

ARTICLE FOR 'HOUSING, CARE & SUPPORT'.

Housing for Adults with a Learning Disability: Exploring their Needs and Preferences.

Abstract

The White Paper 'Valuing People' (Department of Health, 2003) promises to increase choice and control for adults with a learning disability, with housing being one area specifically highlighted for this. However, a lack of knowledge about the preferences of adults with a learning disability means that it is very difficult for services to be planned effectively based on the views of the very group who will use them. This paper discusses the findings of a project which aimed to involve adults with a learning disability in service-planning, through asking them to identify their own needs and preferences in relation to housing. The project clearly emphasises that adults with a learning disability are often very well able to articulate their own needs about housing, and should thus remain the focus of all decisions.

Background

Adults with a learning disability often experience little choice and control over their lives, in particular in relation to the important area of housing. This is despite the fact that the evidence suggests that all adults with a learning disability can make decisions for themselves at some level (Stalker & Harris, 1998). The Department of Health (2001) have attempted to address this in the White Paper 'Valuing People. A New Strategy for Learning Disability for the 21st Century'. Rights, independence, choice and inclusion form the key principles of the

White Paper, with housing being identified as one of the issues requiring development. Thus, one of the objectives of the White Paper is:

“To enable adults with a learning disability and their families to have greater choice and control over where and how they live” (Department of Health, 2001: p. 70).

However, there is a significant barrier to implementing this objective. As Foord et al (1999) have noted, a lack of knowledge about the needs and preferences of users makes the development of effective housing strategies extremely problematic. This means that in response to the White Paper’s objective for housing, local authorities should assess housing needs based on the views of service-users themselves. The aim of this study was to involve adults with a learning disability in service-planning within the locality, through asking them to identify their own needs and preferences in relation to housing. This is essential for the local implementation of the national Learning Disability Strategy, in order to augment choice and control for this group over how and where they live. The entire study involved the collection of data from all three key stakeholders: service-users, family carers and professionals, as follows:

- Seventy-two interviews with adults with a learning disability.
- Two focus groups with family carers.
- Three focus groups with professionals.

The involvement of professionals and family carers allowed for an exploration of the barriers to meeting the expressed needs of people with a learning disability, however these views will be presented elsewhere.

Identifying a sample

The study aimed to directly involve adults with a learning disability and to consult them about their own views and preferences, and sought to be as inclusive as possible by involving service-users with varying levels of communication skills. The most recent data on all known service-users with learning disabilities had been collected in 1996, but this had been based almost exclusively on the views of professionals. However, the associated database did form the most comprehensive local source of information about people with learning disabilities, thus it was used as the basis from which to select the sample. The database identified 816 adults with a learning disability in the area and a total of 120 (15%) were selected to represent the larger population according to age, gender, level of physical disability and challenging behaviour.

Of the 120 people selected, a total of seventy-two participated directly in interviews. The remaining 48 were not interviewed due to lacking communication skills (n=24), personal circumstances such as a recent housing crisis (n=20) or they simply could not be contacted (n=4). For these people, the views of an appropriate other (i.e. a day centre keyworker) were sought, however these are not presented here as the paper aims to focus specifically on the user voice. There is a need for other research to address the views of those people who cannot communicate in formal ways, however this was beyond the scope of this research.

The final sample of seventy-two service-users was made up of forty-seven males and twenty-five females, with only three being from ethnic minorities. All were aged between 22 and 79, with an average age of 42 years. The service-users involved were living in a variety of different settings, however the majority were living either with their families (40%) or in residential care (36%). The remainder were living in hospital, in a nursing home, in supported living, independently, or in an Adult Placement Scheme.

Involving adults with a learning disability.

The seventy-two service-users involved took part in individual semi-structured interviews focusing on their experiences and views of present housing, whether or not they would like to move, as well as their preferences in relation to future housing. The interviews followed the format of a housing needs questionnaire (HNQ) which had been developed from an existing local tool and input on language and content was provided by advocacy and community learning disability professionals. Pictures were also used to enhance involvement. Interviews were conducted wherever possible at a day centre in order to avoid the influence of the home environment and preferably with the service-user alone as the presence of a carer or professional may have influenced responses.

Communication difficulties and powerlessness meant that extra steps were necessary to ensure that genuine informed consent was obtained. Careful and simple explanation of the research was thus necessary, and extra time and clarification was provided for this purpose wherever necessary. In addition, it was very important to be aware of any indications of a potential lack of consent, such as signs of distress, leaving the room or not engaging with the interviewer. It was very important to make participants aware of the role of the researcher and that the research would not result in them moving house, as well as to emphasise confidentiality and anonymity throughout. Reading back participants' responses at the end of the interview proved invaluable in gaining further information, as it had given service-users time to consider their views and to feel more relaxed with the interview situation. All of these aspects of conducting the interviews were extremely important in supporting service-users to feel comfortable and confident in expressing their views about housing.

Service-user views of present housing

The service-users involved in the study were asked to identify whether or not they viewed their present housing as suitable for their needs. Fifty-five (76%) of the seventy-two did indeed think their present housing was suitable for them, but it is important to remember that many of this group may have little experience by way of comparison and may have low expectations of the services they receive. Further, the fact that present housing was not viewed as unsuitable does not necessarily indicate that this would be a person's first choice of how and where they would like to live. This is particularly the case for some service-users who found it difficult to discuss their own preferences as they viewed housing as being beyond their control, with the assumption that decisions would be taken by professionals or family carers, as this service-user highlights:

“It's not up to my, it's up to my niece”.

When asked whether they would choose to live where they live now or somewhere else, a total of 28 service-users (39%) stated that they would in fact prefer to move to alternative housing at some point in the future. Forty (55.5%) would like to remain in their current housing and four are unsure (5.5%). The desire to move by those living in different accommodation types at present is shown in Table 1. This indicates that almost half of the those presently living in the family home want to move from their present housing, a group who may well be unlikely to have the housing needs addressed until their families become unable to continue caring.

Table 1: Desire to move by present housing type (n=72)

Present Housing	Want to move	Want to stay	Unsure	Total
Family Home	14	12	3	29
Residential	8	17	1	26
Supported Living	2	4	0	6
Living independently	1	3	0	4
Nursing Home	1	2	0	3
Hospital	2	0	0	2
APS	0	2	0	2
Total	28 (39%)	40 (55.5%)	4 (5.5%)	72

Independence was important for service-users, with thirty-one (43%) stating that they would like more independence. This included a number of people who do not in fact want to move, but who would appreciate further independence within their current housing. Eleven also said that they would like more support, but the support they required was directly related to enhancing their independence, including assistance with finances, learning new skills such as cooking and taking more responsibility for household chores. This emphasises that the quality of where people live is intimately related to the extent to which they have the freedom and support to exercise their right to autonomy. This is well articulated by this service-user who has moved from residential care into self-contained supported living accommodation:

“It’s the best thing that ever happened to me in my life. I like to be on my own, my own boss. I suffered a lot of depression where I lived before, I was ready to move on. I couldn’t live in a place like that. It’s made a big change to my life. I’m really happy for the first time”.

Preferences of service-users who want to move

For many service-users, the number of other people living in their current housing was a reason for wanting to move. Fourteen of the twenty-eight wanting to move stated that they would like to live with fewer people, of whom ten are presently in residential or hospital. In relation to the area in which they live, there is a certain degree of flexibility among the service-users. Although ten of the twenty-eight wanting to move would not consider

alternatives to the area for which they express a preference, eighteen are flexible about the area in which they live.

Other aspects which are important for service-users wanting to move relate to having a garden, keeping a pet and living near to their day centre. All of these must be considered when planning alternative accommodation for people with learning disabilities. Of twenty-eight service-users interviewed, twenty want their home to have a garden, thirteen want to be able to keep a pet, and living near to their usual day centre was important for ten. The importance of their day centre was emphasised by many more who said they did not need to live near to their day centre providing that they could still travel there by public transport.

Table 2 illustrates the specific expressed housing choices of those service-users who want to move to alternative accommodation. This shows that of the twenty-eight wanting to move, twelve want to live in self-contained accommodation and ten want to live in shared housing. The others want to live with a partner, with a relative or are unsure to where they would like to move, emphasising the need for assistance and support in understanding options so that informed decisions can be made.

Table 2: Future housing choice of service-users (n=72)

Housing choice	No. of service-users
Self-contained housing	12
Shared housing	10
With a partner	2
With a relative	1
Want to move but unsure to where	3
Unsure if want to stay or move	4
Want to remain in current housing	40
Total	72

The people who want to live in shared housing were asked to indicate how many people they would like to share with. The preference was for small groups with everyone stating numbers of five or less. In fact, eight of the ten want to share with between one and three people. The preference is thus not for the traditionally large residential care homes. Instead, service-users are stating that they would prefer to live in ordinary housing, either alone or with small numbers, and importantly with greater independence. This is well emphasised in this quote from one service-user:

“This isn’t the place for me, my heart’s not here. If I got the chance I’d love to have a flat, to have my independence back. That’s what I’d like in the future. I’d love to live on my own”.

Although service-users are expressing a wish for more independent housing, they are also anxious that there will be sufficient support available to them. They are not envisaging a move to housing where no support is being provided. Instead, the availability of support is seen as crucial to any move, and many have questions about how they could be supported elsewhere. These concerns are shown by this service-user:

“I’m a bit worried about being on my own and having no-one to help me ... But I do want to live on my own.”

This draws attention to the fact that service-users are likely to need ongoing information and reassurance in considering and planning any move, to reassure them that such support will be available.

It is important to finally note that while the majority of service-users were very well able to articulate their preferences for future housing, many felt very powerless in making these choices a reality. In fact, many do not even raise this issue with anyone who can assist, as they think that their preferences will not be acted upon. Some service-users commented that

they had suggested that they would like to move, but that they had been dissuaded by family members, as this service-user shows:

“I’ve been talking about living on my own, but I can’t. My Dad says it’s horrible living on my own. He thinks I shouldn’t move”.

Conclusions

This study provided an opportunity for adults with a learning disability to take part in service-planning in their local authority through identifying their own needs and preferences in relation to housing. In summary, the main findings are as follows:

- 31 (43%) would like more independence.
- 28 (39%) of service-users interviewed want to move from their present housing.
- The preference is for ordinary housing with greater independence.
- Many feel powerless in making their preferences a reality, as they believe that such decisions are predominantly the responsibility of carers and professionals.

As promised in the Department of Health’s (2001) White Paper, service-users with learning disabilities should have greater choice and control over how and where they live. It is essential that localities directly involve service-users in decisions not only about housing but all areas of their lives. Without consulting users, services will continue to further marginalise people with learning disabilities. It is essential that this group are provided with accessible information and support to enable them to make genuine informed decisions about how and where they live. Although the views of carers and professionals are important, adults with a learning disability must become the focus of decisions. A lack of choice and control has a detrimental effect on adults with a learning disability, as well described by this final service-

user's quote. Her words emphasise the vital importance of a focus on the voice of adults with a learning disability:

“They forced me and shoved me here. That’s what it was like. I had no choice. Nobody asked me. It makes me fed up, having the same old life. I want to choose for myself, but they don’t listen. It’s like a dream, it’ll never come true. It never does, does it”.

References

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