Misplaced and forgotten?
People with learning disabilities in residential services for older people.

SUMMARY

A large scale survey carried out by the Foundation for People with Learning Disabilities across the UK confirmed concerns found in an earlier study about the placement of people with learning disabilities in residential services for older people. People were found to have often arrived before the minimum age of 65 specified for such services and for reasons unrelated to their own ageing. Once there the services were often ill-prepared to meet their specific needs with limited training and infrequent contact with learning disability professionals. Other serious concerns about people’s quality of life included the few opportunities for recreational or occupational activities and the limited contact with family or friends.

BACKGROUND

One of the emerging concerns of the Growing Older with Learning Disabilities (GOLD) programme at the Foundation for People with Learning Disabilities is the use of residential services for older people. In response to some worrying stories a small study was undertaken to clarify what the problems were (Thompson, 2000). This demonstrated that some people were being made ‘old before their time’ and that such placements were often a consequence of a lack of more appropriate residential provision and the relative low cost of older people’s homes rather than meeting any age related needs. The results of this were fed into the development of the learning disability White Paper in England which subsequently acknowledged that some people with learning disabilities are ‘misplaced in older peoples’ homes living alongside much older and more incapacitated people’ (DoH, 2001, p104). This was also echoed in the recent National Service Framework for Older People (DoH, 2001, p4).

THE RESEARCH

To understand better the reasons why people with learning disabilities enter older people’s services and the experiences once there, a larger study was undertaken. Registration and inspection offices in 53 local authorities across the UK were contacted and questionnaires were sent to the 2570 older people’s homes identified in these areas. The questionnaires sent at the end of 2000 asked about any contact with people with learning disabilities over the preceding five years.

THE FINDINGS

The 53 registration units were very rarely able to provide numbers of people with learning disabilities living in older peoples residential services. Amongst the 18 who could identify people they made up between 0.15 and 13% of the residents of older people’s services and they represented between 0.5 % and 73% of people with learning disabilities receiving some form of residential provision.
The units were asked about their practice with regard to placing people under 65 in services intended for people over 65. Only 13.5% said they would never accept such a placement. The vast majority reported that they would do so for a variety of often contradictory reasons.

Information from the 530 homes which returned the questionnaire revealed how frequently exceptions were being made. 215 people with learning disabilities were identified as currently living in 150 of the homes, 40% of whom arrived before their 65th birthday. Their average current age was 71.0 which was significantly younger than the other residents in the home. The youngest person was 33 the oldest 95. Only 38% of people were over 75 which is the age the Department of Health recently set as a threshold for the potentially appropriate use of older people’s services for people with learning disabilities (DoH, 2001).

The homes generally said that they were suitable for people with learning disabilities living there. However this is contestable because many simultaneously said that: they lacked suitable training; they had inadequate staffing levels; the activities provided were unsuitable; and people did not fit in.

I believe the other residents would be resentful.

Older people can feel that they are in an institution if too many residents have learning difficulties

I feel it would be a tremendous asset to our residents to have someone they can help.

(Comments made about people ‘mixing in’).

Where people were living previously

- 39% came from the family home. Most of these moved because their family carer was either getting too old or died. These were the youngest people on arrival with an average age of 63.0.
- 27% came from learning disability and 23% from older people’s residential services. Half of these people had been moved because of service closure or reorganisation rather than reasons connected with their own ageing.
- 11% of people were previously living by themselves and they were on the oldest people to move at an average age of 67.6.

People’s current lives.

- 49% of the people were getting out of their homes more than three times a week.
- 31% got out less than once a week.
- People’s health was said to be stopping 38% of people getting out more. Poor health did not, for example, explain what was restricting the lives of 19 (31%) people who got less than once a week.
- Lack of family contact, staffing levels and the unavailability of day centres were given as other reasons why people did not get out more.
- 56% of people were reported to be involved in day activities linked to the home. On average these people had activities arranged for four half days.
33% of people attended day services away from the home with slightly greater use of day centres for people with learning disabilities compared to those for older people. On average these people attended for four half days each.

Other regular activities included social clubs and going to church.

Overall people can expect to be involved in regular activities for just two half days in the home and two outside the home. Most of their week will be unoccupied.

Friends and relationships

81% of people had surviving family and 47% had a friend who was neither a worker or service user.

Sometimes the homes did not know if people had family or friends.

Contact ranged from birthday cards and occasional phone calls to visits at least once a week.

Only 43% of people saw a family member or friend at least once a month.

Contact with professionals outside of the home.

68% of people had a named social worker or case manager

36% of people had not had any contact with a social worker or case manager over the last year.

Rates of contact with community nurses, psychiatrists and psychologists over the last year were 43%, 29% and 12% respectively. Only 47% of these professionals were learning disability specialists which meant that only 28% of all people had had access to the key learning disability professionals over the last year.

IMPLICATIONS

People with learning disabilities are thinly spread across older people’s services. Together with the lack of staff training and limited contact with learning disability specialist makes it unlikely that their specific needs are being met.

People have few opportunities for recreation and occupation either inside or outside the home - much less than their peers in learning disability services (Emerson et al., 1999). This contrasts with the Department of Health’s expectation that services for older people with learning disabilities be built around ‘packages of occupational and recreational activities’ (DoH, 2001 p104).

People with learning disabilities are often socially isolated because of limited contact with family and friends. Bigby (2000) has demonstrated the importance of such contact as providing a vital safeguard against abuse in the service system. People’s vulnerability is compounded by the limited opportunities for regular activities outside the home.

The inappropriate placement of people with learning disabilities in older people’s services is facilitated by registration and inspection units who apply arbitrary criteria, particularly in relation to sanctioning the placement of people under 65 in older people’s services.
The general acceptance by staff of the presence of people with learning disabilities, despite limited training, difficulties mixing in and the few opportunities for occupational and recreational activities raises questions about the quality of life for all residents of the homes.

**FURTHER READING**


The Foundation for People with Learning Disabilities is part of the Mental Health Foundation

*This Update was written by David Thompson based on the research he undertook with Sarah Wright. The full report is available from the Foundation.*

For further information about the GOLD programme contact David Thompson, Project Manager, The Foundation for People with Learning Disabilities or visit www.learningdisabilities.org.uk.

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