Residential care in the community for adults with intellectual disability: needs, characteristics and services

J. Mansell\textsuperscript{1}, B. Ashman\textsuperscript{2}, S. Macdonald\textsuperscript{1} & J. Beadle-Brown\textsuperscript{1}

\textsuperscript{1} Tizard Centre, University of Kent at Canterbury, Canterbury, UK
\textsuperscript{2} United Response, 113/123 Upper Richmond Road, Putney, London SW15 2TL, UK

Abstract

Background The pattern of residential services for people with intellectual disability in England has changed dramatically since 1971, with many more places being made available in residential homes in the community. The aim of the present study was to assess the needs and characteristics of residents and features of all the residential homes provided by a national charity.

Method Assessments of adaptive behaviour, problem behaviour and social impairment were completed by staff who knew residents well; information about costs and staffing was provided from central records.

Results A significant proportion of residents have important care needs relating to their skills, their behaviour and their social abilities. Residents with these needs are dispersed throughout services, so that a large majority of services include one or more residents with relatively complex needs.

Conclusions Compared with services in the late 1980s, these services care for a much more disabled client group. Since individuals with high levels of particular needs are typically distributed throughout services, a very high proportion of services require staff who have relatively advanced skills. Current national plans do not adequately address this need and case management arrangements may encourage the re-creation of more institutional services.

Declaration of interest The first author is a Trustee of the charity.

Keywords adaptive behaviour, epidemiology, needs, planning, problem behaviour

Introduction

The pattern of residential services for people with intellectual disability (ID) in England has changed substantially since the 1971 White Paper Better Services for the Mentally Handicapped (DHSS 1971). The number of places in National Health Service (NHS) hospitals has fallen from 49 200 in 1969 to 8880 in 2000, and the number of places in homes in the community has increased from 4200 in 1969 to 44 080 in 2000 (DHSS 1980; DoH 2002a).

A characteristic of this change has been the greater fragmentation of service provision in three respects. Residential services are increasingly made up of small homes on many sites, following the ‘staffed housing’ or ‘supported living’ model (Kinsella 1993; Mansell et al. 1987). They are provided by a much wider range of organizations as part of the ‘mixed economy of welfare’ (Wistow
et al. 1994). The organization of service provision is increasingly carried out through an individualized process of case management (DoH 1989). Different organizations and case managers use different forms of assessment of individual needs and characteristics. These changes have contributed to a lessening of information about the needs of people with ID aggregated above the individual or home level.

Another characteristic of the changing pattern of services has been the reduced impact of specialized training in learning disability. This has happened because of the failure to replace nurse training, largely based in institutions, with training for residential care staff following the rejection of the Jay Committee’s proposals in 1979 (DHSS 1979). This led to an overall reduction in numbers of staff with specialized training (of 25% in the NHS between 1995 and 2000; Ward 1999; DoH 2002b). In dispersed services, the effect of limited numbers of trained staff is that fewer residential homes have staff with specialist training present to lead the work of unqualified staff. Given concern about the quality of residential care, recent Government policy requires a substantial increase in the proportion of staff with some training (DoH 2001).

The overall needs of people with ID in residential homes are likely to have changed since many more disabled people have been served in the community. These needs have important implications for the skills and knowledge needed by residential care staff. Therefore, it is important to obtain information about the needs and characteristics of people with ID in residential care in order to inform the training of future staff. The present study arose from an invitation by a large national charity providing services for adults with ID in England to help assess the needs of the people whom it served. It provided an opportunity to survey the needs and characteristics of nearly 500 adults with ID in 99 community-based residential services provided in every region of England in 2000.

**Subjects and methods**

Every residential service for people with ID operated by a large national charity in England was asked to provide information about the people whom they served.

Questionnaires were sent by post to the manager of every service, who distributed them among staff. Managers were asked to ensure that each questionnaire was completed by the member of staff who knew the individual resident best. Questions and clarification about the information required were dealt with by the second author (B.A.), who also followed up data collection to obtain the fullest information possible and dealt with queries arising during data processing.

Information was obtained from 99 services relating to 495 service users, representing 95% of the services provided by the charity and 91% of the people with ID for whom they provided residential care.

Four kinds of information were collected about each service user:

1. Descriptive information regarding age, gender and ethnicity.
3. A rating of any problem behaviours shown by the person using the Behavior Problems Inventory (BPI; Rojahn 1994). This scale rates 29 specified problem behaviours in groups relating to self-injurious behaviour, aggression and stereotyped behaviour, with the opportunity to specify additional problems. Problems were rated for frequency, distinguishing those which never occurred, and those occurring less than monthly, monthly, weekly, daily, hourly or more than hourly. Each behaviour was also rated for whether it presented a behaviour management problem for staff, distinguishing between those causing severe management problems (i.e. staff have to intervene, upsets other residents, marked effect on social atmosphere or unacceptable in public), lesser problems, those not causing a problem (e.g. self-injurious behaviour was sometimes very frequent, but not rated as a problem by staff) and potential problems (where the problem is controlled in the present environment, but likely to reoccur as a severe problem if the environment changes).
4. A rating of the extent to which the person had any impairment of social functioning using a Social Impairment Scale (SIS). This scale comprised seven
items relating specifically to social impairment from the Abnormal Behaviour section of the Handicaps, Behaviour and Skills Schedule (HBSS; Wing & Gould 1978). These items related to whether the person made and used eye contact with other people, spontaneous show of affection, their response to age peers, social play, willingness to join in leisure activities and overall quality of social interaction.

In addition, some information about each service (i.e. number of residents and staff, and annual cost per place) was obtained from the central records of the charity.

The reliability and validity of the ABS, BPI and the HBSS (from which the SIS was drawn) have been studied and reported as acceptable by their authors. Reliability in the present study was measured by asking the same member of staff to repeat the rating a few weeks after initial data collection (i.e. the measure was of pre- and post-test reliability). Pairs of ratings were made for 4% of the population studied (19 residents for the ABS and 21 for the BPI and the SIS). Item-by-item agreement was calculated for each pair of ratings (Barlow & Hersen 1984); agreement was scored when the two raters scored the item within a difference of one. Table 1 shows the level of reliability achieved.

All information was analysed using the SPSS for Windows 9 program (SPSS 1998) for personal computers.

Results

Service characteristics

The 99 residential homes provided by the charity served an average of five people (range = 1–14). The average number of staff posts established averaged 11 (range = 2–33). The average number of staff actually in employment was nine (range = 1–25). On average, 87% of established posts were filled (range = 32–169%). The ratio of staff in employment to residents averaged 1:0.66 (range = 1:0.29–1:3.59).

The average annual revenue cost per place of these services (at 2000 prices) was £45 026 (range = £8047–94 585). Costs and staff ratio were significantly correlated ($r = -0.68$, $P < 0.01$), reflecting the common observation that staffing contributes about 70% of the total revenue cost in dispersed small homes (Emerson et al. 1999).

Age, gender and ethnicity

Table 2 shows the age distribution of the people served. Sixty-two per cent of the service users were below 40 years of age. Fifty-seven per cent of the people studied were men and 95% were White British.

Adaptive behaviour

Table 3 shows the number and percentage of residents in each decile rank, using normative data presented by Nihira et al. (1993) drawn from a representative sample of 4103 people with ID in the USA. This shows that 63% of this sample had ABS scores which would place them in the most disabled half of all people with ID.

Table 4 compares this data with findings from Raynes et al. (1994) and Elliott & Mansell (1997). The comparison uses items abstracted from the ABS to form a shortened version, the Behavior Development Survey, used by Raynes et al. (1994) and developed by Conroy et al. (1982). This shows that the sample in the present study are much more disabled than those found by Raynes et al. (1994)
in voluntary services a decade ago, with a profile more like the NHS then.

Table 5 presents data on the number of people with selected needs and the number of services in which at least one person has the particular need. Since people are not deliberately grouped according to their functional disabilities, they are distributed throughout services. This is relevant because of its implications for staff training and management.

In general, the distribution of client need means that a much larger proportion of services include people with each particular need. Nevertheless, in some services, all residents share a key disability: in 10% of services (each for between three and five residents) no one could walk unaided; and in 25% (each for between one and six residents) everyone was non-verbal or nearly so.

The mean total score for the ABS Part 1 for each service correlated both with staff ratio ($r = -0.54$, $P < 0.01$) and revenue costs ($r = -0.62$, $P < 0.01$), reflecting the extent to which people with ID in residential care depend on staff support.

**Problem behaviour**

Table 6 presents information about the number of people with the main types of problem behaviour and the number of services in which at least one people...
person has the particular problem behaviour. Seventy-six per cent of service users show some behaviour problem, including nearly half showing either a severe or a potentially severe management problem. Ninety-four per cent of services had somebody with a behaviour problem resident and 70% had someone whose behaviour was classified as a severe management problem.

In 11% of services (two single-person placements, six with two or three residents, and three with four or five residents), every resident was rated as having a severe or potentially severe problem behaviour.

Table 7 shows the frequency of severe problem behaviours in each category and overall. This shows that, out of the people who presented with a severe problem of aggressive behaviour (one-quarter of the whole group), one-third (8.5% of the whole group) presented with at least a daily problem. When considering the proportion of services affected, daily problems of aggression arose in just over one-quarter of services overall: half those where at least one resident had a severe problem of aggression.

Problem behaviour was significantly negatively correlated with adaptive behaviour (r = -0.4, P < 0.01).

Social impairment

The frequency of the different aspects of social impairment are shown in Table 8. Although a large

### Table 5 Adaptive behaviour needs of residents and in services

<table>
<thead>
<tr>
<th>Adaptive behaviour need</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No vision or great difficulty</td>
<td>10/41</td>
</tr>
<tr>
<td>No hearing or great difficulty</td>
<td>7/27</td>
</tr>
<tr>
<td>Cannot walk alone</td>
<td>27/54</td>
</tr>
<tr>
<td>Unable to indicate wants by voice or gesture</td>
<td>19/55</td>
</tr>
<tr>
<td>Non-verbal or nearly so</td>
<td>43/74</td>
</tr>
<tr>
<td>Understands only simple phrases or less</td>
<td>43/74</td>
</tr>
<tr>
<td>Needs help to use knife, fork and spoon</td>
<td>44/77</td>
</tr>
<tr>
<td>Needs help to dress</td>
<td>44/72</td>
</tr>
<tr>
<td>Needs help to wash</td>
<td>75/96</td>
</tr>
<tr>
<td>Incontinent during day or night</td>
<td>66/100</td>
</tr>
<tr>
<td>Has no understanding of numbers</td>
<td>54/76</td>
</tr>
<tr>
<td>Does not use money</td>
<td>50/75</td>
</tr>
<tr>
<td>Does not take care of possible dangers in home</td>
<td>53/83</td>
</tr>
<tr>
<td>Cannot cross road safely</td>
<td>79/94</td>
</tr>
<tr>
<td>Unable to take responsibility at all</td>
<td>40/67</td>
</tr>
</tbody>
</table>

### Table 6 Problem behaviour of individuals and in services

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>People</th>
<th>Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-injury</td>
<td>Lesser</td>
<td>27.3</td>
</tr>
<tr>
<td></td>
<td>Potential</td>
<td>9.1</td>
</tr>
<tr>
<td></td>
<td>Severe</td>
<td>17.2</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>53.6</td>
</tr>
<tr>
<td>Aggression</td>
<td>Lesser</td>
<td>22.5</td>
</tr>
<tr>
<td></td>
<td>Potential</td>
<td>6.9</td>
</tr>
<tr>
<td></td>
<td>Severe</td>
<td>23.5</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>52.9</td>
</tr>
<tr>
<td>Stereotypy</td>
<td>Lesser</td>
<td>29.8</td>
</tr>
<tr>
<td></td>
<td>Potential</td>
<td>4.7</td>
</tr>
<tr>
<td></td>
<td>Severe</td>
<td>4.3</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>38.8</td>
</tr>
<tr>
<td>Other</td>
<td>Lesser</td>
<td>5.9</td>
</tr>
<tr>
<td></td>
<td>Potential</td>
<td>1.4</td>
</tr>
<tr>
<td></td>
<td>Severe</td>
<td>8.1</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>15.4</td>
</tr>
<tr>
<td>Any of above</td>
<td>Lesser</td>
<td>28.5</td>
</tr>
<tr>
<td></td>
<td>Potential</td>
<td>12.8</td>
</tr>
<tr>
<td></td>
<td>Severe</td>
<td>35.2</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>76.5</td>
</tr>
</tbody>
</table>
majority (83%) of service users were rated as not impaired in the way that they displayed affection, 46% showed impairment relating to eye contact and 65% showed impairment relating to their willingness to join in leisure activities.

Table 9 shows the number of people with profound or severe social impairment, and the number of services in which at least one person has profound or severe social impairment. Profound social impairment was defined as scoring less than 25% on the SIS; severe social impairment was defined as scoring between 25% and 50%. Forty-five per cent of individuals had profound or severe social impairment, but these people were dispersed throughout the organization, so that 80% of services had at least one person with this level of social impairment.

Social impairment was significantly correlated with problem behaviour ($r = -0.41, P < 0.01$) and negatively correlated with adaptive behaviour ($r = -0.70, P < 0.01$).

Discussion

The major limitation of the present study is that the services studied may not be representative of all English residential homes in the community for people with ID. Nevertheless, detailed information on nearly 500 people in small homes scattered across England does provide useful information about the needs and characteristics of people in what has become the dominant form of residential care for this client group.

Comparison with the study by Raynes et al. (1994), for which data was collected in 1988–1989, suggests a marked change in the client group served by voluntary organizations. Whereas, typically, voluntary organizations (and local authority social services and private providers) tended to serve mainly the most able clients, with the NHS providing most residential care for the least able, the profile of ability of people served by this organization now is skewed towards the least able. This is entirely con-
sistent with the policy of deinstitutionalization followed since 1971. Thus, people with severe and profound ID, formerly served mainly in hospitals, are now often served in small homes in the community. Evidence from Elliott & Mansell’s (1997) study of all residential services provided by one NHS trust confirms that the NHS now focuses much more heavily on the most disabled people with ID.

Examination of the results in more detail shows that a significant proportion of the people served had very substantial needs for practical help from staff: over one-quarter could not walk alone, two-thirds had toilet accidents and over three-quarters could not cross the road safely. They also presented a high degree of need in terms of social interaction: over 40% were non-verbal or nearly so, could understand only simple phrases or less, or had profound or severe social impairment. Nearly half the residents presented severe or potentially severe behaviour management problems and 17% presented severe problems at least daily. These levels of behaviour problems are actually higher than reported by Kiernan & Moss (1990) in their study of a mental handicap hospital. This may reflect the extent to which some of the more able residents of such hospitals are no longer in residential care.

The increased level of need is partly reflected in much higher staffing ratios than obtained in voluntary sector homes (or in fact in hospitals) in the past. The average staff:resident ratio in these services (1:0.66) is much higher than the ratio found in voluntary sector homes by Raynes et al. (1994) (1:1.18) and is actually higher than the ratio that they found in NHS services (1:0.75). However, the number of staff is only part of the service response required by these residents. They also require a considerable depth and range of skills. This is illustrated by considering the number of services which include someone with particular needs. Almost all services include people with problem behaviour, and in half, severe problems of behaviour management are presented at least daily. Eighty per cent of services include people with profound or severe social impairment and three-quarters of services include people with very limited receptive and expressive communication.

The extent of this need poses a dilemma for organizations providing services. If people are concentrated together on the basis of their needs (as has happened in some services provided by this organization where everyone is non-verbal, cannot walk or has problem behaviour), this may reduce the overall number of skilled staff needed, but it also increases the likelihood that staff in these services will lose important skills (e.g. that they will give up talking to residents who cannot understand or respond) or even that unacceptable care practices (though not found in the present study) will result (e.g. that residents are woken very early so that each can be bathed before being placed in their wheelchair) (Raynes 1980). If people with particular needs are distributed throughout services, then this increases the number of staff groups who must possess higher levels of skill. Since residential care staff in ID services are typically unqualified (Ward 1999), this presents a substantial challenge to employers and to the Government policy of ensuring an acceptable standard of care.

Current proposals for training staff in this sector are at an early stage and give priority to generic care skills (TOPSS 2000). These data suggest that consideration will need to be given to ensuring that the more specialized skills involved in working with people with ID who have, for example, multiple disabilities, communication difficulties or challenging behaviour, are also included in the training given to staff. Much of the professional expertise and advice needed by staff (especially psychiatry,
psychology, physiotherapy, and speech and language therapy) is largely located in health professions and organizations, and it will be important to include their contribution in curriculum development, initial training and continuing professional development.

Despite the size of the task, it has been argued that increasing the skills of staff in all ID services is the best way of, for example, meeting the challenge of problem behaviour (DoH 1993), because needs are not sensibly seen as having discrete boundaries. It is also the case that the early demonstration projects, on which the model of small, community-based housing was developed, provided for people with a relatively wide range of needs because they drew on small, defined catchment areas (Felce 1988; Lowe & de Paiva 1991). Under these conditions, every team of staff needs to possess skills of working with people who have a range of needs, and the variety in their work helps to maintain their skill and motivation. However, the individualized purchasing of residential places through case management may actually work against this. If each individual placement decision is made so as to reduce costs as much as is possible commensurate with a minimally acceptable standard of care, this will tend to group people with less need for help from staff in services with lower staffing ratios, leaving other services with more staff serving only the most disabled.

The implications of the present data are that: (1) the specific training needs of residential care staff working with people with severe and profound ID need to be addressed; (2) health professions and organizations need to influence the training, organization and leadership of staff in social care services to utilize their knowledge and skills; and (3) decision-makers in public authorities purchasing residential care should ensure that a large proportion of the services which they commission have staff skilled in working with people who have a range of major needs.

Acknowledgements

The authors wish to thank the people with ID and their staff who provided the information used in this study, and the charity which provided access to its services and funded part of the study. The study was also partly funded by the National Health Service Executive.

References


Rojahn J. (1994) Behavior Problems Inventory. Nisonger Centre for Mental Retardation, Ohio State University, Columbus, OH.


Accepted 12 June 2002