

# Care standards in homes for people with intellectual disabilities

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Professor Mansell is a Commissioner for Social Care Inspection. The views presented in this report are those of the authors and do not necessarily reflect those of the Commission.

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# Summary

National minimum standards for residential care homes were introduced following the Care Standards Act 2000 in response to concern about lack of consistency and poor quality services. These standards are intended to reflect outcomes for service users and to be comprehensive in scope. This study compared ratings made by care standards inspectors with research measures for 52 homes for people with intellectual disabilities serving 299 people. The research measures focused on the lived experience of residential care, including engagement in meaningful activity, choice and participation in activities of daily living. They also included measures of related care practices and organisational arrangements. The research measures were in general significantly correlated with each other. Most of the care standards ratings were also correlated with each other. However, only two out of 108 correlations between care standards and research measures were significant. Possible reasons for this are discussed. This study confirms that the review of national minimum standards and modernisation of inspection methods recently announced by the Department of Health and the Commission for Social Care Inspection are timely and appropriate.

#### Introduction

Following a serious scandal in residential accommodation for people with intellectual disabilities in England (Buckinghamshire County Council, 1998; Pring, 2003), the Department of Health commissioned a review of regulation and inspection arrangements which concluded that they should be overhauled (Department of Health, 1996). One of the problems addressed in the subsequent policy paper *Modernising Social Services* (Department of Health, 1998) was a lack of consistency in the standards applied by different local and health authorities, for which the Department proposed national minimum standards. These were published as part of the reforms introduced by the Care Standards Act (Great Britain, 2000).

The National Minimum Standards for Care Homes for Younger Adults (Department of Health, 2002) apply to all registered care homes for people aged between 18 and 65. They are intended to "focus on achievable outcomes for service users - that is, the impact on the individual of the facilities and services of the home." They are grouped into eight sections dealing with (i) choice of home, (ii) meeting individual needs and choices, (iii) lifestyle, (iv) personal and healthcare support, (v) concerns, complaints and protection, (vi) environment, (vii) staffing and (viii) conduct and management of the home. Each standard is preceded by a statement of the intended outcome for service users to be achieved by the care home. The standards themselves are largely focused on processes. Performance of homes was assessed by inspectors of the National Care Standards Commission (now the Commission for Social Care Inspection (CSCI)).

The relationship between care processes and outcomes is not entirely straightforward. There are many examples of care practices that are carried out assiduously by staff which do not appear to actually achieve the outcomes desired for residents (eg Mansell and Beadle-Brown, 2004b; Woods and Cullen, 1983). It is also not easy to identify the best procedures or methods of working, because the variability of results achieved by the same methods exceeds the variability between methods (Mansell, McGill and Emerson, 1994). Therefore it is appropriate to ask whether the national minimum standards really do measure outcomes for people using services. When the CSCI took over responsibility for inspection it announced that it would modernise inspection processes, to refocus them on the experience of people using services rather than on administrative and organisational processes (Commission for Social Care Inspection, 2004). Subsequently, the Department of Health announced its intention to review the national minimum standards.

This study addresses whether the national minimum standards really do measure outcomes for people using services, making use of data collected in the course of a larger study of the quality of care provided by residential homes for people with intellectual disabilities. Since the ratings of standards for every home are published, it was possible to compare them with research measures of process and outcome. The primary measures used focused on the minute-by-minute experience of residents, looking at the extent to which they were enabled by staff to participate in meaningful activities in the home. Aspects of service organisation and design which contribute to this aspect of user experience were also studied. These measures have been widely used in evaluation studies (Emerson and Hatton, 1994; Felce and Emerson, 2001) and they typically show relatively good agreement with each other (Perry and Felce, 1995; Perry and Felce, 2005).

The lived experience of residential care is not the only area of outcome of importance. Current approaches to measurement of quality of life of people with intellectual disabilities identify eight domains of personal experience which are important (Schalock *et al.*, 2002):

- ♦ Emotional well-being
- ♦ Interpersonal relations
- ♦ Material well-being
- Personal development
- ♦ Physical well-being
- ♦ Self-determination
- ♦ Social inclusion
- ♦ Rights

However, central to many of these is the actual day-to-day experience of the resident. For example, *personal development* is only likely to be possible if the resident participates in activities which broaden their experience and allow them to develop new skills and interests; *interpersonal relations* depend on interacting with other people. In this way, lived experience is a particularly important outcome in that it is the vehicle by which many aspects of quality of life are realised (Bellamy *et al.*, 1990). The same point could be made about other lists of values or outcomes-such as the four principles (rights, independence, inclusion and choice) in the 2001 White Paper *Valuing people* (Department of Health, 2001); to achieve them entails that people engage in meaningful activity and relationships, with whatever support from staff they need.

The study therefore addressed two questions:

- ◆ Do inspectors' judgements of care standards agree with objective measures of service user outcome and quality of service?
- If they do not, what characteristics of services and service users do they reflect?

#### Method

#### Services

The services included in this study were 52 registered care homes for adults with intellectual disabilities provided by a large national charity in England. The homes had all been part of a larger study looking at the implementation of person-centred active support (Mansell and Beadle-Brown, 2004a). In 24 of the services staff had been trained in active support (Mansell *et al.*, 2005), there were no differences between the homes where staff had been trained and the homes were staff had not been trained in terms of performance on inspections. Therefore all homes were considered as one group for the purpose of the current analysis.

The homes served 299 adults with intellectual disabilities with a mean age of 47 years (range 31-66; SD: 7.5). Fifty-one percent were male, 97% were white British. Size of home ranges from 3 to 12 residents (mean 6). The average staff ratio (staff in post to service users) for these services was 1.5 (range 0.4-7.2). Residents had a wide range of intellectual disabilities.

#### Measures and Procedure

#### **Client characteristics**

A Short User Survey was used to gather information on the ability, social impairment and challenging behaviour of the people in each home. This Survey was based on the short form of the AAMR Adaptive Behaviour Scale Part 1 (SABS) (Hatton et al., 2001); the Quality of Social Interaction question from the Schedule of Handicaps Behaviours and Skills (Wing and Gould, 1978); and the Aberrant Behaviour Checklist (ABC; (Aman, Burrow and Wolford, 1995)). This measure was sent to the service manager in advance of visits by the researchers and completed by the key worker for each person. The scores for all service users on SABS and ABC sections were then averaged for each service. A higher score on the SABS equates to more adaptive behaviour or lower support needs, while a higher score on the ABC equates to less challenging behaviour.

#### **Service User Outcome**

The extent to which service users participated in tasks of daily living was assessed using the Index of Participation in Domestic Life (IPDL: Raynes *et al.*, 1994). The Choice Making Scale (CMS: Conroy and Feinstein, 1986) was used to assess the extent to which service users were encouraged and helped to make choices in their everyday lives. A service level score on both these measures was calculated as the mean score across all individuals within each service.

An observational measure of both service user engagement in meaningful activity and staff contact and assistance to service users, was collected using momentary time sampling (MTS) using category definitions based on those in Beasley, Hewson and Mansell (1989). The original categories were collapsed into the following:

- ♦ Social Activity
- Non-social activity
- ♦ Assistance from staff
- ♦ Other contact from staff
- ♦ Contact from other service user
- ♦ Aggression to self
- ♦ Aggression to others
- ◆ Damage to own or other's property
- Any other challenging behaviour.

In addition, researchers used a "missed observation" code to record if they could not see what the focal person was doing at the point of observation. Researchers did not follow people into bathrooms or observe personal care of service users. The only followed people into their room if it was clear that the person was engaging in an activity there (eg cleaning). Consent or advocate agreement was gained for all service users prior to starting the study. In addition, researchers monitored service user reactions to being observed and either moved to a different room or stopped the observations if any service users appeared upset by their presence. Observations were carried out over a two hour period between 1630 and 1830 and each service user present in the home was observed for 5 minutes in rotation. A time interval of one minute was used. The percentage of time observed was calculated for each service user and then averaged across service users to give a service level percentage.

# **Service quality**

The quality of staff support was measured using the Active Support Measure (ASM: Mansell and Elliott, 1996). This was completed for each service user at the end of the observational period. It includes 15 items, each scored on a scale of 0 (poor, inconsistent support/performance) to 3 (good, consistent support/performance). The items are:

- Age-appropriateness of activities and materials
- 'Real' rather than pretend or very simple activities
- ♦ Choice of activities
- ♦ Demands presented carefully
- Tasks appropriately analysed to facilitate service user involvement
- ♦ Sufficient staff contact for service users
- Graded assistance to ensure service user success
- Speech matches developmental level of service user
- ♦ Interpersonal warmth
- Differential reinforcement of adaptive behaviour
- Staff notice and respond to service user communication
- ♦ Staff manage serious challenging behaviour well
- Staff work as a coordinated team to support service users
- Teaching is embedded in everyday activities

The maximum possible score was 45 and for each person a percentage score was calculated. This percentage score was then averaged across individuals within each service to produce a service level score.

The Revised Residential Services Setting Questionnaire (RRSSQ: Welsh Centre for Learning Disabilities, Institute for Health Research and Centre for the Economics of Mental Health, 2003) was used to collect information about the service setting, the quality of the environment in terms of homeliness, the systems and structures in place within the service to support service user involvement and activity and staff training. The RRSSQ was completed by interview with the service manager in each home. The items from this questionnaire used in the current study are as follows:

- ♦ Mean score on *Homelikeness* items (Dining room, living areas, bathrooms, bedrooms, garden-scores range from 1 being very homelike to 5 being non-homelike)
- Rating of *Person-centred or individual planning working methods* with scores ranging from 1 (no operational planning system) to 4 (operational planning system that meets regularly with clear mechanisms for communication/review among staff).
- ♦ Rating of *Assessment and teaching of clients* with scores from 1 (no regular behavioural assessment and no written individual teaching programmes) to 4 (operational system for assessment and treatment where plans include clear criteria for success and monitoring of progress).
- Rating of *Planning daily/weekly activities for clients* with scores from 1 (no planning of resident activity) through to 4 (operational system of planning of activities and clear mechanisms for monitoring and review).
- Rating of *Staff support of resident activity* with scores from 1(staff support left to staff on duty to work out/staff role undefined) to 4 (written procedure on staff allocation to resident support, staff role defined and staff receive related training).
- Rating of *Training and supervision of staff* with scores from 1 (no formal training or basic induction only) to 4 (induction and further training around resident activity

provided and clear mechanisms for staff supervision and appraisal at least annually).

## **Care Standards Ratings**

The inspection reports for each service were downloaded from the CSCI website or obtained from the local offices where they were not available on the website. The final database was derived using the most recent inspection, supplemented by ratings from previous reports when that standard had not been assessed in the most recent report. Both announced and unannounced inspections were included. Services' performance on standards are rated on a scale of 1 (not met), 2(nearly met), 3 (standard met) to 4 (standard exceeded). The percentage of standards met was calculated for each of the eight domains, covering choice of home (standards 1-5), individual needs and choices (standards 6-10), lifestyle (standards (11-17), personal and healthcare support (standards 18-21), concerns and complaints (standards 22-23), environment (standards 24-30), staffing (standards 31-36), conduct and management of the home (standards 37-43). The percentage of standards met overall was also calculated as a general measure of performance.

### **Analysis**

Four sets of relationships were analysed using Spearman's product moment correlation coefficients. These were relationships between:

- each of the service user outcome and quality of service measures from the Mansell and Beadle-Brown (2004a) study
- the domains of the national minimum standards
- the national minimum standards domains and the objective measures of service quality
- the national minimum standards domains and characteristics of the services and service users.

In addition, the outcome measures, total ASM score and scores for the 'assistance' item of the ASM were recoded into quartiles to reduce the data to nominal level and a chi-square analysis was used to check whether there were any associations between the scores on individual standards (rated 1 to 4) and each of the recoded service user outcome and quality of service.

Due to the large number of individual analyses, results were only considered robust if they were statistically significant at the 0.01 level.

#### Results

Table 1 presents summary information on service user characteristics and the measures of service quality.

Table 1 Service user characteristics and measures of quality

Measure	Mean	Range
SABS percent of total score	57%	9-93%
ABC percent of total score	15%	1-39%
Engagement in non-social activity percent observations	53%	16-81%
IPDL percent of total score	48%	1-92%
CMS percent of total score	85%	50-99%
Assistance from staff percent observations	9%	0-38%
ASM percent of total score	58%	12-97%
NMS percent of standards met overall	82%	53-100%

# Relationships between user outcome and quality of service variables

Table 2 presents the correlation matrix for five service user outcome and seven quality of service variables. Correlations are presented both for engagement in activity overall and separately for social and non-social activity.

In general, there was evidence of association between most of these measures.

Among the measures of service user outcome, engagement correlates significantly with participation in domestic tasks. This appears to be due to social, rather than non-social activity, so that the more social activity observed among residents the more participation in daily living was reported. Social activity was also significantly correlated with choice-making. Choice-making and participation in daily living were also significantly correlated.

There were significant inter-correlations between the subsections of the RRSSQ. The section of the RRSSQ concerned with staff support of resident activity was significantly correlated with the observational measures of the quality of staff support (ASM and Assistance).

Engagement overall was strongly correlated with active support and the RRSSQ activity rating. Non-social activity was significantly correlated with active support and specifically with assistance. Participation in daily living was strongly correlated with active support and with the RRSSQ activity and assessment and teaching ratings.

# Relationships between different domains of care standards inspections

The inter-domain correlations for the care standards ratings can be seen in Table 3.

Ratings for the majority of domains inter-correlate significantly. The exceptions are that *Personal and healthcare support* did not correlate with any other domain, nor with overall score, and *Environment* was only correlated with *Choice of home, Staffing* and overall score.

# Relationships between care standards ratings and user outcome and quality of service variables

Table 4 shows the results from the correlations between the care standards domains and the outcome and service quality measures. Only two correlations were significant. There was a significant positive relationship between *Choice of home* and the percentage of time users were engaged in social activity. The second significant correlation was between non-social activity and *Individual needs and choices*. This was a negative correlation, so non-social engagement was lower in homes where more of the standards within the domain of individual needs and choices were met.

For the most part, the correlations were low and far from significant. Even the two that were significant at the 0.01 level had relatively low r values. The picture is one of few relationships between care standards ratings and other measures of service quality and service user outcome.

In order to check whether this lack of a relationship between variables was the result of focusing on percentage of standards met, rather than actual scores, the ratings for each standard was compared with the outcome and quality variables recoded into quartiles. For example, Standard 12 is focused on the outcome that service users are able to take part in age, peer and culturally appropriate activities, and is assessed by

Table 2 Correlations between research measures

	Engagement overall	Social activity	Non- social activity	CMS	IPDL	ASM	Assistance	RRSSQ IPP	RRSSQ Activity	RRSSQ Support	RRSSQ Training	RRSSQ Teaching
Engagement overall			activity									
Social activity	0.629***											
Non-social activity	0.754***	0.111										
CMS	0.340*	0.590***	0.052									
IPDL	0.596***	0.540***	0.339*	0.617***								
ASM	0.529***	0.327*	0.437**	0.243	0.567***							
Assistance	0.352*	0.166	0.391**	0.231	0.147	0.290*						
RRSSQ IPP	0.028	-0.132	0.103	-0.070	0.165	0.135	0.181					
RRSSQ Activity	0.353**	0.078	0.282*	0.228	0.389**	0.323*	0.284*	0.472***				
RRSSQ Support	0.350*	0.083	0.261	0.129	0.225	0.392**	0.471***	0.317*	0.607***			
RRSSQ Training	0.255	0.161	0.157	0.165	0.314*	0.340*	0.160	0.230	0.48***	0.451**		
RRSSQ Teaching	0.292*	0.036	0.342*	0.166	0.357**	0.228	0.239	0.307*	0.399**	0.350*	0.526***	

<sup>\*=</sup>p<0.05, \*\*=p<0.01, \*\*\*=p<0.001

Table 3 Correlations between care standards ratings

Percentage of standards met	Choice of home	Individual needs/ choices	Lifestyle	Personal/ healthcare support	Concerns/ complaints/ protection	Environment	Staffing	Conduct/ management of home	All standards
Choice of home									
Individual needs/ choices	0.503***								
Lifestyle	0.455**	0.375**							
Personal/ healthcare support	0.063	-0.016	-0.206						
Concerns/ complaints/	0.452**	0.465**	0.339*	0.256					
protection									
Environment	0.490**	0.307	0.164	-0.103	0.153				
Staffing	0.547***	0.446**	0.437**	0.158	0.39**	0.413**			
Conduct/ management of	0.436**	0.395**	0.388**	0.132	0.499***	0.181	0.406**		
home									
All standards	0.760***	0.655***	0.628***	0.081	0.633***	0.591***	0.706***	0.741***	

<sup>\*=</sup>p<0.05, \*\*=p<0.01, \*\*\*=p<0.001

Table 4 Correlations between research measures and care standards ratings

	Choice of	Individual	Lifestyle	Personal/	Concerns/	Environment	Staffing	Conduct/	All
	home	needs/ choices	-	healthcare	complaints/		_	management of	standards
				support	protection			home	
Engagement overall	0.158	-0.189	0.032	-0.188	-0.182	0.025	-0.028	0.256	0.152
Social activity	0.376**	0.143	0.227	-0.24	0.114	0.294	0.141	0.297*	0.358
Non-social activity	-0.002	-0.370**	-0.104	-0.073	-0.25	-0.102	-0.084	0.144	0.05
CMS	0.122	-0.155	0.23	-0.254	-0.129	0.19	0.084	0.021	0.099
IPDL	0.093	-0.053	0.161	-0.150	-0.127	0.063	0.105	0.145	0.109
ASM	0.087	0.144	0.320*	-0.233	0.038	0.106	0.12	0.043	0.332
Assistance	0.015	-0.277	-0.14	0.058	-0.172	-0.003	-0.078	-0.146	0
RRSSQ IPP	0.059	-0.034	-0.076	-0.024	-0.208	0.085	0.02	-0.035	0.048
RRSSQ Activity	-0.009	-0.088	-0.028	-0.186	-0.292*	0.135	0.041	-0.021	0.082
RRSSQ Support	-0.097	-0.117	-0.073	-0.351*	-0.307*	-0.126	-0.062	-0.142	-0.108
RRSSQ Training	0.277	0.238	0.219	0.03	0.021	0.095	0.238	0.11	0.259
RRSSQ Teaching	0.045	-0.149	0.043	0.099	-0.263	0.064	0.006	0.067	0.15

<sup>\*=</sup>p<0.05, \*\*=p<0.01

the extent to which staff help service users take part in activities and facilitate their access to activities. Engagement in meaningful activity and support provided by staff to facilitate participation were the focus of several of the research measures.

Although there were a number of comparisons (11 out of 344) which were significant at 0.05, only one was significant at less than 0.01. This was for the first standard in the *Conduct and management of home* domain ("The registered manager is qualified, competent and experienced and meet its stated purpose, aims and objectives"), which was significantly associated with percentage of time service users were receiving assistance from staff to participate in activity ( $\chi^2 = 17.23$ , p=0.008, df=6, N=52). However, given the number of comparisons conducted, even this result should be viewed with caution.

# Relationships between care standards ratings and service and service user characteristics

Given that ratings against the national minimum standards do not appear to reflect the measures of outcome and process used here, what do they reflect? The care standards ratings were compared with a range of user and service characteristics for which data were available. These included age, adaptive behaviour, challenging behaviour, mean score on the RRSSQ *Homelikeness* scale, number of residents and staff ratio. None of these were significantly correlated at the 0.01 level with any of the care standards ratings. The largest correlation coefficient (-0.286, p=0.044) was between number of residents and *Individual needs and choices*, where larger homes met fewer standards in this domain.

#### Discussion

The summary data suggest that these homes are rather typical of residential homes for people with intellectual disabilities in England. The average size of home (6 places) is similar to that of 5 reported by Mansell *et al* (2002) from a national study of services for people with intellectual disabilities, though a little less than the figure of 8 reported for care homes for all younger adults (National Care Standards Commission, 2004). The average staff ratio (1.5) is the same as that reported by Mansell *et al* (2002).

Residents had somewhat lower support needs and less challenging behaviour than that reported by Mansell *et al* (2002). Participation in daily living and choice-making are rather higher than reported from a national study in the late nineteen-eighties by Raynes *et al* (1994). Engagement in meaningful activity and assistance from staff are similar to those found by Hewson and Walker (1992) in a study of services provided by a health trust, though higher than in a recent study by the Social Services Inspectorate (Felce *et al.*, 1999). Average active support score (58%) was also higher than in the sample studied by Mansell *et al* (2002). Higher scores on the measures used here may well reflect resident ability since this is a consistent finding of research in this area (Felce and Emerson, 2001; Mansell *et al.*, 2003).

The finding that, in general, measures of service user outcomes and related processes do not correlate with ratings made using the national minimum standards is, perhaps, surprising. Given that the national minimum standards are supposed to be comprehensive and to reflect the outcomes experienced by service users, not to find a clear relationship implies that Government intentions are not being given effect.

One possible explanation for this result is that the national minimum standards are measuring either a different set of outcomes or different processes, not detected by the research measures used in this study. It is true, for example, that there is no measure in this study of social inclusion. However, some of the standards do relate quite closely to aspects addressed by the research methods. For example, the failure to find a relationship between homelikeness and the environment standards, or between engagement and participation in daily living and the lifestyle standards, is hard to explain. It may be judged implausible that the standards could be measuring important outcomes which were not reflected at all in the lived experience of residential care, as assessed by measures of engagement, activity and choice.

Even if the national minimum standards measure something else, the question arises whether they should be measuring user experience of participation in activity and choice. These are outcomes of central importance in the day-to-day lives of people and to have a national system of quality assurance which fails to capture them may be difficult to defend.

A further possibility is that lack of consistency between inspectors' judgements is so substantial that it prevents inspectors reliably detecting differences between services. Consistency of inspection judgements has been a major concern for the CSCI (2004).

This study represents an early attempt to match ratings using the national minimum standards against established measures of service quality. Although the services included appear to be broadly representative of those for people with intellectual disabilities in England, further research could usefully include as wider range of research measures, client groups and types of service. However, the findings of this study are quite clear. They suggest that the assessment of services using the national minimum standards does not yet reflect important user outcomes. The review and reform of the standards and inspection processes already announced by CSCI and Department of Health is therefore timely and appropriate.

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