health difficulties in Turkey. At date mental health in Turkey is facing different challenges, for example there is not a specific national mental health law and it has been pointed out that some bad/old practices and abuses as overuse of Electro convulsive still exist Therapy do occur in residential mental health settings and other disability residential settings. However, an Electro convulsive Therapy Directive has been prepared and broadcasted in 2006. The mental health system does not provide community care facilities for people with mental health disorders. Although there is a mental health policy initially formulated in 1983 and a National Mental Health Programme, there are no budget allocations for mental health and details about expenditure on mental health are not available. The Ministry of Health is trying to overcome these challenges and at date different reforms are being prepared in order to improve the quality of curative and rehabilitation services and accomplish with different demands from the EU Commission and International Institutions. In 2006 the Ministry of Health has published a new National Mental Health Policy which analyses the current situation, identifies objectives and proposes different strategies for Mental Health financing, Mental Health Legislation and Quality Improvement of Mental Health among others.

Social care in Turkey is provided by the Turkish Prime Ministry of Social Services and Child Protection Agency (SHÇEK) in coordination with the Turkish Prime Ministry of Administration for Disabled People. The roles of these two governmental organisations are explained below in detail.

Turkish Prime Ministry of Administration for Disabled People.
Turkish Prime Ministry of Administration for Disabled People is the main responsible governmental organisation for formulation and implementation of the policies for people with disabilities. The Administration was established in 1997 to provide services to people with disabilities in a continuous efficient and active manner; to ensure coordination between national and international institution and organisations; to determine policies, concerning people with disabilities.

Prime Ministry Administration for Disabled People has two advisory committees given primary role regarding formulation of policies for people with disabilities. These are Executive Committee for Disability and the Council for the Disabled.

- ***Executive Committee for Disability****:* Members are representatives of governmental organizations that have responsibility to provide services for persons with disabilities, non-governmental organizations (federations – umbrella organizations of associations of persons with disabilities), employee and employer unions, and universities. They are responsible for determining the priorities for applying and selecting projects. Moreover, formulation of policies for disabled and declaration of its opinions about them are among the other duties of this Committee.
- ***The Council for the Disabled:*** The Council is coordinated by the Administration and meets biennially. The aim of the Council is to discuss and analyse all ideas and developments about disability at national and international levels, and to make suggestions about the solutions in broader terms and raise public awareness about disability issues together with representatives of governmental organizations, non-

governmental organizations, employee and employer unions, and universities. The core theme of the first Council was "Contemporary Society, Contemporary Life and Disabled People" and the second one titled as "Local Governance and Disabled People".

The Prime Ministry Social Services and Child Protection Agency is a governmental organization that is affiliated under the Prime Ministry in Turkey. Currently State Minister is responsible from the administration of the Agency.

The **Child Protection Association** was established as a charity organization in 1921 during the Independent War of Turkey. The Association established and run children homes for children who lost their parents during the War.

The General Directorate of Social Services was a unit under the Ministry of health and Social Aid. "The General Directorate of Social Services" and "Child Protection Association" was reorganized together with "the Social Services and Child Protection Agency Law" (No 2828) in 1983, for providing social services to all inhabitants who are in need.

The Agency, SHÇEK, organized in 81 provinces with provincial social services directorates and in 34 district social services directorates across Turkey. There have been broad range of services which are provided by various institutions and centres that affiliated to provincial social services directorates:

- children homes and dormitories for children;
- residential care facilities, rehabilitation and family counselling centres which provide daily care for children and persons with disabilities;
- elderly homes and nursing homes for elderly people;
- community centres that provide services for people and families who live in disadvantaged neighbourhood of big cities;
- women shelters for women who experience domestic violence;
- child and youth centres for children who live or work in the street;
- elderly solidarity centres for elderly people.

SHCEK also has responsibility to permit and monitor the quality of services of private residential and daily care centres for persons with disabilities. The home based care services of persons with disabilities who are depended to care of their relatives started in 2006. It is expected to be served 65,000 people with disabilities in their home environment or in the private care centres.

The rehabilitation services of profit and non-profit special education and rehabilitation centres for children with disabilities were previously permitted and monitored by SHÇEK. The social security agencies have subsidized the services of profit and non-profit special education and rehabilitation centres since 1997. That is why; the number of profit centres has increased from 30 to 500. The majority of these centres have provided services to people with developmental disabilities. These centres can be seen as first step for improving community-based social services.

4.2 Financing

There are three main sources of health care financing in Turkey: state budget, social security institutions and direct payment by the individual patient. Despite numerous attempts to establish a general health insurance, there is still no universal coverage and current insurance institutions have very diverse systems. The sources allocated for health are less than OECD countries: in the period 1980-2002, the ratio of the budget of the Ministry of Health to the budget of State fluctuated between 2.40% and 4.71%.

A monthly disability benefit that varies between 75 Euros and 113 Euros is provided by the Pension Fund for 220 thousand people with disabilities who do not have social security and are in need depending on their age and degree of disability. Those who are not under social security umbrella can have access to free-of-charge health services provided at public hospitals. The care, rehabilitation and education expenditures related to disability of people with disabilities that are not under the coverage of social security system are covered by the State. Social and vocational rehabilitation services are also provided by the municipalities.

5. Definition, eligibility and diagnosis/assessment

International definitions have been applied in Turkey. Disability certification is done by medical boards run by the Ministry of Health.

6. Prevalence of disability

According to the results of 2002 Disability Survey carried out by the Turkish Statistical Institute and Administration for Disabled People, there are approximately 8.4 million people with disabilities in Turkey, which constitutes 12.3 % of the total population. 9.7 % of them have psychological and chronic illnesses; 1.25 % of them have physical, 0.48 % has intellectual, 0.38 % has speech and language, 0.37 % has hearing and 0.6 % has visual disability. The numbers of people are nearly the same for the people with mental disabilities according to the reason of disability: at birth or afterwards. When viewed in the light of proportion of people with disabilities by age groups, it is clearly seen that the number of people with physical, intellectual, speech and language, hearing and visual disabilities and number of people with psychological and chronic illnesses are higher in the age range 15-64 years.

Table 3 Proportion of Population by age and type of disability (%)

A. Total B. Male C.Female (%)									
Total disabled population				**Physical, visual, hearing, speech and language and intellectual disabled population**			**Population having psychological and chronic illnesses**		
	A	B	C	A	B	C	A	B	C
Turkey	12.29	11.10	13.45	2.58	3.05	2.12	9.70	8.05	11.33
Age group									
0-9	4.15	4.69	3.56	1.54	1.70	1.37	2.60	2.98	2.20
10-19	4.63	4.98	4.28	1.96	2.26	1.65	2.67	2.72	2.63
20-29	7.30	7.59	7.04	2.50	3.34	1.74	4.80	4.24	5.30
30-39	11.44	10.43	12.42	2.56	3.18	1.95	8.89	7.26	10.46
40-49	18.07	15.15	21.08	2.65	3.29	1.99	15.43	11.86	19.09
50-59	27.67	22.56	32.67	3.23	3.73	2.74	24.44	18.83	29.94
60-69	36.96	31.60	42.02	5.14	5.65	4.65	31.82	25.95	37.37
70+	43.99	39.77	47.77	7.89	8.45	7.38	36.10	31.32	40.39
Unknown	11.68	6.30	14.17	0.34	0.53	0.25	11.33	5.77	14.09

Source: Disability Survey 2002

Table 4 Proportion of disabled population by type of disability (%).

	Physical disability	**Visual disability**	**Hearing disability**	**Speech and language disability**	**Intellectual disability**
Total	1.25	0.60	0.37	0.38	0.48
Age group					
0-9	0.64	0.33	0.20	0.46	0.42
10-19	0.77	0.36	0.29	0.43	0.58
20-29	1.21	0.45	0.32	0.42	0.65
30-39	1.26	0.46	0.35	0.31	0.54
40-49	1.39	0.62	0.35	0.26	0.39
50-59	1.79	0.91	0.41	0.30	0.26
60-69	2.80	1.56	0.77	0.41	0.27
70+	3.94	2.98	1.70	0.39	0.31
Male	1.48	0.70	0.41	0.48	0.58
Female	1.02	0.50	0.33	0.28	0.38

Source: Disability Survey, 2002

According to 2002 Disability Survey, the rate of people with disabilities benefiting from social security services provided by Social Insurance Institution, Pension Fund and Tradesmen, Craftsmen and Other Self Employees Social Security Institution is 47.55 % for people with physical, intellectual, speech and language, hearing and a visual disability; while this rate is 63.67 % for people with psychological and chronic

illnesses. People with disabilities are entitled to early retirement, and Social Insurance Institution and Pension Fund are related agencies in terms of early retirement for people with disabilities.

In terms of literacy ratio, 63.67 % of the people with physical, intellectual, speech and language, hearing and visual disabilities and 75.19 % of the people with psychological and chronic illnesses are literate. According to the type and degree of the disability, the children with disabilities can have education under the general education system in normal classes or specialized education classes in accordance with the type and level of disability or can benefit from specialized education schools and centres. The families of children with disabilities decide upon to which kind of school their children will attend by taking into consideration the evaluation done by Guidance and Research Centre affiliated to Ministry of National Education made according to the type and level of disability and the education level.

A total of 110,000 disabled children benefit from specialised education schools and centres of the Ministry of National Education. The number of the specialised education schools and institutions affiliated to the Ministry of National Education is 510 and the total number of schools belonging to private sector is 433. In addition, nearly 5000 people with disabilities have been provided care services in 69 rehabilitation centres of Social Services and Protection of Children Agency, 42 of which are residential and 27 of which are daily care.

7. Residential Services for people with a disability

7.1 Overview

Residential and daily care services for people with disabilities are mainly provided by the Prime Ministry Social Services and Child Protection Agency. The Ministry of Health is responsible for mental health care at General Hospitals and Psychiatric Hospitals. According to the data of Ministry of Health 2007, Turkey has a total of 8,276 psychiatric beds (1.3 per 10,000 population). The total number of psychiatric beds is divided into psychiatric beds at mental hospitals (6196) and psychiatric beds at general hospitals (1881). According to this numbers, there are more psychiatric beds at Mental Health Hospitals than at General Hospitals. Turkey is one of the countries with fewer numbers of psychiatric beds if we consider that because of its population it should have at least an optimum number of 60.000 psychiatric beds. There is no residential care facility except hospitals for psychiatric patients affiliated to the Ministry of Health in Turkey.

The Prime Ministry of Social Services and Child Protection Agency provides residential care and rehabilitation to 3213 children and adults in the so-called Rehabilitation and Residential Centres. There are 42 Residential and Rehabilitation Centres for people with Disabilities. These centres aim at providing assistance in day living care, a place to live and rehabilitation programs. Although these Rehabilitation Centres are intended to provide specific care for certain disability groups and ages, at practice many of them admitted at sometime residents with disabilities different to the target population and different ranges of age. The issue of age is of great importance in the Rehabilitation Centres for Children with Disabilities if we consider that 1063 places out of 1870 intended for children are occupied by people above 18 years. Regarding residential services for elderly with disabilities, there are 1505 places at

Nursing homes and residential centres for elderly. These centres are not specific for people with disabilities but around 50% of the places are reserved for disabled people. Only elderly with some type of physical disabilities or any other type of disabilities can be admitted to these settings this means that people with mental health problems, aggressive behaviour or behaviour disorders cannot be admitted. However once that they are admitted they can stay at the service even if they develop some type of mental or behaviour problem.

7.2 Services for children with a disability

Residential Care and Rehabilitation Centres for Children with Disabilities (Ozurlu Çocuklar Için Bakim ve Rehabilitasyon Merkezleri): Children with disabilities whose ages range between 0 and 18 years benefit this type of Residential service. This service aimed at serving mainly to intellectual disability groups. The typical average number of places in this service is 66. There are 1837 places in total in Turkey. Regarding services size, 30 of these places are within institutions with a maximum of 30 people attended; 360 places are within institutions with a maximum of 50 people attended; 649 places are in institutions that serve between 51 and 100 people; 150 are in institutions serving between 101 and 200 people and 648 are in institutions serving more than 501 people. With regard to the number of places by the type of attended disability, 1827 places are for people with intellectual disability, 6 places are for people with hearing, speech and language disabilities, 15 places are for mental health problems and 22 places are for people with physical disability. In terms of the number of places by the residents' age ranges, 42 places are for children between 0 and 6 years old; 271 places are for children between 7 and 12 years old; 494 places are for children between 13 and 18 years old and 1063 places are for adults above 18 years old. In reference to the number of places by the residents' gender, 1108 places are for males and 762 for females. These services are staffed by a total of 460 persons. 97 are care staff, 4 education or day care staff, 113 are clinical staff, 45 administrative staff and 201 ancillary staff. At least 141 of these professionals have a degree or a diploma. 24h medium/long term is provided.

Rehabilitation places for children with spastics (Spastik Özürlü Çocuklar Için Rehabilitasyon Merkezleri): Residential service for children with physical disabilities, mainly cerebral palsy. The typical number of places in these services is 55 and they are intended for children whose ages range between from 0 to 18 years. There are 110 places in total for Turkey. In respect of the number of places by service size, 40 places are in institutions that attend between 30 and 50 people and 70 places are in institutions that attend between 51 and 100 people. With reference to the number of places by the type of service users' disability, 68 of these places are for intellectual disability and 43 are for physical disabilities. Again not all of the beneficiaries are for children nor for physical disability. In relation to children's age range, 94 places are for children below 18 years and 17 are for adults above 18 years. As regards the number of places by gender, 59 places are for male and 28 are for female residents. In total 43 professionals work in this type of service, 5 are care staff, 6 are education or day care staff, 22 are clinical staff, 6 are administrative staff and 4 are ancillary staff. This service belongs to the Social Services and Child Protection Agency and is financed by the Government, although some patients can pay out of pocket costs.

General Hospitals with Acute Psychiatric Units for Children and Adolescents (Çocuklar ve Ergenler İçin Akut Psikiyatri Ünitesi Olan Hastaneler): There are acute psychiatric units at General Hospitals that serve children and adolescents. There are acute psychiatric units for children and adolescents at 5 General Hospital (Çukurova State Hospital (in the provice of Adana), Bakırköy Prof. Dr. Mazhar Osman Mental Health and Neural Diseases Education and Research Hospital (in the province of İstanbul), Manisa Mental Health Hospital, Uşak State Hospital, 1st of September State Hospital (in the province of Uşak). (These are not residential services as such in that they operate on an acute basis, rather than as long-term provision).

7.3 Services for younger adults with a disability

Rehabilitation Places for People with Visual impairments. (Görme Özürlüler İçin Rehabilitasyon Merkezleri): This type of service is intended for adults with visual impairment. The total number of places is 58. 26 out of these places are within institutions that attend between 10 and 30 people and 32 places are in institutions that attend between 31 and 50 people. 5 places are occupied by children below 18 years old and 53 places are occupied by adults above 18 years old. All of the places are serving people with visual impairment. 37 places serve males and 21 serve female.

Residential Care and Rehabilitation Places for people with Intellectual Disabilities (Zihinsel Engelliler İçin Rehabilitasyon Merkezleri): Residential services and rehabilitation places intended for people with intellectual disability although they serve also physical disabilities and other types of disability. There are 1043 places in total in this type of service. 418 places are within institutions serving between 31-50 people, 475 places are within institutions serving between 51-100 people and 150 places are within institutions serving between 101-200 people. With regard to the number of places by the type the residents' disabilities, 865 places are serving people with intellectual disability, 7 places serve people with hearing, speech and language disabilities, 49 serve people with mental health problems, 119 serve people with physical disabilities and 3 is for people with mixed disabilities. As for the number of places by the attendance's gender, 600 places serve male and 480 serve female. Staff working in this type of service is mainly clinical staff (60 places), there are 20 care staff and 20 professionals are administrative staff. 62 people are ancillary staff. There are 13 places for children below 18 years and 1030 places for adults above 18 years.

Residential care and Rehabilitation Places for people with Physical Disabilities (Bedensel Engelliler İçin Bakım ve Rehabilitasyon Merkezleri): There are 165 places in this type of service. Regarding the number of places by capacity, 30 of these places are within institutions between 10-30 places and 135 places are within institutions attending between 51-100 people. The number of beneficiaries of this type of service is 79 (100 males and 79 females). As to the number of places by the type of disabilities, 45 places are for people with intellectual disability, 11 places are for people with hearing, speech and language disabilities, 22 places are for people with mental health difficulties and 101 places are for people with physical disabilities. Regarding the number of staff, there are in total 47 people working in this type of service: 1 is education staff, 3 are care staff, 10 are clinical staff, 8 are administrative staff and 25 are ancillary staff.

Psychiatric Hospitals (Psikiyatri Hastaneleri): There are 8 public Psychiatric Hospitals in Turkey (2 hospitals were located in the province of İstanbul and each one of the following provinces has one psychiatric hospital Samsun, Manisa, Adana, Elazığ, Trabzon and Bolu). According to the Turkish Ministry of Health (2007), there are 6196 hospital beds at Mental Hospitals. Furthermore, there are also 2 private Psychiatric Hospitals in the province of İstanbul and there are 199 hospital beds at these hospitals.

General Hospitals with Acute Psychiatric Units for Adults (Yetişkinlere Yönelik Akut Psikiyatri Uniteleri Olan Hastaneler): There are acute Psychiatric units for adults at 133 General hospitals. According to the Turkish Ministry of Health (2007), there are 1881 psychiatric hospital beds at General Hospitals. There are also acute psychiatric units for adults at 4 private hospitals in İstanbul province (as noted above these are not included in the data on residential services as they operate on an acute rather than long-term basis).

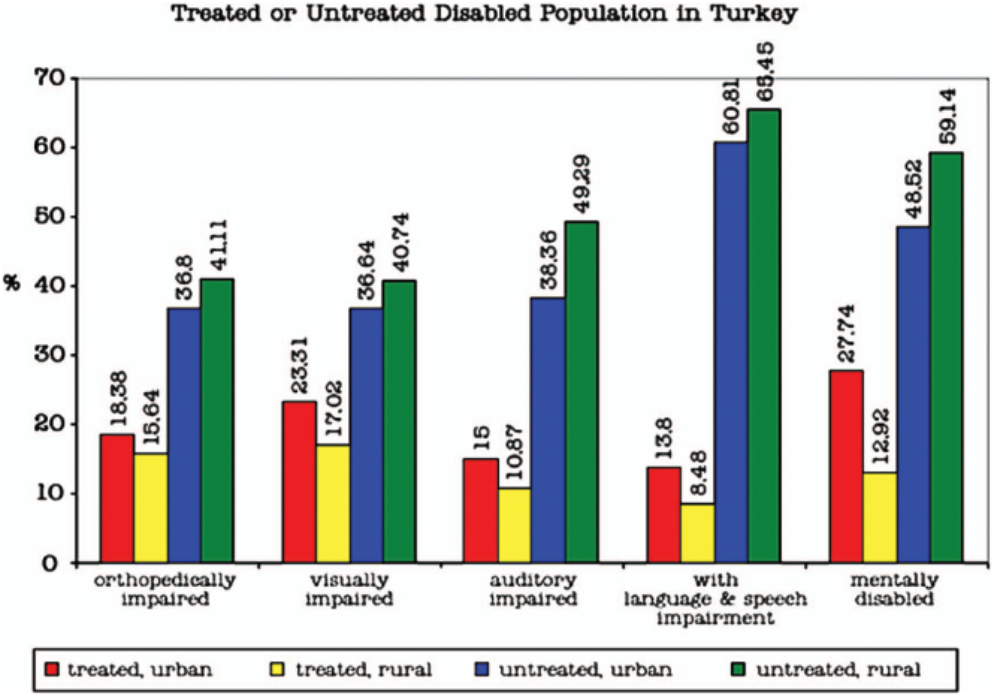
7.4 Services for older adults

Nursing Homes and Rehabilitation Places for Elderly (Yaşlılara Yönelik Huzurevleri ve Rehabilitasyon Merkezleri): The typical number of places in this type of service is 83. This service is intended for people with more than 60 years old and with physical disability. They provide 24-hour support and long-term care and sometimes family respite too. They are mainly public institutions financed by the Government and in some case by pocket money. The total number of places is 1505: 651 for males and 854 for females. 31 of these places are in institutions serving between 31 to 50 people, 239 are in institutions that attend between 51 to 100 people, 315 within establishments serving between 101 to 200 people and 920 for institutions between 201 to 500 people. There are 576 persons working in this type of services: 70 are care staff, 2 education staff, 163 clinical staff, 94 ancillary staff and 270 other staff. This service is not specific for disability but 50% of the places are reserved for people with some type of disability, usually physical disability. We have reported only places for people with disabilities. Although mental health problems and behaviour problems are not admitted in these institutions, patients with this type of problems are attended if they develop the disorder once they have been admitted.

8. Issues

Urban-rural division is an important issue in service provision in Turkey. Untreated population with disability in rural areas is higher than in urban areas as Fig. 1 shows.

Figure 1 Relation between the state of medical treatment and the residence areas of the disabled



DIE, 2002

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10. Information sources on disability used to compile the template and commentary, including people who were interviewed

The main information source for template compilation has been the data provided by the Social Services and Child Protection Agency –SHÇEK- and the Ministry of Health.

Interviews:

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Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

United Kingdom

Julie Beadle-Brown
and Robert Hayward

Tizard Centre, University of Kent.

Summary of the available data

Description of service types

Service descriptions were available for services in all four regions as summarized in the tables below. In most cases these overlapped between the 4 regions of the UK. Information included in these tables for all services, including those providing for older people.

Type of service	Size interval	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length admissions	Age of service
Children's homes/hostels	Less than 6 places	6-18 or 19 years	Mixed but includes those with behavioural and emotional disorders and children in care	24 hour	.	.	.	.
Residential homes (usually for children with specific disabilities)	11 to 30 places	6-18 or 19 years	More than one disability group served (no main group) but not mixed	24 hour	.	.	.	.
Residential special schools	11 to 30 places	6-18 or 19 years	More than one disability group served (no main group) but not mixed	24 hour	.	.	.	.
Residential college	31 to 50 places	young adulthood - 16 to 19 or 23	Mixed	Mixed depending on need	Mainly independent (over 50% private or voluntary)	Mainly state or LA (more than 75%)	Mainly long term	0 to 20 years
Hospital	.	0 - 18/19 years	MH	24 hour	.	.	.	.
Village community	11 to 30 places	Over 18/25 (i.e.	Mixed ID with PD, SD, MH, Behavioural and	24 hour	Voluntary/not-for-profit (over 95%)	Mixed benefits and private	Mainly long term	0 to 20 years

Type of service	Size interval	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length admissions	Age of service
		adults only)	other					
NHS campus settings	100 to 150 places	Over 18/25 (i.e. adults only)	Mixed ID with PD, SD, MH, Behavioural and other	24 hour	State	Regional authority/LA/County and state	Mainly long term	0 to 20 years
Assessment and treatment units/private hospitals/secure units	11 to 30 places	14 + to adulthood (60/65 years)	Mixed ID with PD, SD, MH, Behavioural and other	24 hour	Mixed	Mixed state/local and private contributions (insurance/private)	Mixed	0 to 20 years
Long-stay LD Hospitals	11 to 30 places	Over 18/25 (i.e. adults only)	Mixed ID with PD, SD, MH, Behavioural and other	24 hour	State	Regional authority/LA/County and state	All long term	50 - 100 years
Psychiatric hospital	.	3 into adulthood (60/65 years)	MH	24 hour	State	State	Mixed	50 - 100 years
Small Group homes	less than 6 places	Over 18/25 (i.e. adults only)	Mixed	Mixed depending on need	Mainly independent (over 50% private or voluntary)	Mixed benefits and private	Mainly long term	0 to 20 years
Group homes for older people	less than 6 places	Over 60/65	Mixed ID with PD, SD, MH, Behavioural and other	24 hour	All (over 95%) private	Mixed benefits and private	Mainly long term	0 to 20 years
Secure/forensic hospitals	151 to 200	14 + to adulthood	MH	24 hour	State	State	Mixed	50 - 100 years

Type of service	Size interval	Age Group	Disability group served	Level of support provided	Typical provider	Typical funder	Length admissions	Age of service
	places	(60/65 years)						
Residential care homes (no nursing)	6 to 10 places	Over 18/25 (i.e. adults only)	Mixed	24 hour	Mainly independent (over 50% private or voluntary)	Mixed (any)	Mainly long term	0 to 20 years
Residential care homes	11 to 30 places	over 60/65	Mixed	24 hour	Mainly independent (over 50% private or voluntary)	Mixed benefits and private	Mainly long term	.
Residential care home with nursing	11 to 30 places	Over 18/25 (i.e. adults only)	Mixed	24 hour	Mainly independent (over 50% private or voluntary)	Mixed (any)	Mainly long term	0 to 20 years
Nursing homes (Northern Ireland and Scotland)	31 to 50 places	Over 60/65	Elderly infirm/mentally ill/dementia	24 hour	All (over 95%) private	Mixed benefits and private	Mainly long term	.
Hospital	.	over 60/65	Elderly infirm/mentally ill/dementia	24 hour	State	State	Mixed	21 to 50 years

The tables below summarise of data on places and breakdown by size and disability – these include only those service types which provide at least in part for people with disabilities. Some of service types listed above have been amalgamated in order to present the data available. However, because of the nature of the data available it has been necessary to keep separated the data from the different regions at times) The number of places for those who are elderly and infirm or who have dementia (but no other pre-existing disability) are clearly distinguished. Only places for people with disabilities were included in the final analysis of data reported in the main project report.

Breakdown of places by size and disability group

Type of institution	Places total	Under 30 places	Over 30 places	Size unspecified	ID	MH	PSD	Elderly/ dementia	Mixed/ dual	Other/ unspecified
Children's homes/hostels	620	620	.	0	.	.	.	.	.	620
Residential home for children	80	.	.	.	.	.	.	.	.	80
Residential special schools	982	.	.	.	161	.	.	.	.	821
NHS provision (includes NHS campuses, NHS secure units etc but not long-stay LD hospitals)	15060	.	.	.	2637	8040	792	3591	.	3591
Long stay LD hospital	964	139	683	142	964	.	.	.	.	0
Private hospitals and assessment and treatment/secure units	16864	.	.	.	717	1134	6372	7873	.	8641
Forensic hospitals	.	.	.	.	.	.	.	.	.	.
Small group homes (England)	11513	11513	.	0	7935	990	219	579	1808	561
Residential care homes (England where size data available)	55189	20541	32095	2553	29261	9483	3118	120	9993	3334
Residential care homes with nursing (England, plus NI dual registered homes)	24136	717	16003	7416	1846	2790	3664	1891	6529	9307
All other residential homes (grouped together - e.g. for Wales, Scotland – no size data, including older people)	31809	.	.	.	4073	1902	813	4624	.	25021
Residential homes for older people (England)	210604	3486	207128	10	386	2973	1193	148342	57710	148342

Type of institution	Places total	Under 30 places	Over 30 places	Size unspecified	ID	MH	PSD	Elderly/ dementia	Mixed/ dual	Other/ unspecified
Residential homes with nursing for older people (England)	162387	75	162312	0	91	6591	5268	85729	64708	85729
Small group homes for older people (England)	756	756	.	0	101	60	1	576	198	396
TOTAL	**530964**	**37847**	**418221**	**10101**	**48172**	**33963**	**21440**	**253325**	**140946**	**285743**

Breakdown of places by gender and age

Type of institution	Places total	Male	Female	Gender unspecified	Children	Younger adults	Older adults	Adults over 18	Age unspecified
Children's homes/hostels	620	440	180	0	620	.	.	.	0
Residential home for children	80	50	30	0	982	.	.	.	902
Residential special schools	982	530	161	291	.	.	.	.	982
NHS provision (includes NHS campuses, NHS secure units etc but not long-stay LD hospitals)	15060	.	.	.	835	10236	3989	.	3591
Long stay LD hospital	964	114	56	794	8	135	9	.	812
Private hospitals and assessment and treatment/secure units	16864	.	.	.	49	1118	14929	.	7105
Forensic hospitals	.	.	.	.	.	.	.	.	.
Small group homes (England)	11513	.	.	.	.	11513	.	18	597
Residential care homes (England where size data available)	55189	.	.	.	.	51675	.	300	3094
Residential care homes with nursing (England, plus NI dual registered homes)	24136	.	.	.	.	14869	.	5553	1823
All other residential homes (grouped together - e.g. for Wales, Scotland – no size data, including older people)	31809	.	.	.	.	.	.	.	27185
Residential homes for older people (England)	210604	.	.	.	.	.	210604	.	148342
Residential homes with nursing for older people (England)	162387	.	.	.	.	.	162387	.	85729
Small group homes for older people (England)	756	.	.	.	.	.	756	.	576
TOTAL	**530964**	**1134**	**427**	**1085**	**2494**	**89546**	**392674**	**5871**	**212946**

Staffing data

Only available for one type of service – children's homes/hostels.

Type of service	Total Number of staff in each type of service	Number care staff/nurses/ might include teachers in boarding school	Number managers or other administrative staff (not care staff)	Number educators/day staff	Day and care staff (no distinction made)	Number clinical staff (Drs, therapists, psychologists etc)	Number of other staff (mainly ancillary staff)	Number of other staff (does not include ancillary staff)
Children's homes/hostels	2125	1360	490	.	.	.	280	.

Completeness and accuracy of the data

The four constituent countries of the UK have their own government departments with different degrees of autonomy. Within each country, some social welfare and health care is provided by local government agencies and other health care and social security provided by central government through regional and local organisations that may differ between the four countries. Social care and health care organisation is therefore different in each of the four countries which required consultation of different sources of data in each country. These sources varied in the level of detail available, the nature of the data and to some extent the definitions used. For example, English data is mainly information about places or beds, whilst data from other regions sometimes refers to the number of people supported e.g. by local authorities.

In England access was available to the 2004/2005 data collected by the Commission of Social Care Inspection – the body responsible for registration and inspection of all services providing residential care (as well as those providing domiciliary care, foster care and adoption services). However, for Wales, Northern Ireland and Scotland only summative data was available although for the most part this was data collected by the body responsible for registration and inspection processes.

For England it was also possible to access quite detailed information on long-term care provided by the national health services and although summative in nature it was possible to break this down by age, and to some extent by disability group.

Data on children with disabilities

For the most part the data included in the template refers only to England and uses two main sources: the Annual Reviews in Independent and Non-Maintained Special Schools (available through http://www.scrip.uk.net/) and the Department for Education and Skills/Department of Health, report (2004 and 2005) on *Disabled Children in Residential Placements*. Most recent data on residential services was for 2002. Data on residential schools referred to 2006. It is also known that there are 291 places in residential schools in Wales but there is no breakdown by disability group available for this figure.

Data on adults with disabilities

Health related statistics

Data on NHS provided services is only available in official form for England and data is taken from Department of Health statistics (Returns Form KH03) published in September 2006. Data is available by Health Authority and summarised across England and data refers to the year 2005-2006. Very little data is available on mental health services in other parts ok the UK apart from in the form of admissions to hospital.

Social care statistics

England

As noted above, data for England was taken from CSCI data for 2004-2005. The raw data was made available to the project team and complete for all social care homes registered with CSCI at that time. The data is at home level and provides information

on the breakdown of places by disability group but does not provide any additional information on the people who live there. There is also no data collected about staffing (although some summary data is available from other sources and presented in the country report below).

Wales

The Standards Inspectorate for Wales (CSIW) is responsible for registration and inspection of social care services in Wales. Data for Wales is principally drawn from their reports. Separate tables are available for number of places by LA or private and voluntary provision. Statwales provides some data on hospitals and units for persons with intellectual disability, with information on gender available from census data. Numbers of people on intellectual disability register are recorded by county, LA or private provision with little data available by unit. Very little data on mental health services in Wales is readily available. Data for Wales was not available broken down by size but for the purpose of estimations, it was possible to use typical size as a guideline for processing this information.

Scotland

The Scottish Commission for the Regulation of Care (SCRC) which regulates a wide range of services for adults, children, provides information on over 320,000 people in Scotland using care services. Of these, about 11.2% are residential care homes. Community care statistics provide summary statistical information of summary data (numbers over time) from different sources on older adults, intellectual disability and physical and sensory disabilities, broken down by local authorities. Inspection Unit data lists all private & voluntary residential homes for ID, PSD, mental health by LA, numbers of homes, numbers of beds, residents, age distribution (for 55+). NHSiS collate information on private nursing homes (mainly for the elderly), but the information is not detailed. Published information on staff and staffing levels is minimal.

The figures entered under private hospitals, nursing homes providing nursing care only, assessment and treatment units etc were for nursing homes in Scotland and are mainly for older people – therefore although some private services aren't for older people the ones on which we had data were. The Forensic hospitals listed were also for Scotland although data on the number of places was not available. In general there was little information on mental health services in Scotland.

Northern Ireland

Sources for Northern Ireland included:

- Department of Health Social Services and Public Safety, Registration and Inspection Unit (NI) 2003-2004
- NI Statistics & Research Agency (NIRAS)
- Department of Health SSPS Community Statistics 2003-2004 www.dhsspsni.gov.uk/statistics&research/pubs.asp

Changes within the organisation of inspection and registration and statistics has meant that recently a new body has taken over the process. At the time of completing the template, no new report was available and this was checked by phone conversations with people within the Northern Ireland Statistics and Research Agency [NISRA] and the Registration and Inspection Department within the Department of Health, Social Services and Public Safety.

Some of the data which was available for Northern Ireland is at institution level and no information was available with regard to size from official sources. However it was possible to estimate size from the typical size of most services as described by McConkey et al (2006) and Mulvany et al (2007)

In Northern Ireland children's homes cater for those with ID, PSD or behavioural/emotional problems but without the distinction. Very little information is available on mental health services or on hospital services for those with disabilities.

Some data on staffing (numbers) is provided by Health & Personal Social Services Workforce Census (2003).

Commentary: United Kingdom

1. Overview

The United Kingdom of Great Britain and Northern Ireland was established in 1927 and is made up of 4 nations – England, Wales, Scotland (and island otherwise known as the Kingdom of Great Britain, established in 1707) and Northern Ireland. There are also a number of small Islands which each form parts of the four constituent nations. Each nation has its own capital city (London, Cardiff, Edinburgh and Belfast respectively) and although overall government remains in London, each nation has its own government processes and has devolved powers and responsibilities.

2 Political and social context

2.1 Government organisation and structure

Great Britain is a parliamentary monarchy. The British Monarch is Head of State but executive power is wielded by the prime minister, who is head of government working with a committee of cabinet ministers. Parliament at Westminster in London consists of elected representatives (the House of Commons) and hereditary peers and appointive members (the House of Lords), who pass legislation. In practice, legislation is dominated by the prime minister and cabinet who initiate most bills and are responsible for the administration of the law and affaires of the nation.

The provincial constitutional set up described above means that although health and social services are broadly the same in the four nations, there are certain organisational differences.

The government is elected in a first-past-the post system, with each constituency represented by the elected member represented in the House of Commons. Wales, Scotland and recently Northern Ireland have their own assemblies, but key powers, particularly in the areas of health and social policy are still retained by Westminster. Beyond the formal structures of state power lie well-established pressure group networks ranging from trades unions to corporate enterprises that may have an influence on power, policies and politics.

Wales

For centuries Wales has shared many political and legal institutions with England. The Welsh National Assembly (NAW) is a unicameral organisation of 60 members elected by proportional representation. It has powers to create only secondary legislation which still requires approval from parliament in London. The organisation of health and social services is the responsibility of the Assembly (Health & Social Services Committee). In addition the Director of the NHS also has responsibilities for social services policy. This means that there is much more alignment between health and social care policy at all levels than in the rest of the UK.

Scotland

The Scotland Act (1988) devolved a range of powers to the re-established Scottish Parliament which was elected in 1999 and has 129 members. Health, social affairs, community care and local governments are so-called devolved matters, in which the Scottish Parliament has the right to pass own laws. The “Scottish Executive” is the government of Scotland, its members are the “Scottish Ministers”.

Northern Ireland

Northern Ireland has been a distinct political entity since it was divided from the southern part (later the Republic) by treaty in 1922. It has experienced varying degrees of autonomy having its own parliament until 1972 when it was suspended as a result of the conflicts which began in 1969. Only very recently has the parliament re-opened.

2.2 Disability relevant policy

There have been three strains of general policy over the past decade, which have had an influence on the lives of people with disabilities.

General disability legislation such as the Disability Discrimination Act (1995) has enforced more equal opportunities and anti-discriminatory policies benefiting all people with disabilities. In particular the Act has been important with regard to improved physical access to all public areas and improved access to appropriate treatment in hospitals.

The Human Rights Act (1998) came into force in October 2000 and the Act gives a way for human right infringement cases to be heard in the UK rather than having to go to the European Court of Human Rights.

There have been a number of general community care policies that have aimed at improving the independence, protection and quality of care for all people receiving community care, including Modernising Social Services (DoH, 1998), The Community Care (Direct Payments) Act (DoH, 1996), the Health and Social Care Act (DoH, 2001), and the Care Standards Act (DoH, 2000). The Community Care (Direct payments) Act was particular important as it opened the doors to increased choice as to how services are provided for individuals. Although uptake of direct payments in some groups has been slow, in particular, those with intellectual disabilities, more and more people are now receiving direct payments and recent introduction of personal budgets as part of self-directed support (see http://www.in-control.org.uk/) have allowed more flexible and creative approaches to be taken by and on behalf of those with more severe disabilities.

Other important government papers and guidance, with particular relevance to those with disabilities, have included: The *Valuing People* White paper in England (Department of Health 2001); *Fulfilling the Promises* report in Wales (Learning Disability Advisory Group report to the Welsh National Assembly); Welsh Assembly Government's Learning Disabilities Strategy on Adults and Older people with learning disabilities (2004) - guidance on service principles and service responses;
The same as you? review by the Scottish Executive; and the *Independence, Well-being and Choice* green paper (Department of Health 2005). All of these papers, reviews and reports focus on the need to improve quality of life for people with disabilities, with a particular focus on inclusion, independence and choice. The latter of these papers emphasised the importance of personal budgets and direct payments for the achievement of the aims of inclusion, independence and choice.

3. Demographics

The population of the United Kingdom currently stands at 60,587,000 (mid 2006 estimate by Office of National Statistics) and has been rising in recent years courtesy of increasing life expectancy, rising birth rate and increasing immigration. 7.5 million live within London. Over 90% of the population is white (86% White British). Populations estimates for other parts of the UK are as follows: Scotland – 5,116,000 (2006 estimate); Wales – 2,959,000 (2005 estimate); and Northern Ireland - 1,710,000 (2004 estimate).

There has been a major demographic transition over the past one hundred years as the country has moved from being one of high birth and death rates to being low on both counts due to general improvements in social and environmental factors and advances in medical technology. In health and social care terms, one of the most important factors is the increasing numbers of elderly people (accentuated by the decline in the birth rate) which currently stands at about 7.5% of the population over the age of 75 and is expected to rise to over 8% within 10 years (Wall, 1996). On average a person over 75 consumes around nine times the amount of health and social care resources as the average person of working age (DHSS, 1983) as an increase in conditions associated with ageing population, chronic and degenerative disease and illness escalate. These changes also have implications for the availability of carers within society – more people to care for and a smaller proportion of people of working age within the population.

4. Health and Social Care System

4.1 Organisation of health and social care in England

The Department of Health has overall responsibility for health and social care in England. Health care is delivered through the National Health Service (although private health care is also available in the UK) and social care is delivered through social services seated in Local Authorities across England. Social service departments do not usually provide residential services now – rather they are responsible for commissioning service to meet individual needs, usually from independent sector (private and voluntary) organisations.

Health care

Within England there are 10 strategic health authorities which are responsible for providing leadership, coordination and support to the NHS within a defined area. They lead on strategic development and manage the performance of Primary Care trusts and NHS trusts and they focus on finding the best ways to deliver and improve health care within their local area.

Both the Department of Health and the Strategic health authorities directly feed the work of Primary Care Trusts which assess local need and commission care. This care is both from Primary Care providers, such as general practitioners, dentist, opticians, pharmacists) and from secondary care providers, i.e. NHS Trusts (providing hospitals and health care), Mental Health Trusts, Ambulance Trusts, etc. (http://www.nhs.uk/aboutnhs/howthenhsworks/Pages/HowtheNHSworks.aspx).

Social care

The Department of Health website (www.dh.gov.uk/en/Aboutus/HowDHworks/) reports that "at any one time 1.5 million of the most vulnerable people in society are relying on social care workers and support staff for help". Social care in the UK is defined as services which help people to carry on in their daily lives. There are approximately 25,000 employers, with over one million staff in the field of social care in England and services provide for:

- Elderly people through residential homes, nursing homes, domiciliary/home carers, meal services, day centres, lunch clubs etc.
- People with physical or intellectual disabilities
- People with mental health needs (both in terms of support for those with milder needs in the community and in terms of initiated compulsory admission to psychiatric hospitals for those who are potentially dangerous.

In addition, social care services provide for those with drug and alcohol problems, ex-offenders, and young offenders, families (in particular those with a child with disabilities) and children in care. They also are responsible for children protection.

Social care is managed through social services departments seated within the 150 councils in England. It is the responsibility of councils to assess individual need and arrange care and support to meet those needs. In doing this they work closely with other organisations including the NHS, private and voluntary organisations, education, the probation services, the police etc. Social services in England provide very few residential services for people with disabilities but are generally responsible for commissioning services to meet people's needs.

Almost all residential care is provided by private and voluntary organisations and even those services provided by the NHS are slowly being reprovided and moving to private and voluntary organisations.

Monitoring of quality

With regard to the NHS, performance is monitored by the Healthcare Commission. The Commission also monitors the quality of independent healthcare providers. Performance of social care providers is regulated and inspected through the Commission for Social Care Inspection. Children's services (both social and residential) are monitored through OFSTED.

4.2 Financing

The NHS is financed mainly through central government general taxation together with an element of national insurance (NI) contributions, which are paid partly by individuals who are working and partly by their employers. Basic NHS care is free for all patients. Extended care (dentist, prescriptions etc) is provided free for those under 18 and over 60 and those on low incomes. There is also a substantial private healthcare sector although this is only available to those who can afford to pay for it or who have private health insurance.

Social care financing is more complex. Essential people pay for their own social care but many people receive help from the state, either through welfare benefits or from social service funding. The majority of people have social care services provided directly – i.e. they are assessed as having a particular need, a service is found by their

social service department, usually through their care manager to meet that need. For the majority of people this means that a place in a residential home or another setting is paid for by social services along with the person's benefits which are usually paid directly to the residential home. For a growing number of people, this now means receiving the money to pay for their care directly and then having control over how it is spent in order to meet the assessed need. This is called a "direct payment" (introduced by The Community Care (Direct Payments) Act in 1996. Direct payments cannot be used to purchase a place in residential care, but are usually used to pay personal assistants to support people in their own home. Direct payments are most often used by people with physical disabilities, mental health needs and elderly people but this is becoming more widely used by people with intellectual disabilities too. Direct payments are now by paid to parents of a child under the age of 16 who is eligible for support.

Recently this has been extended to what is called "individual budgets" which have at present been introduced in almost 100 of the 150 local authorities. Individual budgets can be used by people with more severe intellectual disabilities to ensure that they get the package of care they both need and want but are more flexible in that they can be used to purchase residential care if that is what the person wants. Personal budgets are part of a new approach called "self-directed support" (see http://www.in-control.org.uk/) which combines funding with person-centred planning and allows a range of options through which the person can manage their personal budget.

Although the payment of certain benefits (e.g. Disability Living Allowance) is awarded on the basis of severity of disability, the majority of social care funding is means tested. If people have assets of over £16,000 they are expected to pay for their social care in full. If they have assets between £10000 and £16000 then they will pay a contribution towards their services. However over 70 percent of older people living in care homes, for example, get some or all of their costs met by their local council.

There are several types of benefits which people with disabilities would normally be able to access depending on the severity of their disability and living situation.

- Disability Living Allowance (DLA)
- Attendance Allowance
- Incapacity Benefit
- Income support (for those not working)
- Housing benefit (for those living in their own home)
- VAT relief on products and services for disabled people
- Council Tax reduction for disabled people (for those living in their own home)

The Department of Health reports that local authorities spend £10billion a year on social services, and about 70% of this funds community care services for adults (older people, people with physical or intellectual disabilities and the mentally ill). About 27% is spent on services for children.

4.3 Regional variations

4.3.1 Scotland

The Department of Health of the Scottish Office is responsible for health policy and the administration of the NHS in Scotland. The government's Chief Medical Officer for Scotland heads the Public Health Policy Unit and is the Secretary of State's chief medical adviser. The Chief Executive (CE) of the NHS in Scotland leads the central management of the service and is accountable to ministers for the efficiency and performance of the service. The CE heads the Management Executive which oversees the work of the 15 area special health boards, plus the State Hospital Board, Scotland, which also provide learning disability services, mainly short-stay assessment and treatment services, respite and rehabilitation services. As in England, the health boards are responsible for the planning and commissioning of health services for their resident populations and the trusts are responsible for the provision of services. The NHS in Scotland employs approximately 132,000 staff, including 63,000 nurses, midwives and health visitors and 8500 doctors. In addition, there are more than 7000 family practitioners, including doctors, dentists, opticians and community pharmacists. The Health Department is responsible for community care (NHS Scotland). Scotland has 32 directly elected local councils that are responsible for delivering social services. (main sources: http://www.show.scot.nhs.uk/organisations/orgindex.htm; http://www.nhshealthquality.org/nhsqis/files/LDS_LRP_MONR06.pdf)

4.3.2 Wales

The Director of the Welsh Office Health Department is accountable to the Secretary of State for the management and performance of the NHS in Wales. The Director, under the Permanent Secretary, is the Secretary of State's principal policy adviser on the NHS. The Welsh Office Health Department comprises five divisions: Health Financial Management, Health Services and Management, Health Strategy, Primary and Community Health and the Public Health Division. The five Welsh health authorities are directly accountable to the Director of the Health Department. There are 4 regional health offices (North, Mid, Southeast and Southwest) which are self-sufficient for the majority of health care provision. Their role is to ensure implementation of assembly policy and support joint working at local levels between the 22 Local Health Boards (LHBs) and LAs and to monitor local health and social care policies. The 22 LHBs correspond to the 22 LAs whose responsibilities include needs assessment, commissioning of specialist care from the NHS trusts and the management of primary care. Trusts in Wales are constituted in much the same way as their English equivalents, except that each trust provides both acute hospital and community services (including mental health) to the general population. Community Health Councils (CHCs) have been retained in Wales to provide input into the planning process. The Welsh Assembly Government (WAG), since its inception, has sought to tackle the causes of ill-health, particularly through "joined up" policy through partnerships between various parts of the statutory and non-statutory sectors, local communities and individuals (Welsh Assembly Government, 2003). (http://www.wales.nhs.uk/sites3/page.cfm?pid=11600&orgid=452)

4.3.3 Northern Ireland

Close ties with Britain mean that the health and social services are modelled along similar lines, with a NHS established in 1948 and a Department of Health, Social services and Public Safety (DHSSPS). The Department is headed by the Permanent Secretary and comprises a number of core groups. These are the Resources and Social Security Group, Health and Social Policy Group, Health and Social Services Executive, and five professional groups. There are four health and social service boards (HSSBs) that are directly accountable to the Department of Health and Social Services and which are responsible for assessing the needs of the people in their areas and for commissioning services to meet those needs. There are five Health and Social Care Trusts which provide community care and social services within their areas, one for each of the HSSBs plus a separate one for Belfast. As the names of these boards and trusts imply, a major difference between them and the rest of the United Kingdom is that they are responsible for both health *and* social services. It is widely believed that this makes the coordination between health and social care services less problematic in Northern Ireland than in the rest of the United Kingdom. (http://www.n-i.nhs.uk/).

5. Definition, eligibility and diagnosis/assessment

In the UK, the definition of disability is generally medicalised. Diagnosis with a particular condition, confirmed by medical records, is usually important in order to obtain services. However, there is also a sense in which definition is also functional – the extent of and effect the impairments are assessed (but with a need for confirmation by medical professionals) in order to decide whether people are eligible for particular benefits or services. This slightly more functional approach is especially true of people with physical disabilities and older people.

The terminology used in the UK to label people with intellectual disabilities varies between different organisations and in different situations. For example, in the criminal justice system terminology ranges from ‘mental defective’ in the Sexual Offences Act (1956) to ‘mental impairment’ and ‘severe mental impairment’ in the Mental Health Act (1983). Within the social security system the terms ‘severe mental impairment’ and ‘severe learning disability’ are used. ‘Intellectual Disabilities’ is the term adopted internationally mostly by the academic world. The most commonly used term that is used by the government and in most professional and academic circles is the term ‘learning disability’ and ‘people with learning disabilities’. Some organisations, however, use the term “learning difficulties” which usually has a wider definition in that it includes those with specific educational needs (e.g. dyslexia, ADHD etc).

Intellectual disability in the UK is a medico-legal definition based upon the generally accepted diagnostic criteria used internationally. The diagnosis is made by qualified professionals and is based upon 3 core criteria:
(i) significant impairment of intellectual functioning;
(ii) significant impairment of social/adaptive functioning; and
(iii) age of onset before adulthood.

The White Paper, Valuing People (DoH, 2001) expresses these criteria in less clinical terms as "a significantly reduced ability to understand new or complex information, to learn new skills with a reduced ability to cope independently and which started before adulthood with a lasting effect on development" (Beadle-Brown et al., in European Intellectual Disability Research Network, 2003). This is essentially the same definition as used in Scotland, Wales and Northern Ireland.

However, although a diagnosis is usually necessary in order to be eligible for services, it is not sufficient due to a scarcity of provision. It is at this stage that the functional assessment becomes important and it is at this stage that the postcode lottery becomes an issue for those requiring services. In England it is possible to be eligible for particular services in one local authority but not in another. In May 2002, the Department of Health responded to this by issuing guidance on eligibility criteria for adult social care under the "Fare Access to Care" initiative. All councils had to use this guidance to review and revise their eligibility criteria in order to ensure fair access to care for all those needing social care services. The guidance (which can be downloaded from (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009653) states the following:

- Councils should make one decision as to whether someone is eligible for help or not following an assessment of an individual's "presenting needs". They should not have different eligibility criteria for different assessments or different services – but the assessment should be comprehensive enough to encompass all the person's needs. Services should then be matched to eligible needs which may need to be prioritised.
- Reviews and if necessary reassessment should be undertaken to ensure that needs continue to be met.
- The guidance applies to all those with physical, sensory, intellectual disabilities and those with mental health problems.
- The eligibility framework proposed for councils is based on factors that are necessary to maintain an individual's independence over time and makes no reference to age, gender, ethnic group, disability, religion, personal relationships, location or other similar factors. These factors should be taken into account as needs are assessed and services considered but are not in themselves threats to independence and therefore not to be considered when deciding eligibility for services. There are four bands of seriousness:
    - Critical (e.g. life is or will be threatened in some way; significant health problems, little or not choice or control over vital aspects of immediate environment; serious abuse or neglect; vital involvement in work, education, social support systems, social relationships etc cannot or will be undertaken or sustained, etc.)
    - Substantial (e.g. only partial choice and control; abuse or neglect; inability to carry out personal care or domestic routines; involvement in work, activity etc cannot be sustained; etc)
    - Moderate (e..g. there is or will be an inability to carry out several personal care or domestic routines, involvement in some aspects of work, education or learning cannot or will not be sustained etc,)
    - Low (e.g. when there is an inability to carry out one or two personal care or domestic routines, involvement in one or two aspects of work, education etc cannot be sustained, etc.

- Decisions on eligibility remain with councils, however they are encouraged to consult all the major stakeholders involved in each person's situation.

All people with severe to profound intellectual disabilities will fall into the critical band and therefore receive services, even if the local authority is only providing services to those judged to be in the critical band. Those with physical disabilities are likely to be in the substantial category. Those in the moderate and low categories are unlikely to receive services from the majority of councils.

6. Prevalence of disability

Statistics on the number of people with disabilities are not very comprehensive. There are few registers of people with disabilities and figures usually relate just to those who are receiving services or numbers financially supported by local authorities or health authorities. Much of the information that is available with regard to health care is in the form of admissions to services, so for example it is known that in England 5190 people with physical or sensory disabilities (1.7 per 10,000 of the population aged 18-64) were admitted to long term residential or nursing care in the six months up to Sept 2001. However, data on how many are being supported at any one time is not easily available.

With regard to people with sensory disabilities in England, there are registers and Department of Health publications indicate that there were 157,000 people who are blind or visually impaired on the register in 2003. In 2004 there were 55,000 who were deaf or with hearing impairments on the respective register.

Concerning those with mental health problems, there is little information on prevalence. It is known that in 2005-2006 there were 47,400 detentions under the mental health act (1983). The Kings Fund is currently working on a project looking at the numbers of people with mental health problems in England http://www.kingsfund.org.uk/current_projects/review_of_mental_health_funding/index.html).

With regard to those with intellectual disabilities, there is some conflicting information. The Department of Health white paper "Valuing People" (2001) estimated that there were 210,000 people with severe and profound intellectual disabilities in England (with approx 65,000 children, 120,000 adults of working age and 25,000 older people). It was also estimated that there were 1.5 million people with mild to moderate intellectual disabilities. However, in 2004 research work by Lancaster University estimated that there were approximately 985,000 people of which 796,000 were over 20 years old; and in more recent figures published by the Department of Health suggest that there are 55,000-75,000 children with a moderate or severe learning disability in England. As can be seen, different distinctions have been used over the years and so the picture remains unclear – there is no one source of statistical information on intellectual disability in England. However, it is thought that only 20% of people with learning disabilities are known to learning disability services so statistics which use the number of people receiving services, are very much an underestimation.

One of the facts which is relatively clear is that the number of adults with intellectual disabilities is likely to increase and it is predicted that the number aged 15 and over

will increase by 11% between 2001 and 2021. Those over 60 are estimated to increase by 36%. (Institute for Health Research, Lancaster University, 2004 – see (www.learningdisabilities.org.uk/information/learning-disability-statistics for a summary).

In Scotland the main learning disability policy guidance, "*The same as you*?" (Scottish Executive, 2000) estimated that "in Scotland, about 20 people in every 1,000 have mild or moderate learning disabilities and 3 – 4 people in every 1,000 have severe or profound learning disabilities. About 18,000 adults with learning disabilities are currently known to Local Authorities in Scotland". (page 4, *Health Needs Assessment Report – Summary: People with Learning disabilities in Scotland*, 2004 http://www.gla.ac.uk/departments/psychologicalmedicine/UAP%20in%20Learning%20Disabilities/LDSummary.pdf) However, as this report points out, there are no detailed studies specific to Scotland on which to base estimates.

In Northern Ireland (http://www.northernireland.gov.uk/news/news-dfp/news-dfp-july-2007/news-dfp-050707-survey-of-people.htm) the recent survey highlights the extent of some form of disability (including long term illnesses and conditions). 21% of adults (and 6% of children) are thought to have some form of disability affecting activity levels (recent populations estimates of 1.75 million people in Northern Ireland). Of course, the definition used here is very broad (and much broader than the definitions generally used in this study.

The Review of Mental Health and Learning Disability report (2005), entitled *Equal Lives,* stated that over 16,366 people with a learning disability are known to services. Of these it is estimated that 4,468 people have a severe to profound disability. Almost half of the total number known are children and young people aged up to 19 years (http://www.rmhldni.gov.uk/index/published-reports/learning-disability-report.htm).

Overall within the UK, it is estimated that approximately 2% of the population has an intellectual disability. But similar figures are not available for those with mental health problems or those with physical disabilities.

7. Residential Services for people with a disability

7.1 Overview

The pattern of service provision in the UK has changed dramatically since 1970 as provision moved from mainly institutional provision to largely community care and independent living solutions. The shift occurred more quickly in England and Wales than in Scotland and Northern Ireland.

The majority of provision is in small group homes in the community, although there still exist some larger services (mainly private and voluntary sector). Supported living and the use of personal assistants is becoming more and more common in the UK and most people with physical disabilities are now supported to live in their own home. More and more older people are also supported to stay at home for longer, so that it is only the most severely disabled or ill or those with no family to advocate for them, who end up in residential care. People with less severe mental health problems are also generally provided for within their own homes, although again those with more

severe problems and those who are considered dangerous to themselves or others are still hospitalised in general.

With regard to people with intellectual disabilities the Foundation for People with Learning Disabilities (www.learningdisabilities.org.uk/information/learning-disability-statistics) suggest that approximately 60% of adults with a learning disability live with their families. According to Department of health publications (Valuing People – what do the numbers tell us, 2005), 39,500 people in England with intellectual disabilities live in care homes and hospitals, which is about one third of those known to learning disability services. Approximately 11,000 of these are thought to live "out-of-area" – i.e. away from their home area. In addition 34,000 people with learning disabilities are reported to be receiving help from support workers paid for by the Supporting People programme (designed to help people live in their own homes) and are living in hostels or shared housing owned or rented by themselves or housing agencies, not by the organisations providing the support.

With regard to direct payments, the state of Social Care report (CSCI, 2006, http://www.csci.org.uk/pdf/state_of_social_care_05-06_1.pdf) notes than in England there has been a substantial increase in the number of people receiving direct payments, with expenditure on direct payments almost doubling between 2004 and 2006. At 31 March 2005, the report notes that there were 22,000 people in England using a direct payment, which was a 57% increase from the year before. By 31 March 2006 this had risen to 32,000. The majority of people using direct payments are younger adults with physical and sensory disabilities. There has been a three-fold increase in direct payments to young people and their carers and although there was an increase in the number of older people receiving direct payments, the number of older people receiving direct payments remains very small. Despite the overall increase in number of people receiving direct payments, the total expenditure on direct payments amounted to only £1 in every £100 spent, implying that the majority of funds is still spent on residential care and perhaps that only those with lower levels of need are receiving direct payments. The postcode lottery within England also comes into effect here, with more than half of all local authorities in England providing 10 or less direct payments at the end of March 2005.

In Scotland current statistics for 2007 identify 2291 people receiving a direct payment - over ½ of these are people with physical disability and about ¼ people with and intellectual disability (http://www.scotland.gov.uk/Publications/2007/09/24155213/0). There were 570 people in Wales using direct payments in 2004.

The sections below will review the types of residential services available for children and adults with disabilities, along with information about the size and frequency of such places where available. Services across the four regions are very similar, however, were differences arise, these will be highlighted.

7.2 Services for children with a disability

With regard to children's services, the State of Social Care report outlines that council expenditure in England has increased overall in recent years with the biggest increase in the areas of adoption and family support services and the smallest increase in residential care. Between 2003-2004 and 2004-2005, there was a slight decrease in the number of children in residential children's homes and hostels from 6800 to 6,700,

down from 6,800 in 2003-04. Over the same period, the proportion of looked after children cared for in residential settings, including secure units, homes, hostels and residential schools, remained at 13%.

Between March 2005 and March 2006, the number of children's homes in England has risen by 40 to 2,025 homes, providing 11,649 places, representing an increase of 289 places. However the majority of these homes (53%) were for children with emotional or behavioural problems, with 29% of homes registered for children with intellectual disabilities and 12% for children with physical disabilities. In general children with disabilities are supported to live with their families were possible and carers are now eligible for much more support than previously through a carers assessment. Young people can now receive direct payments, which can be paid to family carers. Residential care is in general only used for children with disabilities who have been abandoned by their parents or who have been taken into care for their own protection. Where possible children are placed with foster families but some children do spend large portions of their childhood in a children's care home. These homes are usually quite small in nature – usually about 6 places – and tend to serve children between 10 and 15 although they do take younger children.

In addition, those with complex needs such as autism, challenging behaviour or very profound intellectual or physical disabilities sometimes access residential schools of varying intensity. However, only approximately 1000 children attend 52 week schools in England and Wales – the majority of children attend schools where they go home for the holidays and in some cases for the weekends too. 9176 children attend some form of boarding school, approximately 6000 of these are in maintained and non-maintained schools (i.e. supported by local authorities in some way), the remainder in schools run by the independent sector. Of the 6000 children attending residential schools, over 2000 of these have emotional and behavioural disorders and approx 1700 have a physical disability. 985 have an intellectual disability and 522 have autism (Department for Education and Skills/Department of Health, 2004).

In addition, in England, there are 835 children in NHS provided accommodation – these are almost entirely children with physical and sensory disabilities, with only 26 places for children with intellectual disabilities and 17 for children with mental health problems (www.performance.doh.gov.uk/hospitalactivty/).

7.3 Services for adults with a disability

As highlighted above, the majority of adults who receive support from local authorities, do so in residential care, although there has been a decrease in recent years, with the total figures of people supported in England standing at 267,240 in 2004-2005. In terms of the balance of expenditure across groups, local authorities spent 58% of their budgets on older people, 9% on people with physical or sensory disabilities, 24% on people with intellectual disabilities and 7% on people with mental health problems (http://www.csci.org.uk/pdf/state_of_social_care_05-06_1.pdf). However, in terms of the proportion of people supported in residential care the proportions are similar to the expenditure, with 77% of the people supported being over 65, 13% people with intellectual disabilities, 5% people with mental health problems and 4% people with physical or sensory disabilities.

At the end of March 2006, there were 18,718 registered residential care homes for adults in England, providing 441,335 places. Although the number of registered places has risen by 449, there are now 315 fewer homes than at the end of March 2005. This change represents both the decline in the number of residential services registered with CSCI but the gradual increase in the size of homes (http://www.csci.org.uk/pdf/state_of_social_care_05-06_1.pdf). The most recent figures (March 2006) put the average size of home registered for people over the age of 65 at 34 places, with the average size of residential care home for younger adults ranging from nine places for homes for people with learning disabilities to 45 places for homes for people who are terminally ill. The majority of services are run by the independent sector. Statistics on Wales, Scotland and Northern Ireland are outlined in section 7.4 below.

In general across the UK, the same types of services exist for younger and older adults – as the template data summarised at the beginning of this report illustrates, there are small group homes, residential care homes and nursing homes for people of all ages. However, in general small group homes are more widely available for younger people. Where they are available for older people they tend to be for people with intellectual disabilities. Residential colleges also tend to be for younger adults with intellectual disabilities and usually those aged between 16 and 25, although a few colleges have places for slightly older adults. These colleges vary in design, with some being organised within one large college building and others more in a campus setting where each of the small homes in which people live are dispersed in the area around the college building and are registered separately as care homes but with the educational element integral to the package.

The same is true for village communities. These services usually take the form of a number of smaller homes within the same setting, with day activities (education (school and college), leisure and other day activities such as craft workshops, gardening workshops) also provided on site. In general each of the houses in the community are registered separately. In some of the village communities, there is one bigger house and then several satellite homes. Many of these communities in the UK are based on a particular religious basis but do take people from all backgrounds. They vary in size but are usually between 11 to 30 places on one site (Emerson et al, 1999). In general village communities are provided only for people with intellectual disabilities. In some of these communities (e.g. L'arche) staffing is provided through a number of core permanent staff plus volunteers from overseas who live in the homes with the users of the service but usually only for between 6 months and 2 years.

Therefore in general, statistics don't separate out village communities, residential colleges, small group homes, residential care homes or nursing homes – homes are registered with CSCI in England (and CSSIW in Wales) under just two categories – care home or care home with nursing. These two categories are used for homes registered for younger adults as well as for homes for older adults. A small number of homes in England are dual registered for younger and older people (providing just over 2000 places).

By far the greatest number of places in residential care is for those who are over 65 (mostly people without a pre-existing disability). At the end of March 2006 in England, there are 11,085 residential care homes registered with CSCI providing

57,587 places for people with learning disabilities, 97,580 places for people with physical and sensory disabilities and 39,210 places for those with mental health problems. In contrast, there were 12,215 care homes registered for older people, providing 169,919 places for those over 65.

In addition to social care services, there are several types of NHS provided and funded services:

1. Learning disability hospitals, in their old form, have all but disappeared now in England and Wales, and are reducing in Scotland and Northern Ireland. These were old style hospitals and which have impoverished environments and generally poor standards of care. However, there also are some newer NHS provided hospitals which replaced these in the early days and although smaller they suffer from many of the limitations of the larger settings. Within England there are targets to close these newer settings by 2010. Many for these newer NHS settings take the form of residential campuses in which there are currently approximately 1600 people.
2. NHS campuses are newly built residential campuses that have been developed to provide support and services on a centralised campus site, typically supporting people with more severe disabilities. Usually up to 100 persons are housed in living units for 8-10 people. Currently at least 1600 people who have a learning disability live in NHS campuses. Many campuses are in the South East, but most regions in England have people living in campuses.

Strategic Health Authority	**Campus-Number of people**
South West	317
South Central	123
South East Coastal	101
London	250
Eastern	254
East Midlands	260
West Midlands	195
Yorkshire and Humber	37
North East	66
North West	6
Totals	1609

3. NHS Psychiatric hospitals and wards. Little collated information is available about the size or characteristics of psychiatric hospitals. However, in general these are quite big. In addition to psychiatric hospitals, there are mental health services in the community provided by the NHS, although these are relatively rare. There are also NHS provided assessment and treatment units which although intended for short-term care, often provided longer term accommodation and support for those with challenging behaviour.
4. Private hospitals and assessment and treatment units. Although these services are intended for those with mental health needs, substantial numbers of people with intellectual disabilities and challenging behaviour are treated in these settings. These services tend to be bigger than community based services.
5. Secure units/forensic hospitals/special prisons. People who are considered dangerous or who are offenders are usually placed in these types of locked

settings, which are provided both by the state and by independent sector providers. They vary from smaller locked units in the community to larger units and prisons. In Scotland there remains one larger forensic hospital providing for over 150 people.

7.4 Regional variation in arrangements/service types

7.4.1 Wales

As for England, information is more readily available on intellectual disabilities than other groups. There are just over 12,000 people an intellectual disability in Wales, but the numbers of those who are described as resident in hospital is now only 170, and 65% of these stayed in hospital in excess of 2 years. (http://new.wales.gov.uk/topics/statistics/headlines/health-2007/hdw200701316/?lang=en). As in England, the types of residential accommodation have varied over time and across localities. The moves to community-based housing for people with more severe and complex disabilities (initially in units of 20-24 persons) has given way to services in smaller scale , more domestic units, and, in a parallel development, to those in other kinds of settings such as village communities (operated by charitable organisations), residential campus-style accommodation (operated by NHS), dispersed housing schemes (24 hour support in domestic-style housing) and supported living schemes. The latter only forms about 2% of overall provision, smaller homes with 2-6 people are usually newer homes (and new builds) and this form of provision is the largest single type (Welsh Assembly Government, 2003).

CSSIW regulates care homes, domiciliary services, adult placements and nurses agencies in Wales. They predict that in the next 15 years the numbers of people aged 65 and over will be 28% of the population of Wales, and those over 85 will total 82,000. Some psychiatric hospitals in Wales deal with both mental health problems and learning disabilities and statistical returns include data on both areas. Of people with long-term illness, 1 in 4 report mental health problems. Levels are higher in women than men and there are regional variations. The highest hospital admission rates are for over 75s. In 2000/2001 2, 185 of those over 75 in hospital were described as “resident” patients.

7.4.2 Scotland

Again, as for England and Wales information on learning disabilities is the most prevalent. Statistics on mental health are usually included in general statistics about Britain (http://www.mentalhealth.org.uk/information/mental-health-overview/statistics/).

However, it is known that Scotland has 830,000 people with a physical disability, of which 96,000 are wheelchair users registered with the NHS. (http://www.momentumscotland.org/web/News%20Centre/Factsheets/Physical%20Disability).

With regard to intellectual disabilities, there are approximately 120,000 people with intellectual disabilities in Scotland, 25% of whom were under 15 years of age and 25% of whom were described as having complex needs (NHSQIS, 2006-

http://www.nhsqis.org.uk/nhsqis/files/NHSQIS%20Learning%20Disability%20Nat%20Overview%20((Feb%202006).pdf .

As reported earlier, over 18000 adults with learning disabilities are known to local authorities in Scotland although this includes those who attended day services. 23% of adults known to local authorities were thought to be living independently (http://www.scotland.gov.uk/Publications/2004/02/18919/33275). About 60% of those known to services were men (10,002) and this was true for younger age groups but not for those over 65, where the gender split was almost 50:50 (n=1777).

As noted above, progress with hospital closures and development of community services was slower in Scotland than in England or Wales. By 1999 only one long-stay hospital had implemented a closure plan (Whoriskey, 2003). *The Same as You?* review (2000) highlighted that 37% of expenditure goes on hospitals for people with intellectual disabilities (compared to 15% in England). As might be expected, the contrast is that only 58% of health spending goes through local authority community care services, compared to for example 74% in Wales.

Since 2004, the NHS Quality Improvement Scotland (NHSQIS) and The Scottish Commission for the Regulation of Care (http://www.carecommission.com/) have worked together in monitoring services provided by private sector organisations and contracted by the NHS. The NHSQIS review found that by the end of 2005, 11 of the 19 long-stay hospitals for people with LD in Scotland were closed down and their services re-provided in the community leaving 165 long-stay residents and 106 people on longer term assessment and treatment places in the remaining 8 NHS hospitals that were planned to close by the end of 2007 (although there remain some long-stay residents, predominantly those with forensic needs, people with autistic spectrum disorders, those with severe challenging behaviour or complex physical needs, in NHS assessment units). The remaining hospitals have been described as "in need of refurbishment", although most of the people remaining in hospital have single-bedded rooms. (Stalker & Hunter, 1999; Hunter & Stalker, 2003; NHSQIS (Scotland), 2006).

In Scotland, care homes are identified as being primarily intended for one client/user group, but it is possible that residents in any one home could come from other client groups. Private nursing homes are registered under the terms of the Private Nursing Home Registration (Scotland), 1938 or the Mental Health Act 1960/1984. Information on nursing homes is supplied on a census date once a year to ISD (Scotland) (Scottish Executive, 2004).

7.4.3 Northern Ireland

Community Statistics for Northern Ireland for 2006-2007, provide detailed information on the numbers of people in receipt of packages of care, the nature of those packages and the number of residential services for different groups (http://www.dhsspsni.gov.uk/community_statistics_06-07.pdf). The table below summarises the information provided in the report.

In terms of people with an intellectual disability there is additional information through research. An estimated 440-470 live in long-stay hospitals (of which there are 4), 1,900 in residential care and nursing homes and 14,000 in community setting (McConkey, 2003). In NI the proportion of people with ID living with their families is 61.9% (as compared to 44.1% in the Republic) and the number living in residential care is correspondingly significantly lower in NI compared to their counterparts in the Republic (McConkey, 2007).

In Northern Ireland the pattern of care followed the British model of creating state-managed, long-stay "specialist" hospitals for people with "mental handicap" as the main alternative to family care. Many of these hospitals were opened from the 1950s onwards, in 1962 there were over 1800 persons resident in Northern Ireland (Scally & Mackay, quoted in McConkey, 2007). By the 1980s de-institutionalisation became an accepted policy and in recent years large numbers have been resettled but a sizable number (many under 65) remain. In Northern Ireland, 61% of people on the database were in "special settings", 20% in ordinary housing and 19% in hospital settings (McConkey, 2007).

In NI the main model of special provision is based on registered nursing homes or registered care homes. The private and voluntary sector provide 65% of available places in residential accommodation (In 2007 private accounted for 60%, not-for-profit, 20%, statutory 12% and Housing Associations 8%). These homes have an average of 19 residents and are located mostly in community settings. There are also a number of "village communities" set in rural areas and managed by a voluntary agency. In NI increasing numbers of people reside in supported living arrangements in which they hold the tenancy to a house or apartment which they might share with one or two others. Some of these units are clustered in one area to facilitate staffing arrangements. State-managed hospital accommodation generally consists of dormitory-style wards accommodating up to 20 people with nurses and nursing assistants as the principal carers (Mooney et al., 2004; Mulvaney et al., 2007). There are variations in provision of services between NI and the Republic which can only be explained on the history of services, the philosophy and preferences of providers and the availability of funding arrangements rather than on any determination based on the needs of the recipient (McConkey et al., 2006).

	Total known to services	Number receiving home help or meals	Number benefiting from care management	Number supported at home	Number supported in nursing homes/residential homes	Number of residential and nursing homes and places.
Older people	40,852	19599 home help 6058 meals	15194	5610	6444 in nursing homes (almost all private) 3141 in residential homes (mixed statuary and private with a small number of places in voluntary providers)	189 homes for elderly people with 3945 places
People with mental health problems	14990	403 home help 189 meals	1273	477	337 in nursing care (all private providers) 459 in residential care (mixed private and voluntary)	47 residential homes solely for MH, providing 602 places
People with physical or sensory disabilities	2110/3274 blind/partially sighted 443/452/5775 deaf with/without speech/hard of hearing 7651, general physical disabilities	1889 home help 263 meals	1543	1132	323 in nursing care (almost all private) 88 in residential care (mixed pattern of provision but 50% private).	4 residential homes solely for people with PSD, with 64 places.

	Total known to services	Number receiving home help or meals	Number benefiting from care management	Number supported at home	Number supported in nursing homes/residential homes	Number of residential and nursing homes and places.
People with intellectual disabilities	9459	755 home help 74 meals	2555	1071	835 in residential care (mixed pattern of provision) 649 in nursing homes (almost all private)	75 homes solely for ID, with 1005 places
Total	51,306	23,913 home help (18,769 of these people were not disabled – mainly older people, 1267 of these were under 65) 6670 meals (5128 not material disability, 88 were under 65)	20723	8429	4526 in residential care 7768 in nursing care	329 residential homes homes, 5558 places 252 nursing homes, 9571 places

8. Other relevant information on services for people with disabilities

There is substantial research originating in the UK on the quality of services, especially for people with intellectual disabilities, comparing different services models and documenting the quality of people's lives living in services. In general smaller homes in the community have generally better outcomes than larger group homes which have generally better outcomes than institutions (Emerson and Hatton 1994). Newer paradigms such as supported living have also been found to have positive outcomes for people although there are also some risks which have to be managed (Emerson, Robertson et al. 1999). However, previous research has shown that outcome in terms of the quality of people's day to day lives is variable within settings and therefore more recent research has focused on what is important in ensuring a good outcome for those living in services. This work has concluding that once resident ability has been taken into account, the most important factor is staff care practices – i.e. how staff interact and support people minute by minute (Hatton, Emerson et al. 1996; Felce, Lowe et al. 2000; Felce, Jones et al. 2003; Mansell, Beadle-Brown et al. 2003).

Other important factor in provision within the UK, has been a recent emphasis on person-centred approaches, in particular person-centred planning and person-centred action such as active support (Department of Health 2001; Robertson et al, 2005; Mansell, Beadle-Brown et al. 2005). Whilst this work originated with a focus on intellectual disability, the general approaches are felt to be applicable to people with physical and sensory disabilities and mental health problems. However, in contrast to people with intellectual disabilities, there is much less research or guidance available on good practice for services providing support for people with PSD or mental health problems.

9. Staffing

Data for staffing of residential care in the UK is limited and provides little information about conditions at unit level. There is limited published information on overall numbers of staff, with some indications of the percentages of trained versus untrained staff, but this is not broken down at unit level. There are also figures for the total numbers of different professional groups, but no indication of the numbers of each grouping at individual locations. Council-run accommodation retains some records particularly whose homes that provide for children (Local Authority Workforce Intelligence Group, Social Care Workforce Study, 2006, No. 36; Adult, Children and Young People Local Authority Social Care, 2006), but otherwise only global figures of numbers of staff employed are available.

In terms of staff training, the majority of social care staff are untrained when they first start to work in services. In 2000 it was identified that 75% of staff in social care services have no formal education (Topss England, 2000). In the past 15 years, National Vocational Qualifications in Care have been introduced and services are now expected to support all staff to go through these qualifications. However, these qualifications are rather general in nature and there remain a large number of staff who are unqualified. Even within the NHS based services, whilst there will, by necessity, be more nurses in senior and team leader positions, there are still large numbers of unqualified staff employed. The Sector Skills Council: Skills for Care and

Development set the agenda and issue guidance for training and support of staff in care positions (http://www.topssengland.net/view.asp?id=36).

Recruitment of staff is a problematic issue in many social care services in many parts of the UK, especially where unemployment rates are low – social care jobs are not paid particularly well, there are few opportunities for advancement and opportunities for personal development are also often limited by budgetary considerations. Attracting people of high calibre, with good qualifications can be difficult. Many services especially those in London and the South East of England, employ staff other parts of the world. This can lead to difficulties with communication and also cultural adaptation.

10. Costs

The UK is fortunate in having relatively good literature on cost issues related to community and social care costs going back over 25 years, particularly with regard to mental health re-provision and the hospital closure programme dating back to the 1980s (more detailed information on costs and outcomes within England in particular is provided in the main report). As illustrated above information on expenditure in social care in particular is readily available in reports and statistically summaries such as the "State of Social Care" reports. In addition there is a long tradition of research in this area, including the mapping and evaluation of care management arrangements for people with mental health problems in England (Venables et al., 2006); costs, quality and outcomes (Hallam et al., 2002; Netten et al., 2005, 2006); the financing of care for older people (Wittenberg et al., 2006); mental health economics and policy (Moscone, 2005); and valuing social service outcomes (Burge et al., 2006).

11. Issues

11.1 Regional variation

Variations between the 4 constituent countries of the UK has already been illustrated above. However, as also issued there can be variation in the nature, amount and quality of services available between local authorities or health authorities within each of the countries – this is often referred to as the "postcode lottery", implying that what services are available to you can depend on where you live.

11.2 Issues related to ethnicity

Within mental health services in particular, there are substantial numbers of people from black and minority ethnic (BME) backgrounds. Department of Health publications put the ratio of BME users of mental health services at 1 in 5, which is substantially more than one would expect from the general population. The department of health has published guidelines on working with people from BME backgrounds in order to combat inequalities in service provision. (http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Mentalhealth/BMEmentalhealth/index.htm).

There are also similar issues for people with intellectual disabilities – work by Mencap, for example, has highlighted that people from BME backgrounds with an intellectual disability experience double discrimination due to language and cultural differences (http://www.mencap.org.uk/html/ethnicity/reaching_out_report.asp).

Research by Emerson et al (1997) illustrated that prevalence of severe intellectual disabilities was three times higher in Asian families than non-Asian families (See http://www.library.nhs.uk/learningdisabilities/ViewResource.aspx?resID=34865).

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