Too far to go? People with learning disabilities placed out-of-area

Julie Beadle-Brown, Jim Mansell, Beckie Whelton, Aislinn Hutchinson and Clare Skidmore

"The Tizard Centre is one of the leading UK academic groups specialising in learning disability and community care"

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The Centre provides teaching through short courses, certificate, diploma and degree programmes at the University of Kent and elsewhere. It also maintains an extensive programme of research and consultancy, nationally and internationally. In all our work we are committed to acknowledging diversity and addressing issues arising from social inequality. We seek to align ourselves with service users and to reduce the disadvantage and discrimination they experience. We support user empowerment and the development of services that are responsive to user need. We seek to achieve our mission without further disadvantaging carers and service staff whom, we recognise, are often, themselves, relatively powerless and disadvantaged.

The authors
Dr Julie Beadle-Brown is Lecturer in Learning Disability in the Tizard Centre at the University of Kent. Professor Jim Mansell holds a Chair in the Applied Psychology of Learning Disability and is Director of the Centre. Beckie Whelton and Aislinn Hutchinson are Research Assistants in the Centre and Clare Skidmore was formerly part of the Strategic Development Team for Learning Disability in Kent County Council and is now project manager for active living and telecare in Kent.

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Foreword by Sir Sandy Bruce-Lockhart
Leader of Kent County Council

Kent has areas of deprivation that rank amongst the highest in the UK. The deep-seated social challenges facing the county come from the loss of our coal fields, shipbuilding and heavy manufacturing industry combined with the decline of our coastal holiday towns. These social difficulties are exacerbated by many local authorities and primary care trusts in other parts of the country placing people into residential care in Kent. The largest number of people come from London. The two main groups of people placed in Kent are children being looked after by social services and disabled people, particularly people with learning disabilities.

The large number of people placed in Kent poses particular problems for the county, especially in its provision of social services and health care. Much of the cost of these placements falls on local services and therefore on local taxpayers.

Kent County Council took the initiative to address this problem in 2003. Working with primary care trusts and neighbouring local authorities, it led the way in raising the profile of this issue with the Prime Minister and across government. This report is part of the initiative. With the Tizard Centre at the University of Kent, Kent County Council set out to estimate how many people with learning disabilities are placed from out-of-area in Kent, the reasons for their placement and the effects this has on the individuals themselves, their families, the home in which they are placed and the professionals who work with them.

I welcome this report as providing for the first time some hard evidence about the scale and nature of the issue of out-of-area placement for people with learning disabilities. The County Council will use this information in working out with government and with other local authorities and primary care trusts how to resolve the problems that exist now and improve services for everyone who needs them.

Sandy Bruce-Lockhart.

Preface

This report is part of the Placed in Kent project, an initiative led by Kent County Council to improve collaboration between health and social services agencies placing people with learning disabilities in residential care in Kent to ensure services for everyone that are sustainable and of good quality. The project is located in the Strategic Development Team, led by Des Sowerby.

The Placed in Kent project has three streams of activity:

♦ Finding out how many people are placed in Kent, where they are, what their lives are like and what implications this has for health and social services.

♦ Developing local policies and protocols between social services, housing and health in Kent to ensure a consistent approach to out-of-area placement and build a common understanding of the issues it raises.

♦ Inter-regional collaboration and policy development, working with placing authorities to improve co-ordination, service monitoring and resource allocation and influencing government policy to improve guidance and regulation in this area.

This report is part of the first area of work. It consists of a review of current policy carried out by the KCC project manager (Clare Skidmore) with support from the Tizard Centre, a survey and analysis of social services records undertaken by Kent County Council and analysed by the Tizard Centre and an in-depth study of the reasons for and effects of out-of-area placement carried out by the Tizard Centre with funding from Kent County Council.

The next stage of work in this area are the organisation of information management within Kent County Council in order to allow monitoring of out-of-area placements on an ongoing basis.

Work on the second and third streams will continue this year. A joint project has been agreed with Thanet District Council and a national conference is planned to link up with other authorities and trusts working on this issue with a view to comparing information, sharing good practice and influencing government guidelines and policy.

Summary

Official guidance
♦ The review of official guidance shows a complex administrative framework, in which there are several 'grey' areas where responsibility is unclear, and where there are distinct perverse incentives for placing authorities.

Number of people placed in Kent
♦ At a minimum, between 1,000 and 1,400 people are placed by other authorities in Kent and this number may be as large as 2000 people. Half the placements are in the eastern of the three administrative areas of Kent, with relatively large concentrations in the coastal towns.

Reasons for placement
♦ Residents placed out-of-area are on average less socially impaired, have more language ability and are more challenging; there are also more people from black and ethnic minority groups (which may reflect the number of people placed by London authorities).
♦ A key reason for out-of-area placement is insufficient local services, either because they are not of acceptable quality, or because they are unable to support people with greater needs (for example, because of challenging behaviour).
♦ Some people have been placed out-of-area because locality was perhaps not thought to be important, typically for those people who were in long-stay institutions who may have lost contact with their family.
♦ There appear to be financial or quality incentives for services to accept referrals from authorities other than Kent.

Effects on residents
♦ The effects of out-of-area placement vary across individuals. Generally the most disabled people experience the worst outcomes. Overall, some aspects were worse than comparison studies (choice, community involvement, number of homes meeting all the national minimum standards), some were the same (participation, family visiting and other contact) and one was better (visits to families). Variation was also evident in the involvement of social services staff from the placing authority and in ease of access to local health care resources.
♦ There is some evidence that there are two different groups within the sample of people placed out-of-area, one doing rather better than the other, and that longer length of stay and more severe social impairment might be relevant explanatory factors (but not, for example, cost).
♦ Some individuals experience very poor outcomes and some homes are achieving well below acceptable standards of care. If the third of placements in this category found in the interview study is representative of the whole population then between 300 and 700 people might be in this situation.

Families
- Families could be interviewed for half the sample. A third said they felt they had no say in the choice of placement. Some families felt they had to fight hard to find and fund the right placement for their relative.
- The distance involved and transport problems do cause some families problems in visiting their relative and taking part in review meetings.
- Some families are very anxious about criticising their relatives' care, especially for fear that the resident may be asked to leave.
- Almost all families said that they thought their relative was happy in the placement. However, some families identified concerns about basic levels of care in the placement.

Managers and specialists
- Almost half the home managers report problems contacting care managers from placing authorities. All care managers identified distance as a disadvantage for them (in terms of providing care management and monitoring).
- Nearly half the care managers said they would not normally inform Kent of the placement being made. Members of community learning disability teams said that they were not usually informed in advance of people placed in their area and referrals to them for help were typically made when people were in crisis.
- Most managers report positive changes for residents after moving to the home; negative effects were focused on the home not being able to meet the person's needs. All care managers from placing authorities saw advantages for the person in their current placement; the most common advantage being that the placement met specialised individual needs better.
- Care managers identified distance as a disadvantage for the resident (mostly in terms of being further from family and friends).
- Although they recognised some variation, members of community learning disability teams felt that the quality of services providing out-of-area placements was generally poor, with poorer monitoring of the care provided than would happen if care managers were locally based.
- Kent community learning disability teams reported that the effects on them of out-of-area placements were increased workload, less resource for local people, more difficulties in coordination and liaison with care managers and lack of information about people moved in to their area.

Implications for public agencies
- Steps need to be taken to remove the perverse incentives that encourage out-of-area placement irrespective of individual need. These should strengthen people's entitlement to get the services they need locally and ensure that resources are transferred with them if they do move to another area so that they get the services they need there.
- Social services and health authorities should develop services locally that can support the full range of individual needs, so that people are not driven to seek out-of-area placements. Only if local services develop the competence to support people near their homes, families and communities can people exercise real choice about where to live.

Introduction

Approximately 44,000 people with learning disabilities live in residential care in England, mostly in relatively small residential homes of, on average, 5-6 people (Department of Health, 2004b; National Care Standards Commission, 2004). The need for accommodation with support is growing, because of demographic changes (more people, better survival, longer life expectancy) and there is a growing shortage of places (Emerson and Hatton, 2004). In addition, the distribution of places varies widely between different parts of the country, so that places are particularly scarce in some areas (Emerson and Hatton, 1998).

If suitable services are not available locally, people with learning disabilities may end up in residential homes outside their own local area, sometimes a long way away. Moving away from their own community is likely to make it more difficult for people to keep in touch with family and friends. This was an important criticism of the long-stay hospitals before they were largely replaced by residential homes (Morris, 1969). Generally, contact with family and friends has increased for people moved out of institutions (Emerson and Hatton, 1994). If some people are now not able to find the accommodation and support they need in their local area, this runs counter to the Government policy objective of greater social inclusion for people with learning disabilities (Department of Health, 2001a).

Out-of-area placement may not just reflect a general local shortage of residential care but a shortage of particular kinds of accommodation and support. Among the people for whom this is most likely to be an issue are those who present challenging behaviour. The shortage of good local services to support people in spite of their challenging behaviour has been recognised for some time and concern has been expressed about the quality of alternatives (Department of Health, 1993b).

In general, where residents have moved to a home from another part of the country, they remain the responsibility of the 'sending' social services for funding and care management. They get health services they need from those in their new home's area. The possibility therefore exists for difficulties in communication and co-ordination. A graphic example of this was the Longcare scandal, where failure of care managers to keep in touch with people placed in a residential home contributed to extensive abuse and neglect (Buckinghamshire County Council, 1998; Pring, 2003).

Out-of-area placement is therefore potentially an important policy issue. However, there are no national statistics on the number of people with learning disabilities placed in residential care out of their local area and no evaluative data on the quality of these placements. This study was conceived as part of the Placed in Kent project in order to provide some information on the issue of out-of-area placements. It had three components:

♦ A review of the policy framework for health and social services concerning out-of-area placements, the service context in which these placements occur and the implications for service users, service providers and commissioners.

♦ A survey of care homes and analysis of social services records in Kent to estimate the number of people placed from other areas in Kent.

♦ An in-depth investigation of a number of cases identified in the survey in order to find out what were the reasons for and effects of out-of-area placement on the individuals, their families, the homes and the professionals serving them.

The following sections address each of these issues in turn.

In order to be clear, throughout this report the authority arranging the placement of an individual in a residential home in another area is called the 'placing' authority; the authority to which the person moves is called the 'receiving' authority.

Policy framework, service context and implications

Policy framework

The national policy context relating to this issue is a complex area which is based on inconsistent, even contradictory, assumptions. The two key pieces of Government guidance which impact on inter-authority placement practice are, first, the Department of Health local authority circular on 'ordinary residence' (Department of Health, 1993a) and second, the health guidance for primary care trusts on 'establishing the responsible commissioner' (Department of Health, 2003).

The local authority circular refers back to the National Assistance Act 1948 (Great Britain, 1948), where, under sections 21 and 29:

> 'each local authority has a power, and as far as directed by the Secretary of State a duty, to provide residential accommodation and certain other welfare services for people who are 'ordinarily resident' in the authority's area.'

There is no definition of 'ordinarily resident' in the Act, so 'the term should be given its ordinary and natural meaning subject to any interpretation by the courts' (Department of Health, 1993a , para 2) Under section 24 of the Act,

> 'where a person is provided with residential accommodation he shall be deemed to be ordinarily resident in the area in which he was ordinarily resident before the residential accommodation was provided to him'.

What this means, as the guidance explains, is that

> 'where, following an assessment, a local authority arranges a placement in a private or voluntary home in another authority's area or in a home provided by another local authority, the placing authority will normally retain for that person the same responsibility that it has for someone living in its own area.'

So adults with learning disabilities placed in one local authority area from other areas do not become 'ordinarily resident' for social care purposes. Instead, they remain the financial and social care responsibility of the 'placing' care management services. This is different to the situation of people who arrange their own residential care in another area without the involvement of the local authority social services, where responsibility for social care transfers to the 'receiving' authority immediately (paragraph 10):

> 'when an individual arranges to go into permanent residential or nursing home care in a new area, without any local authority having taken responsibility for the arrangements, they usually become ordinarily resident in the new area. If subsequently social services help is sought the person will look to the authority where the residential accommodation is situated.'

The guidance also includes some clear instructions setting out how placements should be arranged and managed, when they are being made out-of-area. Section 8 says that:

> 'A local authority should not place a person for whom they are financially responsible in accommodation provided by a private proprietor or voluntary

organisation in the area of another authority without informing the other authority. They should also ensure that satisfactory arrangements are made before placement for any necessary support services, such as day care, and for periodic reviews, and that there are clear agreements about the financing for all aspects of the individual's care.'

There is one key exception to the rule whereby the placing authority retains responsibility for the needs of people placed out-of-area. That is when an adult protection alert is raised. As in child protection, the host authority is responsible for the initial investigation of all adult protection alerts, and for co-ordinating liaison with other agencies, such as local police and health services, as well as with the placing authority.

The other major piece of guidance which directs agency and financial responsibilities as regards people placed in residential care from out-of-area, is guidance for primary care trusts (PCT) on 'establishing the responsible commissioner', published in October 2003 (Department of Health, 2003). The key feature of this guidance, from the point of view of out-of-area placements, is that the responsible PCT for commissioning health services for any individual is the one associated with the general medical practitioner with whom the patient is registered. This is the case even where people are placed in a residential home in another authority area by their 'sending' social services department. Paragraph 69 states:

> 'Where a person is permanently resident in a care home and the placement is not fully funded by a PCT, the PCT responsible for providing health care, including nursing care, is determined in the usual way based on the GP or the GP partnership with whom the patient is registered. If the patient is not registered with a GP, the responsible PCT is determined by the person's usual residence.'

This is the case as soon as the person moves; there is no delay in the transfer of responsibility.

The guidance is different for people requiring continuing health care. It states (paragraph 67),

> 'The Department of Health intends to introduce new legislation concerning the transfer by PCTs of patients who require continuing NHS healthcare to care homes in the area of another PCT. When in force, these changes will mean that in future the 'placing' PCT will remain responsible for providing the care home placement and most secondary care services for such persons, even if the person changes their GP (and associated PCT).'

A draft of the new regulations has been issued (Department of Health, 2005).

Where people move to health-funded placements out-of-area, their access to social services in the 'receiving' authority is unclear. Guidance in the 'ordinary residence' circular (paragraph 11) was that specific agreements should be reached so that social services were clear about their responsibilities:

> 'Health authorities might negotiate with local authorities to provide finance in respect of people moving from long-stay hospitals…Funding may be provided to a particular local authority for a number of individuals regardless of their original

'ordinary residence'. In entering into such agreements local authorities must be clear about the responsibilities they entail. Such agreements should always be recorded in writing to avoid disputes…'

These two pieces of government guidance are the most important in relation to placement in residential homes out-of-area. Another source of guidance which interacts in important ways with the principle of 'ordinary residence' and of responsible statutory agencies, is that relating to housing legislation and policy. Under the Housing Act 1996 (Great Britain, 1996), section 193, a local housing authority must provide accommodation for two years to those with a local connection, who are in 'priority need', and who are not homeless intentionally. Importantly, once a person has signed a social housing tenancy in another local authority area from where they originated, they sever their claim to a 'local connection' in their 'home' area or anywhere else, and so have no rights to social housing there any longer – even if all their family and social networks remain in the area that they came from.

The effect of this is compounded by paragraph 7 of the ordinary residence circular, that if a person, once placed in a residential home in another local authority area, then decides to move on from that home of their own accord, either into another residential home or into more independent living, they would be likely to be deemed to have decided to locate themselves as a permanent resident in that geographical area and would thus become 'ordinarily resident' there, should they ever require social services support in the future.

These two statements of law and policy have implications for people moving from residential care into their own accommodation with support, under the 'Supporting People' scheme (Department of the Environment Transport and the Regions, 1998). Since the introduction of the scheme, a large number (2,700 by October 2003) of formerly registered care homes have been converted to accommodation with support funded by 'Supporting People' grants (National Care Standards Commission, 2004). The significance of this is that Supporting People services cannot be provided under section 21 of the National Assistance Act 1948, since taking up a Supporting People service involves signing a tenancy. In accordance with housing law and ordinary residence protocols, in doing so, service users who were originally placed in the homes from out-of-area when they were still registered care facilities, thus sever their connections and rights in their 'home' authority area. Should they require Section 21 assistance again, they would be deemed to be 'ordinarily resident' in the area in which they have signed the tenancy.

These three sources of official guidance – the ordinary residence circular, the responsible commissioner guidance and the 1996 Housing Act – all have to be taken into account in defining responsibility for the health and social care of someone who moves out-of-area. The different possibilities are summarised in Table 1.

Table 1 Responsibilities of 'placing' and 'receiving' authorities for health
and social care

| | | Responsibility | |
		Social care	Health care
Person makes own arrangements and moves to home in new area	Stays in new home and needs care	Receiving	Receiving
	Moves to new residential home in 'receiving' area		
	Moves to 'Supporting People' placement but needs care		
Person placed by social services and moves to home in new area	Stays in new home and needs care	Placing	Receiving
	Moves to new residential home in 'receiving' area	Placing	
	Moves to 'Supporting People' placement but needs care	Receiving	
Person placed by primary care trust and moves to home in new area	Stays in new home and needs care	Depends	Placing
	Moves to new residential home in 'receiving' area	Depends	Depends
	Moves to 'Supporting People' placement but needs care	Receiving	Receiving

The changes proposed to guidance on the responsible commissioner (Department of Health, 2005) would modify this picture slightly. For out-of-area placements made by primary care trusts or jointly by primary care trusts and social services, the placing authority should confirm with the receiving primary care trust whether the person has any health care needs as part of their care package. If they have, the placing authority will continue to pay. If not, the receiving primary care trust will meet the cost of any health care arising after placement.

Service context

Official guidance on the responsibilities of health and social care agencies for people moving to residential care in another area was prompted by two major developments in the organisation and delivery of services since 1980. The first of these was the process of replacing long-stay institutions for people with learning disabilities with services providing staff support in housing in the community (Mansell and Ericsson, 1996). The second was the creation of a 'mixed economy of welfare', by which many social care services came to be provided by private and not-for-profit organisations instead of by Government (Department of Health, 1989; Wistow *et al.*, 1994).

As the long stay 'mental handicap' hospitals began to close from the late 1980s, large numbers of people with learning disabilities were re-located in smaller institutions or residential homes. The number of people with learning disabilities in NHS long-stay hospitals in England has declined from about 46,000 in 1980 (Department of Health and Social Security, 1987) to about 750 in 2003 (Ladyman, 2003). Having, in many cases, lost their links with wherever they came from or were born – many had spend all their adult lives in the hospitals – relocation largely

took place on the basis of where accommodation was available. People setting up new residential facilities often used less expensive property in the rural and coastal areas of the country, rather than in urban areas. Health and social services, faced with the need to get the maximum amount of service from their budgets, have sometimes been able to purchase more places if they move people out-of-area. The effect of this has been that many people in residential care are placed in areas a long way away from their original home, and often a long way away from the institution in which they lived.

In the context of out-of-area placements, this is a significant group, because this influx of vulnerable people, many with complex health needs, concentrated into areas of the country often already deprived, is thought to have had a large impact on the time and resources of local health and social care services.

It is not only 'dowry-funded' residents of the long-stay hospitals who move out-of-area. There are marked variations between geographical areas in the availability of accommodation and care. Emerson and Hatton (1998) analysed 1991 Census data for England and found that the number of residential care places for people with learning disabilities in each of the 14 health regions varied between 77% and 145% of the national average. The types of provision also varied dramatically: non-government care homes accounted for 16% of provision in the northern and north-western regions but 60% in the south east Thames region. More recently, the National Care Standards Commission (2004) reported that in 2003 the number of places in registered care homes for younger adults (ie all service user groups) in each of nine regions varied between 77% and 131% of the national average. This variation means that it is likely that many people with learning disabilities entering adult residential care for the first time continue to be placed in homes in other local authority areas.

Implications for service users, service providers and commissioners
Given the rules set out in official guidance and the context in which services for people with learning disabilities have been developing, it is possible to identify a series of implications for everyone involved in out-of-area placements.

Incentives
First, there are some obvious financial incentives embedded in these arrangements. For social services, if a person they support can be argued successfully to need secondary health care, then the cost of that will be born by the health service rather than the local authority. Thus, for example, if a person's challenging behaviour deteriorates and they need a much more carefully structured environment in which psychological, psychiatric or other health inputs play a guiding role, social services may be able to argue that the person needs to be in a health care placement. This applies whether or not the person is placed out-of-area. The impact on out-of-area placement is that since such placements are scarce there is much more likelihood of them being outside the local authority area. A shift to health-funded placements is likely to mean a shift to out-of-area placement.

The second cost incentive for local authorities is that if a person is placed out-of-area, either in accommodation with support funded by the Supporting People arrangements or in a residential home but then subsequently in such

accommodation, the 'placing' local authority ceases to fund them and their social care becomes the responsibility of the 'receiving' authority. Similarly, if a primary care trust funds this kind of development, the cost of health care will fall on the 'receiving' authority.

Then, there is also a financial incentive to place people out-of-area if the price of care is cheaper, because more people can be served with the same resources. The price of care for out-of-area placement will not necessarily be less than for comparable local placements and may in fact be more expensive – for example, placements for people with learning disabilities and challenging behaviour are often more expensive than the placements from which people move – but in so far as price reflects housing costs then urban authorities can probably save money by placing people in rural or coastal areas. Where capitation payments are higher, as in London, then authorities can either pay more for placements elsewhere or use the extra funds for other local services.

In addition to these financial incentives there are some practical incentives to place people out-of-area. The most important of these is likely to be the shortage of time when decisions are being made to place people. As the programme of closing long-stay hospitals got under way, the time allocated for the closure programme tended to be reduced in order to minimise the transitional ('double-running') costs. Thus for example, one of the earliest hospitals to close (Darenth Park) took nearly ten years (Korman and Glennerster, 1990); one of the last (Royal Earlswood) took three (Kinsey, personal communication). Faced with demands to resettle a large number of residents quickly, a shortage of services, and given the lack of effective local ties for many people who have lived in institutions, it is not surprising that people have been placed in homes away from where they or their family lived.

Similarly, under conditions of shortage of places, when people living in their own home or in a residential home in their home area have a crisis, the probability of them being placed out-of-area will be increased. Probably the most common example of this is out-of-area placement due to the breakdown of existing arrangements due to challenging behaviour. Mansell, Hughes and McGill (1994), for example, describe a case study of an organisation facing repeated placement breakdowns due to challenging behaviour, leading to out-of-area placement, because local services were not sufficiently well-organised to meet the needs of people with long-term problems.

Effects
The potential effects of out-of-area placement on the individual person served could be mixed. On the one hand, they may get the benefit of a service they have chosen, that better meets their needs. If they have moved from another setting, they may be able to stay with people they have known for many years.

On the other hand, the possible disadvantages include the difficulty of maintaining contact with their family and friends, due to the expense and time involved in visiting. It may also be difficult for people placed out-of-area to access other social services. For example, people placed in residential care may not have access to local day care or supported employment facilities. Thus, their opportunities for meeting

other people with learning disabilities in the area where they now live may be reduced. It is less likely that they will have a voice on the local partnership board. Living in a distant residential home especially in an area where they may be lots of residential homes is likely to make it harder to enjoy the independent life envisaged in the 2001 White Paper *Valuing people*. Local links may be harder to build and opportunities for ordinary experiences and jobs may be less available.

Although they should have access to local health services they need, in practice this may be lessened if concentrations of out-of-area placements in particular areas overwhelm the capacity of local health services to cope.

There might also be problems for the providers and commissioners of services. For the placing authority, it will be more expensive and more difficult to provide effective care management. For example if will be more difficult to attend reviews or person-centred planning meetings and more difficult to contribute to improving the person's quality of life because of lack of knowledge of local opportunities.

For the receiving authority, it may be more difficult to plan and fund services, especially where the number of incoming placements imposes more than marginal requirements. Even if the expectation in official guidance of proper notification and co-ordination between placing and receiving authorities is met, the essential unpredictability of this kind of migration is likely to pose problems. This is especially important for the health service, where resource allocation does not yet take account of these migratory flows (Russell and Stanley, 1996). The increased used of pooled budgets, in which health and social services money is put together, actually exposes more of the local resource to being used to deal with people placed from out-of-area. For professionals, the extra work involved in dealing with people from out-of-area who evidently need support may impair their ability to provide an adequate service. There may also be difficulties in sustaining proper joint working with placing authorities.

The research
It is clear from the discussion above that out-of-area placements are potentially a problematic area. The official guidance sets up a series of incentives which could have adverse effects on service users, their families and on the providers and commissioners of services. However, despite this, there are no national statistics on the number of people placed out-of-area. Individual service user information is not collated by the Commission for Social Care Inspection when it inspects residential care homes nor by the Commission for Healthcare Audit and Inspection in relation to health care placements. The financial and case management information that must exist lies within the records of local authority social services and primary care trusts.

There is also no information about the effects of out-of-area placement. The possible advantages and disadvantages outlined above remain hypothetical in the absence of fieldwork to explore the lives of people placed out-of-area.

The following section reports the results of a study to find out how many people are placed by other authorities in Kent.

Placed in Kent: estimating the number of people with learning disabilities placed in residential care in Kent by other authorities

Introduction

The survey of people with learning disabilities placed in Kent arose as a response to a large number of expressions of concern. It was suggested that the needs of this population were causing an intolerable burden that local health teams did not have the capacity to meet. Local agencies and a number of Kent people with learning disabilities were concerned that in many cases people were suffering due to not having their social, health, cultural or other needs properly met. The Valuing People Support Team was concerned that a largely hidden population was not benefiting enough from the new arrangements introduced by the 2001 White Paper *Valuing people*. The first step was therefore to assess the size of the population of people with learning disabilities placed in Kent by authorities elsewhere.

Method

The method adopted to estimate the number of people with learning disabilities placed in Kent was a postal survey supplemented by further investigation in relation to two placing authorities, Essex and Lambeth.

The survey was carried out of all residential care homes in Kent. A list of registered care homes was obtained from the National Care Standards Commission. This included 400 homes, providing capacity for 3484 residents. A letter was sent to each home, under the signature of the Director of Social Services in Kent. This explained the reasons for and objectives of the survey and asked for a list of residents, identifying which were people placed from and funded by local authorities or primary care trusts outside Kent.

For each resident, the information requested included name and date of birth, dates of admission, names and contact details of the responsible care manager, date of the last care manager review and the authority responsible for funding the placement. Information about price of each placement was not requested since this was thought likely to be seen as commercially confidential and likely to prejudice return of the questionnaires.

Incomplete returns were followed up by telephone to ensure as complete a set of responses as possible. Three homes refused to provide information. Two expressed suspicion about the motives for the survey (one quoting recent statements from senior Officers and Members of the Council setting out the Council's aim to reduce the number of vulnerable people being placed in the County, and expressing concern about the detrimental effect that this aim, if successful, would have on their business). The third expressed unwillingness to respond because of concerns about data protection.

In order to estimate the accuracy of this information, a second source was sought in respect of three placing authorities – one county and two London boroughs. These authorities provided lists of the people they recorded as placed in Kent. This information was checked against the results of the survey.

The data were then tabulated in a spreadsheet before being imported into the Statistical Package for the Social Sciences (SPSS Inc, 2004) for analysis.

Results

Of the 400 homes surveyed, responses were received from 325 (81%) in respect of 759 people.

When checked against information supplied by three placing authorities, substantial discrepancies were found (see Table 2). Only 53% of the total number of people identified by either source were found by both, and the survey only identified 76% of the total. Some of the people identified by the placing authorities might have been in homes that did not complete the questionnaire, or home managers might have omitted them from their reply. People identified by homes but not by the placing authorities may have been incorrectly recorded by the home or by the authority.

Table 2: Agreement between survey and placing authorities' data

Authority data (number of people)	Survey data (number of people)		
	Found	Not found	Total
Found	52	24	76
Not found	22	-	22
Total	74	24	98

This suggests that a more accurate estimate of the number of people with learning disabilities placed in Kent by other authorities would be at least 1000 people. If all the people identified from either source were included, this suggests a total number of people placed in Kent of approximately 1400 people. These are likely to underestimate of the true figure of all out-of-area placements in Kent, because the survey excluded NHS and private health care facilities. It also excluded people in 'supporting people' placements in Kent funded by other authorities, who may add to demand for local services.

The total number of residential places in Kent recorded by the National Care Standards Commission was 3484. The number of placements funded in the county by Kent is estimated as approximately 1500. This gives an upper estimate of the total number of people placed from out-of-area of almost 2000 people.

The range in these estimates indicates the poor quality of information on out-of-area placements and implies that improving information about placing authority will be an important first step to addressing the problems identified in this area.

The information gathered in the survey is presented below under three headings: the characteristics of the people placed in Kent, the placing authorities and the residential homes concerned.

Characteristics of the people placed in Kent
759 people were identified placed by other authorities in Kent. 63% were men and
37% women. Their average age was 41 (range 17-96). Figure 1 shows the age
distribution of these people.

Figure 1: Age distribution of people placed in Kent
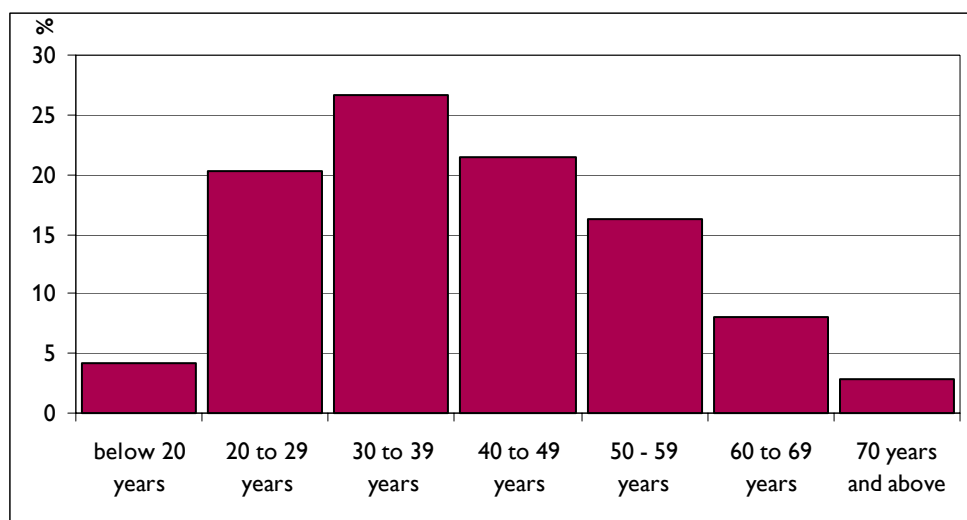
n=730

The age distribution was compared with that reported by Mansell *et al* (2002) from
a study of 99 services located throughout England and provided by one national
charity. Although this is not a random sample it does give some indication, in the
absence of national data, of the age distribution in residential homes for people
with learning disabilities generally. There was no significant difference between the
population in this study and the national study (Mann-Whitney, Z= -1.732,
p=0.176).

Figure 2: Length of stay
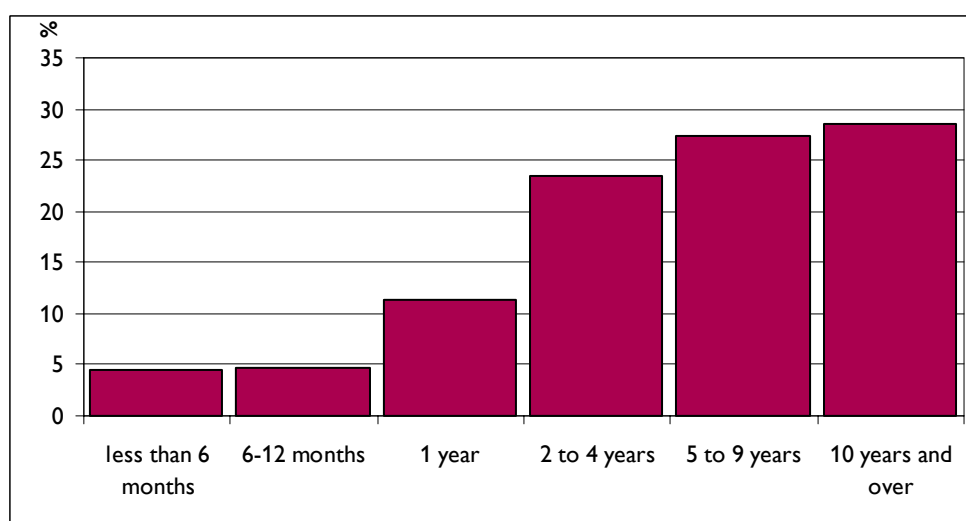
n=720

On average, the length of stay was 7 years 10 months (range 1 month to 37 years 5 months). Figure 2 shows the distribution of length of stay. The great majority (96%) of placements were described as long-term. The 29 cases classified as short-term average length of stay was 3 years 5 months (range 2 months to 8 years 1 month). 13 of the 29 had been in short-term residential placements for 4 years or more.

Placing authorities

99 authorities placed people with learning disabilities in residential care in Kent. The largest number (65) were placed by Medway, the unitary authority which was formerly part of the county of Kent. 62% (473 people) were placed by London authorities. The furthest authorities were in Scotland and Wales. Figure 3 shows the geographical distribution of placing authorities.

The people placed by authorities outside the home counties were compared with those within in order to see whether they had been placed in Kent for longer or were older. No significant differences were found (length of stay: $t=0.252$, df=718, p=0.801; age: $t=1.57$, df=728, p=0.117).

The average number of people placed by each authority was 8 (range 1 to 65).

Details of a care manager were provided in relation to 506 people, 67% of the 749 total. On average, the date of the last care manager contact with residents was 9 months before the survey date (range 1 to 124 months). Figure 4 shows the distribution of last contacts. 70% of residents had received a contact from their care manager in the last year. However this result needs to be interpreted with caution given that in 253 cases no information was provided. If these cases reflect lack of contact with a care manager then over half the sample would not have had contact in the last year.

The frequency of contact was compared for the group placed by authorities beyond the home counties and the others, in order to see whether care managers visited less often for people placed by authorities further away. There was no statistically significant difference ($t=0.854$, df=504, p=0.394).

There was a weak but statistically significant correlation between time since the last care manager visit and both length of stay ($r=0.094$, n=499, p=0.035) and resident age ($r=0.089$, n=505, p=0.045). Older people, or people who had been resident in Kent for longer, tended to have a longer gap since the last care manager visit.

Figure 3: Location of placing authorities
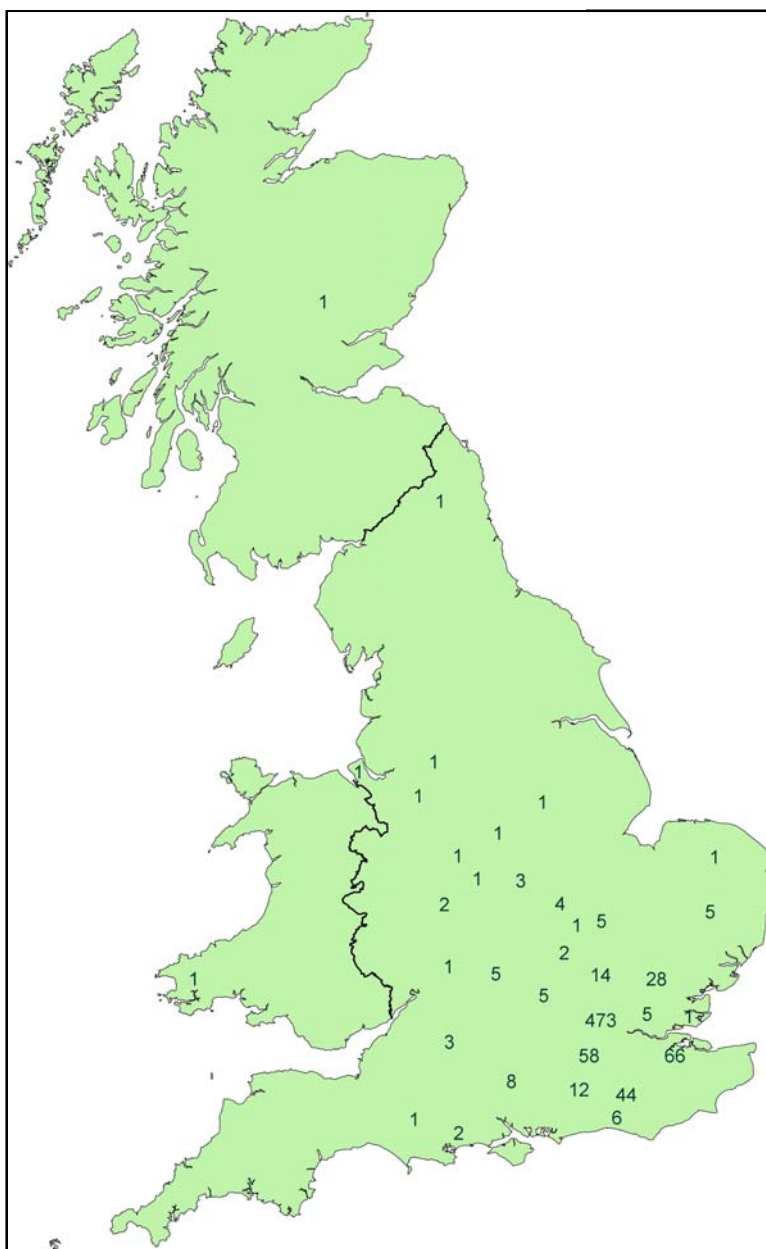
Residential homes used in Kent
Placements were made in 197 different homes in Kent, provided by 104 organisations. The average number of people from out-of-area placed at the same address was 4 (range 1-30).

Figure 4: Months since last contact with care manager
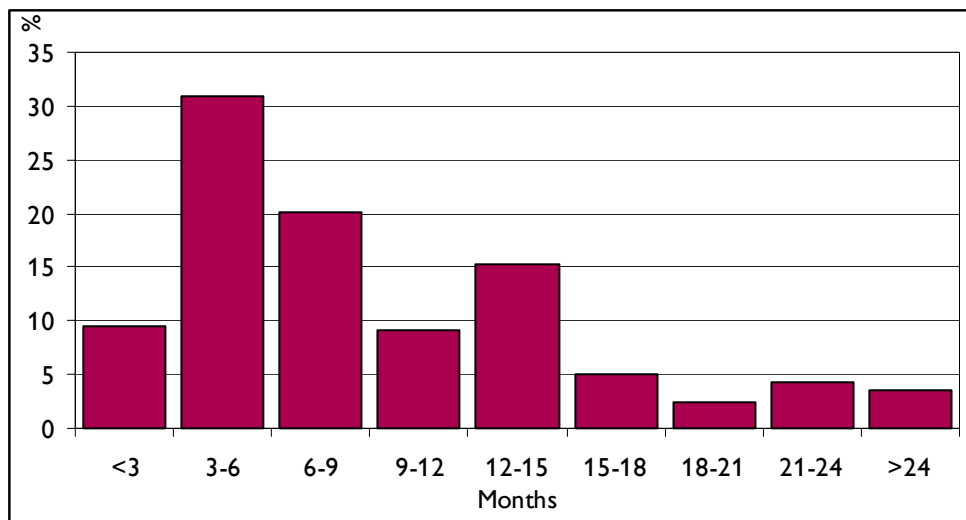
There was a strongly significant association between the placing authority and the

Figure 5; distribution of out-of-area placements in Kent
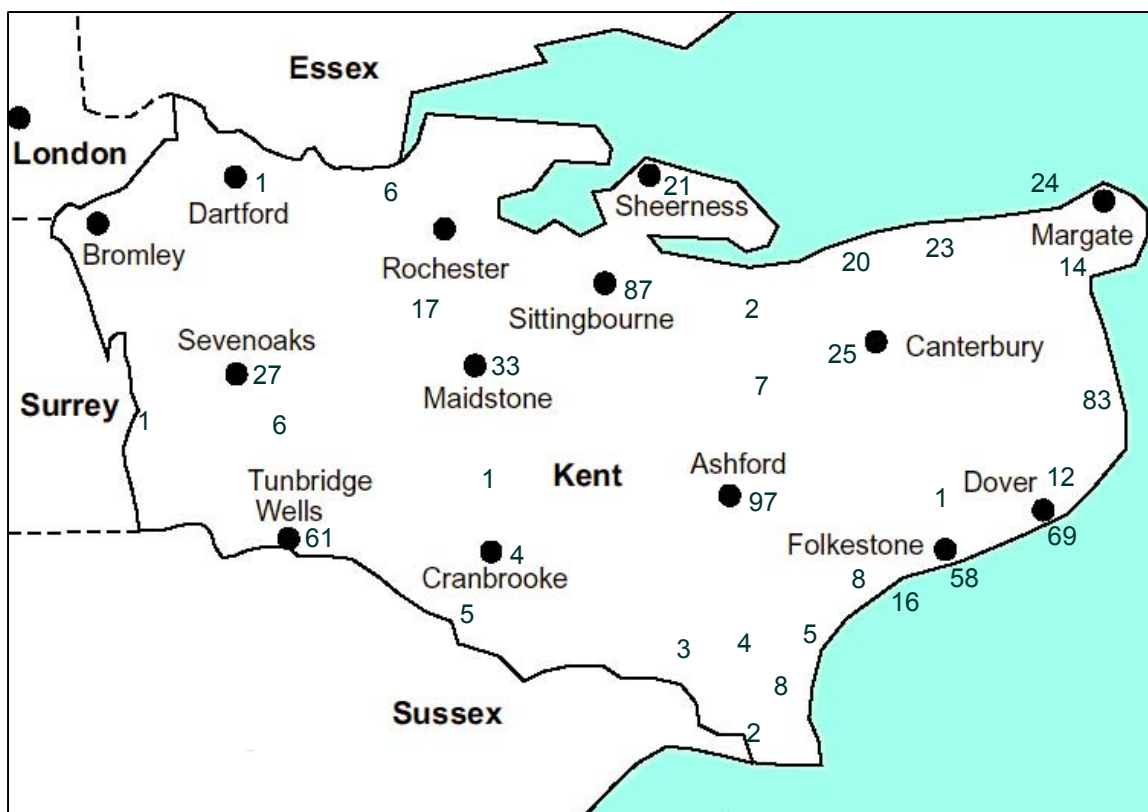
organisations receiving placement (χ^2 =11575.54, df=10094, p=0.000); that is, the same organisations tended to receive placements from particular placing authorities.

The geographical distribution of homes in Kent shows many more places being provided in East than in West Kent (Figure 5).

Conclusion
This survey was carried out using the ordinary administrative resources of the authorities and organisations involved and that places limits on the interpretation of the results.

The rather poor agreement between the survey results and the returns provided by three placing authorities would benefit from further investigation. Many home managers seemed unsure about funding arrangements when questioned. Therefore it seems likely that mistakes will have been made by some homes when providing this information. Similarly, there were practical problems extracting information from official record systems in Kent and in the three placing authorities and it is likely that this was also a source of error.

It would also be useful to replicate the survey for people placed in NHS and private health care facilities in Kent. Although it might be expected, if official guidance had been followed, that the local authorities providing social care to these individuals (whether they were the placing authority themselves or whether their local primary care trust had made the placement) would have them on their list of people placed out-of-area, this may not have been the case.

Similarly, people in 'supporting people' placements were not included in the survey. This kind of placement is significant because under these arrangements, residents sign a tenancy agreement for their home, which makes them ordinarily resident in the area in which their home is located, and thus entitled to local social services support should they need it (and should they fit the local eligibility criteria). It also means they lose any rights to future housing support in their 'home' area.

In spite of these limitations, the survey suggests that, at a minimum, between 1000 and 1400 people with learning disabilities are placed in Kent and this number may be as large as 2000 people. These people occupy 30% to 50% of all learning disability placements in the county. They include people of all age groups, with 51% under 40 years old, so this is not a historical phenomenon reflecting past patterns of service provision but an ongoing practice. Compared with other recent studies of populations of people with learning disabilities in residential care (Mansell *et al.*, 2002; Mansell and Beadle-Brown, 2004) there are more men than would be expected. 70% have lived in their current placement for more than three years and the great majority are deemed to have been placed for long-term care. 62% are placed by authorities in London. Between 30% and 54% have not been visited by their care manager for at least a year.

Authorities tend to place people in the same homes, and half the placements are in the eastern of three administrative areas of Kent, especially in the coastal towns. In the district of Dover, for example, there were more people with learning disabilities placed from other local authorities than there were from Kent.

There is, therefore, a prima facie case that the number of people placed in Kent by other authorities pose a considerable extra demand for health and social care services. Care management arrangements could be potentially problematic in a significant proportion of cases. What is not clear is whether this is the case in practice. That question is addressed in the next section.

Out-of-area placements of people with learning disabilities: introduction to the interview study

Introduction
Knowing that there are a large number of people with learning disabilities placed in Kent from other authorities does not, of itself, help clarify whether there are problems with these placements. If people placed out-of-area are having their needs met and appear content, if their families are content and if placements are being properly monitored then arguably the social care market is working properly. On the other hand, if people are not receiving appropriate services, or if the disruption of family ties is important or the placement costs local services time and money to support, then such placements need to be re-examined.

In order to address these questions it was necessary to find out why people had been placed and what were the effects of placement on them, their families, the homes in which they were placed and the authorities which had placed them. Since there is no previous research on this issue, an exploratory study was carried out.

Method
The plan was to select 30 people with learning disabilities from the original survey and to interview them (where possible), their family, the manager of the home in which they lived and their care manager. In addition, focus groups and interviews were held with members of community learning disability teams in Kent.

Details of the procedures, schedules and questionnaires used are in Appendix 1.

Thirty service users were randomly selected from the 759 people discovered in the survey described in the previous section. The managers of the homes in which they lived were contacted and information about the placement and the individual were screened. If individuals were removed from the list (eg because they had moved since the survey, the residential home had already been approached about another resident or where consent was refused), the next person on the list was contacted. Forty-eight service users were contacted in total, with 18 not able to take part (four service users declining, two parents declining on behalf of their children, one person because the service user was about to leave the service, two because the manager felt it was not in the best interests of the person and nine because the person who normally gave agreement in these situations could not be contacted).

Each home was visited and the manager was interviewed using several schedules:
♦ Background information on the service and on the service user (eg placement history, current placement, cost, family contact)
♦ Service users' needs and characteristics (adaptive behaviour (Hatton *et al.*, 2001), social impairment (Wing and Gould, 1978) and challenging behaviour (Aman *et al.*, 1985))
♦ Service quality (participation in daily living (Raynes *et al.*, 1994), choice making (Conroy and Feinstein, 1986) and community involvement (Raynes, Sumpton and Pettipher, 1989))

In addition, a semi-structured interview explored home managers' views about liaison and co-ordination with the placing authority, and the effect of the placement on the service user.

Semi-structured interviews were also carried out with the service user where this was possible, a family member, where contact existed between the participant and their family and they were prepared to take part (by visit) and with the care manager (by telephone). These interviews explored the reasons for out-of-area placement and the benefits and disadvantages perceived by the respondent.

Focus groups and interviews were conducted with members of five community learning disability teams. These were selected to provide coverage of the county and included two teams from East Kent, one from Mid Kent and two from West Kent. The discussion and interviews used a semi-structured interview to explore team members' experiences of out-of-area placements, the quality of services provided by these placements and any difficulties in communicating with the placing authority. It also explored whether teams had specific policies on whether and in what circumstances they became involved for people from out-of-area placements.

In all but two cases, interviews were tape recorded. All interviews were then transcribed. Quantitative data were analysed using the Statistical Package for the Social Sciences (SPSS Inc, 2004). Qualitative data was analysed by identifying themes and issues and using quotations from interview to illuminate the matters raised.

Reasons for out-of-area placement

The residents

The residents were a diverse group, with different levels of learning disability and different backgrounds.

For example, Maggie[1] is a 24 year old Black African. She has profound learning disabilities, does not speak and is autistic. This is her fifth placement – all of her previous placements broke down because Maggie presents challenging behaviour. She has lived in her current placement for four years. Maggie's family telephone regularly but visit infrequently as they live a long way away. Maggie does not have a care manager and the home contacts the duty team rarely. A local authority representative was at her last review within the last year.

Yasmin is a Chinese woman in her late 20s. She has profound learning disabilities, communication difficulties, and has shown challenging behaviour. Yasmin moved into residential care after living at home with her family. She has been at her current home for 5 years. She moved there after a long search by her family, who struggled to find an appropriate placement near to them. At first Yasmin's family visited frequently but now due to pressures of daily life and the distance Yasmin only sees her family every six weeks when she goes to stay with them. Yasmin does not have a care manager but a reviewing officer was present at her last review, which was within the last year.

George is a 58-year-old white British man who is blind, with moderate learning disabilities. He displays self-injurious behaviour and repetitive movements such as rocking. George lived in a local long stay institution from the age of 15 and moved into his current placement 10 years ago when the institution closed. George has no known family. His placing authority have now decided to move him to another placement in a completely different area, as his current placement does not meet national minimum care standards.

James is a 36 year old white British man with a dual diagnosis of mild or moderate learning disability with mental health problems and challenging behaviour. He moved to his current placement from home for a 2-3 year assessment. He has been there for 14 years. His family have been concerned that the placement is not meeting his needs and have actively been trying to get him back to a home near where they live. His home was closed during the research and he went back to live with his family. They are now waiting for an appropriate placement.

The average age of participants was 39 years and 9 months (range 18-69 years). Sixteen of the thirty people (53%) were men and 23 (77%) were of white British ethnic origin. Four people (13%) came from black Caribbean background and the other three people were black African, Indian and other Asian. Ten people (33%) were rated by their care staff as having mild to moderate levels of disability, 22 (73%) as showing at least occasional challenging behaviour or mental health

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[1] Names and personal details have been changed.

problems, 21 (70%) had impairments in communication skills, 6 (20%) had physical disabilities, 7 (23%) sensory disabilities and 7 (23%) epilepsy.

In terms of social impairment, 14 (47%) of the sample were rated as having a social impairment. Two people had a diagnosis of Down's syndrome, 3 of autism, 4 of cerebral palsy and 1 of Down's syndrome and autism. One person was diagnosed with Fragile X syndrome and two with Asperger's syndrome. The remaining people had diagnoses of learning disability in association with other complex needs (for example challenging behaviour, epilepsy etc).

Of the 22 people reported as having challenging behaviour, 8 were described as showing only one main type of challenging behaviour; the others all presented multiple challenges. 14 of the 22 showed aggression to other people or damage to property (usually both).

More detailed information on the adaptive and challenging behaviour of participants is presented in Table 3. This shows scores on the short version of the Adaptive Behaviour Scale (SABS) and the Aberrant Behaviour Checklist (ABC), expressed as percentages of the total possible scores.

Table 3: Adaptive and challenging behaviour of participants

	Mean %	Min-Max %
SABS total score	55.2	26.5-91.2
ABC Factor 1 (irritability)	23.9	0-66.7
ABC Factor 2 (lethargy)	15.7	0-62.5
ABC Factor 3 (stereotypic)	15.1	0-85.7
ABC Factor 4 (hyperactivity)	25.6	0-95.8
ABC Factor 5 (inappropriate speech)	15.8	0-91.7
Total ABC score across 5 sub-domains	20.5	0-57.5

Are the residents placed in Kent by other authorities different in some respect from other people in residential care? The data on the people themselves can be compared with results from other studies which used the same measures. Table 4 compares selected characteristics of this group with the results of two other surveys: a national survey of the homes provided by one charity (Mansell *et al.*, 2002) and an unpublished study of 40 homes provided by another national charity (Mansell and Beadle-Brown, 2004). Participants in this study fall generally between the other two in terms of the proportion of people with these characteristics. However, they have on average more language ability and less social impairment and they include more people from black and ethnic minority groups.

Table 4: Comparison of participant characteristics

	Present sample (n=30) %	Mansell *et al*, 2004 (n=398) %	Mansell *et al*, 2002 (n=495) %
Mean age	40	46	39
Percent <40 years	50	35	62
Percent male	53	50	57
Percent white British	77	97	95
Percent SABS score	55	57	43
Percent socially impaired	47	67	63
Percent unable to walk alone	17	10	27
Understands only simple phrases or less	17	24	43

Table 5 compares the participants of this study with those of the study by Mansell and Beadle-Brown (2004) and with two samples in institutions reported by Aman and Singh (1986). In this table the data are the mean scores on each domain of the Aberrant Behavior Checklist. The comparisons show that the group taking part in this study were more challenging on four of the five domains than the 2004 study, especially in terms of hyperactivity and irritability. On these two domains they were also more challenging than either men or women living in American institutions in the early 1980s.

Table 5: Comparison of challenging behaviour

ABC domain	Present sample (n=30)	Mansell *et al*, 2004 (n=398)	Men 31-50 in institutions★	Women 31-50 in institutions★
Irritability	10.77	6.26	7.38	7.88
Lethargy	7.53	6.24	10.38	8.83
Stereotypy	3.17	2.12	4.88	3.80
Hyperactivity	12.30	6.65	10.56	8.48
Inappropriate speech	1.90	2.03	1.84	1.92

★ from (Aman and Singh, 1986)

Thus in summary the people placed out-of-area appear, as a group, to be less socially impaired, have more language ability and be more challenging than other people with learning disabilities in residential care in Britain. They also appear to include a higher proportion of people from black and ethnic minority groups.

Resident circumstances before placement
Is there something about the background of the people which explains why they have been placed in Kent? Twenty-two people (73%) were placed by authorities in London. Seventeen people (57%) had lived in long-stay hospitals at some time in their past. The largest number (13 people, 45%) had lived in their current home for between 3 and 5 years. Seven (24%) had been in their current placement for 6-10 years and six (21%) had been there longer than 10 years. Only three people had

moved in the last two years and in one case the home manager did not know when the person had moved to the home.

On average, people had had two placements before this one (range 0-4). Table 6 shows that the majority of people had had one previous placement, with just over a quarter having had three or four previous placements. Four people had three or more previous placements that were out-of-area.

Table 6: Previous residential placements

Number of previous placements	Number (%) of participants
0	2 (8%)
1	14 (54%)
2	3 (11%)
3	4 (15%)
4	3 (12%)

Home managers were able to give the main reason for the present placement in 25 out of 30 cases. In practice, there was usually more than one reason involved in the move but these answers give some indication of the main reasons for placement. In six cases, people had moved out of long-stay hospitals or (one person) a previous home that was closing.

> 'At the time they were trying to empty a large long stay hospital and basically anyone that stated they had a placement they interviewed and you just went up there and chose who you wanted and [this person] was one of our choices.' (Home manager)

> 'When a lot of the long stay institutions got closed down, wherever the services were that paid the lowest, that is where they got shipped to…I think it is just funding, because the cost of the service was relatively cheap in comparison to others…so that is why people got placed out of area and because it kind of said it was focusing on autism and there weren't a lot of services around when this opened, that focused on autism.' (Home manager)

For seven people, the move had been planned, for example to be nearer the person's family or to meet family wishes.

> 'She was in a children's service but over the age of 18. Her parents moved down here. She was moving on anyway so she moved into this area.' (Home manager)

> 'Have you seen the others? [We were]6 years looking. I just don't know what to say except they were just awful, miserable, dire, no stimulation, sitting round the walls with people of all ages including elderly...There didn't seem to be anywhere with just his age group around here where he would have proper stimulation, be taken out, have work to do. [This] is the only place I've seen where he is part of a family, a nice clean home with staff who are chatty and an upbeat atmosphere.' (Family member)

> 'We went around everywhere, so many places and every time I came out of there I went "no." We saw this home in the newspaper and we called them and they put his name on the list – he was 13 then. We used to have to go up to [his earlier placement] which was 250 miles each way and when this came up, it was only 70 miles' (Family member)

> 'I looked at 17 homes and that was by far and away the best one I felt. There were quite a few that were near here. One of them was all right, it wasn't anything special but that was full up. Another one was totally unsuitable. Of course a lot of the places didn't have any spaces but none of them compared with the this place.' (Family member)

For five people, the move was made in an emergency.

> 'We were approached by social services for a possible temporary placement. We went through the admissions process, but before the visit, he was moved rapidly into a 'respite' house because the council had concerns about his existing placement. So we collected him early.' (Home manager)

> 'It was a crisis situation, behavioural problems, absconding and really aggressive behaviour, I think it was 8 months before I came and it was managed to some extent then and now she's sort of settled in here.' (Home manager)

Finally, for seven people, the move was made in order to secure access to specialist input of some kind, often because of the resident's challenging behaviour.

> 'We were approached originally because he was being so uncooperative, violent physically as well as verbally' (Home manager)

> 'We were looking for a client group [for a new house], people with autism, high support needs, people who would want the environment to be controlled and remain fairly static. He was one of the people we felt more than competent to provide the right type of behavioural support and care setting.' (Home manager)

> 'I think it was the only option, I don't think there was anything in London that was specialised in that area. The first choice is always to try to place someone in their area but then because of specific needs, certainly with people with dual diagnosis or very challenging behaviour, services within the borough are very limited and sometimes you need specialist services that are only available out of borough then we would place out of borough.' (Care manager)

Thus, broadly speaking, two themes come through strongly as explaining why people have been placed away from their home area. First, many people suggest that there are insufficient services locally – either because they are not of acceptable quality, or because they are unable to support people with higher needs for support (for example, because of challenging behaviour). This was an important factor in respect of three-quarters of the participants. In the second case, people have been placed out-of-area possibly because locality is not thought to be important, for example for those people who were in long-stay institutions. In this group, the people who had been in long-stay hospitals were no longer in touch with their families.

The homes in which people are placed

Understanding the reasons for out-of-area placement would not be complete without considering the characteristics of the homes that provide support and accommodation for the residents placed out-of-area.

The average distance from the home to the placing authority was 59 miles (Figure 6).

Figure 6: Distance between residential home and placing authority
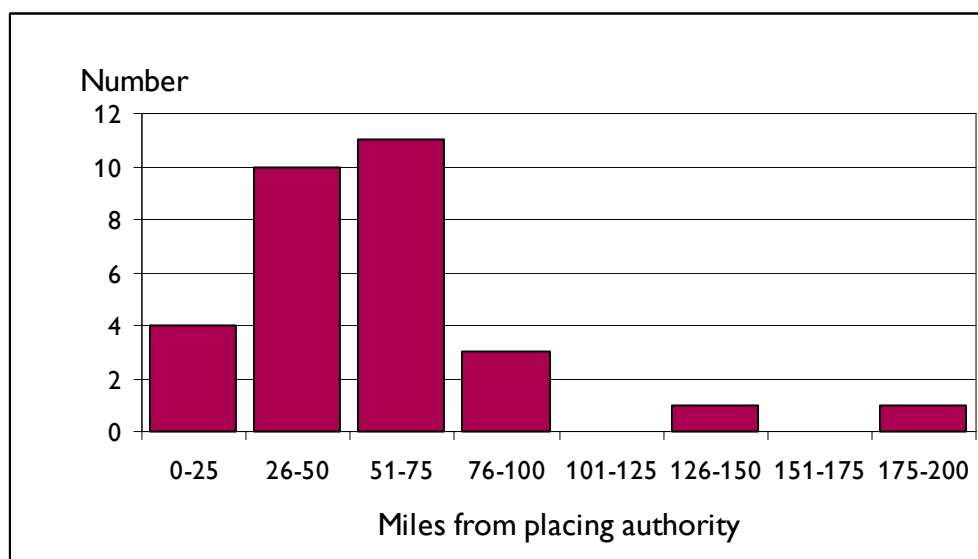
Twenty-three (77%) were provided by private care organisations and three by charities. Twenty-six (87%) of the homes were part of a larger organisation (Figure 7).

Figure 7: Number of homes in wider organisation
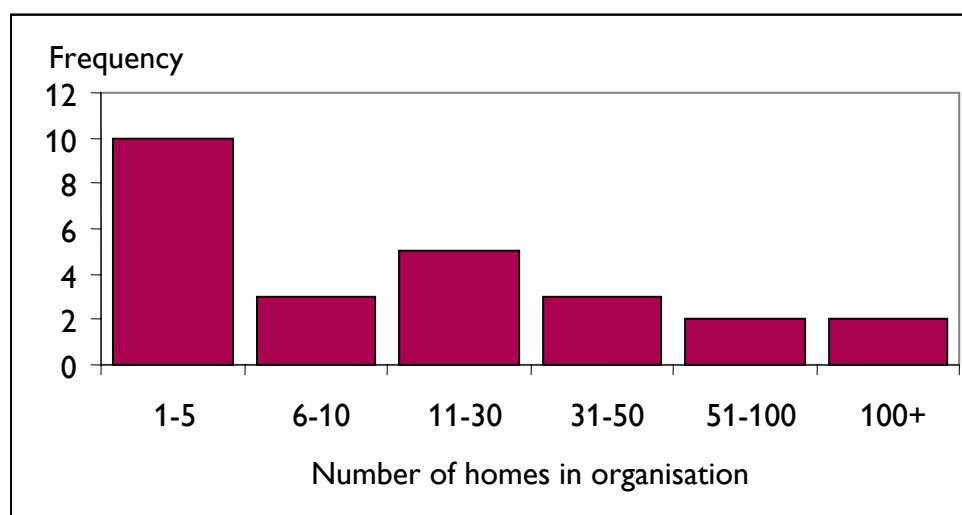
The average size of home was 3 people (range 1-6). However, five homes were part of larger campuses and for these the average number of service users on site was 17 (range 9-21). The average cost of placement was £47,411 (range £12,019 to £102,313). This is similar to the cost reported by Mansell *et al* (2002), where the mean cost (updated by the Retail Prices Index) was £49,362 (range £8,822 to £103,694). There was no significant difference in cost of care package by level of disability (SABS total score divided into quartiles) or by whether the person had

been in long-stay hospitals and there was no relationship between SABS score, age or any of the challenging behaviour measures and cost.

The distribution of cost did appear different from that reported by Mansell *et al* Figure 8. The numbers in this sample are too small for these data to be anything other than suggestive, but it may be that there are two groups of out-of-area placements – one rather less expensive and one rather more than the average.

Figure 8: Distribution of cost
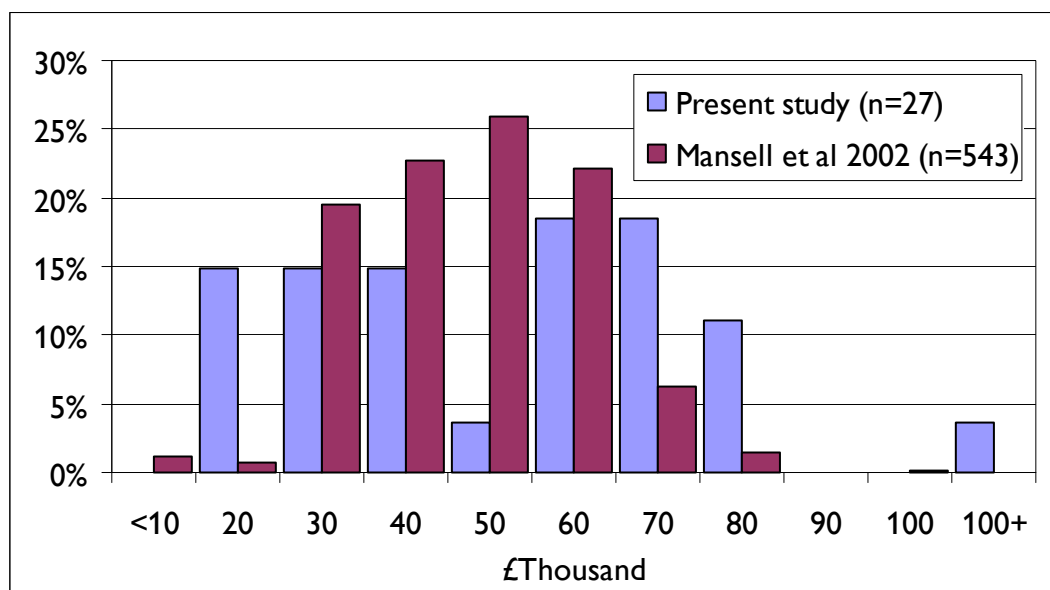
Two-thirds of the homes specialised in the needs of residents they served. Eleven of the thirty specialised in challenging behaviour or mental health, sometimes in addition to autism. Four specialised in serving people with physical disabilities as well as learning disability, three specialised in serving people with autism and learning disability and one was for elderly people with learning disabilities. Specialised homes cost more than the others, though this difference was not statistically significant (z=1.858, p=0.066). They did have a higher proportion of residents from out-of-area (z=2.189, p<0.05).

Home managers were asked how many other residents were placed by other authorities and this information was provided for 27 out of 30 homes. Sixteen (59%) had more than half their residents placed out-of-area. In six of them (22%), every resident was placed out-of-area.

Managers were asked why they received referrals from out-of-area. Half said that these were the only referrals they got. Some managers identified specialist skill or family contacts as a reason people came to them from other areas.

> 'We're usually approached, we don't actually approach anybody. They approach us in the first place. Sometimes it's because of the sort of home we've got that they're looking for, sometimes they've got a link with the town, like…they've still got some family or friends here. Sometimes it's just because of lack of homes in their own town.' (Home manager)

Echoing the finding in the survey that placing authorities typically use the same homes, one manager said

> 'It just seems that they all come from London borough – I don't know why, it just seems that social workers have set down the details…It's not done on purpose, it's just those are the referrals [that] have come through the system.'

A more common explanation was fee level

> 'Kent would rarely meet our fee. The fee is based on the standard of care that we provide, the skills that we have in the team, and what we are here to provide for the residents, and will Kent match that?" (Home manager)

> 'Everyone always assumes that Kent struggles with budgets and can't always give the care they would like to give with what they can afford…[we] are quite expensive in level of staffing and training and so were not considered in the past by Kent…we [now] have quite a few from Kent in other services' (Home manager)

> 'Money basically. It's the cost. Not only that but obviously in London the prices are higher and they look for cheaper alternatives which would be down this way.' (Home manager)

> 'Originally we expected and wanted to target local [commissioners]. Our first places were purchased locally…but the other places we couldn't sell locally and we ended up filling those with out of borough clients. What was good business sense was not to drag our feet and wait for Kent…So not out of choice but out of necessity and about being able to survive as a business.' (Home manager)

It was pointed out during the study that it had at one time been common practice for contract managers in Kent to tell local residential care providers that there was a cap on fees, irrespective of the needs of particular individual residents, and that they would have to look elsewhere for business if they wanted higher fees.

A slightly different perspective on this was given by a member of one of the community teams for people with learning disabilities interviewed.

> 'I think… it was quite true that a lot of the homes that were mainly full of people from out of area, nobody would place from the local area because they would avoid those homes, that's the same here.' (Occupational therapist)

Thus, in addition to the factors already identified, it seems that there is often a financial incentive for services to accept referrals from authorities other than Kent, either because other authorities pay higher fees or because they accept poorer quality.

Conclusion

The fieldwork provides confirmation that the reasons for out-of-area placement of people with learning disabilities include

♦ Personal characteristics – residents are on average less socially impaired, have more language ability and are more challenging; they also appear to include a higher proportion of people from black and ethnic minority groups.

♦ Insufficient local services, either because they are not of acceptable quality, or because they are unable to support people with higher needs for support (for example, because of challenging behaviour).

♦ For some people, locality was possibly not always thought to be important, for example for those people who were in long-stay institutions who may have lost contact with their family.

♦ Financial or quality incentives for services to accept referrals from authorities other than Kent.

It is also worth noting that the cost of placements appears similar to those of other services and that there is no relationship between cost and the resident characteristics measured. However there is some evidence suggesting that there might be two groups of out-of-area placements – one rather less expensive and one rather more than the average. This requires further investigation.

Effects of out-of-area placement on the residents

This section looks at the effects of out-of-area placement on the residents themselves, using the views of those who were able to be interviewed and quantitative assessments of the quality of their experience in the home and the community and the kind of services they receive.

Do residents have a good quality of life?
Fifteen of the 30 residents were able to take part in an interview, at least to some extent. Twelve of the 15 said they had wanted to move to the home. When asked what was good about the home, residents mentioned they liked the staff and/or other residents, the opportunity to become more independent and most frequently (8 people) the activities in which they could take part.

> 'Because of the activities. I like the staff more here because they take me out; they didn't in the other place. I just played in the back garden. I just watched telly. I'd say here is better. I like all the service users, especially T' (Resident)

> 'I've got people to chat to and do things, I've got my own room and got my own videos and telly, do things that I want that I couldn't do at home' (Resident)

> 'It's nice, I like living here, they take me out a lot, quite a lot.' (Resident)

> 'The other two places were really worse. I got picked on and called names and they blamed my epilepsy too, to pick on me. I prefer here…people can support me better, not like the other place where they were nasty and spiteful, had me "grounded" every day.' (Resident)

When asked what was bad about the home, six people identified problems – mainly relationships with other residents or staff.

> 'If I'm naughty I don't go out. I stay here, they punish me. If I'm naughty, or loud or walking around in circles, I don't go out.' (Resident)

> '[Other resident] fighting' (Resident)

> 'People kicking off, I go upstairs to chill out. They get violent. We've got one of those charts, where you get money, if you kick off you get a cross. 50p, and 25p. I got £1 last week, Friday I got £3.' (Resident)

Interviewers also assessed quality of resident experience using two measures used in other studies – the Index of Participation in Daily Life and the Choice Making Scale (see Table 7).

As would be expected given the wide range of levels of adaptive behaviour of residents, there was wide variation in the extent to which people participated in activities of daily living (like shopping, cooking, cleaning, laundry and gardening) and making their own choices. There was a statistically significant relationship between adaptive behaviour (as measured by the total score on the Short Adaptive Behavior Scale) and participation in daily living (Spearman's rho=0.502, p<0.01) and between adaptive behaviour and choice making (Spearman's rho=0.527, p<0.01). The residents with lower support needs exercised more choice and

participated to a greater extent. This is a common finding (Felce and Emerson, 2001; Mansell *et al.*, 2003) which has led to a focus on staff providing 'active support' (Brown, Toogood and Brown, 1987; Felce, Jones and Lowe, 2000; Jones *et al.*, 1999; Mansell *et al.*, 2005; Mansell *et al.*, 1987) to enable people with high support needs to participate. These homes did not appear to be providing this kind of 'active support'.

Table 7: Resident participation and choice

	Mean %	Standard Deviation	Min-Max %
Index of Participation in Daily Life	38.3	25.5	0-88.5
Choice Making Scale	70.2	21.1	1.4-97.2

A series of partial correlations controlling for age and level of adaptive behaviour showed statistically significant positive correlations between participation in daily living activities and shorter length of stay ($r=-0.538$, $p<0.01$), smaller size of home ($r=-0.486$, $p<0.05$) and higher proportion of residents from out-of-area ($r=0.498$, $p<0.05$). More choice was correlated with longer time since the last review meeting ($r=0.441$, $p<0.05$). It is not clear why these latter two correlations should be significant and this requires further study.

There was no statistically significant relationship between challenging behaviour and either participation or choice. When age and level of adaptive behaviour were controlled by partial correlation, a statistically significant positive correlation was found between smaller size of home and more stereotypic behaviour ($r=-0.454$, $p<0.05$).

There was no statistically significant relationship between whether the home was specialised or how much it cost and either participation or choice.

The overall level of participation was similar to that reported by Raynes *et al* (1994) in a study of community-based residential services for 2031 people with learning disabilities in 1988/89. They found that on average residents scored 38.8% on this measure. A more recent study by Mansell *et al* (2004) of 398 people in small group homes, who were of similar level of adaptive behaviour though slightly older than this group, found a rather higher average score (47.3%), though this is not statistically significant ($z=1.866$, $p=0.062$). It does suggest, though, that these homes might not be achieving the same outcomes as other contemporary services.

Similarly, Raynes *et al* (1994) found that on average residents scored 64.2% on the Choice Making Scale. Mansell *et al* (2004) found a significantly higher average score of 80.5% ($z=4.722$ $p<0.001$).

Given the relatively small sample size these results should be interpreted with caution. However they do suggest that overall, people in this group of 30 residents placed out-of-area appear to achieve poorer outcomes than other, broadly comparable, residential homes, at least in respect of choice and possibly in terms of participation.

Are they part of the local community?

In general, service users reported themselves as going out at least sometimes – 7 out of 13 people who answered the question said they went out a lot, the remaining 6 said they went out a little. Of those able to be interviewed, three people had a job but only two people could say what this was – both of these people worked on special projects – one on a farm and one on a gardening project. Home managers identified that 5 people had a job although they only had further details for four of these (a horticultural project, farm work and a workshop onsite. One person worked full-time, the remainder part-time.

Managers reported that 17 residents out of 30 went to a day service, 7 of which were on the same site as the home. Two people went to local authority day services and 8 went to private or voluntary day services offsite.

Seven (out of 13) residents said they went to college, mostly to do cooking, although one person did life skills and one person did first aid and relaxation. Home managers reported that 14 people went to college, for classes ranging from 1 hour to 35 hours per week.

Twelve residents said that they went shopping and of these, 8 did shopping for food and snacks, 3 for clothes and 4 said they went shopping for whatever was their own personal interest. When asked what they did for fun, 12 people said they went to the cinema, 8 went swimming, 6 when to the town, 14 went to the pub, 6 went to a club, one person went to church, 7 went to a sports centre, 2 went to a café, 3 went bowling, 4 went walking, 2 went to parties and one went to the hairdresser.

Interviewers also assessed the extent to which residents used community facilities using the Index of Community Involvement (Raynes *et al.*, 1994). The mean percentage score for these homes was 45.6% (range 20.0-73.3%). This compares with 47% reported from a study of Scottish homes by Ager *et al* (2001). It is rather lower than another recent study in England (Emerson *et al.*, 1999), which found a mean percentage score of 67% over 13 items (which compares to 43.6% for this group). Overall, therefore, it appears that this group may be experiencing less community involvement than people living in other similar residential homes in England.

As with daily living activity and choice, there was a statistically significant relationship between adaptive behaviour and community involvement (Spearman's rho=0.413, $p<0.05$), so that the more independent residents were involved in more community activities. There was no relationship with challenging behaviour. Partial correlations to control for age and adaptive behaviour were statistically significant for community involvement and shorter length of stay ($r=-0.580$, $p<0.01$), and for less family contact other than visits to or from the family ($r=-0.533$, $p<0.05$).

There was no statistically significant relationship between whether the home was specialised or how much it cost and community involvement.

Are they in touch with family and friends?

According to the home managers, 23 (77%) of the 30 residents had some family contact. The frequency of contact as reported by the home managers is illustrated in Table 8 below.

Table 8: Family contact

	Weekly %	Monthly %	Less than monthly %	Never %
Visit from family to residential home	7	17	45	31
Visit from resident to family	7	25	39	21
Other forms of contact (eg letter, telephone call)	36	14	29	21

This pattern is rather different from that found by Raynes *et al* (1994). They found double the percentage of people having weekly visits to or from the family, a lower proportion (21%) never being visited. It is plausible that people placed out-of-area receive less contact than the much larger sample studied by Raynes *et al,* which included many people placed in their home areas. However, Raynes *et al* also found a much higher proportion (42%) of residents never visiting their family. This may reflect the substitution of visiting modes – when it is easy to visit the residential home people are less likely to have the resident visit the family home; or it may represent a change in the proportion of people who have lost contact with their family with the passage of time.

There was no statistically significant relationship between distance from home area and pattern of family visiting for this group. However, the number of residents studied is small and other studies of larger groups have found that family contact declines with distance (Dalgleish, 1985; Walsh *et al.*, 2001). Difficulties experienced by families are described later in this report.

When age and level of adaptive behaviour were controlled by partial correlation, statistically significant positive correlations were found between less non-visiting contact and more community involvement ($r=-0.533$, $p<0.05$), and more contact other than visits and three of the challenging behaviour factors – irritability ($r=0.530$, $p<05$), lethargy ($r=0.482$, $p<0.05$) and hyperactivity (0.489, $p<0.05$).

Ten of the 11 residents interviewed, who expressed a view, said they would like more contact with their family.

Fourteen out of 15 residents interviewed said that they had friends. Ten people said they had met their friends at the home where they lived or a previous home and four people identified staff as friends. Only four people said they had friends beyond the home where they lived. Nine out of 13 people who answered the question said they would like more friends. Home managers reported that 21 out of the 30 residents (70%) had friends, although only 4 (13%) had friends beyond the home site.

Are the homes of good quality?

All the homes were inspected at least twice a year by the National Care Standards Commission and are now inspected by the Commission for Social Care Inspection. Reports of inspections were available for 27 of the 30 homes. Inspections report whether national minimum standards are met in respect of 43 standards in eight areas (Department of Health, 2002). Although these assessments are of unknown accuracy and reliability, they are intended to be used to assure that minimum standards are being met.

Figure 9: Choice of home: percentage of standards met by each home
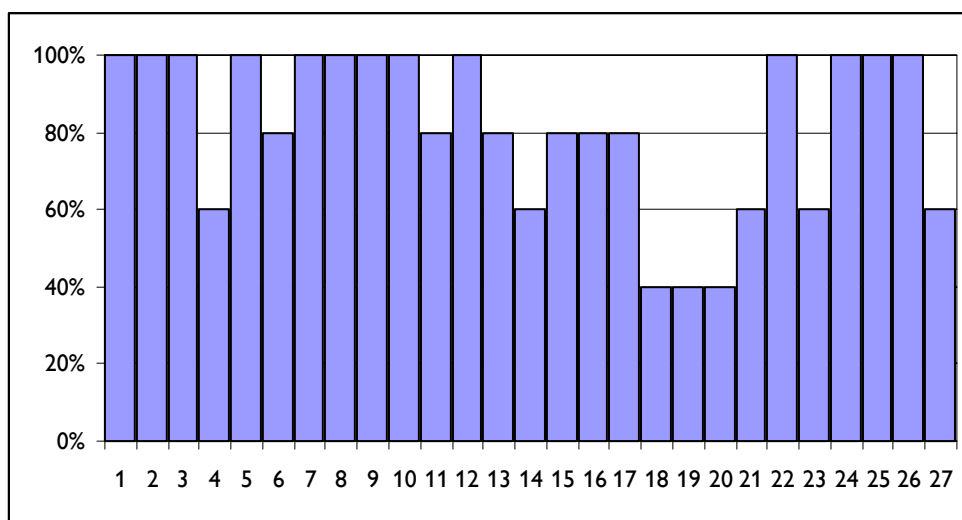
The first area is choice of home and covers five standards relating to whether there is a clear statement of purpose for the home, residents have an assessment before moving in, the home can demonstrate it provides the specialist care residents may need, prospective residents visit the home and each resident has a written contract. Occasionally not all standards are assessed. Figure 9 shows, for each home, the percentage of these five standards met. Fourteen homes were assessed as not meeting the minimum standards in this area.

Figure 10 presents the same information for the area of individual needs and choices. This area concerns the existence of an individual plan for each resident, respect for their rights to make decisions and to be consulted in the running of the home, to take risks and to have privacy. Thirteen homes were assessed as not meeting the minimum standards in this area, including one home that did not meet any of the five standards.

Figure 10: Individual needs and choices: percentage of standards met by
           each home
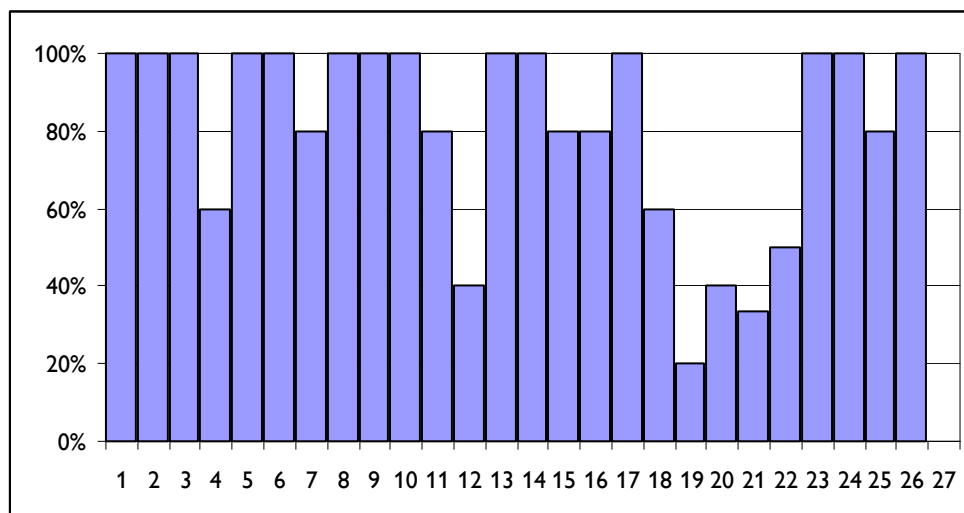
The third area of the national minimum standards is lifestyle. This includes
standards on opportunities for residents to develop new skills, take part in activities,
be part of the local community, have access to leisure activities, be supported to
maintain friendships and family contact, have good food and also that the operation
of the home should promote independence and choice. Figure 11 shows that more
of the homes met all the standards in this area, with 10 assessed as not meeting the
minimum standards in this area, including one home that did not meet any of the
seven standards.

Figure 11: Lifestyle: percentage of standards met by each home
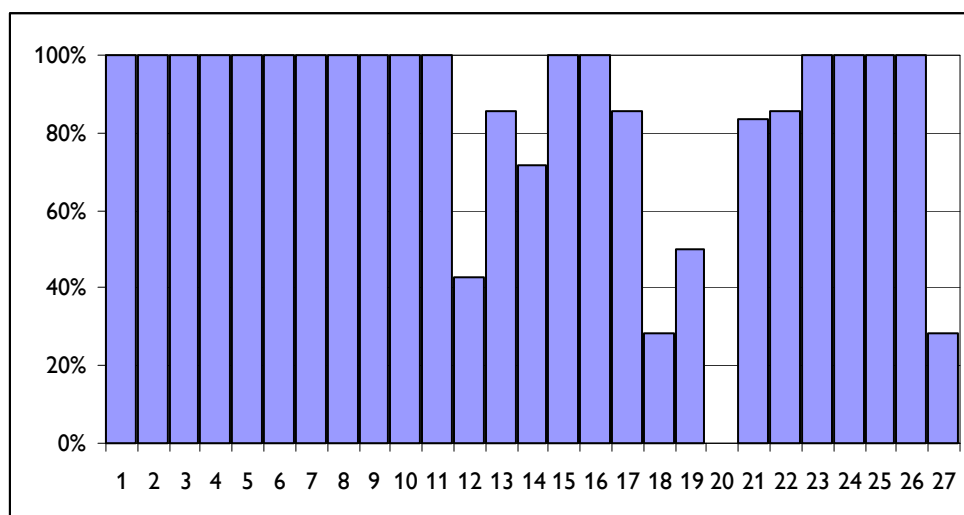
Figure 12 shows the percentage of standards met in relation to personal and
healthcare support. This includes whether staff provide personal support that
maximises residents' privacy, dignity, independence and control, whether they meet
people's health care needs, whether they support appropriate self-medication and

deal well with ageing, illness and death. Seventeen of the homes did not meet the minimum standards in this area.

Figure 12: Personal and healthcare support: percentage of standards met by each home
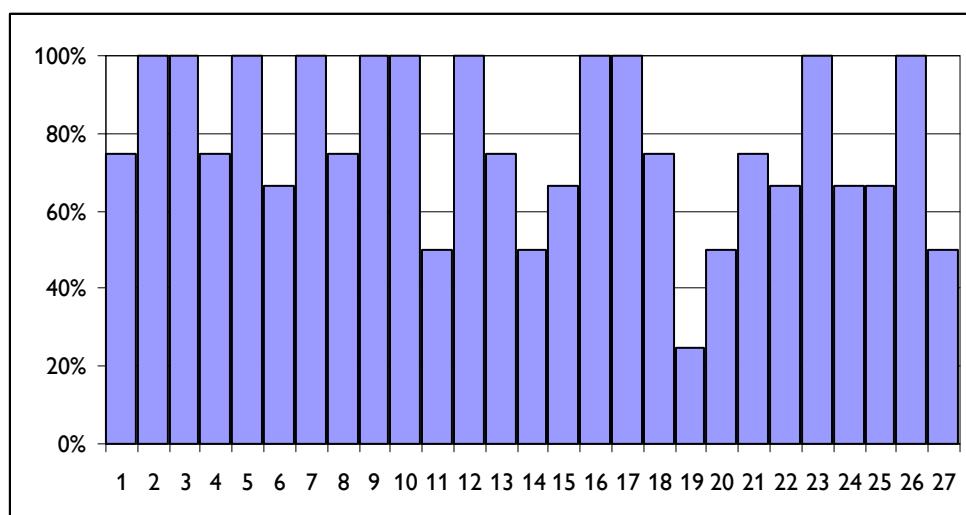
The fifth area contains just two standards concerned with complaints procedure and safeguarding residents from abuse. Fourteen homes did not meet the national minimum standards, with two homes meeting neither standard in this area (Figure 13).

Figure 13: Complaints and protection: percentage of standards met by each home
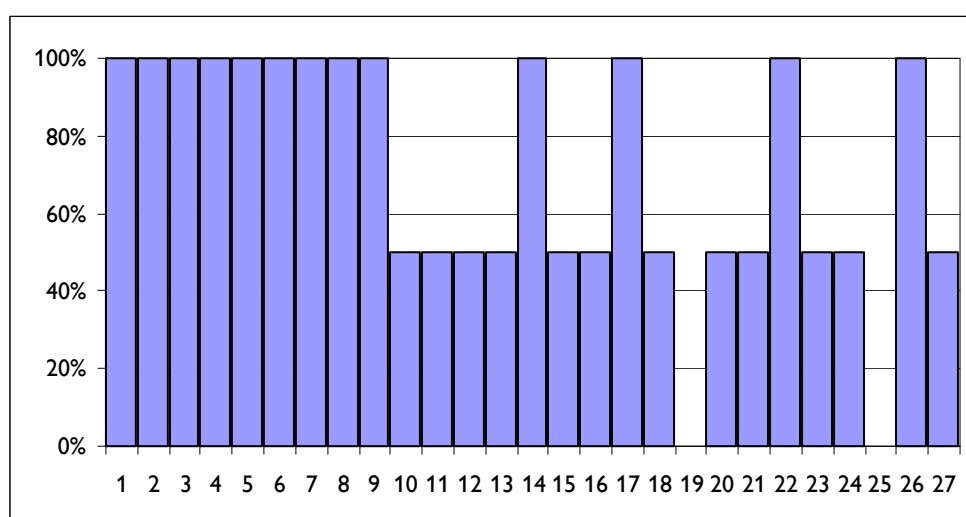
Figure 14 presents the percentage of standards met in relation to the physical environment of the residential home. This group of standards cover the size of the home, space, facilities, furnishings and adaptation and the cleanliness of the home.

Seventeen homes did not meet all the national minimum standards in this area, with one home meeting none of them.

Figure 14: Environment: percentage of standards met by each home
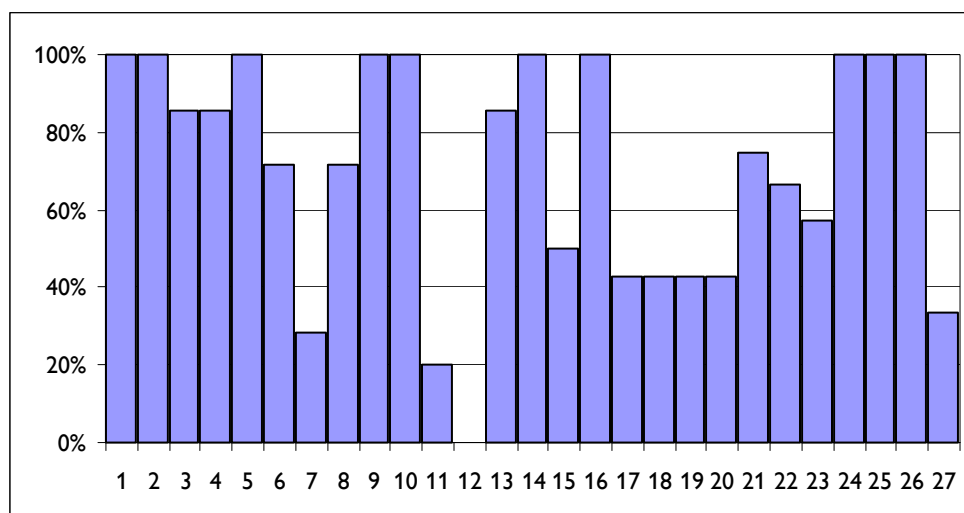
There are five standards relating to staffing (Figure 15), referring to job descriptions, training, number of staff, recruitment process, training and supervision. Fourteen homes did not meet all the national minimum standards in this area, including three which met none of the standards.

Figure 15: Staffing: percentage of standards met by each home
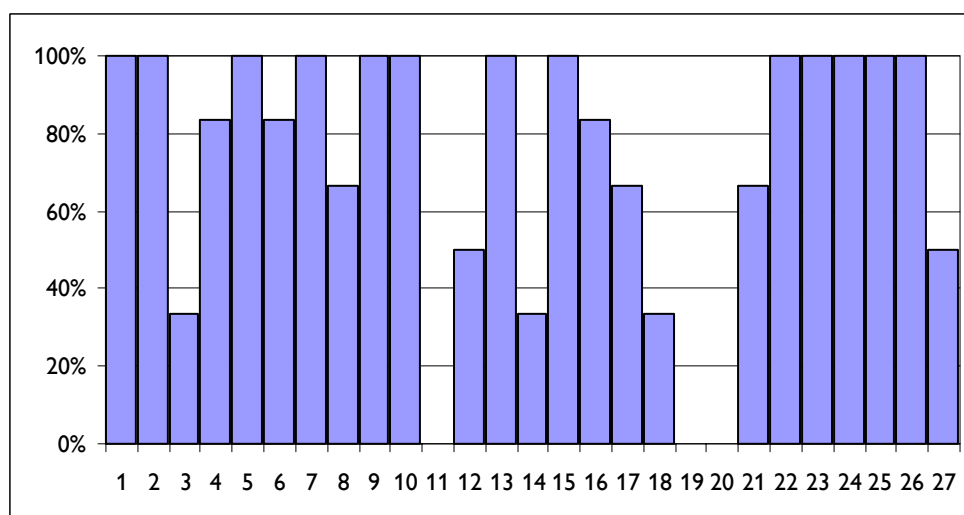
The last group of standards refer to the conduct and management of the home and covers matters including the qualifications and responsibilities of the manager, management style, quality assurance processes, written policies and procedures, records, staff health and safety and financial viability. Figure 16 shows the percentage of standards met in this area. Nineteen of the 27 homes did not reach

all the national minimum standards in respect of conduct and management of the home.

Figure 16: Conduct and management: percentage of standards met by each
           home
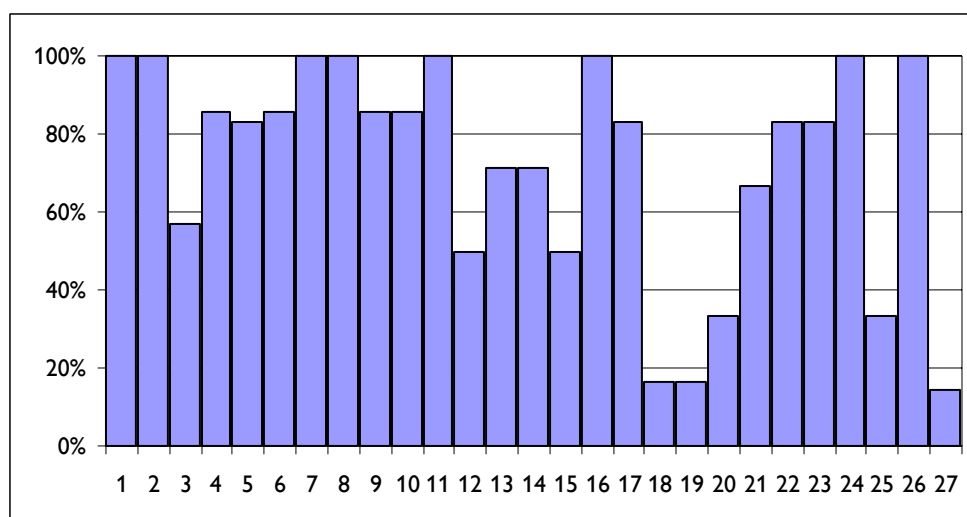
Overall, the mean number of standards met was 31 out of a possible 43 (range 11-43). Five services met 50% of standards or less. There was no statistically significant relationship between whether the home was specialised or how much it cost and the percentage of national minimum standards met.

Comparing these data with Commission for Social Care Inspection reports for services included in the study by Mansell *et al* ((2004) found no statistically significant differences between the groups. The National Care Standards Commission (2004) published national data for all care homes for younger adults collected by September 2003. These data show that, in the year 2003/4, the proportion of homes achieving every standard was 46%. In this group of 27 homes providing out-of-area placements, only two homes (7%) met every standard.

Although these data must be treated with caution, given the lack of information about the accuracy and reliability of the assessments, they suggest that these homes may be similar to others for people with learning disabilities, though worse than the average of all homes for younger disabled people.

Inter-relationships between measures
Consideration of all the data concerning the effects on residents suggested that there might be, broadly speaking, two different groups. One group consists of those who live in homes not meeting at least 50% of national minimum standards and/or with a pattern of lower scores on measures of quality of life and quality of service (n=10) and the other of those meeting both of these criteria - where homes met at least 50% of national minimum standards and the pattern of scores across outcome measures, although variable, was somewhat higher (n=20). This differentiation was checked statistically and these two groups were found to differ significantly on participation (z=-2.271, p<0.05), choice (z=-2.995,p<0.01), community

involvement (z=-2.669, p<0.01), non-visiting family contact (z=-2.308, p<0.05) and percentage of national minimum standards met (z=-3.082, p<0.01).

However, in terms of explaining the existence of these distinct groups, there were no significant differences between the two groups in terms of challenging behaviour, overall ability, cost of placement or number of previous placements. Those who had been in the home for more than five years were more likely to be in the poorer outcome group; 80% of those in the poorer outcome group had been in the service for more than five years, compared to 25% of the better outcome group (χ^2=8.213, p<0.01). Whether or not the person was socially impaired also appeared to be important and approached statistical significance (χ^2=3.281, p=0.07), with 70% of those in the group with poorer outcomes/quality of service being socially impaired compared to 35% of those in the better outcome group.

Given the small and uneven group sizes, these results should be interpreted with caution. However, it does suggest that there are two different groups within the sample of people placed out-of-area, one doing rather better than the other, and that length of stay and social impairment might be relevant explanatory factors.

Do people receive social care from their placing authority?
Only 19 of the 30 residents were said to have a care manager or reviewing officer, although home managers reported that care managers were in touch at least every six months for 7 residents, between 6 and 12 monthly for 2 residents and less frequently or 'when required' for 13 residents. This discrepancy is due to the provision of duty care managers or reviewing officers in some cases.

When residents were asked about their care manager, 10 (out of 15 interviewed) were able to say that they had a care manager and 7 were able to name them. Ten said the care manager visited, 8 said they came to review meetings.

Of 17 care managers interviewed (4 of whom were reviewing officers), only four had actually arranged the placement of the person in their current home. Sixteen had met the resident but for nine of these it was only in the context of the annual review. Two care managers felt they knew the person really well, 9 fairly well and 6 said they did not know the person very well at all.

Home managers reported that they knew the date of the last review for 28 of the 30 residents; 14 had had a review within the last six months, 8 between 6 and 12 months ago and 6 over 12 months ago.

Do people receive health care from the receiving authority?
All 30 residents were reported to have access to a permanent family doctor in Kent. Only in four cases had there been difficulties in obtaining a doctor.

Family members reported that access to healthcare was satisfactory for 10 out of the 13 service users for whom responses were available.

All but one person had access to specialists including eye, epilepsy, gynaecology, chiropody, audiology, oncology, dental, and orthopaedic specialists. For the most

part, these specialists were accessed through the NHS, with only one service user accessing private health care.

Other types of health specialists included physiotherapists (5 people), SALT (9), psychiatrist (13), community nurse (3), psychologist (4), behaviour support team (1), occupational therapist (4), other therapists (2) and the community learning disability team in general (5). Twenty-five people accessed these specialists in Kent, two accessed specialist help from elsewhere and three accessed specialists both in Kent and elsewhere.

Despite the extensive involvement of specialists, home managers reported difficulties in getting referrals for seven people. 39% of the specialists were in private practice and in six cases, people received financial support from the placing authority to help access specialists.

> 'We have been told they cannot get speech and language therapy – I don't know why. Makaton is not widely used but it is her way of communication. She did know a lot of language which she doesn't get to use or is not prompted to use.' (Family member)

> 'They were on a lot of medication and it seemed to take quite a long time to get a referral through to the local community team and to a specialist psychiatrist, but that has actually happened now.' (Care manager)

> 'We have just managed to get him down from London to be registered within Kent. Travelling up and down to London is not a good idea every 6 weeks to see a professional. It takes it out of him and he also misses a whole day at college which he did not appreciate… it has taken a long time' (Home manager)

> 'The care manager was quite keen for S to see a speech therapist and she mentioned that if we had problems trying to get one she could contact one. Well we did have problems, it is very hard to get one so I spoke to the care manager and she was going to try and see one.- that was about 6 months ago.' (Home manager)

In some cases access to local services was a requirement of the placement being accepted:

> 'there has been a pretty good handover; because it was from the hospital then it was set up with the psychiatrist that she sees now… otherwise the placement couldn't go ahead really…Where someone has a mental health problem as well as autism or Asperger's then we would need to be assured that the mental health team here is going to take them on as their patient, because we need that support, we are not specialists in that or trained in that, we are not medical professionals, so the placement would be supported by them accepting them as their patient, otherwise we wouldn't be able to take them, it wouldn't be fair on the individual to lose that support that they obviously need.' (Home manager)

Sometimes support continued to be provided from the placing authority

> 'her consultant is extremely interested and wants to keep her on until she is settled and then she is more than happy to refer her on. She wants to hang on to her and get her settled which is nice and the resident knows her and will converse with her, whereas she never used to.' (Home manager)

Conclusion

The purpose of this part of the study was to find out whether the potential problems identified in the earlier sections of this report were found in practice. This is a small sample and so the results can only be indicative.

♦ The most important finding is that effects of out-of-area placement vary across individuals. Some people experience better care and better outcomes than others.

♦ Generally the most disabled people experience the worst outcomes.

♦ Overall, some aspects of service user experience were worse than found in comparison studies (the extent of choice, community involvement, number of homes meeting all the national minimum standards), some were the same (participation, family visiting and other contact) and one was better (visits to families).

♦ Variation was also evident in the involvement of social services staff from the placing authority and in ease of access to local health care resources.

♦ There is some evidence that there are two different groups within the sample of people placed out-of-area, one doing rather better than the other, and that longer length of stay and social impairment might be relevant explanatory factors.

The views of the families

Twenty-four residents (77%) were reported to have some contact with their family. It was possible to interview 15 family carers, of whom 11 were parents and 4 were siblings. Their ages are given in Figure 17. 10 (67%) carers were of white UK or Irish ethnic origin. The relatives of the carers interviewed were different from other residents in one respect: they were as a group less challenging in terms of the Aberrant Behavior Checklist domains of irritability, lethargy and hyperactivity.

Figure 17: Age of carers
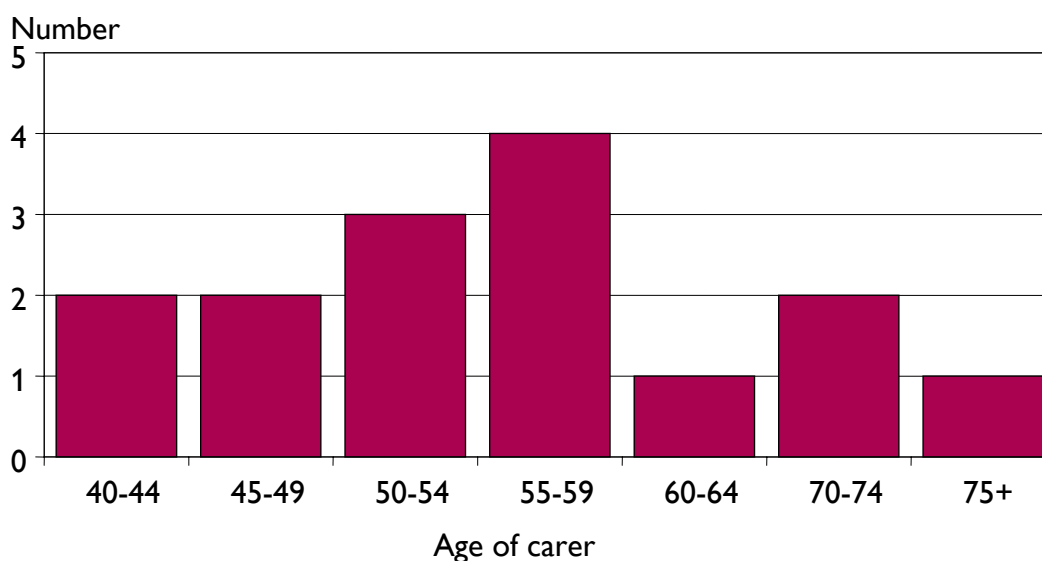
Finding and moving to a new home

Of the family carers interviewed, 14 (93%) had visited the service prior to the their family member moving there. In relation to how much say they felt they had regarding the placement, 5 (33%) felt they had no say at all, 6 (40%) felt they had some say, 3 (20%) felt they had most say over the choice of placement and one person (7%) felt they had a complete say in where their relative was placed.

> 'A lot of say, If we didn't like it we could have said. We were given the choice, not made to feel that this was the only placement she could go to.' (Family member)

> 'Absolutely, I found the home and told them that I wanted them to pay.' (Family member)

> 'None – the social worker arranged it. We looked at a variety of places - most were a long way away. There were few places close by…when this did come up it was like he was going to Eton. It was wonderful. It's a wonderful place.' (Family member)

> 'He was supposed to be going to another home…just down the road from Mum. It didn't come off. Then he tried other places but that didn't happen. And then suddenly I was called the next day (after being told the previous day that he definitely wouldn't be moved away) to be told that he had to go to Kent. Having being reassured earlier that he wouldn't be…I couldn't do anything about it. Oh I was told that I could have the money…if I could look after him myself. That was the alternative they gave. What a crazy idea, they would pay me the money…That

was the attitude. I had no say in the matter, there was nothing I could do, he had to go. I couldn't look after him, I was working.' (Family member)

Some families reported how they had to fight for the place in the home the person was in now.

> 'It had to be a joint decision with social services but the family had to fight for him to be placed there as it was more expensive. The family argued that her previous residential service was got for cheaper than they had thought, so social services had 'got away' with years of a cheaper placement.' (Family member)
>
> 'He has got us, we know how to do things and we don't just accept it when people say "oh no that's far too much money, we won't pay that, this is our ceiling," which is about £500 a week less than we were asking for, and you have got to find a home that costs no more a week than that and we just didn't accept that because we know you don't have to and we know that there are other finances available. But I feel very much for people because I think that everything we have got we have had to fight for. They make you jump through hoops for it… (Family member)

Do families feel they are as involved as they want to be?

Of the 15 families interviewed, seven (47%) reported difficulty getting to the service. Difficulties mentioned included the frailty of the parent, the location of the home, being unable to access the service by public transport and having to rely on others for transport, sometimes because of the cost.

> 'I used to but can't now – used to get a taxi and can't afford it now. When I still lived at home [respondent lives in a care home herself], I used to go down and stay for Christmas, Easter and holidays. Christmas last year was the first year we haven't been together since he was born. It just wasn't possible.' (Family member)
>
> 'her sister usually visits twice a year, but not so far this year, and she puts that down to funding. She does have a point, she struggles to get travel warrants from social services and that's wrong. She has to contact them and say that she's coming down to see her sister and they will give her a travel warrant but they won't give them for her children and she can't come without her children, they obviously haven't got a lot of money.' (Home manager)

In terms of the service user visiting their family, six families (39%) said they were responsible for transport when the service user visited them, six said the service were responsible, two reported someone other than the family or service were responsible, and one family said the service and family took turns to arrange the transport.

Home managers reported that of the 24 people that had some contact with their family, six families attended the last review meeting, five did not and in 13 cases the manager did not know whether the family attended the last review.

Twelve of the 15 families interviewed said they did attend review meetings. When asked if they had any difficulties getting to the review, 5 families (33%) said they did. Problems mentioned included because they had to rely on others for transport, because the home was not accessible by public transport, and difficulties with the times and dates of meetings.

> 'No I can't. It's never happened yet when I haven't been working and I've had a lift, because the only time my friends can take me is out of school time.' (Family member)

'We've just had to reschedule, this is the third different date we've got now. It's not because of us, it was actually the care manager couldn't make it and I've had to reschedule to suit them and not us.' (Family member)

Are they satisfied with the home?

Fourteen of 15 families interviewed said that they thought that their relative was happy living in the home. However, a strong theme in some interviews was fear of losing a place which had been difficult to obtain.

'I think there is the worry that if I was to bring up any issues they would use the excuse to withdraw the funding and the placement and it seems all wrong that you should live with this worry. But my concern is the system all together and those that haven't got someone to look out for them.' (Family member)

'There's lots of things I'd like to say but I'm frightened to because sometimes what I've said has been misinterpreted and it has come back that I've been having a dig at them…A couple of times they've thought that maybe this wasn't the right place for him, after these incidents. But what do you do. I can't physically look after him at home all the time while we look for another place. There's the funding and all that business…I don't know what the situation is, we haven't said anything.' (Family member)

'If services get a bit better and any other places come up that meet his needs, obviously I'm looking for if this place deteriorates any more. I don't think it's intentional. I think it's the turnover of staff, them getting to know the clients. I don't know I'm looking at that. I can't take him out of there because there's nowhere else for him to go.' (Family member)

When asked what the home does well, the issue raised most frequently by family carers was that they felt that staff supported service users well (8 people). Other examples were that staff were good at teaching new skills, that the person was well looked after in terms of physical care, that the service was good at involving families and they were good at providing activities.

'I think the staff treat them with great respect – that's what I like about it, they are treated as equals and they are very well looked after. They have lots of activities' (Family member)

'I think they find him easier to manage him now because the staff doesn't change all the time…he now has a good relationship with and I think that makes it easier, and also easier for them, instead of having conflicts all of the time, but from where we are concerned he has just grown up but whether that has just happened or it's the home we'll never know.' (Family member)

Five people said that there was nothing the home could do better. Of these five, three were people who said that they had found the home.

'In general the service is good. They have long term staff which is good. They have had, like every care home, times when they were run down and short staffed, but this has not lasted for any length of time. In general I am happy with the service.' (Family member)

Other family members interviewed said they would like a range of possible improvements. Some of these concerned better basic care – providing toilet paper, helping people use their aids and adaptations, better laundry.

'He comes home and he doesn't look very clean and that, nails are sort of down here. I don't know whether it's due to what staff is on or whatever… sometimes he comes home and his hair looks like it needs cutting and sometimes he's come home a bit scruffy looking but what can you do, I don't really know a way around that to be honest. I don't want to make them feel that I'm having a go…' (Family member)

'there's never toilet roll, I know that he will put it all down the toilet but it bothers me that somehow they can't seem to sort that out…That's important, that he's able to clean himself properly and not just go to toilet and leave. That's something that I think about. I did mention it before and I can't see it happening. ' (Family member)

Some people wanted more consistent staffing and better communication; better opportunities inside the home and in the community for residents to engage in activities; and changes to the type of service – making it smaller and serve only people with learning disabilities.

' a more stable full staff team. She finds it upsetting when staff leave. We have had huge problems previously when several staff were fired due to negligence…Still lots of problems, bad feeling and backstabbing going on. [They need a] more experienced staff team. Most are very young and don't know the best way of handling her. ' (Family member)

'She's had two other people living there that have attacked her, they still live there, they're more watched now apparently…I've told them I want people watching, I don't want him in the room on his own' (Family member)

'They should make more of the opportunities available to them' (Family member)

Conclusions
Interviews with 15 families of people placed in Kent from out-of-area confirm that
- A third of families said they felt they had no say in the choice of placement.
- Some families felt they had to fight hard to find and fund the right placement for their relative.
- The distance involved and transport problems do cause some families problems in visiting their relative and taking part in review meetings.
- Some families are very anxious about criticising their relatives' care, especially for fear that the resident may be asked to leave
- Almost all families said that they thought their relative was happy in the placement. However, some families identified concerns about basic levels of care in the placement.

Managers and specialists

The residential home managers
In 17 (57%) homes the manager had been in post less than 2 years but 10 of 18 managers who answered the question had more than 10 years experience of learning disability services.

Are care managers easy to contact?
Home managers were asked whether they had any difficulties contacting care managers; 13 of 28 who answered the question (46%) said they did have problems.

> 'I've never met her. The care manager he had before that placed him here, used to come every 6 months and was easily accessible he then went on secondment from team and had to give up. Been a long gap between then and giving another named care manager. We were then given one but she still did not come down and meet or visit. Had been writing, emailing, 'phoning frequently for month or so as well overdue 6 monthly review certainly and have had no contact and then got told she is on long term sick. She has now returned and is coming down next week.' (Home manager)

> 'It's just really hard to get hold of people, everyone's in meetings, they have the same problem getting hold of me really….as you well know! It's just trying to catch people at the right time, it's not anything other than that. We all experience the same thing really. Too much to do, not enough time, but she will generally get back to me. She always phones back if I have left a message.' (Home manager)

> 'one of the things that has been lacking is monitoring, an omission on both sides, hasn't been as robust as it could have been…Huge amount (of contact) a year ago – making sure the level of care was as it should be so has been monitoring, but long distance monitoring, they hadn't been to visit.' (Home manager)

Is the home able to meet the resident's need?
Managers were asked what changes they had seen in the resident since coming to the service. Twenty-one of the 26 who answered this question reported a positive change in service users since coming to that service; five reported both positive and negative changes and one person reported a negative change.

> 'He is happy. He's content here. I think the telling thing was he used to ask often to go home visits. Now he rarely instigates that himself now and when he has been at his sisters he has said "I want to go home now" which everybody is comfortable with. This is his home.'

> 'He would have an incident [it] would carry on for well over 24 hours. I think the longest was about three and a half days. Now they are very few and far between and he has managed to calm his behaviour right down and he is a pleasure to be with now.'

> 'She has come on leaps and bounds. Culturally she is really, really good, it's really positive because…her previous placement did not know how to care for her needs – her skin was scaly and her hair was falling out. We are now using creams and treatments specifically for black skin and managing her hair. Now her skin is soft and her hair is growing back. She is also a lot calmer, we haven't had as much challenging behaviours that they had in the other homes.'

Negative aspects identified by home managers were focused on whether the service could continue to meet the person's needs.

> 'lack of being with people who would complement her [abilities]. She is a lot more able than the majority of our other service users and the placement has pulled her back.' (Home manager)

> 'We've contacted them again last week and now we've written to them and said that we want an emergency review for this lady. They're saying is she in crisis, we're saying she's not in crisis but there are a number of issues with this lady at the moment - she's been ill physically, medication, and behaviourally we've had a severe increase in assaults. From a funding point of view she is actually one of our lowest fee-paying clients. Because she's been here so long her fees have not caught up. People generally stop here 2-5 years, she has been here 9 years and her fees have not caught up with anybody else and from a risk assessment point of view she's a 3:1 in the community. So whilst that's not my priority but somewhere along the line somebody's going to be saying to be this girl takes all your resources up and she's your lowest fees.' (Home manager)

> 'I suppose an awful lot of effort does go into the physical disability, just the workload. It's possible she misses out there but we put the activity side in to counteract that anyway. I think ideally if we were doing the whole placement again we would go for a small group home where she could have a more normal life.' (Home manager)

Is there sufficient access to local services?
Home managers were asked about ease of access to specialist services. Of the 25 who felt able to answer this question, 19 (76%) said they had no difficulties. Transport was a problem mentioned by two managers and one person said that access would be difficult because the resident was placed by another authority.

> 'What would be difficult are local specialised services, like if she needed a referral to a local team. Now they do consider the fact that she's from out of borough. We haven't had any reason to do that with her but we have had the problem with other service users from out-of-area. The placing authority has to send in the referral. They have been told that they should inform the local team when a service user from an outside authority comes in.' (Home manager)

> 'Sometimes we have had issues around it….If they come in with a known mental health problem the funding placement authority have to arrange mental health provision for the client as the local health authority won't touch them. If they develop a mental health problem while they are here then the local authority will assist. But if they arrive in the area with it already the local authority won't touch them' (Home manager)

There was no relationship between whether services were specialised and whether the resident concerned used specialist local services.

Care managers from the placing authorities
Thirteen care managers and four review officers from placing authorities were interviewed (all referred to as care managers in the subsequent text). Two (13%) had only been to the most recent review, 10 (63%) had been in post less than two years, 3 (19%) between 3 and 5 years and 1 (6%) between 6 and 10 years. Of those

who were not interviewed, 7 were duty officers, 4 could not be contacted despite repeated attempts, 1 interview was booked and then cancelled and in one case, the resident refused to give permission for the contact details to be made available to the researchers.

The majority of care managers had caseloads below 40, with a very wide range (7 to 150). The distribution of caseload sizes is given in Figure 18. Fifteen were able to estimate how many people on their caseload were placed out-of-area. This ranged from less than 1% (1 out of 150 cases) to 100% (50 cases).

Figure 18: Caseload of care managers/review officers
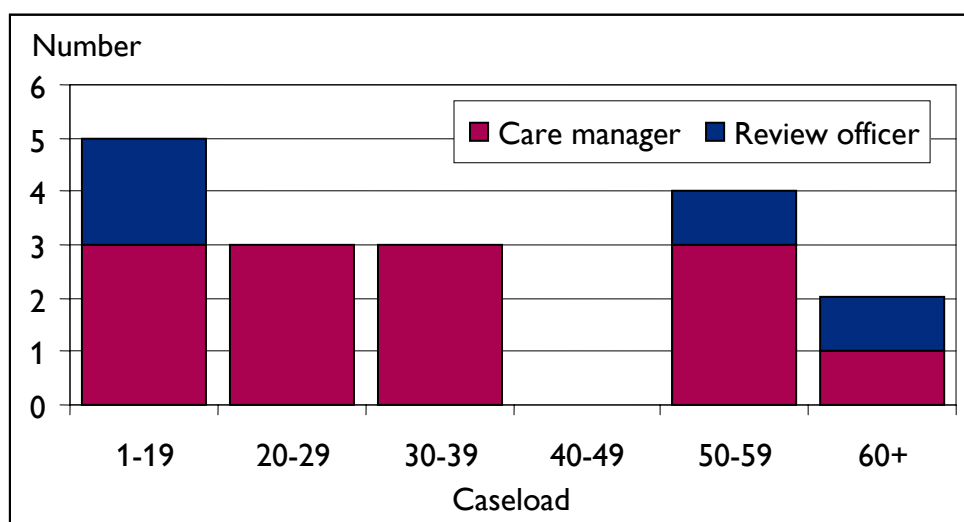
Do care managers see advantages to these placements?
Care managers were asked whether they saw advantages of the particular placement to the person resident there. All saw such advantages, mentioning that the out-of-area placements met people's specialised needs (6), were nearer to their family (2), were further from family (1), were in a rural location (4) and were in a familiar setting (4).

> 'It meets her needs. It hits the nail on the head and always has done. When she went in there it just clicked into place. The structure of working with people with autism and Asperger's difficulties is just right for her. Whether she has that or not, it doesn't matter, it works! The diagnosis is never 100% certain. It meets her needs.' (Care manager)

> 'He is appropriately placed now, they can address his physical disability needs and have worked on his challenging behaviour through providing appropriate social interaction, which he really enjoys. Therefore he has lost the label of 'challenging'. He is more outgoing and social and has interests and hobbies' (Care manager)

> 'She is a very outdoor person, she likes working in the local stables, she likes working with animals. She has currently started working on a new placement on a farm not too far from where she lives. She gets a lot out of that, she is very hard working. She's an outdoors person and I think that's where any future placements would be, I imagine she would want to live somewhere like that, if not in that area, then somewhere very countrified.' (Care manager)

> 'He loves Kent, that freedom of movement in the community, I'm not sure he would get that in London, he likes gardening, he likes pushing a wheelbarrow. There is so much land to move around in, where would I find that in London?' (Care manager)

In terms of disadvantages, 12 of 16 care managers who answered the question reported disadvantages for service users. The most common disadvantage was being further from family and friends (9), but issues also mentioned were being isolated from the wider community (1), the home no longer being appropriate to the resident's needs (1) and the move being an upheaval from a familiar environment (1).

All care managers identified distance as hindering their own work, especially where it interacted with caseload and other priorities.

> 'Obviously when we have to do the reviews then we have to travel to wherever it is, travel costs [are a disadvantage]. We can't obviously get there quickly if we had to, perhaps if there was a protection of vulnerable adults issue that came up, it would take us a while to get there. And the fact that they are probably away from their family and friends. The visits they would get would be limited; they wouldn't be familiar with the local area and things like that. There's quite a lot of disadvantages really.' (Care manager)

> 'Travel, the time it takes, the difficulty of contacting staff in the unit. The difficulties of knowing in which direction they are going in, distinct from the plans we have laid down. Changes in the pattern of care, if something goes wrong, we usually hear about it perhaps a week later and that can have a dramatic effect on what was needed and if wrong decisions were taken, it's difficult to know.' (Care manager)

> 'I think he is as good as got forgotten about… I've been a care manager in a situation where you've got a case load and crisis coming in and you have got a review that is due like him 100 odd miles away…and everything's alright, no problems, I'll cancel. And we've all been guilty of that.' (Care manager)

Three care managers found that distance also gave them an advantage in that it freed them from other work pressures.

> 'That little bit of distance…it gives you space to take the review away from everything and you can give really dedicated, devoted time to that review, that day. I don't do anything else that day. If it was in borough I would go to the review in-between working at my desk, coming back doing something else, and not give that dedicated time psychologically in quite the same way. That really is an important point. My mind is clear that day.' (Care manager)

Care managers also revealed different approaches to their job, with some clear that a relationship with the resident was important while others having a greater focus on particular tasks.

> 'I guess that the amount of contact I would have would depend on priority needs at the time, so if somebody had an ongoing issue then I might have a lot of input and if it was somebody else I might only see them at the review or occasionally. Obviously we don't have time to swan about and see, just jolly, we have got urgent work that needs doing and we have to prioritise it. If I had an issue then I would have to put more input in and if it was out of area I would still have to do that - I would still have the responsibility to do that.' (Care manager)

'I think because…my primary aim is placing new people and dealing with crises and problems, the more long-term people, who are in settled accommodation, get reviewed but I feel that I don't have a great detailed working knowledge of the case because my involvement…has been fairly minimal.' (Care manager)

'Since June of last year I've met him about five times…one of those visits, we've actually gone out and had something to eat and gone out to the cinema, which is what he wanted, to try to get to know him a little bit. The difficulty with that, is that…when you do one thing he expects it all the time and he gets very anxious. It's trying to meet his needs but not set his expectations too high, because he would like to see me every week I think. But if I set up a system that, if I leave, another social worker can't follow, then that's setting him up to fail. So it's trying to be realistic with him about what my role is and what he can expect from me.' (Care manager)

What policy does the placing authority have?
Care managers were also asked about the policy of their local authority using the three categories defined in the Mansell Report (Department of Health, 1993b):
♦ 'Removers' do not want to develop locally the competence to serve people with challenging behaviour (perhaps because they perceive the task as too difficult, or not worth the effort). They seek instead to place people who cannot be served locally in out-of-area residential placements, often at considerable expense.
♦ 'Containers' do seek to provide local services (perhaps because of the cost of out-of-area placements) but seek only to contain people in low-cost (and therefore poorly-staffed) settings.
♦ 'Developers' seek to provide local services which really do address individual needs, and therefore give higher priority to funding services which, with more staff and more training and management input, are more expensive than ordinary community services.

No-one said that they thought their authority was a 'remover'; six people said their authority was currently a 'container' but five were moving towards being 'developers'; eight were 'developers' and the remaining three were said to be moving towards being 'developers'. When asked more generally about policy, nine people said that their authority's policy was either to place people locally or to bring people back to their home area wherever possible. Only one person said their authority preferred to use out-of-area placements (though that authority was classified as a 'container' moving towards being a 'developer'). Higher costs, including travel costs, associated with out of area placements and difficulty in monitoring quality were commonly cited reasons for changing policy.

Of 13 care managers who answered the question, only six said that they would normally inform Kent of the placement being made.

Care managers were also asked about the balance of advantages and disadvantages to the local authority of making an out-of-area placement. Ten (out of 14) care managers who answered this question reported that there were benefits of out-of-area placements for the placing authority. These included access to specialist providers not available locally (7), passing on difficult cases to other health authorities (1), reducing the need to develop services in their own area (1) and in one case the therapeutic benefits to the residents of greater distance from their family. 15 out of 16 care managers answering the question reported that there were

restrictions or disadvantages to the local authority when placing people out-of-area, the main ones being cost (7), and difficulty in monitoring and getting to in emergency (5). Other disadvantages included loss of control to the receiving authority in adult protection cases (1), difficulty of working with or getting access to health professionals in a different area (2) and the person's cultural needs may not be met (1).

Members of community learning disability teams
The information presented here was collected from four of the five teams who took part in this study - one team from West Kent reported at the focus group that they did not support people from out-of-area (and indeed tended to place people out-of-area).

Community learning disability teams in Kent became integrated health and social services teams, managed by social services, in April 2004. At the time interviews were conducted, mainly health professionals attended the meetings and the focus of discussion was primarily on the health needs of individual placed out-of-area.

Within the five teams, discussions were held with 22 individuals, ranging from 3 to 5 people in each team. The team members were from a variety of backgrounds: 1 psychiatrist, 2 psychologists, 2 senior nursing practitioners, 4 occupational therapists, 5 speech and language therapists and 8 community nurses. They were an experienced group with only 4 people (18%) having less than 6 years experience.

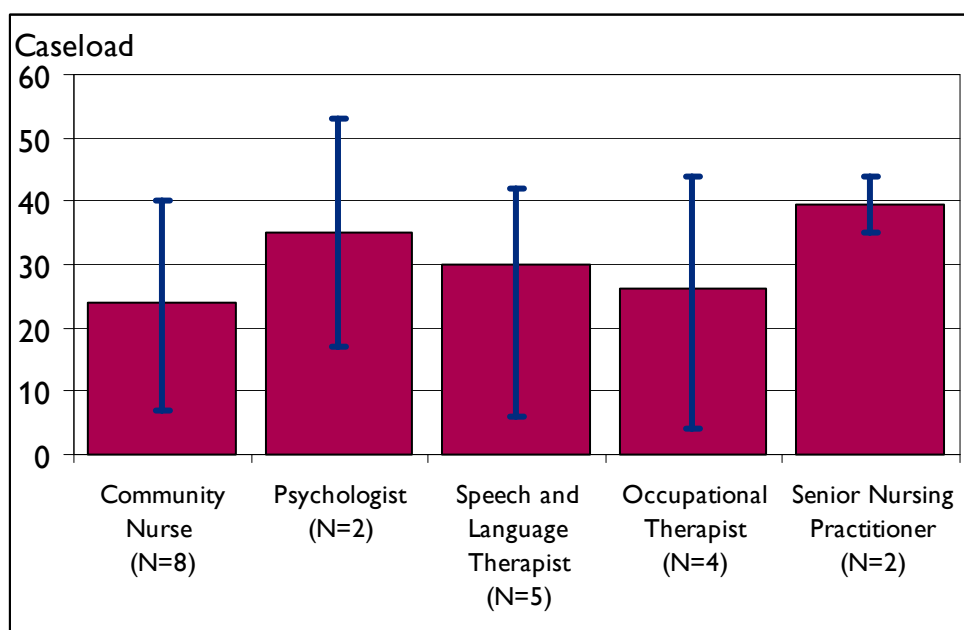Figure 19: CLDT members' caseload

Figure 19 shows the average caseload for each profession interviewed (except for the one psychiatrist, for whom this information was not available), together with the range. Team members were keen to stress that their caseload changes frequently.

How are referrals made of people in out-of-area placements?

The teams were asked whether they had a policy of not serving people placed from out-of-area or of refusing to work with homes serving these people. None of the teams had such a policy and all said that they would respond to people in need as a duty of care. Three teams had procedures to try to recover funding from placing authorities (or their primary care trusts).

Referrals to the teams typically came from home managers; only two teams had experience of referrals being made from care managers. All of the teams said they were only rarely informed of plans for service users from out-of-area being moved into the area. Typically, referrals were only made when people were in crisis.

> 'in the majority, people have been here for over a year…and suddenly they have got all of these health needs!' (Speech and language therapist)

> 'a lot of boroughs… who have placed historically around here, deliberately don't do through assessments, they deliberately don't…contact us…it's just that culture, "well, if actually if we do try to find out a lot of information and we get a lot of information back and it's negative on our assessment of that individual then I can't place him there, and then I have to start all over again and start looking elsewhere" and I think that's got a lot to do with it.' (Community nurse)

Sometimes the teams made efforts to prevent such placements.

> 'we have been able to respond and say we cannot meet this person's needs here…For example someone who was going to come out from a secure hospital, having had a number of [sexual] incidents involving children and young people, was going to be placed by the seaside, when one of his previous behaviours was seeing children… undressed when of course a beach area…seemed to us completely inappropriate for this guy…And we did actually stop that placement.' (Psychologist)

However, sometimes they were not successful.

> 'he'd actually been in a secure unit for 18 years, not had any community release at all. I wrote to them and said no, I do not feel that this is appropriate, I didn't feel the home could meet the needs, no discharge pathway, nothing. I said no, it's not on; the team will not pick this up, and its forensic anyway - he's a fire-starter as well. They placed him, they just don't write to me anymore. (Team Manager)

All four teams which had people from out-of-area on their caseloads said they would only refuse to work with a home after persistent refusal to implement the recommendations made by the professionals.

> 'We can't refuse to support the home although we tend to give less support to homes where…there is evidence over quite some period of time that they haven't actually implemented our recommendations and aren't actually doing the work and so we don't just stop doing the work with them we inform the care managers and everyone else involved, including the advocates etc'. (Senior nursing practitioner)

> 'We're probably very good at providing service level interventions and mentoring and training and things like that…and yet…three months later where's the speech and language therapy reports? And the staff have changed, all the ones that have learnt Makaton have all gone.' (Psychologist)

What is the quality of the out-of-area placements?

The teams were asked what was the quality of the out-of-area placements they dealt with. In terms of the physical environment, all the teams felt that the general standard was poor.

> 'the homes are usually smelly, big horrible, sprawling frightening, just horrible, grey, dirty, depressing environments. It takes you back years.' (Speech and language therapist)

Team members felt that staff did not have the skills required to support people with such complex needs.

> 'we've thought, goodness me, this must be picked up by care standards inspection, very often it isn't. It's just astounding…these things have just been passed, whatever the word is, allowed to continue, when things looked to me very clearly very impoverished, the environment, the quality of the work, the way that staffing levels are permitted. One staff to five people and these are very high need complex residents with learning disability and it's permissible. We are told that is perfectly acceptable. But it's these out of area homes that use that, that work to that standard. Minimum standard. (Senior nurse practitioner)

> 'the environment is quite poor…some of the staff attitude, it may be right across the board, but some of these homes where they have got people placed out of area, I find the actual attitude and standard of care is quite below the other homes in the area.' (Community nurse)

> 'they are constantly changing staff groups as well. We never get to see the same person so there is no continuity or consistency of care or approach really.' (Speech and language therapist)

All the teams felt that the quality of care in out-of-area placements was often poor and that there was insufficient monitoring of placements by the placing authority's care manager.

> 'because there isn't the support from the placing authority in a lot of cases, unless it's crisis driven, things are let slide that shouldn't be let slide. That they are placed with quite significant complex needs and quite often clearly specified needs that are then not provided for and I think that's a care management difficulty. I don't think it should be a health led issue. For example, somebody placed on medication that should be regularly reviewed and it's stated clearly in his placement notes that came with him and hasn't seen a psychiatrist until I picked up the lack of supervision on these medications, for nearly a year now. Somebody else, where they are placed knowing that they have in their child services been using physical intervention strategies and high use of Makaton and the service they are placed in has no competency in either. Yet it is clearly detailed in their care plan that this should be in place. Which I think puts both the client and others at risk, significant risk.' (Psychologist)

> 'a lot of them in out of area homes tend to have their own day services or share with another house in the community, so they don't integrate very well. They don't tend to go to the Kent colleges or adult education colleges or those other services that are out there. They tend to stay within, very institutionalised.' (Speech and language therapist)

Team members acknowledged that there was variety in quality of placements.

> 'it is very difficult…to put all out of area placements in one bracket…because there are good and bad in both and we have a few good services that are proactive…but

> we have another company called X and a lot of their services are really, really poor.'
> (Speech and language therapist)

But in general team members could only name one or two services offering higher quality care out of the large number in their area. Some people pointed out that many residential homes for people with learning disabilities were of mediocre quality.

> 'I think there's generally quite poor services all round. They may be slightly worse in some aspects. What they do tend to do generally is take people with more complex needs that they can't meet but there are examples of that in other homes as well.' (Community nurse)

Accepting this, some team members felt that the difference was that a local person's service would be monitored more closely by the care manager and the team would have more influence to change things.

> 'we would liaise quite closely with the care managers in area, we're on the ball as to what is happening in the home and if there are any issues, who to contact, it's just the communication side is so much better when you've got a care manager and the team members who you are working with you can contact and have a relationship with' (Speech and language therapist)

> 'I think that [the] whole monitoring is lost actually, the care manager role is really, really crucial in monitoring the quality of the placement. The care manager remains out-of-area, and then they are usually either closed upon placement and just go on to the duty system, at every review it's a different care manager each time so there's no continuity or they keep the same care manager but it's an annual review, so it's a one-off meeting, a snap-shot for 40 minutes, when they have time to prepare, looking absolutely brilliant in time for the review, of course we know that that's not actually the reality but we're not in that monitoring role are we.' (Speech and language therapist)

> 'Well we have bad services locally as well but I suppose the big difference is the monitoring of services and out of area placements…[the services] take on people with very, very complex needs and they haven't got the most basic training in things like autism, epilepsy and so on, they are just really ignorant and that is so worrying.' (Speech and language therapist)

Are problems properly addressed?
Given difficulties, team members believed that the interest of the individual resident were not given priority.

> 'There was an adult protection case that I was involved in recently and really the motivation for the care manager was just to keep the placement going because she didn't want the person back.' (Speech and language therapist)

> 'I would say the care manager, out of area, thoroughly agreed with what we were saying, they were really, really at a loss as to where else to place this person…it gets to something like the home being closed down by care standards or an adult protection case [before] it seems to get some movement. It seems unlikely that people will be moved just because of their needs, or when their needs change. It is very difficult.' (Speech and language therapist)

> 'He wanted to go back to London and the care manager said no, I'm going to keep him down there. He made a clear statement that he wanted to go back to London, a person of 18. It didn't suit the care manager.' (Psychologist)

Some team members felt individuals were placed out-of-area because the cost of care was cheaper

> 'they just think it's cheaper actually…they don't even think it through.' (Everyone in one team)

> 'the fact that the services provided by the homes here are relatively cheaper compared to other parts of the country, there's a huge amount of referrals coming in…setting up standards which they cannot meet and then they're falling back on us to provide services.' (Psychiatrist)

What is the effect on the community learning disability team?

Team members were asked to consider what the positive and negative effects on their own teams were of serving people placed from out-of-area. In the main, teams struggled to see any advantages. The only issue mentioned was that some members felt it led to skill development as they were supporting a larger range of people from diverse backgrounds with complex needs.

Increased workload

All the teams commented on the increased workload caused by what they felt were services setting up on false pretences. People suggested that organisations set themselves up as specialist units advertising access to specialists – who are in fact the members of community teams. The homes were charging a substantial fee but it was the community learning disability team, not the home, that was meeting the client's needs.

> 'very often houses set themselves up as challenging behaviour specialist placements or assessment units and they are in fact not that, they want to use us then as their special resource.' (Psychologist)

Commenting on one home that described itself as having challenging behaviour, treatment and assessment units, which had block referred all 15 out-of-area service users to the community team, one person said

> 'I don't know if they come under trading standards law, but they set themselves up for assessment, treatment or behavioural units and don't deliver.' (Team manager)

There was also a sense for some team members of placing authorities 'passing the buck'.

> 'somebody from duty attended and he just didn't want to take any responsibility for the changes that are happening to this man. His needs have changed. And he just kept on saying "it's your responsibility, you are Health, you do it". But they are the funding authority and the home have to meet this person's needs which they are not doing, but he just wanted to push the responsibility straight off.' (Speech and language therapist)

Lack of resources for local people

All teams felt out-of-area placements meant lack of resources for local clients.

> 'it gives us less time for our local population' (Community nurse)

> 'I think the people that are moved down here are just as much victims of the system as well. If the money or the resources followed them then that would be an answer to it all, or if there was a transfer process that somehow allowed that to happen but it's the fact that that doesn't happen.' (Community nurse)

> 'The team want…to be very proactive…and we just can't because the out-of-area clients are so challenging they take up the majority of the time. When they go into crisis, they go into a major crisis. People from [two London boroughs]…don't place your quiet little old lady; they place the most severe or challenging.' (Team Manager)

> 'we have just got so many people that are being referred now… most of us now have caseloads that are way beyond that from what we used to have and we just feel very, very stretched.' (Occupational therapist)

Difficulties in coordination

Members of all the teams raised problems with access to care managers being much more difficult when people were placed by authorities out-of-area.

> 'some of them don't have a care manager, they are with duty so most of the people you are speaking with don't have a clue who you are talking about and have never set eyes on the person so it's extremely time consuming and then it's chasing people all of the time because a lot of these people don't get proper reviews either.' (Community nurse)

> 'nobody wants to take responsibility, not even to turn up to the reviews. So some people don't even have annual reviews and that feels really wrong, that somebody is placed, particularly if they have got some ongoing needs, and yet as soon as it starts going wrong you can't contact the person that's placed to get them to come down and assist.' (Occupational therapy)

> 'my worst-case scenario was someone where I felt their needs weren't being met and between the time of my first making contact to attending a review…about six weeks later, was that there were five different care managers I had been informed had been allocated and then when we did turn up to the review, nobody came, and she rang saying "I have decided to leave the post, so I'm not coming". (Psychologist)

One team reported that they are using adult protection procedures more frequently in order to ensure a response from the placing authority.

> 'as soon as you go down the adult protection route it involves our local care managers, they then a responsibility to pick up and we get the support from them. So what we are doing is we are grappling to get the support we can and using the adult protection route as well.' (Senior nurse practitioner)

Lack of information

All the teams felt that they did not have access to accurate information, claiming that assessments were either not completed by people competent to do so, or if they had been completed they did not have access to them.

'the lack of communication…like if it's an assessment of baseline skills, there's nothing come over from where the person lived previously, so you've got to start from scratch. It must be very frustrating for the client…[There is] no history of that person. It means trawling through the notes and they haven't got the time to trawl through the notes.' (Occupational therapist)

'when I asked the keyworker of that particular man, some of the history, he just could not tell me, he didn't know. He has known the man for a year and he just could not tell me basic stuff.' (Speech and language therapist)

Conclusions

The fieldwork with managers and professionals provides evidence of problems with out-of-area placements in co-ordination and liaison, quality of services and effects on local health services. The balance of views differs however, with home managers and care managers from placing authorities having a more positive view than health professionals.

Co-ordination and liaison:
- Almost half the home managers report problems contacting care managers from the placing authority.
- All care managers identified distance as a disadvantage for them (in terms of providing care management and monitoring).
- Nearly half the care managers said they would not normally inform Kent of the placement being made.
- Members of community learning disability teams said that they were not usually informed in advance of people placed in their area and referrals to them for help were typically made when people were in crisis.

Quality of services:
- Most managers report positive changes for residents after moving to the home; those managers who identified negative effects focused on the home not being able to meet the person's needs.
- All care managers saw advantages for the person in their current placement; the most common advantage being that the placement met specialised individual needs better.
- Care managers identified distance as a disadvantage for the resident (mostly in terms of being further from family and friends).
- Although they recognised some variability in quality, members of community learning disability teams felt that the quality of services providing out-of-area placements was generally poor, with poorer monitoring of the care provided than would happen if care managers were locally based. They thought that individual needs were not given enough weight in placement decisions and some felt that people were placed out-of-area because it was cheaper.
- Three-quarters of managers said they had no problem accessing specialist services.
- There was no relationship between whether the home was specialised and whether it used local specialist services.

♦ Most care managers said that their authorities were moving towards or already were 'developers' and only one person said their authority preferred to use out-of-area placements. Higher costs and difficulties in monitoring out-of-area placements were the most commonly cited reasons for changes in policy.

Effects on local health services:
♦ Community learning disability teams reported that the effects on them of out-of-area placements were increased workload, less resource for local people, more difficulties in coordination and liaison with care managers and lack of information about people moved in to their area.

Discussion

Introduction

This study had three aims:

♦ To find out what was the policy framework for health and social services concerning out-of-area placements, the service context in which these placements occur and the implications for service users, service providers and commissioners.

♦ To estimate the number of people placed from other areas in Kent, carrying out a survey of care homes and analysis of social services records in Kent.

♦ To find out what were the reasons for and effects of out-of-area placement on the individuals, their families, the homes and the professionals serving them, through an in-depth investigation of a number of cases identified in the survey.

The resources that were available limit the conclusions that can be drawn from the study. The survey of care homes and analysis of social services records indicated some anomalies between different data sources which make it impossible to give a precise count of the number of people placed out-of-area in Kent. The small number of cases (30) included in the in-depth fieldwork limited the opportunities for statistical analysis. Nevertheless, the results of the project do indicate the nature and scale of out-of-area placement in Kent. They identify some serious problems which need attention.

Main findings

Official guidance

The review of official guidance shows a complex administrative framework, in which there are several 'grey' areas where responsibility is unclear, and where there are distinct perverse incentives for placing authorities.

The guidance comes from three different sources – the ordinary residence circular issued to local authorities by the Department of Health in 1993, the 'responsible commissioner' guidance issued to the National Health Service ten years later and the Housing Act of 1996. These were written in response to different pressures at different times – in 1993, for example, there were still over 18,000 people in long-stay hospital places for people with learning disabilities, whereas by 2003 this number had more than halved.

Taken as a whole, the guidance is inconsistent. So, for example, a person who makes their own arrangements to enter residential care in another local authority area immediately becomes the responsibility of the receiving authorities for both health and social care. A person who is placed by the local authority remains the responsibility of the placing local authority but (at present) becomes the responsibility of the receiving health authority. The distinction between a person arranging their own placement and being placed may not now be particularly useful, at a time when direct payments, enhanced choice and personalisation of service provision is a priority.

There are perverse incentives for placing authorities to override the best interests and wishes of individuals and to define the needs of people they serve as health

care, to move people placed out-of-area into 'Supporting People' housing (where they become the responsibility of the receiving authorities) and to use out-of-area placements where these are cheaper or just more readily available. These are all factors which are likely to contribute to the growth of out-of-area placements.

Number of people placed in Kent

The main finding of the survey of care homes and analysis of social services records was that, at a minimum, between 1,000 and 1,400 people are placed by other authorities in Kent and this number may be as large as 2000 people. Half the placements were in the eastern of the three administrative areas of Kent, with relatively large concentrations in the coastal towns.

This is a very substantial additional demand on those services provided by Kent authorities – adult protection by the local authority and health services by the primary care trusts. The estimated number is an increase over those in Kent, placed by Kent, of between 66% and 132%.

Reasons for placement

The fieldwork confirmed that the reasons for out-of-area placement of people with intellectual disabilities included their personal characteristics, the lack of suitable local services, the possibility that locality was not thought to be important and financial or quality incentives.

The residents placed out-of-area were, on average, less socially impaired, had more language ability and were more challenging than other populations in residential care; they also appeared to include a higher proportion of people from black and ethnic minority groups. Drawing on the wider survey, it also appears to be the case than men are disproportionately represented.

The finding that an important reason for out-of-area placement was the lack of suitable local services refers to two different motivations. Sometimes local services were not judged to be of a high enough quality (an issue raised particularly by family members) so that out-of-area placement was best. Sometimes local services were unable to support people with higher or more complex needs (for example, because of challenging behaviour). Arguably either of these is a reflection of the failure by authorities to develop a sufficiently wide range of levels and styles of support in local accommodation. If each local area had a fuller, more comprehensive range of help available then families and authorities would not be forced to seek out-of-area placement.

For a quarter of the fieldwork sample the main reason for out-of-area placement seemed to be that people had been in institutions, were not in contact with their families, and possibly therefore the people arranging their placements did not think that locality was important.

Finally it seemed that out-of-area placements were being made because in some cases authorities other than Kent would pay higher fees, while in others they were more likely to accept poorer quality services. This was a view reported both by home managers and by members of community learning disability teams. The

average costs of the placements studied was not different from that found in a larger study of residential services (a national study, so it might still be true that these rates were on average higher than Kent rates). The data did raise the possibility that the distribution was different, with a low cost and a high cost group rather than an approximately normal distribution, but the sample is too small to make this anything other than a subject for further study.

Effects on residents

The effects of out-of-area placement vary across individuals. Generally the most disabled people experience the worst outcomes. Overall, some aspects were worse than comparison studies (choice, community involvement, number of homes meeting all the national minimum standards), some were the same (participation, family visiting and other contact) and one was better (visits to families). Variation was also evident in the involvement of social services staff from the placing authority and in ease of access to local health care resources. The study did not include people placed by Kent within the same services, so it is not clear whether systematic differences are based on being placed out-of-area or on other characteristics of individuals or services.

Again, the data suggested that there might be two different groups within the sample of people placed out-of-area, one doing rather better than the other. These were not related to cost or most other resident or service characteristics, but longer length of stay and more severe social impairment might be relevant explanatory factors.

What is clear is that some individuals experience very poor outcomes and some homes are achieving well below acceptable standards of care. If the third of placements in this category found in the interview study is representative of the whole population then between 300 and 700 people might be in this situation.

This study did not examine the effects on local residents with learning disabilities of having large numbers of other people with learning disabilities placed in the same area. Local ties may be an important factor in enabling people with learning disabilities to secure their rights as local citizens and the support of their local community. This would require further study.

Families

Families could be interviewed for half the sample. A third said they felt they had no say in the choice of placement. Some families felt they had to fight hard to find and fund the right placement for their relative. The distance involved and transport problems do cause some families problems in visiting their relative and taking part in review meetings. Some families are very anxious about criticising their relatives' care, especially for fear that the resident may be asked to leave. Almost all families said that they thought their relative was happy in the placement. However, some families identified concerns about quality of care in the placement that included some of the most basic issues (like hygiene and use of prosthetic aids).

Managers and specialists

Almost half the home managers report problems contacting care managers from placing authorities. All 17 care managers interviewed identified distance as a disadvantage for them (in terms of providing care management and monitoring).

Nearly half the care managers said they would not normally inform Kent of the placement being made (despite the clear expectation in official guidance that this would be done). Members of Kent community learning disability teams said that they were not usually informed in advance of people placed in their area and referrals to them for help were typically made when people were in crisis.

Most managers report positive changes for residents after moving to the home; negative effects were focused on the home not being able to meet the person's needs. All care managers from placing authorities saw advantages for the person in their current placement; the most common advantage being that the placement met specialised individual needs better.

In contrast, members of Kent community learning disability teams felt that the quality of services providing out-of-area placements was generally poor, with poorer monitoring of the care provided than would happen if care managers were locally based.

The discrepancy between the basically positive views of home managers and care managers of placing authorities on the one hand, and Kent community learning disability team members on the other, might reflect several factors. Community learning disability teams presumably see a larger number of out-of-area placements in Kent than either home managers or the care managers, and may therefore be better placed to form a judgement about placements in general. It might be argued that home managers and care managers from the placing authorities have a vested interest in saying that their placements are good. Alternatively the different judgements may reflect different criteria being used by the different disciplines (health and social care). This is also an area which would require further research to unravel.

Community learning disability teams reported that the effects on them of out-of-area placements were increased workload, less resource for local people, more difficulties in coordination and liaison with care managers and lack of information about people moved in to their area.

Implications for public agencies

The processes at work here seem fairly clear. Families and local authorities faced with no suitable local services are driven to seek placement out-of-area. This is more likely if people have challenging behaviour or are from an ethnic minority, or if their family is dissatisfied with the quality of local services. Financial incentives make out-of-area placement an attractive proposition for some authorities.

Co-ordination arrangements are typically poor, with the receiving authority not being notified in about half of all cases. Some placements, in some respects, turn out well, although this may be at the expense of more difficult contact with family

and friends. Family members in these cases often fear making any criticism lest their relative loses their home. Some placements face problems and these place a major demand on local community learning disability teams. Official guidance is too muddled to effectively regulate out-of-area placement in the face of the practical difficulties.

Steps need to be taken to remove the perverse incentives that encourage out-of-area placement irrespective of individual need. The cost incentives to use less expensive services in rural or coastal areas would be difficult to deal with directly, so that appropriate counter-balances may need to be provided elsewhere. Examples of this might include creating a stronger entitlement for people using services to get the help they need locally, or requiring that the costs of visits to and from family and friends when people are placed out of area are met by the placing authority (instead of being met by the service user or their family).

The second group of perverse incentives concern the opportunity to escape responsibility for properly managing the care package and even providing some or all of it by placing people out-of-area. Here only one arrangement makes sense from the service user's perspective. If they move to live in a new area, they need to become part of that community and have a legitimate claim on local services. A key part of this would be arrangements for local authorities to provide care management and health care services to people living in their area. Local services would then need to be reimbursed for this extra work and this could be done either by changing existing resource allocation mechanisms or by making greater use of direct payments or other personalised budgets.

This would be entirely consistent with the principles that funds should follow the individual in the service system and that the total cost implications of services should be considered to avoid perverse incentives (Great Britain Cabinet Office Prime Minister's Strategy Unit, 2005). However this is achieved, it requires planning by the Department of Health and Office of the Deputy Prime Minister working together.

However, the most important implication for local social services and health authorities is that they should develop services that can support the full range of individual needs in their own local area, so that people are not driven to seek out-of-area placements. This was a key recommendation of the Mansell Report (Department of Health, 1993b) in respect of challenging behaviour and it has recently been reiterated by the Department of Health (2004a). The development of local services to reduce reliance on out-of-area placements is a priority for the Learning Disability Development Fund (Department of Health, 2001b). Only if local services develop the competence to support people near their homes, families and communities can people exercise real choice about where to live.

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Appendix 1: Methodology of the interview study

Sample
Thirty service users were randomly selected from the Kent County Council database described on pages 11-18. The number of 30 was chosen to allow a reasonable spread of different ages, levels of disability and other relevant characteristics (eg presence of challenging behaviour). Individuals in the database were given a random number and the database sorted by that number. The managers of the homes in which the first 30 people on the list lived were contacted and screened for the following criteria:

♦ Whether the service user still lived in that service
♦ Age
♦ Gender
♦ Ethnicity
♦ Level of disability
♦ Presence of additional/complex needs such as challenging behaviour, physical disabilities, sensory disabilities, epilepsy and communication problems.
♦ Whether there was contact with the family
♦ Who would give consent
♦ How long they had been at the placement
♦ Funding authority

Where individuals did not meet these criteria (for example, they had moved back to their funding authority), where individuals had already been included from that service or where consent was refused, the next person on the list was contacted. The participant's characteristics were monitored throughout and at the point of contacting 34 participants, it was noted that a selection bias had been created, as candidates were primarily men. Therefore women were specifically selected in the final stages of sampling – the aim was not to have equal numbers of each, as this would not have been representative of the population, but to have a big enough sample to ensure that any potential differences between the genders could be explored.

Forty-eight service managers and service users were contacted in total, with 18 refusing to take part. For four of these, it was the service user who refused. For two participants, the parents did not want to give consent for the service user to be included. In one case, the service user was about to leave the service and in two cases the manager felt it was in the best interests of the person not to be included at that time due to very difficult situations (the short timescale of the project meant that it was not possible to wait until the situation was more stable). In the remaining cases, the person who normally gave agreement in these situations could not be contacted.

In addition, focus groups and interviews were conducted with members of five community learning disability teams. Teams from all districts of Kent were approached and five teams were selected from those who came forward to take part in this research. Two teams from East Kent, one from Mid Kent and two from West Kent participated.

Measures

The Home Manager Questionnaire was developed to collect background information on the service and on the service user. It included questions on type of current placement, cost, placement history, family contact, contact with the care manager, etc. This questionnaire was sent in advance of the researcher's visit and the manager was asked to complete it prior to the visit. However, the researcher went through this questionnaire with the manager at the beginning of the interview to ensure that it was fully completed.

A Short User Survey was used to collect data on participants' needs and characteristics, in particular their level of ability and any social impairment and problem behaviour. This measure comprised off:

♦ The Short Adaptive Behaviour Scale (Hatton et al., 2001)
♦ The Quality of Social Impairment question from the Schedule of Handicaps, Behaviours and Skills (Wing and Gould, 1978).
♦ The Aberrant Behaviour Checklist (Aman, Burrow and Wolford, 1995)

Index of Participation in Daily Living (Raynes *et al.*, 1994) was used to assess how much each participant did around the home. The 13 items are scored 0, 1 or 2 with 0=does not do, 1=does with help and 2=does on own. The total possible score was therefore 26 and a higher score represented greater participation in household activity.

Choice Making Scale (Conroy and Feinstein, 1986) was used to assess the opportunity for choices offered to each participant. It is a 24 item questionnaire each scored on a scale from 1-4, a higher score representing more opportunity for choice.

The Index of Community Involvement (Raynes and Sumpton, 1986) is a 15 item questionnaire assessing whether people have accessed various community activities such as a hairdresser, pub, cinema in the past month (or in the case of a holiday, in the past 12 months). Maximum score is 15.

All of these measures were conducted by interview with the home manager/deputy manager.

Semi-structured interviews were also conducted with the home manager, the service users were possible, a family member where contact existed between the participant and their family and the care manager. In addition to the interview with the family member, a brief questionnaire was filled out at the beginning of the interview collecting information about the family member in terms of age group, ethnicity and occupation. There was repetition across interview schedules as a way of validating and assessing the reliability of responses. Consequently, this repetition also served to highlight if there were inconsistencies across respondents.

The home manager interview explored home managers' views about liaison and co-ordination with the placing authority, plus the effect on the service user.

The parent interview focused on the reasons for the placement out-of-area, the experience of the service user and the benefits and costs of the placement as they experience them.

The care manager interview was conducted by telephone. This interview also focused on why the person was placed out-of-area and what were the benefits and costs the of the out-of-area placement as experienced by the care manager.

The community learning disability team interviews also used a semi-structured interview schedule and explored the issues of team members experiences of out of area placements, the quality of services provided by these placements and any difficulties in communicating with the placing authority. It also explored whether teams had specific policies on whether and in what circumstances they intervened for people from out-of-area placements.

Procedure

Home managers were written to with information about the study and sent the consent forms. Within one week, the researchers phoned each manager to ensure that the letters had been received and to conduct the screening questionnaire. Following this, managers were asked to pass on an information letter and the consent forms to whoever should give consent. Once consent was received, a visit to the home was arranged and managers were asked to complete the home manager's questionnaire in advance of visit. At the same time, family carers and care managers were contacted were possible.

During the visit to the participant, the researcher checked the home manager's questionnaire and completed this with the manager if necessary. They then completed the Short User Survey, the IPDL, CMS and ICI by interview. Finally, they conducted the semi-structured interview with the managers. The whole process took between 1.5 and 3 hours depending how much preparation the manager had done before the visit and also how much they wanted to talk.

The service user interview was conducted in the participant's home usually on the same day as the home manager interview and took between 20 and 45 minutes on average.

The family interview was conducted in the family home at a time convenient to the family member. These interviews took approximately 1 hour.

All interviews were tape recorded, providing the respondent was happy for this to happen.

The care manager's interview was conducted by telephone – a conference telephone was used so that the interview could be recorded.

The community learning disability teams were consulted by focus group or interviews. Interviews were conducted by telephone when people were unable to attend the focus groups held during their team meetings.

Transcription, coding and analysis

All interviews were transcribed fully and then processed in two ways:

1. The main responses were coded and entered into Excel and finally analysed using Version 12 of the Statistical Package for the Social Sciences (SPSS Inc, 2004).
2. Quotations from each interview were highlighted for their potential to illuminate the issues being examined.

Questionnaires were also entered into SPSS for analysis.

Analysis was mainly at a descriptive level but non-parametric inferential statistics were used to explore possible relationships and differences that emerged from the descriptive analyses. Comparisons between two groups were conducted using Mann-Whitney U tests and chi-square as the majority of that data were at ordinal or categorical level. Association between categorical variables was analysed using chi-square analysis and relationships for ordinal level data were analysed using Spearman's Rank Order Correlation co-efficient. In some cases relationships were examined using a partial correlation coefficient in which age and ability were held constant.