Full title:

Assessment and treatment units for people with intellectual disabilities and challenging behaviour in England: an exploratory survey

Abstract

Background

Evaluative studies have shown that special units for people with intellectual disabilities who have challenging behaviour units have advantages and disadvantages. There has been no survey of their number or characteristics for nearly 20 years.

Methods

A questionnaire was sent to all NHS Trusts that had intellectual disability inpatient beds, and all private or voluntary health care establishments providing services for people with mental health problems or intellectual disabilities. This asked for information about the unit, its residents and the views of the unit manager.

Results

44 agencies confirmed that they provided assessment and treatment units, of which 38 returned questionnaires. These units served 333 people of whom 75% had mild or moderate intellectual disability. A quarter had been there more than two years. Forty per cent of residents had a discharge plan and 20% had this and the type of placement considered ideal for them in their home area. The main strengths of the units were identified as the knowledge and experience of the staff and having sufficient staff; the main problems as inappropriate admissions, bed-blocking and the relationship with other services; difficulties with recruiting and retaining staff; the location and environment of the unit and the mix of residents.

Conclusions

There has been an increasing rate of provision of special units, which now predominantly serve people with moderate or mild intellectual disability. This model of service provision is becoming more widespread but the potential problems identified 20 years ago are still present. Areas are identified for further research.
Introduction

During the main phase of the replacement of long-stay institutions by community services for people with learning disabilities in England, in the nineteen-eighties, the best form of service provision for people with intellectual disabilities who presented challenging behaviour was the subject of debate. On the one hand, it was argued that special units should be set up to provide backup to community services, to cope with placement breakdown and to provide specialist assessment and treatment in more controlled circumstances and with more expert staff than community-based services could provide (Day, 1983; Royal College of Psychiatrists, 1986). On the other, critics suggested that such units would not help develop the capacity of community services, would fill up with people for whom no suitable long-term placement could be found, would mix residents with very different needs and thereby risked perpetuating models of congregate care consistently shown to be of poor quality (Blunden and Allen, 1987; Newman and Emerson, 1991).

The evidence of empirical studies of special units suggests that they can provide expert assessment and sustain effective implementation of treatment, with good results, at least in the short-term (Bruhl et al., 1982; Clare and Murphy, 1993; Dockrell et al., 1993; Fidura, Lindsey and Walter, 1987; Hoefkens and Allen, 1990; Murphy et al., 1991; Murphy and Clare, 1991; Xenitidis et al., 1999). However, it also shows that they do have problems with transfer of successful methods of management to the community (Fidura, Lindsey and Walter, 1987; Hoefkens and Allen, 1990) and with ‘bed-blocking’ or ‘silting-up’ (Clare and Murphy, 1993; Dockrell et al., 1993; Hoefkens and Allen, 1990; Murphy and Clare, 1991; Smith and Berney, 2006). Recent data from the Healthcare Commission (2006) shows that a quarter of people with intellectual disabilities placed in assessment and treatment units by primary care trusts have finished their treatment. Investigation of abuse and neglect in services for people with intellectual disabilities in Cornwall found no assessment and treatment plans in two of three units, coupled with poor-quality practices associated with institutional care (Healthcare Commission and Commission for Social Care Inspection, 2006).

Given mixed evidence for the success of special units, policy guidance (Department of Health, 1993) emphasised the importance of developing the capacity of local services in the community, reserving the role of special units for short-term assessment and treatment. There
is no central register of such units but their use is thought to have grown. In 1987, a survey by Newman and Emerson (1991) identified 19 such units in England and Wales. Three-quarters of the people served had severe intellectual disabilities and 61% had lived in the unit more than 2 years. Units served many functions (including assessment and treatment, containment, residential and day care, respite care and staff training). A minority (38%) of units provided outreach to community-based services. The average size of units was 17 places but this varied widely, from 4 to 30. Average occupancy was 71%. Informants’ ‘ideal’ size for the unit averaged 10 places. The purpose of this study was to repeat this survey for England to find out how many units there were, what were their characteristics and what advantages and disadvantages they were perceived as having.

Method

Ethical approval
Application for ethical approval was made to a Multi-Centre Research Ethics Committee of the English National Health Service. Having considered the application, the Committee determined that ethical approval was not required since none of the data collected identified individuals.

Participants
The project aimed to survey all assessment and treatment units for people with intellectual disabilities and challenging behaviour in England. The definition of assessment and treatment units was adapted from the Specialised Services National Definitions Set (Department of Health, 2002):

“An inpatient facility that provides intensive treatment and assessment for people with severe complex needs that cannot be managed in a community setting, including:

♦ People with learning disabilities and severe challenging needs presenting major risks to themselves and/or others
♦ People with learning disabilities who have severe mental health problems which cannot be addressed by general psychiatric services
♦ People with learning disabilities and autistic spectrum disorder with severe challenging and/or mental health needs.”
There is no central list of assessment and treatment units for people with intellectual disabilities and challenging behaviour in England. Therefore a questionnaire was sent to (i) all NHS Trusts that had intellectual disability inpatient beds, using data from the current edition of the Health Services Yearbook (Institute of Health Care Management, 2004) and (ii) all private or voluntary health care establishments registered by the Healthcare Commission to provide services for people with mental health problems or intellectual disabilities. The questionnaire was sent by post to 158 agencies.

Where possible, the questionnaire was sent directly to the manager of the assessment and treatment unit. However in many cases it had to be sent to the agency with a request that it should be passed on to the manager if such a unit existed. The covering letter asked recipients to forward the questionnaire to the manager of “any assessment and treatment unit for people with learning disabilities that the Trust/agency provides.” After three weeks, 140 organisations that had not responded were telephoned and further questionnaires were sent out as necessary to try to ensure the best return rate.

**Questionnaire**

The questionnaire was developed specially for this study. It covered the same areas as Newman and Emerson (1991) but sought more information about resident characteristics and plans. The questionnaire included 31 items covering the following topics:

**Characteristics of unit**
- Location
- Building characteristics
- How long unit has been open
- Number of places
- Number of places occupied
- Main function of the unit
- Whether unit provides outreach service
- Staff establishment and number of staff in post

**Characteristics of current residents**
- Age
- Gender
- Ethnicity
- Level of intellectual disability
- Additional disabilities and problems
- Family contact
- Whether detained under the Mental Health Act
- Type of accommodation this person previously lived in
- Actual length of stay

**Views of unit manager**
Perceived strengths of unit

Perceived problems faced in fulfilling unit function

Required changes in community based services for people with challenging behaviour to better meet the needs of service users

Projected length of stay

Whether a discharge plan been completed

Ideal type of placement after discharge

Whether such a placement exists in person’s local area

Type of placement to which person is expected to return

Copies of the questionnaire can be obtained from the authors. Questions about characteristics of current residents were asked by presenting a grid of items by residents so that information was collected (anonymously) at the level of the individual. It was not considered practicable to assess the test-retest reliability of the questionnaire.

Results

Of the 158 agencies contacted, no information could be obtained from 39. Seventy-five reported that they did not provide an assessment and treatment unit for people with intellectual disabilities. Of the 44 who confirmed that they did provide this kind of service, completed questionnaires were received from 38 units (86%). No organisations reported providing more than one unit.

Characteristics of units

Fifteen units (40%) were on their own sites. The remainder were located with other intellectual disability services (11, 29%), mental health services (6, 16%) or other health or social services (6, 16%). The majority (23, 61%) were pre-existing buildings which had been adapted for their current purpose. Units were on average 9 years old: 6 opened before 1990, 15 from 1990 to 1999 and 14 from 2000 to 2004. It was not possible to distinguish units provided by the National Health Service from those provided by private or voluntary organisations.

The average number of places available in each unit was 13 (range 4-88, sd 15.4). Two units, one of 6 places and one of 16, had no-one currently resident (in the former case because of funding problems and in the latter because it was new). On average 78% of places were taken, with half the units being full. Two of these had one more person resident than they had
places. Managers were asked what would be the ideal unit size, and all but one replied. Four (11%) said the ideal size would be larger; nine (24%) said the unit capacity was the ideal size; and 24 (65%) said the ideal size would be smaller, including two who said that ideally they would not need a unit at all.

The majority of units said that their main function was to provide assessment and treatment; 21 (55%) said that their focus was assessment and treatment of challenging behaviour, 10 (26%) said that their focus was mental health and one (3%) both. Four units (11%) said their main function was to provide accommodation in response to a crisis and two units (5%) that their main function was permanent accommodation. Eleven units (29%) provided an outreach service. For units where the main function was assessment and treatment, there was a strong association between whether their focus was challenging behaviour or mental health and whether they provided an outreach service. Nearly half the challenging behaviour units provided an outreach service, whereas only one of the ten mental health units did so ($\chi^2=4.188$, df=1, p<0.05).

The number of posts established for nursing or care staff varied widely and was correlated with the size of unit ($r=0.92$, p<0.001). Of the 34 units where information was supplied, 24 provided an average number of nursing or care staff per resident of less than 3.4 (enough to provide 1:1 support). Seven units provided between 3.4 and 6.8 nursing or care staff per resident. The remaining three provided, respectively, 22 staff for 3 residents in a unit with 5 places, 19 staff for two resident in a unit with 5 places and 18 staff for one resident in a unit with 4 places. There was a correlation between unit size and the amount of nursing and care staff per resident. Excluding the unit where 18 staff supported one person and the unit of 88 places as outliers, the larger the unit the less staff time was available per resident ($r=0.71$, p<0.001).

Three units reported more nursing and care staff in post than they had posts established; 7 had a full complement; 26 had less than their establishment and 2 did not provide data. Of the 26 which had fewer staff in post than post established, the average shortfall was 19% (range 4-53%).
Twenty-six units (68%) reported that they had a psychiatrist in intellectual disabilities in post and 20 (53%) that they had a psychologist. Other medical doctors were reported by 18 (47%). Only 10 units (26%) reported that they had physiotherapists in post; 10 (26%) that they had speech and language therapists in post; and 6 (16%) units reported either a music or an art therapist. Twenty units (53%) reported other therapists (such as occupational therapists) in post.

Characteristics of current residents

There were 333 people living in the units at the time of the survey. Their average age was 36 (range 14-74, sd 12.8), 69% of them were male and 91% of them were white. The age distribution is given in Figure 1 and shows that the male population is significantly younger than the female (t=-2.534, df=327, p<0.05).

The largest group of residents (73%) had mild or moderate intellectual disability. 20% had severe or profound intellectual disability, 7% borderline or no intellectual disability. In addition, 12% were identified as having another disability, such as a visual or hearing impairment or physical disability and 19% had a diagnosis of autism. Forty per cent of residents were detained under the Mental Health Act. Half the units had both residents with severe or profound intellectual disabilities and residents with mild, borderline or no intellectual disability.

Sixty percent of people had been visited by family or friends from their home area within the last month. Twenty percent of residents were not visited.

People in units where the main function was described as permanent accommodation have been there on average 9.3 years (range 3 months to 27 years 7 months). Residents in the other units had been there on average 21 months, but with a very wide range (0-285 months). A quarter of residents had been there more than two years, with 9% having been there more than five years. (Table 1). Eighteen (47%) of the units included both residents who had been there less than six months and residents who had been there more than two years.
Table 2 shows the distribution of residents admitted from different types of placement, the type identified as ideally suitable for them and the type they were actually expected to go to by their managers. The main shifts in the pattern of placement between admission and what managers judged were ideal, were a marked reduction in the number of people living with their parents or in their own home (24% to 5%), increases in the use of supported living (17% to 45%) and residential homes (30% to 35%) with reductions in hospitals and other placements. These shifts were slightly lessened when managers were asked what kind of placement they actually expected the person to move to.

When managers were asked whether the ideal type of placement existed in the person’s home area, they knew such a placement existed for 39% of residents. There were discharge plans for 40% of residents. Twenty-one per cent of residents had both a discharge plan and the type of placement considered ideal existing in their home area. People with a diagnosis of autism were significantly more likely to have a discharge plan ($\chi^2=7.18$, df=1, p<0.01). There was no relationship between existence of a discharge plan and previous accommodation, length of stay, family contact, level of intellectual disability, presence of other disabilities, detention under the Mental Health Act, ethnicity or gender.

**Views of unit manager**

There were recurring themes in what managers identified as the particular strengths of their unit. The largest number of respondents (28) described the *knowledge and experience of the staff team* as a strength:

> “Experience of supporting individuals with complex needs. Has positive value base and person centred approach. Good communication with community teams. Experienced staff team.”

As well as the skills of the staff team some managers highlighted their *philosophy*:
“A firm belief in the use of non-aversive, low arousal, non-confrontational approaches to managing challenging behaviour. Many service users admitted to the unit have been excluded from other assessment and treatment services or refused admission, yet we have been able to offer a service with good success and discharge rates.”

Links with professionals and effective multi-disciplinary teamwork were the next most common response (13):

“The service has a number of skilled and expert clinicians who respond to the needs of clients whose needs are of a complex nature that they cannot be addressed in the mainstream.”

“Very flexible. Good team – full multi-disciplinary team and hands on working together. Lots of reflection – sharing good practice built in, self critical – striving to improve and move on. Person centred – pro active. Genuinely aims to get to see the world from client’s point of view and support them. Good communication. Aiming to keep people at home.”

Other strengths were identified as sufficient staff with low turnover (6), a small scale environment (3), adequate space (2) and the ability to achieve good standards of care (3).

The problems identified by managers could be grouped under four broad headings: problems with inappropriate admissions, bed-blocking and the relationship with other services (20 respondents); difficulties with recruiting and retaining staff (17); the location and environment of the unit (9) and the mix of residents (5).

Some managers suggested that their unit was used inappropriately:

“Inappropriate use of the unit for crisis respite when placements break down”

Many managers commented that placements for people once their assessment and treatment was complete were often not available:

“Patients are admitted and sometimes this results in long term care due to the unsuitability of potential placements. People become delayed discharge due to areas they were admitted from being unable to take them back”
This caused problems of hurried discharge or placements which were unable to sustain the person:

“Delayed discharges – clients become long stay patients. Staff lose assessment and treatment focus. Beds not available when emergencies occur. Hurried discharges of clients when unit is full and an emergency admission is required – not always to the most appropriate setting. Unit has a number of clients who have been re-admitted following discharges”

Co-ordination with services in people’s home area was also identified as a problem:

“Geographical isolation from referring teams and patients’ home localities…as we admit from around the country this impacts upon developing established relationships with community teams and the patients/families opportunity to engage with local rehabilitation programmes.”

Difficulties with recruiting and retaining staff included both direct-care staff and professional specialists:

“Constantly short-staffed. Staff work long hours, reliance on agency (often little or no experience of challenging behaviour)”

With regard to the physical and geographical environment of the units, managers identified poor quality and also location as problems:

“The environment is without doubt the biggest problem. The unit is purpose built and becomes damaged very easily.”

Finally, 5 managers identified problems of mixing residents with very different needs in one unit as a problem:

“The other issue is being able to nurse service users in separate environments when there are compatibility problems or service users who have severe challenging behaviour/autism having to be in the same place as people with mild learning disability and mental health issues.”
How should community based services change to better meet the needs of people with challenging behaviour and mental health problems?

Managers were asked their opinions as to how services could change to better meet the needs of service users with challenging behaviour and mental health problems. Thirty-five managers responded to this question, making suggestions that fell into four groups: better community services (20), better outreach or support to community services (21), more effective joint working (10) and different approaches to treatment or management (9).

In terms of better community services, managers identified the need for more small-scale accommodation in the community that could support people with challenging behaviour or mental health problems:

“Better commissioning process for setting up services ie more variety of placement options – group homes/supported living etc; speedier process for setting up new services.”

Support for families caring for individuals at home and the provision of day care that could support people with challenging behaviour was also frequently suggested:

“Provision of suitably trained staff to support people in their homes in times of crisis and, or mental health deterioration; Adequate day care services, paid occupation, further education, skills training.”

Better staff training and more skilful work by staff in community services were also identified:

“Skill levels of care staff in services offering specialist care and support need to be driven up. Current standards seem variable.”

Suggestions for better outreach and support for community services mainly concerned specialist teams:

“Emphasis of all such services should be outreach/community based services. Some in-patient services need to remain, but in terms of resource focus community outreach teams should be heavily resourced, rather than the other way round. Access to mainstream central health services for people who have mild learning difficulties is very difficult, almost
impossible…Need to be dedicated liaison people to work between services and access to services based on need.”

A second theme in this area was that services needed to be available out of ordinary office hours, and needed to provide hands-on support.

Of the 10 managers identifying joint working as an area for improvement, 6 focused on better co-ordination between intellectual disability and mental health services and better access for people with intellectual disabilities to generic mental health services:

“Need to join up community learning disability services to assertive outreach mental health services to respond to people with dual diagnosis or mild learning disability.”

Other issues raised related to better co-ordination between specialist challenging behaviour services and the intellectual disability services they help.

Suggestions relating to the treatment and management of challenging behaviour were all different and included suggestions for more use of person-centred planning and psycho-social approaches, less use of medication, more activity, better accommodation, less mixing of residents with different needs and more skilled and multi-disciplinary staff support.

Discussion

Adequacy of the data

Although this study obtained a relatively high response rate (86%) from those units identified in the survey, it is clear that there must be many other units. Units in this study served 32% of the 1045 people identified as in assessment and treatment beds commissioned by primary care trusts at 31st March 2005 (Healthcare Commission, 2006), implying that there may be approximately 130 assessment and treatment units in England. It is not known what overlap there might be with units classified as forensic services or as mental health services. Since it is not possible to know how representative were the units surveyed, the results should be treated with caution.
Main findings
The survey found double the number of units provided in the period from 2000 compared with the period 1990-1999. This increased provision may reflect any of a number of factors: the difficulty for the health service of improving the capacity and resilience of community-based services mainly provided in the social care sector; the loss of long-stay hospital places which could be used as a backup for failed placements in the community; and the targeting of development monies associated with the White Paper Valuing People (Department of Health, 2001a) on services for people with challenging behaviour (Department of Health, 2001b).

The units now seem to serve a substantially different population from those studied by Newman and Emerson (1991). Whereas they found that 75% of residents have severe intellectual disability, with a further 10% having profound disability, only 20% of residents in this study had severe or profound disability. Whereas Newman and Emerson (1991) found that 61% of residents had lived in the unit for more than 2 years, in this study only 25% had done so. The reasons for this change in profile are likely to include the growth of staffed housing providing long-term support for people with severe or profound intellectual disabilities and challenging behaviour (Mansell et al., 2002; Mansell, McGill and Emerson, 2001; Robertson et al., 2004; Robertson et al., 2005); the decline in long-stay hospital places; and the difficulty in obtaining support from ordinary mental health services for people with mild intellectual disabilities (Hassiotis, Barron and O'Hara, 2000).

Most respondents identified strengths of their assessment and treatment unit, particularly the knowledge and experience of the staff team. However, they also identified problems of the unit relating to community-based services for people with intellectual disabilities. A quarter of residents had been in the unit more than 2 years. Reasons for length of stay were not explored but may include the failure of attempts to place residents in the community. Only 40% of residents had a discharge plan and only 20% had this and the type of placement considered ideal for them in their home area. Managers commented frequently about the difficulty of liaising with local services in the area from which the resident had come, finding suitable placements and difficulties of sustaining placements in the community. Coupled with the Healthcare Commission (2006) finding that a quarter of people placed in such units by primary care trusts have finished treatment, this suggests that the concerned expressed in policy guidance in 1993 (Department of Health, 1993), that there is still too limited capacity
of community-based services to support people with challenging behaviour or mental health problems, remains valid.

Managers identified more skilful, better organised, small-scale community services as important changes to better meet the needs of people with challenging behaviour or mental health needs. As well as residential homes and supported living, they mentioned day care and family support as important.

The expertise of the staff and the availability of multi-disciplinary support were seen as a major strength by many managers. Despite this, staffing problems were reported by about half the managers and a third of the units had fewer nursing and care staff in post than they were funded for, the average shortfall being 19%. Although learning disability psychiatrists were in post in just over two-thirds of the units, other relevant professionals were much scarcer.

A small number of managers identified the mix of residents as a problem. In fact, half the units included both residents with profound or severe intellectual disability and those with mild, borderline or no intellectual disability, and nearly half mixed long- and short-term residents. Not enough is known about the care provided in special units to comment on whether mixing residents like this is helps or hinders their assessment and treatment. There is some evidence (Hoefkens and Allen, 1990) that the different functions such units often serve (respite care, emergency placement, assessment and treatment, waiting for accommodation) interfere with each other.

**Conclusion and further research**

Health care facilities (whether provided by independent organisations or the National Health Service) are the most expensive type of residential placement for people with intellectual disabilities and challenging behaviour (Hassiotis et al., 2006). It is particularly important therefore to ensure that they provide value for money. The results of this survey suggest that this model of service provision is becoming more widespread but that the potential problems identified 20 years ago – that units would not help develop the capacity of community services, would fill up with people for whom no suitable long-term placement could be found and would mix residents with very different needs (Blunden and Allen, 1987; Newman and Emerson, 1991) are still present. In so far as special units are unable to move people on to
community-based services, or mix people with different needs inappropriately, they are not likely to offer value for money without action to address these issues.

Progress in addressing these issues is likely to require several linked lines of enquiry. First, the reasons for poor adoption and implementation of successful models of individualised support in the community for people with intellectual disabilities who have challenging behaviour or mental health problems need to be understood. Such models have been developed, evaluated and described (Department of Health, 1993; Mansell, McGill and Emerson, 2001) but are not sufficiently widely commissioned by officials responsible for planning and purchasing services.

Second, the importance of locality in the planning and organisation of services needs to be better understood. Reform of the health and social care system in the UK to create a quasi-market has weakened the principle of local comprehensive provision set out in early guidance (eg King's Fund Centre, 1980). Now, local authorities make over 30% of their residential care placements outside their own area (Department of Health, 2004). Given the difficulty of transferring practices from special units to community services, it may be that such services need to be local for them to be effectively integrated into a complete system of services (Mansell, McGill and Emerson, 1994). This would allow more joint work by assessment and treatment services with other services for people with intellectual disabilities, with more opportunity to share skills and knowledge.

Third, comparative evaluation is needed of different approaches to meeting the different functions served by special units for residents with different characteristics. At present, many units serve a mix of people and there is evidence that their multiple functions cause problems (Hoefkens and Allen, 1990). It may be that separating out these functions rather than addressing them all through the provision of a residential unit would allow each to be met more effectively.
References


London Strategic Health Authority area: full report of the findings from the scoping project. London: North Central London Strategic Health Authority


Figures

Figure 1 Age of residents

![Age of residents chart](image-url)
### Tables

**Table 1 Length of stay (not long-stay units)**

<table>
<thead>
<tr>
<th>Length of stay (months)</th>
<th>%</th>
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<tr>
<td>Up to six months</td>
<td>32.9</td>
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<tr>
<td>6 months to 1 yr</td>
<td>18.8</td>
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<tr>
<td>1-2 yr</td>
<td>23.1</td>
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<tr>
<td>2-5 yr</td>
<td>15.7</td>
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<tr>
<td>More than 5 yr</td>
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<tr>
<td>Not given</td>
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*N=255

**Table 2 Placement pathways**

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<tr>
<th>Placement on admission</th>
<th>Ideal placement</th>
<th>Expected placement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Own or parental home</td>
<td>24</td>
<td>5</td>
</tr>
<tr>
<td>Supported living or unstaffed group home</td>
<td>17</td>
<td>45</td>
</tr>
<tr>
<td>Residential home</td>
<td>30</td>
<td>35</td>
</tr>
<tr>
<td>Hospital</td>
<td>13</td>
<td>4</td>
</tr>
<tr>
<td>Other/not known</td>
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