Chapter 3:

Accommodation and Support Needs of People with a Learning Disability

Overview

By definition people with a learning disability need to be 'looked after'. Throughout most of the last century this was mainly the responsibility of the family. The only alternative was to be cared for in long-stay hospitals. In December 1962, over 1,800 persons were resident as 'special care' patients in Hospitals in Northern Ireland (Scally and McKay, 1964).

From 1970s onwards, new forms of accommodation and support options began to become available especially for people who were resettled from long-stay hospitals. This included the provision of community-based hostels, residential care and nursing homes, group homes and latterly supported living arrangements located in ordinary housing.

In 2003 around 450 persons now live in three long-stay Hospitals and nearly 2,000 are in some other form of accommodation options.

This chapter is structured into five main sections.

Section 1 gives an overview of where Northern Irish people with a learning disability are living in 2003 and draws comparisons with Great Britain and the Republic of Ireland.

Section 2 summarises research findings relating to people in long-stay hospitals is presented.

Section 3 focuses on existing residential provision and supported living schemes.

Section 4 examines the future accommodation needs of people living with family carers and the options favoured by people with a learning disability and family carers.

Section 5 contains a synopsis of the national and international literature relating to key themes that have not been well explored in the Northern Irish context.

Section 1: Where are people living?

Nearly all children (up to 19 years of age) live in family homes either with natural, adoptive or foster parents (McConkey, Spollen and Jamison, 2003).

Accurate figures are not available for all of Northern Ireland but a study in the EHSSB area identified 34 children (aged up to 19 years of age) who were living in some form of residential accommodation with 26 in foster care arrangements.   Together these represent 2% of all children known to HSS Trusts in the Board area (McConkey et 1l, 2004).

Figure 1 shows where adult persons are living.

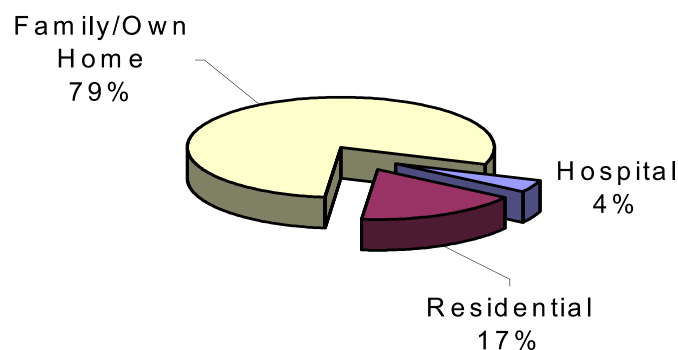

Figure 1: Percentage of adults person in different forms of accommodation in N. Ireland in 2003 (N=7,970)

The bulk of people live with family carers (66%) although a small proportion have their own accommodation (10%) or live with a spouse/partner (3%).

Around 450 are resident in hospitals (mostly learning disability hospitals) and on average will have lived there for 20 years.

Nearly 1900 persons are in some form of residential provision and have lived there for around 8 years on average.

Comparable figures across these three forms of provision for the Republic of Ireland (Health Research Board, 2003) are: Hospitals (4%); Residential services (5 day and 7 day) (39%); Community (57%).

In Great Britain, an estimated 63% of adults live in private households and 37% in some form of residential accommodation. The numbers living in long-stay hospitals are now less than 1% (Kavanagh and Opit, 1999).

This data suggests that over twice as many adult persons are in residential provision in Great Britain and in the Republic of Ireland than in Northern Ireland.

Section 2: People living in long-stay Hospitals

The annual census of Hospital In-patients (DHSSPS) identifies the number of people in the three main learning disability Hospitals in N. Ireland on a specific date. However this data does not distinguish between those patients for whom the hospital is their home and those who are undergoing short-term admissions. Hence in the study undertaken by McConkey, Spollen and Jamison (2003) further information was obtained from Boards and Trusts to clarify this.

In 2003, it was estimated that there were around 440 –470 persons living in learning disabilities hospitals who had no where else to live. The breakdown was as follows:

Muckamore Abbey Hospital @ 300 persons

Longstone Hospital @ 115

Stradreagh @ 40

Around 62% were male and 38% female. The mean age of residents was 49 years, with ages ranging from 9 to 96 years. The over all age profile of the patients is given in Table 1. The EHSSB had a slightly older population, with a mean of 52 years, compared to the other boards where the mean is 47 years (One way Analysis of Variance; $F=3.0$: $p<0.05$).

Table 1: The number and percentage of patients by age bands

Age Band	Hospital Census	Census Percent
0-19	18	4.0
20-44	201	44.4
45-64	181	40.0
65-74	29	6.4
75+	24	5.3
Total	453	100

Given a life expectancy of 70 years, this data suggests that over the next ten years a maximum of around one quarter of these patients will die (presuming that there is no replacement of places.) Hence upwards of 350 persons may need to be resettled in the immediate future.

The mean length of time these patients had been in Hospital ranged from 16 years in WHSSB to 24.5 years in SHSSB.

A census of all patients in Longstone Hospitals in 2001 (Slevin et al, 2002) found that of the 135 patients; 14% were rated as having mild learning disabilities; 33% moderate learning disabilities; 41% severe learning disabilities and 12% profound learning disabilities. However people who had been in the Hospital for less than 10 years (N=63) tended to have mild/moderate learning disabilities (78% of this grouping) whereas people who had stayed for greater than 10 years (N=72) tended to have severe/profound disabilities (69%). In addition, 27% of patients were reported to have significant challenging behaviours and 17% significant mental health problems.

This data suggest that the more able and less demanding patients have tended to move out of the Hospitals leaving behind people who have greater needs in terms of service provision.

Delayed discharge

In recent years, Muckamore Abbey Hospital has been reconfigured into resettlement wards and assessment and treatment wards. In May 2001, 172 patients were in the latter wards but 33% were considered by their consultant psychiatrist as having their treatment completed and they were awaiting discharge (McConkey and Marriott, 2001). However there was no available place to which they could be safely discharged. This phenomena of ‘blocked beds’ has been reported also in Scottish Hospitals (Whoriskey, 2003). The consequence is that a new ‘long-stay’ population emerges in Hospitals. Of 154 people admitted to Muckamore Abbey Hospital over a two-year period, 17 (11%) were unable to be discharged and of these 11, had been in hospital for greater than a year. The main reasons given for not discharging the patients were: no capacity available in any appropriate care home/supported housing; care planning was in progress; no funding was available and necessary equipment and adaptations were not available (McConkey et al, 2002).

Likewise in Longstone Hospital a total of 19 people had been admitted in the previous five year period and had been there for at least one year; they account for 15% of the present Hospital population (Slevin et al, 2002).

Offending behaviours

Long-stay hospitals have provided another function; namely detaining people with a learning disability who have offended in semi-secure accommodation although those who require to be detained in high security are sent to Carstairs in Scotland. The precise numbers of people are not known.

The needs of people with intellectual disabilities who break the law are generally thought to be better met within health and social services than through the criminal justice system (Murphy and Fernando, 1999). This means it can be very difficult to determine the numbers of people who commit offences as they may not come before the courts or the police may decide not to press charges. Simpson and Hogg (2001) concluded after a systematic review of published studies internationally that “there is no compelling evidence that the prevalence of offending among people with ID is higher than for the wider population” (p.394).

They did however find some evidence to suggest that the relative prevalence of sexual offending (particularly against younger and male children), criminal damage and burglary (but not theft) are higher among people with borderline disabilities. Arson also seems to be more common (Day, 1993). However there is little reliable data on which to base estimates of need for secure/semi-secure accommodation (Fraser, 2002).

An international working party (IASSID, 2000) noted that additional mental health problems, drug and alcohol abuse, and social factors, such as homelessness and unemployment, may increase the risk of offending by a person with an intellectual disability and lead to further social exclusion. Preventive measures would include meaningful employment opportunities, and housing, together with assessment and treatment services, and that should be available to people with intellectual disabilities, including those with mild/borderline disabilities whose need are often ignored in present social cares systems.

Persons who pose an ongoing danger to others may need to be detained against their will. Full legal safeguards need to be in place for recognised places of detention outside of the criminal justice system and these could be located outside of existing

hospitals. To date there has been a great reluctance to develop community-based alternatives on the grounds of public opposition. However there are instances in Northern Ireland and elsewhere of offenders being successfully rehabilitated into community services (Murphy and Fernando, 1999). In addition, more attention needs to be given to preventative social measures for at risk adolescents and young adults.

Conclusions

As Hospital provision is reconfigured to provide short-term assessment and treatment services, careful attention needs to be paid to the resettlement of patients with more complex needs and offending behaviours. This will require a much higher level of funding than has hitherto been available. Failure to do this will result in treatment beds becoming filled and the creation of a new-stay population as has happened in Scotland (Whorisky, 2002) .

Alternatively increasing numbers of these difficult patients could be placed in private hospitals (most likely in Great Britain) as is happening in England but at per annum costs in excess of £100,000 per person (Russell, personal communication, 2004).

Resettlements from long-stay hospitals

From the early 1980s, long-stay patients began to be resettled into hostels and other community facilities. Five studies have monitored the resettlements of these patients.

McGinnity, McVicker, Marriott et al (1990) followed the first 100 patients discharged from Muckamore Abbey Hospital in the period 1987 to 1992. All had been re-settled in the Northern Board area although nearly half came from other Board areas. In all, 88% went to nursing homes provided by the private sector and only 6% to voluntary accommodation; 5% statutory provision and one person lived independently. Over 90% of residents and 72% of relatives interviewed expressed satisfaction with the placement. However the authors noted that some people could move on to more independent living arrangements but "*there are clear gaps in provision and a definite possibility of people being "trapped" into a particular level and form of care*. (p.16).

Kavanagh (1994) reported on 73 clients who had moved from hospital to community settings. Data as obtained from semi-structured interviews with clients, staff members and relatives. A significant increase in adaptive functioning was noted along with a decrease in maladaptive behaviours. People with a learning disability had more contact with relatives in the new settings and expressed a preference for living there.

Donnelly et al (1997) reported on a random sample of 114 patients discharged from three hospitals in the period 1987 to 1990. Few of the sample had major problems with daily living skills and behavioural problems were also uncommon. Nevertheless around 70% were resettled into residential or nursing homes. Former patients were satisfied with their new homes and reported feeling happier, healthier and more independent since discharge. However social networks were poor and there was no evidence to suggest that people were undertaking new or ordinary daytime activities.

Donnelly et al (1996) followed up at 12 and 24 month intervals a group of 214 patients who had been discharged in the period 1990-1992 mostly into nursing homes (60%); residential homes (22%) and hostels/group homes (12%). Only five persons (2%) went into some form of independent living. Although little or no change was found in patient's competences, certain aspects of challenging behaviour had improved after 12 months. People were also less depressed and more satisfied with their new homes.

Few changes were found in their patterns of activities or social networks. The authors recommended that purchasers and providers in N. Ireland *"give more attention to ways in which the principles of normalisation could be incorporated in the process of contracting and delivering of services"* (p. 598).

McConkey et al (2002) followed up 68 patients from EHSSB area who were resettled from Muckamore Abbey Hospital period in the period 1996-2000. As in previous studies, nearly three-quarters of people moved from the Hospital to residential homes and a further 15% to nursing homes. Only eight persons moved to ordinary housing. Care-managers reported that only ten persons (15%) who were resettled had a choice of alternative accommodation open to them. At the follow-up date, four of the 68 were presently back in hospital with a further ten people having had one or more treatment admissions since discharge. The latter tended to be people with mental health and behaviour problems living in community settings.

Around half the people resettled were considered by staff as having challenging behaviours that they rated moderately serious or severe. These were mainly aggression to others and to self. However for 21 people (41%), staff thought that their behaviour problem had improved since the move although this was less evident in those with severely challenging behaviours.

Nearly all former patients who were interviewed were happy to have moved. Only one person said they had not wanted to move from the hospital and another wished they could move back there (McConkey et al, 2003).

Although a majority of families welcomed the move from the Hospital; a significant minority (26%) had been unhappy at the prospect of the move. After the move all families felt the residence was at least equivalent to the Hospital with over four out of five families rating it as much better than the Hospital (McConkey et al, 2003).

There was nearly a four-fold difference between the lowest cost package (£11,000 per annum and the most expensive (£41,500). The most expensive packages were in private residential homes. Nursing homes and statutory residential homes had lower cost packages. However when other sources of funding are added in, supported living arrangements in community settings are also among the highest in cost. These costs appear to be lower than those quoted for Great Britain (Emerson et al, 2000).

Costs incurred by Hospital-based multi-disciplinary teams in resettling patients was estimated in a study by Hughes et al, (2003) on one long-stay hospital. These ranged from £1,500 to £8,000 with an average of £3,400 per patient. The authors argue that these costs need to be factored in the overall monies allocated for resettlements.

Conclusions

- People were relocated mainly into congregated settings with little use made of more individualised options such as supported living arrangements. This continued in recent years despite the expressed policy of HSS Boards to community-based services (e.g. EHSSB, 1996).
- Although people were happier in their new accommodation, the dearth of social networks experienced by people in the new settings was marked.
- The failure of people to move on to more independent living arrangements despite them having the competence to do so and this need being identified by both key-workers and care-managers.
- The monies available for Northern Irish resettlements is less than in Great Britain.

Section 3: People living in residential accommodation and supported living.

In 2003, around 1,900 persons with a learning disability were living in some form of residential provision provided by both statutory and non-statutory agencies (McConkey, Spollen and Jamison, 2003).

Figure 2 shows the proportions of people living in three types of accommodation options.

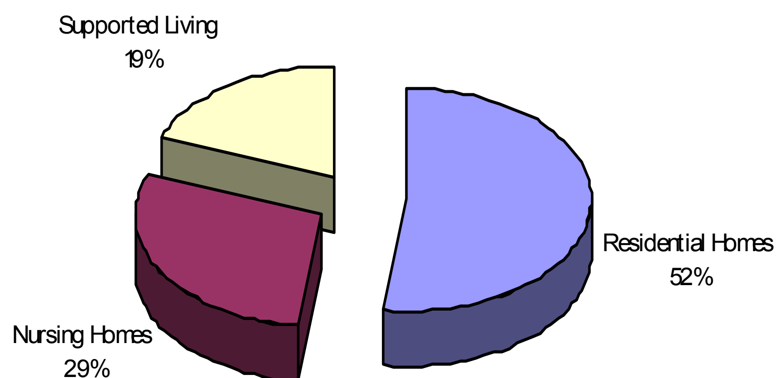

Figure 2: The proportions of people aged 20 years and over living in different accommodation options.

Around half of those in residential care were living in registered residential care homes. On average the homes have around 20 residents. Most people have their own bedroom.

Over one quarter live in registered nursing homes modelled on care of the elderly even though the average age of these residents is around 50 years. The proportion of nursing home places is higher in Northern Ireland than in England and Wales. In 1997, 7% of their places was in nursing homes (Emerson and Hatton, 2000).

A growing number of people live in supported living arrangements. The proportion is comparable to that for England and Wales (Emerson and Hatton, 2000). These individuals have tenancy agreements and live on their own or with one or two other persons. Support staff are on hand, with 24 hour cover provided as needed.

Around half of the residential the places (53%) were in the private sector; with 27% provided by voluntary agencies and 20% in statutory provision. However this distribution varies across Boards. The WHSSB has the highest proportion of private provision (93%) and the EHSSB lowest (28%). Voluntary provision is highest in the EHSSB (35%) and lowest in the WHSSB (7%). Statutory provision is also highest in the EHSSB although many of these are in supported living (36%).

However there is great variation across HSS Boards in the type of accommodation that they have available in their area[1]. For example, the NHSSB has the highest proportion of people in nursing home accommodation (46%) with the EHSSB (22%) and WHSSB the lowest (21%). The EHSSB has the highest proportion of people in supported living arrangements (31%) with the lowest proportions in WHSSB (4%) and SHSSB (3%).

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[1] This data is taken from a series of reports prepared for the NI Housing Executive and the four HSS Boards by McConkey and colleagues, 2000, 2001, 2003a, 2003b).

There is also proportionately more accommodation options in certain Trust areas than others; ranging from 6.8 places per 10,000 of population to 13.2 places per 10,000 (see Table 3). However none of the Trusts achieve the minimum number of places that the Department of Health has suggested for England and Wales, namely 15.5 places per 10,000. A wider range of geographical variation is reported in Great Britain: range 1 per 10,000 to 41 per 10,000: overall mean 15 per 10,000 (Office of the Deputy Prime Minister and Department of Health, 2002).

Table 3: The numbers of people in residential accommodation for each Community HSS Trust and the rate per 10,000 of the trust population (2001 census).

Trust	Trojan + Board updates	Rate per 10,000
Armagh & Dungannon	132	12.94
Craigavon & Banbridge	83*	6.80
Newry & Mourne	113*	12.99
SHSSB	**328***	**10.54**
Foyle	134	8.27
Sperrin Lakeland	149	12.52
WHSSB	**283**	**10.07**
Homefirst	346	10.55
Causeway	104	10.51
NHSSB	**450**	**10.54**
Down Lisburn	206	11.94
NW Belfast	190	13.24
SE Belfast	248	12.38
UCHT	179	11.97
EHSSB	**823**	**12.36**
Total NI	***1884****	***11.18****

* *these figures may be an underestimate as they may not include people living in statutory accommodation. There may be an extra 50 residents in Newry & Mourne and around 20 in Craigavon & Banbridge Trust.*

Of those living in these three forms of accommodation, the majority came to their present residence from living in a long-stay hospital (42%) and a further 25% from another residential facility. In all, 34% came from the family home. The average length of stay in residential accommodation was 7.0 to 8.3 years. This contrasts with the average stay of those still living in hospitals of 16 to 24 years (see earlier).

Recent research by McConkey and colleagues suggests that at least 12% of people in existing provision (220 persons) could be more suitably accommodated elsewhere; mostly in supported living arrangements. Moreover around 30% of the people in all existing options are likely to require extra support in the future as they age.

Characteristics of residents and tenants

In all, 51% were male and 49% female (which is different from the community population of 64% male and hospital population of 62% male). This may reflect a greater longevity of females coupled with more females being selected for resettlement than males (see earlier).

The mean age of residents was 48 years (significantly higher in WHSSB – 52 years; compared to SHSSB mean of 47 years). The age also varied significantly across

Trusts with UCHT having the lowest average age (41 years) and Foyle Trust highest (55 years). Table 4 shows the age bands of residents. Given a normal life expectancy which now seems likely for those aged over 20 years (see Chapter 1) this data suggests that over the next ten years only 25% of these residents are likely to die.

Table 4: The numbers and percent of residents by age groupings

Age Band	Numbers	Percent
0-19	9	0.7
20-24	42	3.0
25-29	56	4.0
30-44	425	30.2
45-59	502	35.6
60-64	138	9.8
65-74	146	10.4
75+	91	6.5
Total	**1409**	**100**
Missing	32	-
Total	**1441***	

**** Age information was not available for 400 persons***

Overall, around two-thirds of residents were considered by their key-workers to have mild/moderate learning disabilities and the other third to have severe/profound disabilities. However this breakdown varied by age bands as Table 5 shows.

Table 5: The proportion of residents by age and level of disability (Data based on census returns from four HSS Board Housing Studies (2000-2003) (N=1,528) (Data missing for 2% of cases).

Age Bands	Moderate*	Severe/Profound*
0-19	0.5%	0.5%
20-34	9%	7%
35-49	21%	10%
50+	36%	14%
Totals	**66.5%**	**31.5%**

**ratings used by key-workers*

The largest sub-grouping of residents are aged over 50 years with mild/moderate disabilities.

Evaluation of residential and supported living options

Despite the widespread use of residential and nursing home placements in Northern Ireland, there has been no evaluative studies that we could find into the impact these options had on the lives of residents. However studies undertaken in Great Britain and reviewed by Hatton and Emerson (1996) suggest that congregated living options do not provide residents with opportunities for developing their independence, nurturing friendships and promoting their social inclusion.

Maybin (2000) undertook an evaluation of the supported living services developed by Ulster Community and Hospitals Trust for 45 persons. This involved the relocation of residents in registered accommodation into their own tenancy with support staff provided by the Trust. Using information provided by tenants, relatives and professional workers, it was concluded that the tenants were happy, settled and achieving a higher level of functioning than in their previous accommodation. They were also leading ‘normal’ lives within their communities and staff were also reported to

be happier and felt supported. One instance of an unsuccessful move was noted mainly due to the unsuitability of the selected neighbourhood.

Another study examined three supported living schemes in Northern Ireland (McConkey and McConaghie, 2001). These consisted of clusters of houses within one contained area with one or two tenants in each property which had opened from 1992 onwards in two rural towns and in a suburb of Belfast. Comparisons could be drawn with data reported for supported living schemes in England (Emerson et al, 2000) as the same measures were used.

In both N. Ireland and England, tenants were being supported with challenging behaviours, mental health problems and epilepsy although this was less evident in two of the three Northern Irish Schemes.

The tenants had more choices open to them and to enjoy life experiences comparable to those of non-disabled persons. Sizeable proportions had health checks carried out although not to the same extent as reported in Britain. There were concerns about the risks of abuse and exploitation that Northern Irish tenants might experience and in some instances these concerns appear to be higher than those reported in Britain.

However people in supported living per se did not experience any greater degree of social inclusion. For this to happen, these schemes need to integrate with a range of initiatives in employment, advocacy and befriending. In Northern Ireland, Triangle Housing Association has been active in developing such services.

The costs of the three schemes in N. Ireland fell into the lower range of costs reported for the British schemes and yet they appear to be serving a comparable tenant group and producing similar outcomes. In two of the schemes the costs were met entirely by housing monies and social security payments while in a third scheme, the HSS Trust contributed 20% of the costs. This contrasts sharply with the British schemes which were funded by a higher proportion of monies from health and local authorities.

Conclusions

- Significantly fewer residential places are provided for adult persons in Northern Ireland compared to Great Britain and the Republic of Ireland. Moreover the bulk of this accommodation is taken up by people relocated from Hospitals or other residential homes. Only one-third people have moved into the accommodation from family care.
- Residential care homes and nursing homes form the predominant model of provision in Northern Ireland even though the majority of persons are rated as mild/moderate disabilities. This model provides a relatively low-cost option but requires to be wholly funded by HPSS monies.
- The emerging supported living schemes show promise in terms of the improved quality of life they offer people with a learning disability and the value-for-money they provide for HPSS providers.

Section 4: People living with family carers

Close to 6,000 persons with a learning disability aged 19 years and over are living with family carers (McConkey and colleagues, 2000, 2002, 2003a, 2003b). Of these, nearly one third presently live with a single carer and over 25% with carers aged over 65 years. Around one in six carers were rated as being in poor health. These are all risk factors that make present care arrangements vulnerable and may necessitate alternative accommodation having to be found for the person, sometimes with little or no notice.

Over half of the families (54%) are dependent on State benefits as their main source of income and a further 6% were rated as having an income of less than £12,000 per annum. Of the remaining 40%, only 6% were rated to have an income in excess of £24,000.

Just over half of family carers live in owner-occupied accommodation (50% to 60% across the four HSS Boards) with the bulk of the remainder living in accommodation rented from the Housing Executive or Housing Associations. This proportion is much higher in certain HSS Trust areas than others, e.g. North & West Belfast 60% and Foyle 55% rented accommodation. However home ownership by families of people with a learning disability throughout Northern Ireland is lower than the regional average of 68%.

Trust staff rated present housing arrangements and inadequate or unsuitable for around 9% of families. The main shortcomings were lack space and overcrowding, and the need for better bathrooms and ground floor accommodation.

In Northern Ireland, the most common adaptations made to family homes have been the installation of showers, new bathrooms and toilets and safety devices. These have been paid for by the disabled person's family (33% of instances); the NI Housing Executive (31%) or by Health and Social Services (29%). Adaptations are twice as likely to be found in privately owned homes than those rented from the Executive or Housing Associations (Monteith, McLaughlin, Milner and Hamilton, 2002).

A particular concern has been the delays in obtaining means-tested grants for home adaptations and the degree of bureaucracy involved (Monteith et al, 2002).

Future needs

Community personnel from HSS trusts estimated that up to 1600 persons throughout Northern Ireland may require alternative accommodation and/or support arrangements in the coming five to ten years. Of these around 170 are likely to be required in the next two years. Half of these were in the EHSSB area.

An increase of 700 places in Northern Ireland would bring the overall ratio of provision to the *minimum* suggested for England (Office of the Deputy Prime Minister and Department of Health (2002) giving a total of 2,600 places: 1.55 per 1,000. This increase would make the proportion of people living in some form of residential accommodation similar to the proportion in the Irish Republic (see earlier).

An additional 2,000 places would bring it to the upper range suggested by the Department of Health of 2.33 places per 1,000.

The people whom trust staff saw as needing to move tended to live with older carers who were in poor health and whose housing was deemed inadequate. Hence the

decision was not seen by Trust staff in terms of the availability of carers rather than on the demands placed on carers, such as a relative with challenging behaviours.

In all HSS Boards the number of people known to be on a waiting list for alternative accommodation was very low and never higher than 13% (EHSSB area) of those who were thought to require a move. This suggests that 'futures planning' is not occurring with these families (see later).

Trust staff felt that around half these persons could be relocated into some form of supported living arrangements – either on their own; with one or two friends or continuing to live in the family home – and up to 10% with another family member. Placement in a residential home was noted for around one quarter, although this option was more frequently mentioned in the WHSSB area perhaps because there are fewer supported living schemes in that area. Nursing home placements were recommended for around 8% and some form of specialist provision (usually because of challenging behaviours) for around another 8%.

Views of people with a learning disability

Research undertaken in Northern Ireland with 180 people attending 20 centres across Northern Ireland identified the features that were important to them in their living arrangements (McConkey et al, 2003). Just over half were living with family carers and the others in a range of other accommodations.

Four themes were common to all participants in regards of their living arrangements: they had their own room, they participated in household activities; they had access to community activities and contact with family and friends. People living with families mostly wanted to remain there.

Those living independently or in supported housing valued their independence and having access to support staff whereas those in residential homes spoke of the importance of their relationships with co-residents and staff.

Those living in ordinary housing – whether with families, independently or in supported tenancies - were more likely to report harassment and stressed the importance of living in a pleasant neighbourhood than did those in residential homes.

Consultations undertaken with people with a learning disability (Review of Learning Disability Services, 2004) identified a number of concerns. People often have no choice about where they live or whom they live with. They have no access to help and advice if they want to move. Staff members felt it was too risky for people to live on their own but people felt that they should have a chance to do so.

Carer's views

Four studies, using a range of methods, have been undertaken in Northern Ireland to ascertain carer's views (McConkey et al, 2003). In all, 387 carers responded.

The majority of carers envisaged the person continuing to be cared for within the family. The most commonly chosen out-of-home provision was in residential or nursing homes, supported living in their own homes and homes for small groups of people. Few carers chose living with another family.

However only small numbers of carers envisaged alternative provision being needed in the next two years and few had made any plans for alternative living arrangements.

The most frequently unmet need reported by carers was for their relative to have greater opportunities to take part in leisure activities; for day services and increased

short break (respite) provision. These echo the views of parents with children (see Report of that Task Group).

Seltzer et al, (1996) examined the extent of future care planning done by carers aged 55 years and over. In a sample of 151 Northern Irish carers, 62% reported no plans having been made whereas comparable percentages for families in the Irish Republic was 39% and 13% for a sample in the United States. Moreover the US sample rated their health as being significantly better than the two Irish samples and they had lower levels of parenting stress. The Northern Irish mothers had the highest percentage of health problems that impeded everyday tasks and they had the highest levels of parenting stress.

In consultations held with carers as part of the Review (Bogues, 2004), they stressed their need for support to plan for the future of their relative when they were no longer able or available to do so. This offer of support needed to be restated over time as a refusal at one point might be overtaken by subsequent changes in family circumstances.

Carers did not want professionals to assume that other family members would take over the caring role and they were concerned that hospital resettlements would reduce the availability of funds to meet the resettlement needs of their relative.

A recurring theme was their need for greater support in their caring role through respite breaks, domiciliary help and the provision of a phone alarm link should anything happen to them.

Conclusions

- Families caring for a person with a learning disability tend to be poor; around half live on State benefits and more reside in rented accommodation than is the case within Northern Ireland as a whole. Nearly one third of carers are lone parents.
- Living with their own families is the preference of people with a learning disability and the hope of many parents. However there was evidence that support services to families with adults as well as with children need to be improved.
- People with a learning disability want to maintain contact with family and friends if they have to move from the family home. They prefer to live in homely accommodation and to be involved in household tasks and community activities.
- Carers are willing to consider a range of accommodation options as being suitable for their relative and increasing numbers appear to be interested in making future plans which could include options outside the family circle.

Section 5: International Research

In recent years, a growing literature has emerged on the experiences of people living in different accommodation and support options and the impact these have on their lives. There are clear differences among the different models that are commonly used. This data should help to inform future commissioning decisions.

Congregated models of care

Current residential services in UK and Ireland for people with a learning disability tend to be dominated by settings that are larger than 'ordinary homes'. Emerson and Hatton (2000) undertook an analysis of the 1997 Census of residential accommodation in England and Wales. This suggested that only 13% of adults lived in homes with less than 5 persons; 38% were in homes with between 5-9 persons and nearly half (49%) lived in settings with 10 people or more. Likewise following hospital resettlement programmes, very few people (4%) were found to be living independently (Cambridge et al, 1994).

In recent resettlements from a hospital in Scotland, an increased use of smaller accommodation units is evident, in that 8% of people moved into a single person flat and a total of 55% of people moved into accommodation for five or less people. However 25% of people moved into accommodation for between 6-10 people and the remaining 25% of people moved into facilities with 36 or more people living there. Interestingly, the people moving into the larger facilities, although older, were not assessed has having the greatest degree of behaviour problems nor the highest level of dependency (Ager et al., 2001).

The move from hospital to community settings has been largely positive for people with a learning disability, especially in their adaptive behaviour scores and opportunities to take part in a wider range of leisure pursuits (Emerson and Hatton, 1994; Donnelly et al, 1996). However, sustained improvements in challenging behaviours and increased social integration are not commonly reported (Ager et al., 2001). As most people were resettled into nursing homes and residential accommodation with 10 plus residents, these findings are not unexpected.

Although there has been a paucity of UK studies specifically focussing on nursing home provision; one study in N. America followed nearly 250 persons over a three year period - 50 of whom had moved into smaller community settings and the remainder stayed in nursing homes. It was found that those in community settings had better health and greater levels of community integration (Heller et al, 1998).

With resettlement programmes nearing completion in Great Britain, recent research literature on the topic of housing has focussed on three main themes:

- Special residential (village) communities
- An evaluation of small group homes
- Supported Living models.

1. Special residential (village) communities

As part of the Hospital closure and redevelopment programmes, special campus-style accommodation was developed by the NHS as an option particularly for clients who had additional and complex needs. Typically these consisted of a cluster of houses for six to eight persons on the same site. This option had a number of attractions; it

provided economies of scale to commissioners while carers saw it as offering a more protective environment for their relatives. However proponents of an ordinary life philosophy warned of the danger of recreating mini-institutions. The Department of Health commissioned a major research project to identify the possible advantages of this model of provision alongside two others; 'village' (or intentional) communities such as Camphill where people lived in communities alongside able-bodied co-workers often in rural settings and community-based residential supports in dispersed housing schemes (Emerson et al; 2000).

The best examples of each type of model was sought through consultations with expert informants throughout England and the data analyses conducted by the researchers took account of differences in the characteristics of clients in the different settings.

All options were considered to have some advantages as well as disadvantages. However the residential campuses providing fewest benefits despite being selected as representing the best examples of this model of service provision. The distinct features of the residential campus model were:

- More likely to be supported by senior staff with nursing qualifications;
- Better organisational procedures for assessment and treatment.
- More residents had a general health check in the last year and a vision check in the last two years.
- Staff consider residents to be less at risk of exploitation fro members of the public.

However many more benefits were found for people in the other two models of provision.

For example, village communities that had a strong value base provided more health checks, more routine day activities, less institutionalised routines, had higher quality person-centred planning and also training and supervision of staff.

2. Small Group Homes

A common model internationally has been a small group of people with a learning disability sharing an ordinary house with staff support available on a 24 hour basis if required.

The research project described above (Emerson et al 2000) found that in the main, people living in dispersed housing in community settings were more likely to:

- live in homely environments;
- had increased access to independent advocacy;
- involved higher quality person-centred planning procedures;
- had more overall choice in the way they were supported;
- had larger social networks
- and have care which was rated as less institutionalised.

An important review of the small group home model conducted by Hatton and Emerson in 1997 concluded that, "it is clear that smaller community-based homes are associated with better performance and more positive outcomes than either hostels or hospitals".

Nonetheless small group homes are not consistently good and the quality of the settings is variable. The best determinant of quality appears to be the way staff support

individual service-users. Improvement of services requires a management emphasis on staff training, leadership and practice instead of focussing on buildings and location (Mansell, 1998).

Felce and colleagues (1998) also argue that a combination of person-centred planning with activity planning and staff training, will yield results better than 'further appeals to ordinariness." Staff training in providing 'active support' appears a particularly effective approach to promoting opportunities for people with severe disabilities (Jones et al., 1999). These views are echoed by Simons (1998a) who identified variability in the quality of small group homes / staffed housing, the relative isolation of people living there and an insufficient number of services as recurrent difficulties with this model. He also highlighted that a focus on form and not content, poor management and the lack of, or poor quality with individual planning as main reasons for the failure of these models to improve the quality of life for people with a learning disability. These are factors which should be taken into account in a Best Value assessment (Cambridge, 2000).

3. Supported Living

"Supported living is primarily about enabling people with a learning disability to be actively engaged citizens through:

- Supporting them to live in their own homes (owned or rented by them)
- Enabling them to participate in their communities (for example through working if they wish)" (Simons and Watson, 1999: p.41).

However Simons and Watson acknowledged that this is not a single model and that this can lead to some difficulties in understanding the principles involved.

Proponents of this model argue that it is built around five principles; separating out housing and support, focusing on one person at a time, providing as much choice and control for service users as possible, zero rejection (not giving up on people), a focus on relationships and acting in ways which complement natural supports rather than simply replacing them (Kinsella, 1993). Hence supported living is more than de-registering homes and giving people their own tenancy which has tended to be the two main consequences of the implementation of the new Supporting People funding arrangements.

The research carried out by Emerson et al (2000) identified the following as advantages of supported living over group homes and residential campuses:

- people are more likely to have tenancy agreements;
- they tend to deliver more intensive staffing;
- there are better internal procedures for allocating staff support on the basis of the needs of tenants;
- evidence of greater tenant's choice (especially over where and with whom they live).
- better social integration and access to leisure and recreational activities

The disadvantages compared to other models were found to be:

- fewer hours of scheduled activity;
- more likelihood of having their home vandalised;

- poorer implementation of habilitative procedures such as individual plans; key-workers and reviews.

Despite, these disadvantages it is widely acknowledged that supported housing adds important options to the range of possibilities for providing support and accommodation for people with a learning disability (Simons and Watson, 1999; Mansell, 1998).

New models of provision

A number of emergent models are being explored in order to widen the range of service options for people with a learning disability. Some of these are better established in North America and continental Europe than they are in these islands. However a recent publication by the Foundation for People with Learning Disabilities (2001) described these options using British case studies.

Adult Placement Schemes

There is a long history of people with a learning disability living with substitute families; for example boarding arrangements of patients from hospitals were common in Scotland from the 1930s onwards. More recently this notion has been formalised in schemes in which families or carers are actively recruited, supported and paid to provide a long-term homes for selected individuals. Although certain problems have been identified, on the whole such schemes did fulfil the aspiration of people to be part of a family and they were preferred over other care arrangements (Robinson and Simon, 1996). In Northern Ireland to date, this model has been used successfully but more for short-term breaks rather than longer-term placements (Roberts, 1998, McConkey et al, 2004).

Networks of Support

These schemes are suited to people with low level needs but who may need intermittent support. Around nine people form the network and all have each other's phone numbers. In addition community living workers are recruited from the same area and are paid to give around 10 hours support per week to the network members. In addition telephone support is provided at evenings and weekends (Simons, 1998b).

Home Ownership

The capital costs of acquiring a property can be obtained through a mortgage funded by Income Support payments (Simons 2000). Mencap's Golden Lane Housing is one of the organisations pioneering this scheme. There are also possible co-ownership options with Housing Associations. Some individuals may inherit a property from their family but this needs to be carefully planned in advance (Simons and Watson, 1999). However one drawback can be funding the maintenance costs of the building.

Personal Assistants

Direct payment schemes may make it possible for people with disabilities to recruit and employ their own personal assistants. Although this is becoming more common for people with physical disabilities, there are few instances of this occurring for people with a learning disability (Holman and Collins, 1998). However those who have experience of them are broadly favourable (Gramlich et al., 2002).

Sheltered Housing for the Elderly

In N. Ireland, there have been instances of an aging carer and their son/daughter with a learning disability both moving into sheltered accommodation for the elderly. If the carer dies, the relative may continue to live there with augmented staff support as

required. Similarly aging carers might move with their relative into services provided primarily for people with a learning disability.

Housing models – Conclusions based on research findings

Emerson et al (2000) concluded that "residential campuses" offered a significantly poorer quality of care and quality of life than community-based, dispersed housing schemes". Moreover, they felt that "village communities operated by independent sector organisations should continue to be included on any 'permissive list' of acceptable options for the provision of residential supports". They went on to note that:

"comparison of the costs and benefits associated with supported living and more traditional small scale, community based provision, indicate that it would be appropriate to include supported living schemes in any future list of permissible options".

Simons and Watson (1999) also supported the further development of supported living options and concluded that it 'claimed to be a practical as well as principled option' (p47). However they highlight the need to clearly define the concept of supported living and caution against viewing it as a panacea, highlighting that in particular it does not necessarily appear to lead to people being active participants in their communities and the actual operations of any scheme need to be clearly defined.

Howard (1996) found that supported living arrangements most effectively supported people with complex needs when services included – a sustained commitment to individuals combined with skilled personal care, clear identification of risk behaviours and strategies to appropriately manage such risk and the ability to mobilise additional problem solving resources and skilled assistance at short notice.

On the basis of a review of current literature Simons and Watson (1999) concluded that a 'modernised' housing and support service would have the characteristics listed in the Box below.

A modernised housing and support service would …

- ❑ Be based on the principles of citizenship and civil rights
- ❑ Be comprehensive and inclusive
- ❑ Draw on a synthesis of the supported living models and developments like 'active' support
- ❑ Be based on person centred planning, along with community development strategies to open up a wider range of opportunities
- ❑ Take the issue of self determination seriously
- ❑ Use resources efficiently and flexibly
- ❑ Require the creation of a coherent funding base
- ❑ Involve regulatory reform
- ❑ Be complemented by a range of other services (including employment, continuing education and supported leisure services)

Commissioning Guidance issued to English authorities

In 2002 the Department of Health issued draft guidance to English local authorities based on the past research findings (Office of the Deputy Prime Minister and

Department of Health, 2002). They identified three key messages relevant to developing a housing and support strategy:

- Smaller community-based housing and support services provide higher quality support and better outcomes for people with a learning disability than larger more 'institutional' forms of provision.
- The quality of support and outcomes provided by existing community-based housing and support services is often unacceptable when judged against the aspirations of choice, social inclusion and promoting independence.
- There are few robust relationships between measures of resource input and either the quality of support or outcomes for people with a learning disability. Quality is determined by how resources are used. Further research is needed into the cost-benefits of service models and particularly into the roles of staff and managers in producing valued outcomes for tenants and residents.

Special Needs Housing

The main emphasis in the literature has been on different forms of residential accommodation and support they offer to individuals. Very little analysis has been made of the physical requirements in housing but a summary of the main conclusions now follows.

Most attention appears to have been paid to the adaptations required in ordinary housing to assist families caring for a child or adult person with physical and/or sensorial disabilities (e.g. Beresford and Oldman, 2002).

Here the main issues highlighted were:

- Families with disabled children experience far greater problems with their housing than families with non-disabled children. Nine out of ten families reported at least one difficulty with their housing and many reported multiple problems. Families on low incomes experienced most problems.
- Many families would prefer to deal with their housing problems by moving rather than adapting their current home. Over one third of families found the location of their home to be a problem either because it was an unsafe place of the child or because of difficulties with neighbours.
- They needed extra space in the house to allow for use of wheelchairs and walking aids; storage space for aids and equipment; privacy or time-out space, play space and for carrying out therapies.
- Downstairs toilet, well-designed bathrooms to allow easy use of lifting or mobility aids.
- Ground floor bedrooms, kitchens designed with safety as well as access in mind.
- Easily-managed stairs – installation of chair lift
- Suitable gardens, car parking, located on level ground – not on steep hills and located close to services.

The report noted that only 10% families had received assistance from statutory agencies in order to address their housing needs. Typically there was no single agency or department with lead responsibility for meeting the housing needs of disabled persons living with families.

Challenging behaviours

With regard to housing for persons prone to exhibit challenging behaviours such as screaming; destruction of property and aggression to others; the following recommendations have been noted (Felce et al, 1998):

- Separate living area available as well as bedroom;
- Sound-proofing
- Flexi-glass installed and strengthened fabric such as doors
- Secure outdoor space available
- Use of detached properties with large gardens; distanced from neighbours
- Small number of residents sharing

For people with dementia and other who may be inclined to wander, sensors can be fitted to external doors to alert staff.

Housing clusters

Little evaluation appears to have been undertaken of the impact of the physical grouping of special needs housing. The so-called 'core and cluster' model is well known; in which a staff team works from a central base – such as a residence that is staffed 24 hours - to support people living in close proximity in their own homes. However there appears to have no evaluations of this model undertaken for people with a learning disability.

Two cautions have been noted. The cluster houses need to be well dispersed in the neighbourhood in order to avoid a segregated 'campus' facility developing by default. (Heller et al 1998b). Second, it is questionable whether the same staff team can successfully combine the different roles needed in the two settings.

Another issue that has been alluded to is the danger of different special needs groups being housed in the same locality. However no formal evaluations appear to have been undertaken on this issue.

Some housing providers have begun to experiment with new styles of buildings so that within the same complex, there can a range of accommodation suited to people's needs, such as self-contained flats for one or two people as well as traditional shared housing arrangements with staff always available. Again, these developments are novel and little formal evaluation appears to have been undertaken as to whether or not they live up their intentions. It is likely that very determined efforts would be needed to ensure that they do not become another form of congregated living arrangements – albeit with better standards of housing - with all the disadvantages that are known to flow from this model.

Finally, it is apparent that advances in computer-assisted technology, communications and alarm systems will enable many people with physical and sensorial disabilities to be less dependent on people living with them and assisting with their daily living needs. A telephone support line can provide constant emergency contact over 24 hours with personnel available to visit if required.

Modern technology promises further extensions, such as the use of video-phones and control of electrical equipment. These means could be used to maintain people in the family home when the carer dies or reduce to need for face-to-face support. However

these can represent a significant capital investment at present and they are prone to breakdowns.

The costs of housing and support

In recent times a variety of sources have been used to fund housing and support services. In Great Britain, these can include funds paid separately from Health Authorities and Social Service/Social Work (whereas only one source of funding is available in N. Ireland) as well as income maintenance benefits; disability benefits; housing benefits and housing subsidies (Simons and Watson, 1999). But these changed in 2003 with the introduction of Supporting People arrangements.

Research into the costs and factors that determine costs have been remarkably rare in view of the scale of expenditure on residential services. Of work done to date, a number of conclusions can be drawn (Felce, 1996).

- Cost variation is considerable, even between services of similar types.
- Generally costs increase with more dependent clients. However there is only a weak link between resident needs and the determination of staffing. It appears that providers when determining staffing levels use inconsistent criteria
- Independent sector costs tend to be lower than statutory sector.
- Community housing costs are generally greater than those of hospitals but they produce better outcomes.
- Economies of scale do not appear to operate in facilities larger than six and there may be no cost disadvantages in providing smaller settings down to three persons.

The largest element of the revenue costs of services is attributable to staffing. The majority of economic evaluations of specific forms of support services for people with a learning disability (e.g., residential supports) have reported a modest positive association between indicators of ‘need’ and the costs of staff-user ratios of provision. People with greater needs usually have more greater levels of staffing.

However there is no simple correlation between the amount of money spent on services and the outcomes attained. This involves taking into account differences between services in the needs of people served, especially as there is extensive evidence to suggest that people with greater or more complex needs often experience poorer outcomes. The findings of the few studies that have attempted to examine costs-benefits suggest that the link between resources (costs or staff-user ratios) on the one hand and quality on the other is tenuous. Some studies have reported that increased resources are linked to an extent with increased quality but others have failed to find a link at all (National Assembly of Wales, 2002).

Supporting People

In April 2003, new arrangements came into place in Northern Ireland for setting up, monitoring and funding housing support services. The ‘Supporting People’ initiative is managed by the Northern Ireland Housing Executive in partnership with a range of agencies such as HSS Boards, local government, support services and users.

The aim is to make the process of setting up housing related support services less complex and no longer is funding for support attached to the tenure or accommodation the person occupies. Support can be provided in a range of accommodation options

including supported housing, hostel-type accommodation and independent living, as well a new type of 'floating support' where support funding is linked to the individual rather than to the accommodation. Support systems can also be varied in intensity as client needs change.

Supporting People has two separate funding 'pots'. Housing Benefit which only pays for the housing costs (from the benefits section of NIHE) and new block grants for the cost of support services to vulnerable people. These will be financed from various existing streams brought together in one pot, such as transitional housing benefits and income support, and special needs management allowances. Supporting People monies are cash-limited.

All providers must have accredited status in order to provide support services and they will be subject to monitoring and scheme reviews to determine that they meet the Supporting People Standards, notably quality and cost-effectiveness in the delivery of services.

Experience in Great Britain

Prior to the implementation of Supporting People in Great Britain, a study by Watson et al, (2003) expressed concerns that service commissioners lacked agreed definitions of marginal, hard-to-reach or high-risk groups such as individuals with complex and multiple needs. Also lacking was a systematic needs analysis showing demand pressures, exclusions and service-user's preferences along with an understanding of service options.

In February 2004, the Government published the results of an independent review of Supporting People (www.odpm.gov.uk). This found that although Supporting People was funding many valuable services, the unit costs varied widely among local authorities. It recommended that efficiency savings should be made starting in 2004/5. Further research and analysis of spending by high cost local authorities is proposed and the development of a new allocation formula.

Other funding sources

The Department of Health (2002) note the following funding sources that can also be accessed alongside or instead of Supporting People monies.

Direct Payments: HSS Trusts can offer people cash payments as an alternative to arranging for social care services, so that they themselves can purchase the relevant services. These payments can be made available to adults over 16 years of age; parents of carers of disabled children and to carers aged 16 and over in respect of carers' services.

Independent Living Fund: This is an independent trust funded by the Department for Work and Pensions which helps to subsidise the cost of intensive home packages. To be eligible the disabled person must be in receipt of higher rate DLA and have been assessed as needing £200 or more of social service support. The HSS Trust must make a minimum contribution of £200 a week but this can take the form of directly commissioned services or Direct Payments.

Home ownership: Although a possibility for people with a learning disability it is not a straightforward process. Detailed advice needs to be taken and finding a lawyer competent in this area can be difficult. However home ownership can either full or shared; e.g. with a family member, co-habittee or Housing Association. Mortgages can

be obtained through banks on the basis on personal income including benefits. Trust funds set up by families are another way of repaying mortgages.

Planning for the Future

To date, much of the planning into the housing and support needs of people with a learning disability in the UK has focussed solely on the resettlement of people from long-stay hospitals. The needs of persons living with family carers or in their own accommodation have been addressed largely through reaction to crises.

Both of these strategies distort the type and quantum of provision that is provided within a given locality. The old 'long-stay' population have needs and aspirations that differ markedly from people who have never been institutionalised. Accommodation options that suit them may become redundant in meeting the future needs of people living in community settings. Likewise people who require an urgent placement in a crisis end up in whatever accommodation is available rather than the sort that is best suited to their needs and wishes.

In England, the Department of Health (2002) recognised that "*current provision falls far short of demand and need … and that the quality of life experienced by many people living in community-based housing and support services continues to fall short of the aspirations underlying current policy"* (p.1).

In 2002, they issued draft implementation guidance to local authorities (Office of the Deputy Prime Minister and Department of Health, 2002) which placed a requirement on Partnership Boards[2] to develop a local *Housing Strategy* for people with disabilities that will identify plans for the future commissioning of care and support services. This was to be done through effective links with local Supporting People teams and Local Housing Authorities.

The following tasks were to be undertaken:

- *Assess the contribution made by, and the effectiveness of current services*. This would entail mapping local housing supply for people with a learning disability; notably inequalities in current system of provision and the range of options available;
- *Finding out what people want and need*. This would involve undertaking a needs analysis based on information from consultations with local people who have a learning disability, their families and other stake-holders along with local information on current and projected needs, e.g. from survey data.
- *Work out the service changes or developments that might be needed*. Plans should be developed in the context of evidence on good practice, cost-effectiveness, statutory requirements, policy guidance and national and local performance indicators.

Recommendations are given for how these tasks might be undertaken, including pro formas for gathering information about client needs. The plans were to be submitted by winter 2002/2003. However current guidance does not make clear the next steps in the process.

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[2] *Partnership Boards are the main vehicle proposed by the Department for the implementing the changes recommended in Valuing People. They operate under the general guidance of Local Strategic Partnerships and bring together relevant statutory services, people with learning disabilities and family carers.*

The Department predicts that on the basis of past policy, research and expert opinion the level of provision of housing and support services required is equivalent to between 1.55 and 2.35 places per 1,000 of the adult population (aged 16+). These estimates are based on research reported by Braddock et al., (2001) as well as expert opinion documented by the Mental Health Foundation (1996).

Conclusions

The last two decades have seen a major sea-change in thinking about service provision for people with a learning disability; albeit within the context of increasing demand and inevitable resource-constraints within Health and Social Services.

It is highly unlikely that a return to institutionalised provision could be advocated for this group, even if there were financial gains to be had, which in itself is a most unlikely proposition.

There is widespread agreement that current housing and support services in the UK are inadequate in terms of quantity and the quality of life they offer. The trend towards supported living arrangements in which people with a learning disability hold tenancies or are owner-occupiers is likely to gain momentum underpinned as it is by equality legislation and practices. There is greater likelihood that these options will provide for a better quality of life for people with a learning disability although more efforts will be needed to maximise the opportunities they present for greater social inclusion.

There is greater recognition of the need for improved future planning and new funding arrangements should make it easier to provide a wider range of housing and support options. However significantly increased resources will be required to ensure that hospital resettlements are completed; that the standards of existing residential provision are improved and most significantly of all, the increased number of places that will be required in Northern Ireland as ageing carers pass on.

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