

Misplaced and Forgotten:
***People with Learning Disabilities in
residential services for older people***

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This report would not have been possible without the generosity of those people completing the questionnaires. These staff and others working in older people's services should be clear that this document is not a criticism of the support they personally provide people with learning disabilities. Indeed in preparing the study very many committed staff were met who were very concerned about the welfare of people with learning disabilities and were keen to have attention drawn to their circumstances.

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1 Summary

- 1.1 One of the emerging concerns of the Growing Older with Learning Disabilities (GOLD) programme at the Foundation for People with Learning Disabilities was the use of residential services for older people. This work informed the recent learning disability White Paper in England which acknowledges that some people with learning disabilities are '*misplaced in older peoples' homes living alongside much older and more incapacitated people*' (DoH, 2001a, p104). This was also echoed in the recent National Service Framework for Older People (DoH, 2001b, p4).
- 1.2 To understand better the reasons why people with learning disabilities enter older people's services and the experiences once there this 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.
- 1.3 The registration units were very rarely able to provide numbers of people with learning disabilities living in older people's 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.
- 1.4 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.
- 1.5 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. Only 38% of people were over 75 which is the age government in England and Scotland recently set as a threshold for the potentially appropriate use of older people's services for people with learning disabilities (DoH, 2001a, Scottish Executive, 2000).
- 1.6 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.
- 1.7 The reason people entered the homes were largely unrelated to their own ageing. Most people coming from living with family moved because of their relative's ageing or death. It was common for people coming from other

residential services to have been moved because of the previous service closing or being reorganised.

- 1.8 The people with learning disabilities had very impoverished lives with few opportunities to get out. Poor health did not explain why most people did not get out more. Other reasons given included limited family contact, the unavailability of day services and low staffing levels.
- 1.9 Only a third of people attended day services outside of the home for an average of two days each. Other regular activities were very limited and highlighted the very different lives people are living compared to people in small-scale learning disability services.
- 1.10 Most people had surviving family and nearly a half had friends who were neither staff or other services users. Contact ranged from birthday cards and occasional phone calls to visits at least once a week. Less than half of people saw a family member or friend at least once a month leaving many people very socially isolated and without a vital safeguard against abuse.
- 1.11 Over a third of people had not had contact with a social worker or care manager in the last year and only about a quarter had had contact with either a community nurses, psychiatrists or psychologists specialising in learning disabilities.
- 1.12 Improving the lives of this neglected group of people with learning disabilities requires action on number of fronts:
 - ending exclusion on the basis of age from any adult learning service or support
 - ensuring learning disability services are better equipped to meet age-related needs
 - preventing people entering older people's services which are unable to offer them an appropriate quality of life
 - reviewing the placements of all people with learning disabilities in residential and nursing homes for older people.
- 1.13 There are financial incentives for local authorities to use older people's services rather than developing good quality learning disability provision. Unless this is addressed, the common practice of *misplacing* people with learning disabilities in older people's homes and then *forgetting* them will continue.

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2 Introduction

The Growing Older with Learning Disabilities (GOLD) programme is a four year initiative at the Foundation for People with Learning Disabilities. It aims to improve the lives of older people with learning disabilities through a range of research and service development projects.

As people with learning disabilities grow older they are less likely to be living in the family home. It also appears that they are increasingly likely to be living in residential services for older people. This report is a follow up to an exploratory study which raised questions about the appropriateness of people with learning disabilities entering residential services for older people (Thompson, 2000). It reports the findings of a quantitative study, which aimed to gain a representative picture of why people with learning disabilities are in these services and their experiences once there.

2.1 Background

Under the Registered Care Homes Act 1984 (amended 1991) local authorities are able to regulate the age and category of persons who may be admitted into private and voluntary nursing or residential homes. This legislation covers England and Wales and is soon to be replaced by the provisions of the Care Standards Act 2000. Similar legislation exists in Northern Ireland (The Registered Homes Order 1992) and Scotland (Registered Establishments Act 1998). The aims of these various provisions are to ensure that people are living in homes that are able to meet their needs. The principle that different groups of people need different types of support is underlined in the Care Standards Act 2000. This has led to the development of distinct standards for people between the ages of 18 and 65 and those over 65 (DoH, 2001c,d).

People are individuals and their needs do not necessarily fit into simple or single categories. This paper considers older people with learning disabilities who have specific needs as people with learning disabilities but who may also have additional needs as ageing individuals. Outside of the family home they may be living in either facilities for people with learning disabilities or those for older people. In Scotland it is estimated one tenth of placements are in residential services for older people (Scottish Executive, 2000). Recent government policy in England has suggested that some older people with learning disabilities may be '*misplaced in older peoples' homes living alongside much older and more incapacitated people*' (DoH, 2001a, p104, also DoH, 2001b). The purpose of this report is to examine the circumstances of people with learning disabilities living in residential and nursing homes for older people to identify whether they are appropriately placed.

3 Methodology

Contact was made with the offices responsible for registration and inspection of nursing and residential care homes in 53 of over 450 local authorities across the UK. These were selected to provide a range that included rural and urban locations as well as being inclusive of England, Wales, Scotland and Northern Ireland. Information was requested about the numbers of people with learning disabilities in older people's

homes as well as their practice with regard to placement of people under 65 in these homes. The local authorities were also asked to provide details of all residential and nursing homes for older people in their area.

Telephone follow-up ensured that the addresses of local homes were provided from each authority. Once these were available questionnaires were sent to each home individually. These were accompanied by a covering letter, which explained the purpose of the survey and guaranteed confidentiality. To try to ensure that people were reliably identified by a group of people who may not be familiar with the term learning disability the following description was included:

People with learning disabilities have previously been called mentally handicapped. What makes them special is that they have needed help and support all of their lives. This is different to people who need help just late in life, for example, if they get dementia. People with Down's Syndrome often get dementia but they have usually needed extra support all of their lives.

In total 2570 questionnaires were sent at the end of 2000 and 530 were returned completed giving a response rate of just over 20%. The questionnaire had been piloted and was in three parts. Part one provided general information about the home and asked about any contact with people with learning disabilities over the last five years including requests for placements. Part two recorded information about people with learning disabilities who had lived in the home during the last five years whether or not they were still there. Part three provided further details of just those people with learning disabilities currently living in the home. In addition to providing a snapshot of the lives of people with learning disabilities in the homes, the five-year period was chosen to help understand recent practice concerning their arrival and departure from the homes. The questionnaires contained a mixture of quantitative and qualitative data, which were coded and analysed on SPSS.

4 Findings

4.1 Registration and Inspection Units

The registration units were very rarely able to provide numbers of people with learning disabilities living in older peoples residential services. Many said that they did not record this specific information or did not know. The figures given seemed highly reliant on the personal knowledge of the staff in the units. From the 18 authorities who did identify people with learning disabilities in older people's services the numbers ranged from 1- 325 people. To cancel out the effect of the very different sizes of local authorities these figures were compared with the numbers given for the total local provision for older people and also the specific local provision for people with learning disabilities. This reveals people with learning disabilities making up between 0.15 and 13% of the residents of older people's services (mean 1.7%, sd 3.5). Further this group represented between 0.5 % and 73% of people with learning disabilities receiving some form of residential provision (mean 10.4%, sd 18.7). These figures are likely to be underestimates as the registration units were reporting on only known individuals.

One question specifically asked whether a minimum age of 65 was strictly applied for homes registered for older people. Only 5 out of 37 (13.5%) of units said they did.

The majority said that exceptions were made - the range of reasons given is cited in table 1. Two units said that such placements were subject to regular review. Although having a learning disability was given as a possible reason for these placements, one authority said they would be particularly reluctant to make an exception for a person with learning disabilities. Another authority said that they would only make exceptions in local authority establishments, which were not covered by the 1984 Registration Act (England and Wales). Only two forms indicated that the placement of younger people in older people's homes was a compromise, which was forced by a lack of a more appropriate accommodation.

Table 1 Why people under 65 are resident in older people's homes?

The best interest of the person,
 The home being able to meet the person's needs
 Pre-senile dementia,
 Korsahoff's syndrome
 Mental illness
 People with mental illness being resettled from institutions
 Learning disability
 Physical disability
 People who have had strokes.
 People moving with their ageing parent.
 People moving with their partner
 Women over 60 justified by a retirement age for women being 60.
 Behaviour akin to older people: "55 going on 80".
 Person with learning disability moving with their ageing parent
 Exceptions were only made in local authority provision.
 Suitable facilities not being available at the time when the placement is needed.

4.2 About the homes

Of the 530 homes returning a completed questionnaire, 375 were identified as residential, 86 nursing and 82 dual registered homes. On average the homes had 29.4 residents (sd 17.2) and their average ages appeared to be between 80 and 85 based on estimates given. A total 215 people with learning disabilities were identified currently living in 150 of the homes with a maximum of 4 in any one home. This means that people with learning disabilities made up 1.4% of the current population of these 530 homes. A further 47 homes recorded having someone with learning disabilities living there during the last five years which gives a total figure of 37% of homes having experience supporting people with learning disabilities in this period.

76 homes (14.3%) had been asked to provide accommodation for a person with learning disabilities, which had not resulted in the placement. The major reasons given were the home not having any vacancies and the placement being inappropriate (both 36.8%). The other major reason given was that the placement was prevented by the local registration and inspection unit (11.8%).

4.3 People who were no longer there

Information was provided about 69 people who were no longer living in the older people's services. Table 2 shows why they were no longer there and the age at which they left the service. Just over half (50.7%) of this group had died at an average age of

72.4 (sd 8.29 range 54- 88). This is higher than the average death rate found amongst people with non-organic forms of learning disabilities in other studies which is given to be between the late fifties and mid sixties. (Janicki et al. 1999). This variance may be attributed to sampling techniques. Namely, as is shown below, people had survived to enter older people's service at an average age of just under 65. The women were found to live significantly longer than men ($p<0.02$) with an average age of death of 76.3 (sd=7.8) compared to 69.6 (sd 7.6), a trend that is repeated in the general population (Janicki et al., 1999).

Eleven people (15.9%) had been moved because of a need for greater nursing care. For the other people the reasons were more positive including returning to the family home, going to a learning disability service or moving to more independent accommodation. These people were significantly younger and on average had spent less than one year in the homes.

Table 2

Why were they no longer there? (n=69)	Number	Average age (sd)
Died	35	72.4 (sd 8.3)
Moved for greater nursing care	11	70.4 (sd 2.9)
Temporary placement	6	50.7 (sd 0.5)
Moved to more independent accommodation	3	60.3 (sd 1.3)
Moved to a learning disability service	6	62.9 (sd 1.4)
Moved back to their families	2	67.2 (sd .15)

4.4 Suitability for people with learning disabilities

93.3% of homes with people with learning disabilities currently resident said they were suitable for people with learning disabilities. Although this is promising it means that 17 people (7.9%) were in homes which themselves considered themselves inappropriate. Where no one with learning disabilities was currently resident, a much higher percentage (41.7%) of the homes felt they would be unsuitable.

Table 3 records reasons given why the homes may be inappropriate for people with learning disabilities based on agreement / disagreement with specific statements. It separates the responses according to whether there were people with learning disabilities currently resident. It is interesting to note that although only 6.7% of the homes with a person currently resident felt the placements were unsuitable very many more of these were concerned about the lack of training of their staff, staffing levels, the activities available and people fitting in. This suggests acceptance of a compromise service. Those homes with no one currently resident showed the same pattern of concerns but at higher rates.

Table 3

Statement	Disagree – People with LD currently in service (n=150)	Disagree - No People with LD currently in services (n=362)
Staff have appropriate training?	41%	66%
Staffing levels appropriate?	27%	47%
Activities inside and outside of home appropriate?	23%	42%
People fit in with other older people?	14%	41%

Although people ‘fitting in’ emerged as the least of the four concerns, comments given which are shown in table 4 underline how difficult this can be. They also show how even those people who were positive about the presence of people with learning disabilities were very clear about their difference.

Table 4 Statements about ‘fitting in’

I believe the other residents would be resentful.

It would be wrong to accept a client who would be ostracised by the others. If they were able to "fit in" there would not be a problem.

Older people can feel that they are in an institution if too many residents have learning difficulties. They can't always make distinctions and allowances.

In my experience older people have difficulties in accepting others' differences which they do not perceive as normal.

I feel that one person with learning disabilities in a total of 8 is enough otherwise the balance of the home is upset which is not fair to the other elderly persons.

I feel it would be a tremendous asset to our residents to have someone they can help. This will have the added benefit of making the more able residents feel worthwhile and with a sense of feeling needed.

4.5 Age of people currently in the homes

More detailed information was available for 253 people were either currently living in the homes or had done so in the past five years. The average age people arrived in the services was 64.8 (sd=11.5, range 17 to 88 years). This means that in 40% of cases people with learning disabilities were entering these services prior to their 65th birthday – the accepted minimum age for older people’s services. This indicated how

commonly registration units are making 'exceptions'. On average people had been in the homes for 6.2 years (sd=8.2) giving an average current age of 71.0 (sd=10.6, range 33-95years). This is over 10 years less than estimates given for the average ages of all residents in the homes. At the time of the survey only 38% of the people with learning disabilities were over 75. This is the age which the Department of Health in England recently said it was acceptable for support for people with learning disabilities '*who have shown significant physical and mental deterioration with age*' being '*developed in the context of services for elderly people*' (DoH, 2001a p104, DoH, 2000b). The Scottish Executive similarly identified 75 as a suitable threshold (Scottish Executive, 2000).

4.6 Why people were in the services?

To help understand why people had arrived in these services information was requested about where they were living before and, if they had been living in a residential service, why they had moved on. This information is shown in tables 5 and 6. About a third of people had come from the family home and these were statistically the youngest people at the time of the move ($p<0.05$), who had spent the longest time living in the older person's service ($p<0.05$). 9% of people had been living by themselves, and these were amongst the oldest people at time of move ($p<0.05$). 23% of people had come from a learning disability services and 19% had moved from another older person's service. For the remainder it was unknown where they had come from.

Table 5 Where did people live previously? (n= 253)

Previous Accomodation	Number (n=253)	Average arrival age	Sd	Average time in home (years)	Sd
Family home	83	63.0	13.0	7.0	9.15
Other older people's residential home	49	67.3	11.0	3.6	3.7
Living by themselves	23	67.6	6.9	3.6	3.7
Learning disability service	58	65.6	9.6	4.0	3.8

Looking at why people had been moved from other residential services showed that service re-organization or closure was more likely to be the cause than anything to do with the needs of the individual. Therefore in over half the cases, older people with learning disabilities were having to endure what could be potentially traumatic moves because of service change. It is not possible to say how many people in this study were in the older people's homes as a direct consequence of the closure of institutions.

The average age of people coming from learning disability services because of closure or reorganisation was 69.9 (sd=8.7) with a range of 46-78.

Table 6 Why did they move from another residential service?

Reason for leaving previous accommodation	Service Closing	Service re-organised	Couldn't meet needs
Other older residential (n=49)	26	2	16
Learning disability service (n=58)	20	3	28

Table 7 shows the reason why people had left the family home. It identifies that most often it was because of their relative's ageing or death rather than their own needs changing because of age. The other reasons given included giving two families a break, one family breaking up and another no longer wanting the person to live with them.

Table 7 What prompted the move from the family home? (n=83)

Reason	Number (n=83)	Percentage
Family carer died	19	22.9%
Family carer getting to old to continue care	24	28.9%
Person needed more support	25	30.1%
Other	12	14.4%

4.7 Why the current service?

An attempt was made to identify why individuals were in their current home rather than any other service. The most common reason given (41.1%) was that it was the most appropriate place for the person. Family preference was also highly scored (30.8%). In 15.4% of cases the reasons were negative including saying that either nothing else was available or there were no vacancies in a more appropriate services. Other explanations included the person's own choice (6), moving in with family (2) and joining a friend (2). Several people said they did not know why the specific home was selected. Of those people who answered 85.8 % said that the person and/ or their family had had some choice over living in the home. 14.2% were given as having had no options.

In 245 (of 253) cases the move was identified as being either temporary or permanent. For 18.0% of people it was meant to be only temporary. These people were significantly younger than people moved permanently (mean 60.5 years, sd=13.4, range 21-80, $p<0.01$) and they had been in the homes on average 1.9 years (sd=2.1, range 1 month to 8 years).

At time of entry the majority of services (81.1%) said they understood how to meet the needs of the person when they moved in. The 18.9% of services who disagreed with this said they would have wanted: additional funding to meet their needs; more information about the person; more time to get to know the person; and training including dealing with challenging behaviour.

4.8 People's current lives.

The third part of the questionnaire attempted to gain a snapshot of the lives of people with learning disabilities currently living in the homes. The forms provided information about 196 people. Respondents were asked how often the person had the opportunity to do things outside the home and whether there were any limiting factors. Table 8 combines the results of these two questions. It shows that about half (49.4%) of the people were getting out more than three times a week. It also shows that about a third (31.1) of people did not have the opportunity to get out every week. The most common restriction on this aspect of people's lives was their health and not surprisingly we see this as a biggest issue for those who got out the least. However health was only identified as a limiting factor in 38.3% of all cases. It also did not explain why 10 people were getting out the door less than once a month. The availability of resources frequently explained why people's lives might be restricted: either because of limited day centre opportunities (24.0%) or staff or money shortages (17.3%). In 29.1% of cases limited contact with family was given as the reason which suggests that they often saw relatives as having responsibility for this areas of people's lives.

Respondents also had the opportunity to give other reasons why people weren't getting out more. Most of those given which accounted for 10% of all cases was that the person didn't want to go out anymore and indeed was nervous about doing so.

Table 8 Opportunities to go out

How often does the person have the opportunity to do things outside of the home?	Number of people (n=196)	Number limited by Health (n=75)	Number limited by staff or money (n=34)	Number limited by family contact (n=43)	Number limited by day centre opportunities (n=47)
Every day	46	19.6%	15.2%	6.5%	13.0%
At least three times a week	51	29.4%	17.6%	29.4%	31.4%
At least once a week	38	26.3%	21.1%	23.7%	42.1%
At least once a month	22	59.1%	13.6%	36.4%	22.7%
Less than once a month	39	71.8%	17.9%	20.5%	10.3%

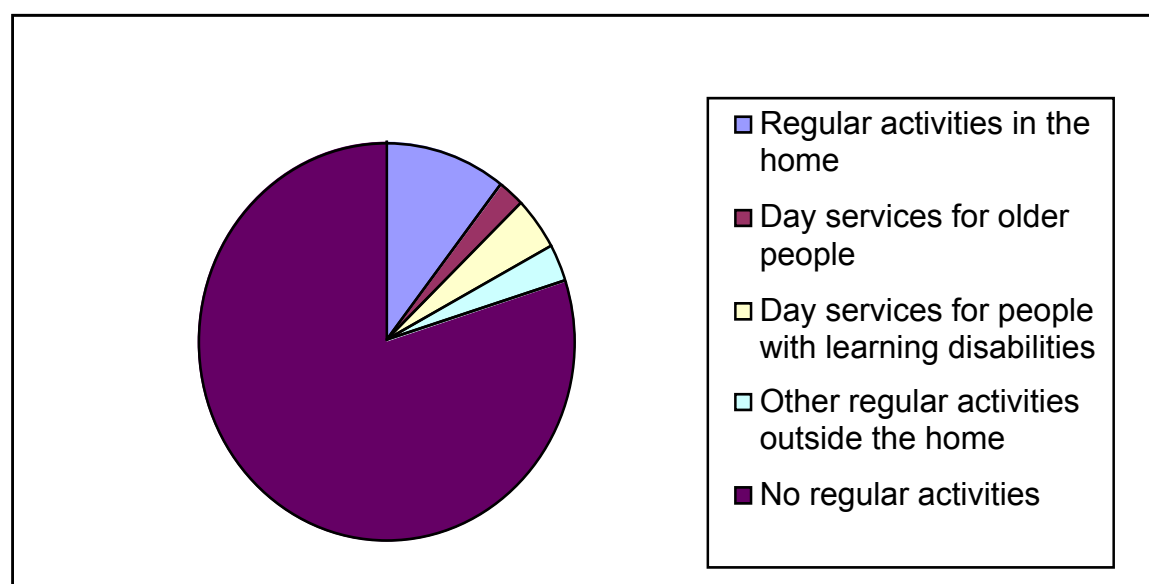
4.9 Regular activities

To find out in detail how people were spending their time, information was requested about regular weekly and monthly activities either attached to the home or outside. Just over half of people (55.6%) were reported to be regularly involved in day services or activities linked to the home with an average of 4 half days each a week accounted for in this way. Outside of the home there was greater use of day services for people with learning disabilities compared to those specifically for older people. However this accounted for only 40 and 31 people with average attendance of 4.3 and 3.0 half days a week respectively. Since six people attended both types of services, only one third (33.1%) of people were regularly attending day services away from the home. This is significantly less than rates found for people with learning disabilities in services for people with learning disabilities (Emerson et al., 1999). For example in this study 93% of people in small group homes and 83% in larger group homes were found to be involved in regular day time activities outside of the home including day centres (40% and 65% respectively), adult education and voluntary work.

Only 33 (16.8%) of people were recorded as regularly attending social clubs for either older people or people with learning disabilities in the evenings or at the weekend. This was balanced between the two types with the average person attending once every two weeks. 45 people were said to be involved in other regular activities away from the home. The most common being going to church and meeting family. Other activities included shopping, going to the pub, hairdressers, voluntary work and catching buses.

To graphically illustrate how often people were involve in regular activities, average rates were calculated across the whole population. The results are shown in figure 1 against the possibility that people could potentially be involved in regular morning, afternoon and evening activities each day. It demonstrates how little regular activities were available. On average people were involved in two sessions a week in the home and two sessions outside of the home.

Figure 1



4.10 Friends and relationships

The majority of people were said to have surviving family (80.9%). The others either did not have any family (14.9%) or it was unknown whether they did (4.1%). It was also asked whether people had any friends excluding staff of people sharing the same services. Of 181 people who responded less than half (47.5) were said to have such a friend. Again there were a number of services (12.1%) that did not know about this aspect of a person's life.

Table 9 shows the level of contact people had with their family or friends. The pattern of contact is very similar for the two groups. For example less than half of people see their friends or relatives more than once a month. People's friends are showing a similar level of commitment to the relationship as those family members who have maintained contact. Over all 42.7 % of people saw a family member or friend at least once a month. This means that the majority did not have regular contact with anyone outside services. Aside from the potential for social isolation, Bigby (2000) has demonstrated the importance of such contact as a providing a vital safeguard against abuse in the service system

Table 9

Level of contact	Family (n=157)	Friends (n=86)
Birthday/ Christmas cards and occasional phone calls	18 (11.4%)	16 (18.6%)
Phone contact or letters at least once a month	8 (5.1%)	7 (8.1%)
Visits at least twice a year	47 (29.9%)	23 (26.7%)
Visits at least once a month	10 (6.3%)	3 (3.4%)
Visits at least once a week	68 (43.3%)	30 (34.9%)
No recorded / unknown	6 (3.8%)	7 (8.1%)

4.11 Contact with professionals outside of the home.

Most people had a named social worker or case manager (68.3%). A quarter of people (24.5%) had seen a social work or case manager during the preceding month and a further 40.3% had contact within the last year. This leaves 35.8% who had not seen anyone in these roles for over a year. Table 10 shows the level of contact over the last year with psychiatrists, psychologists and community nurses together with their speciality. The most common contact was with community nurses with 43.3% of people seeing them. Contact with psychiatrists and psychologists was less common at 29.1 % and 12.2% respectively. In just under half of cases (47.0%) the professionals were learning disability specialists. This means that only 27.5% of people had contact with any of these learning disability professionals over the last year.

Table 10 Professional contact over the last year

Speciality	Older People	Learning Disability	Other/ unknown	Total (n=196)
Psychiatrist	10	34	13	57
Psychologist	2	14	8	24
Community Nurse	28	28	29	85

4.12 People with Down's syndrome and dementia

Because there is a high prevalence of dementia amongst people with Down's syndrome over the age of 40 (Holland, 1999) the homes were asked specifically if the individuals with learning disabilities had either Down's syndrome or dementia. In 11 cases (4%) the forms recorded that it was not known whether the person had Down's syndrome which does raise concerns about these services' awareness of basic information about learning disability.

Over the past five years there had been contact with 24 people with Down's syndrome and 45 people with dementia. The average age of the people with Down's syndrome on entry was 60.0 (sd=9.7). Eight (33%) people with Down's syndrome were identified as having dementia which is slightly lower than what might be expected compared to other studies (Prasher, V., 1995, Zigman et al., 1996). Five of these had come from learning disability residential services, four of whom were moved because the learning disability service was reported to be unable to meet the person's needs. Interestingly only two people with Down's syndrome and dementia were in registered nursing homes, only one of whom had come from a learning disability service. Also of note were two people who had been moved from learning disability services because they were seen as needing greater nursing care and yet they were not in nursing homes. Although the numbers are small it suggests a pattern of people with Down's syndrome having to leave learning disability services where dementia is suspected, but moving to services which are not necessarily better equipped to meet their needs. The poor attention to the needs of people with dementia generally in older people's carer homes has recently been highlighted (Disability Now, 2001).

The average age of the 12 people with Down's syndrome still in the services was 65.1 (sd=7.5, range 54-76). They had lived in the services for an average of 5.7 years (sd=7.4, range 4 months to 29years).

5 Discussion

Whilst the majority of respondents said that people with learning disabilities were appropriately placed in residential services for older people, this study does raise serious questions about how well their needs are being met. The major concerns raised include:

- Meeting age-related needs did not explain why most of the people with learning disabilities were in older people's services.

- People with learning disabilities are sharing services with people significantly older than them and so are in danger of being made old before their time.
- Because people with learning disabilities are thinly spread across older people's services this mitigates against staff having the experience to meet their specific needs. This is compounded by a lack of staff training and limited contact with learning disability professionals.
- There are often very complex issues of integration with the other residents of the service which have been noted elsewhere (Ward, 2000). It is worthwhile noting the contrast between support expected for children with learning disabilities in mainstream schools and the neglect of integration issues in older people's services.
- People's lives are very restricted in terms of both activities and relationships outside of the home.

One possible explanation for the staff's acceptance of the services they were providing for people with learning disabilities was that they were judging the quality of people's lives in comparison with the other, largely older, residents. It was also probably true that the people with learning disabilities themselves were accepting of the services, being generally of a generation which has missed out on opportunities to learn how to speak up. From different perspectives drawn throughout the GOLD programme considerable concern had been raised about the use of older people's homes which had prompted this study. For example, staff in learning disability services almost exclusively report a sense of resignation rather than enthusiasm when they speak about people transferring to older people's services. Family members have also expressed concern. In one remarkable case, a sister who was anxious about the care being given to her sister who was in her fifties, firstly took a job in the older people's home in which she had been placed and then purchased the home.

There are indeed many constraints to providing a good quality of life in older people's services. The most obvious being the relative low cost of these services which impacts directly on staffing levels etc. The average cost of what is considered good quality residential support for people with learning disabilities is just under £43K a year. The average cost of a placement in older people's residential and nursing homes is £13.3K and £18.3K respectively. The cost of this was very apparent on talking to some people with learning disabilities in older people's homes and their carers. For example, it was rare for people to go to the local shops because of not having the staff cover necessary. One woman spoke about the staff going out to buy her clothes – a practice which would be considered unacceptable. Another woman had not seen her surviving sisters for over two years because they themselves were too old to travel and staffing wasn't available to escort her for the hour's taxi ride for which she had the money saved.

People's lives are also restricted by the policies concerning day centres which partly explains the fact that only about a third of the people in the study were found to be attending one regularly. Some learning disability services have been found to both exclude and 'retire' people above arbitrary ages. One man forcefully retired after many years was understandably distressed about being kept away from friends he had known all his life to stay at home and do nothing. All that was offered was counselling. Older people's services can also be inaccessible to people with learning

disabilities in older people's homes. For example in some local authorities day centres are reserved for people living in their own homes as people in older people's residential and nursing homes are considered to be already receiving 24-hour care.

The limited contact people with learning disabilities have with family and friends exacerbates concerns about their quality of life. Their situation is generally different to their fellow residents in that they will have been unlikely to have children, reducing the potential pool of visitors. It is very alarming that less than half of the people in the study had a friend who was neither another service user or staff member.

In many ways people had been abandoned by learning disability services. They had been moved on from learning disability services because they didn't fit, few continued to attend specialist learning disability day or social activities and most had not seen a learning disability specialist within the last year. The question arises as to whether their specific needs as people with learning disabilities had vanished or whether there was no longer any interest in meeting these? In some local authorities the practice is for all case management of people over 65 to be handled by those people responsible for older people. It is difficult to equate this with a person-centred approach to care management and means there is a danger that people will be denied a skilled assessment of their needs as people with learning disabilities.

The survey also highlights the vulnerability to abuse of people with learning disabilities in older people's services. In addition to the risks associated with having a learning disability, many are with limited safeguards because of poorly trained staff, the infrequent visits of family, friends and social worker, and limited activities outside the home. People can be too easily forgotten. In this context it is not surprising to find that one of the worst cases of abuse reported recently was of a man with learning disabilities under the age of 65 who had been locked in an unheated attic of an older people's home. He was eventually found lying in his own faeces and urine (Hill, 2001).

6 Recommendations

Preventing the misplacement of people with learning disabilities in residential services for older people requires action which prevents people entering these services in the first place and a review of all placements of people already there. Specific actions which could be taken are listed below.

6.1 Flexibility of learning disability services to meet age related needs

Ensuring learning disability services are better equipped to respond to age related needs. This will mean that less people will be moved on when, for example, their mobility declines or they develop dementia. Training for staff is required as well as the ability of funding mechanisms to respond to changing need, for example, to allow for an increase in staffing if an individual develops dementia.

When planning day and residential services for people with learning disabilities consideration should be given to predictable age-related needs. For example, choosing homes with bedrooms and bathrooms accessible without stairs, or which can be easily adapted if necessary. This means thinking ahead, possibly having these in mind when people are 50, or 30 for people with Down's syndrome because of premature ageing.

6.2 Ending exclusion from all adult learning disability services on the grounds of age

Needs do not change at arbitrary ages and so learning disability services should end any practices where services are denied to people with learning disability simply on the basis of their age. It is arguable that such practice is illegal because under community care legislation services cannot be withdrawn without a reassessment of need, and consequently showing that need is no longer there.

Some people with learning disabilities are still missing out on any contact with learning disability services. At particular risk are the 25% of people with learning disabilities who do not become known to services until late in life when their family carer dies or is unable to continue to provide the support required because of their own ageing.

One way to ensure continuity of learning disability input is to locate care management for all adults with learning disabilities within a learning disability team. Automatic transfer to older adult teams at the age of 65 undermines the potential for these people to have lives similar to their younger peers. Ideally services for people with learning disabilities and older people should work in partnership to provide the best possible outcomes for older people with learning disabilities.

6.3 Preventing inappropriate placements to older people services

The study showed that a few registration units were much more careful about considering the appropriateness of placing people with learning disabilities in older people's homes. The new NCSC in England and Wales has the power to prevent placements where it believes that the intended service is not able to meet a person's needs. Minimally this should ensure that no-one enters older people's services prior to their 65th birthday and ideally not until after their 75th birthday as recommended in English and Scottish policy (DoH, 2001a, Scottish Office, 2000).

6.4 Reviewing the placements of all people currently in older people's homes

The study identified many people with impoverished lives. Local authorities should prioritise person centred planning for all people with learning disabilities in these services. This would include seeing whether the placement is appropriate and, if not, working with the person to identify more appropriate accommodation, and focusing on occupational, recreational, and social activities.

Unfortunately many authorities do not actively review such placements once made. For example, a fifty-three-year-old man had moved with his mother to an older people's service after she had a short spell in hospital. Moving them together seemed like the right thing to do at the time, not least because they had always lived together. She died a year later and since then no-one has taken the time to review the man's placement.

6.5 Addressing the funding shortage for learning disability services

The reason why many people with learning disabilities are misplaced in older people's services is that there is a shortage of more appropriate accommodation. The

huge deficit of residential supports identified (MHF, 1996) means that many people with learning disabilities are found 'beds' wherever possible. If people with learning disabilities are kept out of older people's services this will be felt 'down the line' unless there is an increase of provision. The people who will pick up the bill are family carers who already find options outside the family home to be very limited.

7 Conclusion

This report shows that people with learning disabilities are very often misplaced in older people's residential services in two distinct ways. Firstly they be misplaced in the sense of the services not meeting their needs. Being younger and having learning disabilities sets them aside from other residents but there was very little evidence of the services providing them with a specifically tailored service. Secondly they are misplaced in the sense of being lost or invisible. This is evident from the difficulty establishing how many people with learning disabilities are in these services and their low numbers compared to the total population of older people's services. They also become hidden because of the limited contact with family, friends or learning disability specialists. Their invisibility is compounded by the high level of acceptance by residential staff of the service provided. This is in spite of their own concerns about, for example, their lack of training or staffing levels. In some ways 'fitting in' works against people with learning disabilities as it undermines any call for special attention. 'Fitting in' can mean they are required to live the life of the much older and frailer people in these services.

The responses from the registration and inspection units suggest that there is a high level of dishonesty about why people with learning disabilities are placed in older people's services. Only two people identified a lack of suitable placements as a reason for people under 65 entering them and there was a silence on substantial cost savings for local authorities. Their willingness to make 'exceptions' betrays what appears to be a common practice in that they appear more than ready to make exceptions to registration requirements to allow people under 65 to enter these services.

Ultimately many older people with learning disabilities are misplaced in older people's services with restricted lives because it is a tempting way for local authorities to balance their books. They are also a group who are easily forgotten because their own voice is not strong and they have few relatives or friends left to shout for them.

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