

## **Housing: The Users' Perspective**

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### **MOVING TO INDEPENDENT LIVING IN THE COMMUNITY**

Until relatively recent times, large numbers of disabled adults were compelled to live either with their parents or within institutions, but with the rise of the disabled people's movement in the 1970s this situation started to change. Disabled people who lived in institutions devised imaginative schemes (which were usually opposed by professionals) in order to live within the community and to gain some control of their lives. An early initiative was the *Grove Road* scheme where residents of an institution negotiated with a housing association to build a block of flats for disabled and non-disabled tenants. The non-disabled tenants paid a subsidised rent in exchange for offering their services to the disabled tenants (Davis 1981). Oliver and Barnes state that:

.....the principle objective behind the scheme was that it should not be conspicuous, but must blend into the local community and must cater for disabled people's needs in the privacy of their own homes in a way that encourages and supports independence and individuality. (1996:82)

At the same time the residents of a Cheshire Home, *Le Court* in Hampshire, persuaded the local authority to use the resources to enable them to live in the community. It was not only suitable housing that was required but also the provision of personal assistants. Briggs (1993) gives a graphic account of the struggles she experienced in reaching her goal of community living:

I hadn't anticipated so much pressure in my new life. I had not been prepared for the volume of decisions I had to make. Simple things, such as sorting out looing routines; how to use the local laundrette; finding out where all the allowances come from and how to get them; sorting out local tradespeople; sorting out dustbin collections, milk deliveries,

a doctor, a chemist, and so on. But the worst thing was the incomplete building work, I was trying to start a new life on a building site.....Sometimes I thought that within a few months I would be back in Le Court, because I did not think that I could continue. (1993:134)

These early initiatives, which involved enormous energy and struggle on the part of disabled people, have, over time, led to legislation, such as the Direct Payment Act (1996) whereby local authorities grant disabled people a sum of money, following an assessment, to buy their own personal care. The Disability Discrimination Act (1995) also requires modifications to be made to buildings 'where reasonable'. This legislation is weak, however, and 'less favourable treatment' can still be justified on a variety of grounds, including of health and safety (Hogan 2001).

Despite some advances, it is still the case that many disabled people live in unsuitable housing, including institutions, and that many have been unable to leave their childhood homes. Morris (1990) believes that disabled people who live in institutions should be considered homeless as homelessness does not necessarily imply living on the street but includes living in unsatisfactory conditions such as in hostels and bed and breakfast accommodation (Pryke 1998). Esther Hurdle, a disabled woman with four children, for instance, lived in a hospital ward for three years while adaptations were being made to her home (Peace 2003). What then are the housing options for disabled people, the barriers to and opportunities for independent living in the community?

## **HOUSING OPTIONS FOR DISABLED PEOPLE**

### ***Barriers to independent living in the community***

Disabled people are among the poorest in the country and are less likely than others to own their own homes.. Morris (1993) makes the point, however, that even if disabled people are home owners they may be disadvantaged:

Housing departments often exclude homeowners from being eligible for rehousing. The property of disabled owner-occupiers may be totally unsuitable for them. They may consequently be unable to leave hospital or institutional care,

may be made dependent on others or imprisoned within a physically unsuitable home. (1993:139)

Money for maintenance and repair may also be limited (Peace 2003) and disabled people are often 'stuck' in their homes with little prospect of moving or, alternatively, having to move when they want to stay. Rabiee et al (2001) highlight the lack of choice available to disabled young people, especially those with learning difficulties, who may be denied housing opportunities because of a lack of appropriate support. Hawker and King (1999) found that only seven per cent of people with learning difficulties owned their own home or had a private tenancy, 53% lived with their parents and the remainder lived in various types of residential settings.

Marginalised groups, including many disabled people, occupy the worst housing and this impacts particularly on disabled women (Morris 1993) and black disabled people (Drake 1996). As Abberley states:

The least satisfactory housing tends.....to be that inhabited by sections of the population of which disabled people form a disproportionately large percentage; elderly people and people on low incomes. (1993:113)

Beresford and Oldham (2002) interviewed the parents of disabled children regarding their housing. Nine out of ten families reported at least one problem with the most common being lack of space. A third found the location of their home unsuitable and only a minority had received statutory assistance. White families were more likely to be suitably housed than black families. Bevan (2002) found that families appreciated information and being treated as individuals (rather than being fitted into an existing framework). They were appreciative if the needs of children, for example opportunities for play, were considered.

It has been known since Victorian times that the quality of housing impacts on people's physical and mental health and this is no less true today (Best 1997). Housing has been central to social policy for the past hundred years (Baldock 1999) from the building of 'garden cities' (such as Welwyn Garden City) and new towns (such as Stevenage and Bracknell), to the building of tower blocks and council estates. The effect of such projects on people's health and well-being has ranged from beneficial to disastrous but has always largely excluded the needs of disabled people.

### ***'Special needs housing': overcoming barriers?***

One policy in overcoming such barriers to independent living in the community has been the development of special needs housing. In Britain there is a limited supply of 'special needs' housing most of which is owned by local authorities (Morris 1990, Stewart et al 1999). This consists of 'wheelchair accessible' housing and 'mobility' housing which contains a few basic features such as a flat entrance into the house. The stock of 'special needs' housing has always been inadequate and has declined since the 1970s despite the fact that it is cheaper to build accessible dwellings than to adapt inaccessible ones (Barnes et al 1998). Between 1984 and 1989 local authorities and housing associations built 168,665 'mainstream' homes but only 1,840 homes accessible to wheelchair users, while the private house building sector built no wheelchair accessible dwellings at all (Barnes 1991). Resources for building public housing was drastically cut by the Conservative government of the 1980s and the 'right to buy' policy meant that many council houses which would have been suitable for adaptation were sold. Between 1980 and 1988 homelessness among disabled people rose by 92% and that did not include those who were living in institutions or with their parents (Oliver and Barnes 1996). Johnstone (1998) states that there are over four million people in Britain with mobility impairments but only 80,000 accessible dwellings. Many dwellings are only partly adapted and if disabled people have savings they may be compelled to spend it on house adaptations (Barnes et al 1999). Even if public money is available for adaptations many disabled people experience long delays in being assessed. Frazer and Glick quote one of their research participants as saying:

When I moved into the area I was told there was an 18 month waiting list for an OT visit for assessment. I had to borrow money to pay for bathroom equipment and stair-lift as I could not wait 18 months as I have two small children to care for and I was not safe without this equipment. (2001:21)

A criticism of 'special needs' housing is that it has concentrated almost exclusively on people with physical impairments rather than on other disabled people such as those with visual impairments (Imrie in press). Research undertaken by the *Pocklington Trust* (2003) found that, although the majority of older people who acquired a visual impairment did not alter their housing

arrangements (partly because of its familiarity) others found changes to lighting and colour schemes useful and were concerned about the availability of natural light. They reported needing more space to house equipment and to work safely in the kitchen and preferred not to have to 'zig-zag' between rooms. Space was also important for entertaining friends especially as many people were unable to go out unaided. Some of the research participants spoke of problems with landlords when they required alterations to lighting or when they wanted white edges painted on communal stairs. Maintenance of the house and the upkeep of the garden also caused concern as did safety matters, such as climbing on chairs to reach high cupboards.

An irony is that a large proportion of wheelchair accessible dwellings are occupied by people who do not use wheelchairs (Stewart in press). One of the reasons for this is that wheelchair accessible housing usually provides single accommodation. Barnes and Mercer state:

.....segregated 'special needs' housing remains central to government plans for 'community care'. Even so many of these properties do not satisfy people's requirements. For example too few have more than one bedroom, even though most disabled people live with families, and a significant minority of single disabled people need two bedroom housing to accommodate a personal assistant. (2003:50-51)

Stewart et al interprets this situation in the following way:

We argue that the individual model of disability led planners to regard disabled people as sexless and without families and that, as the development of special housing was conceived as an alternative to residential care, the emphasis should be on the provision of one-person dwellings reflecting the single life style of many residents in these homes. (1999:10)

Many disabled people reject the idea of 'special' housing, which has the potential to stigmatise and exclude, and would prefer housing to be designed with everybody's needs in mind. The full inclusion of disabled people requires that all housing is accessible. As Hurst states:

Why do we have to move if we're disabled? Conversely why should we not be able to move once we have suitable

accommodation? And why can't we visit our friends and neighbours? (1990:9)

The concept of 'special needs' housing has arisen through the medical model of disability where disabled people are viewed as different and abnormal. Most research into disablement has focused on disabled people themselves, for example the number of people with particular impairments and the severity of those impairments, rather than investigating the physical and social environment. Oliver is critical of government surveys of disabled people (for example Martin et al 1988) and has poignantly rephrased the questions (which are based on the medical model of disability) to questions that are underpinned by the social model. For example, instead of the question 'Can you tell me what is wrong with you?' he asks 'Can you tell me what is wrong with society?' (1990:8) and instead of the question 'Did you move here because of your health problem/disability?' he asks 'What inadequacies in your housing caused you to move here?' (1990:7-8). Most research which has taken a social model approach has been undertaken by disabled people themselves (see Barnes and Mercer 1997). Macfarlane and Laurie state:

This individual or 'medical' model has determined the range of services on offer to disabled people and how those services should be provided and has been the basis of the training for individuals working in the areas of health, rehabilitation, social work, residential, home care and 'special needs' housing. This training encourages professionals to pursue a role of influence in the lives of disabled people and to view themselves as experts on various aspects of disability. The experience and expertise of disabled people who face discrimination on a day-to-day basis is therefore seen as of little value. (1996:7)

### ***Towards accessible housing***

The dissatisfaction with the very notion of 'special needs' housing has led to the concept of *Lifetime Homes* promoted by the *Joseph Rowntree Foundation*. *Lifetime Homes* are built with many standard features, such as a downstairs toilet and sufficient turning space for a wheelchair, and are built to be easily adjusted as circumstances change, allowing, for example, the fitting of a stair lift (Macfarlane and Laurie (1996). Stewart states that:

Lifetime houses can be thought of as universalist in that anyone could occupy them and in consequence they neither stigmatise nor create dependency, whilst the decision to adapt fully can still be related to individual needs and circumstances. (1999:17)

The extension of the Building Regulations in 1999, whereby all newly built homes must meet certain criteria of accessibility, reflect this approach. Similar standards, such as switches and sockets at an appropriate height from the floor and a level approach to the principle entrance, have been produced by the *Access Committee for England* (Walker 1995) and the *Centre for Accessible Environments* (Peace 2003). These criteria do not, however, consider the needs of visually impaired people (Allen et al 2002). In general terms, the identification of those characteristics in housing which make it useable or adaptable for people with a range of disabilities needs further investigation.

Other groups within society have also noted the inadequacy of housing design. Women, for example, have complained about the design of kitchens and the unsuitability of housing when caring for children (Peace 2003). Imrie states:

.....the myth of a 'normal' person, of the white male, has been a powerful dimension of the design process, yet one which has had and continues to have, clear racist, sexist and ableist underpinnings. (1999:133)

Part of the blame for this can be directed at architects who, according to Drake (1996), are often more concerned with aesthetics than function when designing buildings and expect people to perform in a uniform way. Imrie (1999) believes that disability, if considered at all, is usually an afterthought or is regarded as a 'special interest' in the curriculum of architects. This leads Walker (1995) to conclude that:

.....to meet the challenges successfully architects must be prepared to learn from the people for whom they have been creating a disabling environment – the real experts who know about access needs. (1995:46-47)

Imrie (1999) asserts, however, that the work of architects must be put within a wider framework of social structures, values and ideologies and that architecture is '..... pre-determined by political

and economic power including laws, statuses, codes and corporate clients.’ (in press)

### ***Beyond accessible housing***

It cannot be emphasised strongly enough that inclusion in society goes far beyond the design of domestic dwellings. The early pioneers of community living were well aware that accessible housing in isolation would not be sufficient. Personal assistance in the home may be required and, to become fully involved in the community, an accessible environment is essential in terms of accessible transport, public buildings and information, appropriate attitudes and behaviour, and flexible social structures which, for example, allow disabled people to participate in education and paid employment. Imrie states that:

Western cities are characterised by a design apartheid where building form and design are inscribed into the values of an ‘able-bodied’ society.....This has led some commentators to regard the built environment as disablist, that is projecting ‘able-bodied’ values which legitimate oppressive and discriminatory practices against disabled people purely on the basis that they have physical and mental impairments. (1999:129)

Allen et al undertook research with visually impaired children concerning their housing needs. They found that:

.....children with visual impairment did not consider the built environment of the home and neighbourhood to be a problem. This is mainly because the visually impaired children were able to construct a memory map based on ‘fixed’ points (for example sounds, textures, objects and so on) in the built environment. These maps provided the visually impaired children with predictive confidence. (2002:16)

They found, however, that the children needed a garden to increase their confidence and needed more space for equipment which could be a problem if they shared a bedroom with a sibling. Minor adaptations to lighting were sometimes required.

Allen et al (2002) found that it was the outside environment (for example how safe it was perceived to be) that impacted on the independence and well-being of visually impaired children rather

than the environment within their homes. The outside environment also caused conflict between children and their parents because, whereas parents were inclined to respond to it by restricting the freedom of their children, the children themselves were prepared to develop strategies for coping with it and tended not to be intimidated. Older visually impaired people who acquire their impairments, however, are less inclined to venture out alone. In a survey by the RNIB (2002) 27% of older people did not feel confident enough to walk alone in their immediate neighbourhood. Sue and Paul Nicholls, a blind couple interviewed by French et al, illustrate the contrast of functioning within the home and the outside environment. Paul said.:

In your own home there is a more equal relationship because you can do things for other people.....but when you're in a restaurant or pub you are reliant on other people. You've got to know a place very well before you can even get up and go to the toilet without asking for help. It's a very unequal situation indeed. (1997:31)

Talking of bringing up their two sighted daughters, Sue said:

In a way it's an extension of your own life and your own home and that's where you feel capable and secure. We brought up the children as we wanted to, nobody interfered.....Having the children wasn't a problem, it was under our control, and in our own environment; we were not being compared to what other people do either. Whatever we did it was normal to them. (1997:32)

An understanding that the whole environment needs to be accessible has led to the concept of 'universal design' which has at its core the principle of designing for all people and in such a way that environments are flexible and adjustable. A major flaw, however, is that it ignores the political and social dimensions of inclusion. As Imrie points out:

Its principles are apolitical in that there is little explicit recognition of the relationship between the social, technical, political and economic processes underpinning building and design. (in press)

If disabled people are to be truly included in the community then a profound transformation of society, in all its aspects, is required.

## **DISABLED PEOPLE'S EXPERIENCES OF HOUSING ADAPTATIONS**

This section of the chapter is based on interviews we conducted with disabled people who have had significant experiences with housing and who, between them, have experienced considerable contact with occupational therapists in recent times. Four interviews focus specifically on housing issues and were conducted for the specific purposes of this chapter, three others explore the relationship between occupational therapists and clients more generally. The purpose was not to provide a representative sample of service users but to gather some "real world" experiences which we hope will illustrate some of the attributes clients value in therapists and some of the problems which may arise in therapy from the client's viewpoint. The interviews also illustrate, with specific examples, many of the issues discussed above and found in disability studies literature.

### ***1. Location***

What, then, might be important to disabled people in relation to where they live? Perhaps not surprisingly, many issues were similar and, in a general sense, would be significant for many non-disabled people too. Location, for example, can matter for many different reasons. David told us:

Location, where it is, is very important to me. I like to have a degree of accessibility in and around where I live, so the site needs to be accessible, and then I would say that about quarter of a mile around would be nice to be accessible, though it's not top of my list because I have the car. So obviously proximate parking, or building adjacent covered parking, because to function, especially in the winter months, I need it to be right bang on my doorstep.

As a wheelchair user, access within the house starts for David with plenty of room to move around.

Space, because I use the chair. Lots of space. I find that most adapted premises are short on space, unless they are purpose built for a wheelchair user they are inadequate.

Access to the whole of the property, including the garden, is also important and, as David indicates, can have an impact on family life.

One of the things that often falls short in terms of access for me is the garden. If it's there I can't get to it. And I certainly think the way the grant schemes are structured at the moment, that's a shortfall, particularly for things like child care - if you can't get to your garden you can't supervise or care for your children adequately.

Dawn lives with her partner and seven children from previous marriages, two of whom are disabled. They have recently moved and consideration of the whole family was crucial for Dawn. Access is clearly very significant, particularly as it provides a context for relationships within the family.

It's important that the whole family have access around the entire house. That's the biggest priority. We have just moved house and the thing that was imperative was that everyone could get access to every room, that includes the laundry room, the cupboards. Obviously for us having M with mobility difficulties, and balance, it means that there has got to be circulation space. . . . It's single storey. The reason for that is simply that M has access without having to shout for anybody. It is terribly intrusive to have to ask somebody to escort you if you feel you would like to go on your own and M does like to wonder round on his own.

## ***2. Home is where the heart is***

A major theme in the interviews was that a house is not simply a place to live, but a 'home' with all the psychological and social connotations this holds. Housing issues for disabled people, as for non-disabled people, are certainly more than the building or place. Home has a variety of meanings for the person who lives in it and is not entirely a separate entity from that person: Home can play a part in making manifest a personal identity and affect the construction of social relations (hence the current popularity of home decorating programmes). Having a home, and having the choice to stay within it, is of the utmost importance to most people. Norman, talking of older people, states:

It is not sufficiently realised that the loss of one's home - how ever good the reasons for losing it - can be experienced as a form of bereavement and can produce the same grief reaction as the loss of a close relative. (1998:76)

Even if the home is not entirely suitable physically, many people still prefer to stay where they are because of the memories and associations that surround it (Peace 2003)

Barbara is a woman losing her sight in old age. The notion of home, together with associated relationships, is clearly apparent in the following exchange, .

Sally Have you made any changes to your house since you had problems with your sight?

Barbara No I haven't made any changes at all because I've lived here so long I know the number of stairs to go up and down. The two steps we have in the passage don't bother me because I know where they are. It might be a different problem if I was moving to a new place to live.

Sally Would it put you off moving?

Barbara I wouldn't want to move from here because I like the house and we've got it nice and warm and it's convenient – not too far from the shops. Crossing the road is a difficulty but I'm fortunate that I have a husband who always accompanies me but it must be very, very difficult for somebody on their own.

The notion of home is linked with many personal and social understandings, including comfort, security, love, caring, quality of life and lifestyle – although it can, of course, be associated with the lack of these qualities. Central to this is choice and control – or lack of choice and control. Home is the place that we make our own, the expression of ourselves, starting with the choice of where we live. Choice is, of course, always limited and disability can play a major part in such limitations. Choice is important for Arlene, a woman with multiple impairments and a powerchair user, but her experience illustrates what it is like to have no choice.

I had no choice in the area where I had to live when I became disabled. It was a choice of living here or living in hospital. This house was found for me and adapted while I spent a year in hospital. I hadn't been in this area before and I didn't know anybody. So not only was I facing the fact that I was going to be disabled, and that was a new experience, I had no social network round here. I came into sort of an alien environment, they didn't want a disabled

resident to live here and I wasn't told this. I have approached counsellors and said 'Get me out of here' on numerous occasions, and they've said 'Well we can put you in a pensioner's bungalow but it is too small for your needs'.....The housing situation is also that I've got such an array of adaptations now that to re-house me would cost them a lot of money and they are not prepared to do that.

The limitation of choice experienced by Arlene is not restricted to bricks and mortar.

They actually got a petition up to stop a disabled person moving in here. So I came in, said hello to my neighbours, and was told we don't want you.....like you shouldn't be in the building, you should be in an institution. They put me in a situation where I faced harassment. They hadn't explored the environment I was going to be living in. They also caused problems because they asked able-bodied people where my ramp should be situated, rather than asking me, and even to this day, it's 13 years since I moved here, my ramp is at the back of the building and the able-bodied people come in at the front. Up 'til about two years ago I had no lighting coming in at the rear entrance because it's down past garages. They didn't have a street light there so it was jet black.....The tenants, even after 13 years, have caused problems.....I had to seek advice from a solicitor. I got a warning letter about my conduct as a tenant from the council saying that I was slamming doors within the flat and it's an open plan flat – there's only one sliding door and the other one's automatic. So they hadn't checked anything out. They complained about my district nurses coming in in the morning, they come in at 8.30, and they complained about the noise the nurses made coming into the building. So the council, instead of telling them to get lost, carpeted the outside of the flat – it's the only block of flats here to have any carpeting – and there was also in the letter of complaint about the fact that my wheelchair left trailing marks, as I came in the back door, on the carpet.

### ***3. Experiences with Occupational Therapists***

Turning to experiences with occupational therapists, the theme of choice and control, or lack of it, again ran through this strand of the interviews. This was apparent in both positive and negative

examples. When communication breaks down, or is never initiated in an equal manner, the possibility of choice and control by the person involved is precluded, or contested. The power relationship with the OT and Kate's resistance to it is clearly apparent in the language that she uses to describe her experiences with occupational therapists, such as 'battle'.

What I did find incredibly difficult to come to terms with was somebody coming into my home and saying, 'This needs to be done and this is how it's gong to be done.' I had no say whatsoever to the point where.....well one of the things is the front door which is completely flat because I'm in a wheelchair. I could cope with a small rise very easily and I demonstrated that I could manage. What happens now is that whenever you open the door the leaves blow in because it's so flat. I had quite a long argument, added to which the builder had difficulty finding such a flat front door.

The other thing is the front lounge, it was designed without any discussion. I couldn't deviate from it one millimetre. It was designed as an adaptation without any thought to the fact that it was affecting my home and that it wasn't just me that it affected.

The only battle that I won, and it was a major argument that held up all the work for about three months, was that they wanted to lower all the work tops in the kitchen to my height and I kept pointing out that there were three other members of the family and I didn't want to have to do all the work! What we actually did was a carpenter friend of mine put roll-out tops under the existing tops so I have something my height and they've got something at their height. It was as if I was living on my own and that the property was theirs.

The other major argument I had was that initially they weren't going to put a stair lift in at all (Kate has a ground floor and a basement). They said I could live on the top level. I pointed out that I had two teenage daughters who would be completely cut off from me and I wanted to know what was going on down there. It was partly expense but they weren't looking at me holistically at all. I did get the stair lift but it wasn't done in the first wave, it was an ongoing argument. She just came in, there was no awareness of me as a person, it was a practical issue - we had to get a wheelchair

around this building. But I'm a person - it's not a wheelchair that has to go through that door it's me!

A similar experience is apparent in Arlene's narrative of her experiences. Here she describes her first involvement in occupational therapy and the agendas and values that she confronted.

My first experience was after I was given the wheelchair in hospital when I was in for that year. I was in the middle of doing my OU degree and studied from my bed because I was in my bed more often when I was in hospital. I got pushed, because I didn't have my powerchair, to the occupational therapy department one day and they said to me did I want to make a cake or make a basket and I didn't want to do either. I said 'What else?' and she said 'No you can either make a cake or make a basket or you can fry an egg' that was the other thing they suggested. And I thought 'Well this is great, I have no interest in doing this' and I would rather be doing what I was doing in the first place which was reading my book. They didn't think I had any need to do any sort of study. As a disabled person I wasn't going to be able to cope with cooking and things within my home environment - I probably wouldn't have baked a cake if I hadn't been disabled and I wasn't going to start just because they wanted me to.

In her interview, Arlene provided a number of examples where she experienced considerable difficulty in having her views heard or believed. For instance she had been experiencing difficulties closing the backdoor to her block of flats and the other tenants started to complain that the door was being left open.

So I started to get notices pinned on the back door that said, 'Please keep this door locked at all times, close the door'. And if I put two wheels over my ramp they would slam the door even if I was going into my garden area and I've always had to have keys to get back in. An OT visited me.....and I explained that I couldn't drive the wheelchair and shut the door and she said could they attach a hook thing on to my shoulder that would hook on the door and, if I was able to manoeuvre the chair properly, this hook would grab on to this other thing and the door would shut behind me. And I thought 'Well I might get decapitated or something'. I said 'I don't think that's going to work'. It took many, many months for the OT system to put this right. I had to demonstrate that

I couldn't actually shut the door to three different people.....Then they said yes I could have my remote on that door.

Dawn had similar experiences. From her viewpoint, occupational therapists are limited in what they can do by the system.

I think the difficulties have been with the previous OT. She was all too aware of what she was allowed to recommend from a financial point of view and she was very aware of what the process was.....But instead of saying.....'We aren't going to get funding for a downstairs toilet until M is eight because that's the way the system works', if she'd said 'Yes I really feel that M is entitled to a downstairs toilet, of course he should have a toilet, but I just cannot get it for him', then I could have understood that. But she didn't, she kept saying that until he's eight he doesn't need a toilet downstairs. And she'd turn up with commodes and all sorts of ridiculous equipment.

The provision of designs and equipment and the style of relationship initiated are elements that go towards constructing a power relationship. Sandy, for instance, found her occupational therapist distant and inflexible and was helped by a friend and her carer when the equipment from the occupational therapist could not be used:

When I got home the social service OT came and she started as if it was day one with a big assessment when I'd had the whole thing done in hospital. I was ill and in a lot of pain, sick most of the time, couldn't eat, and I couldn't be doing with it. I thought, 'Just go away, just go to the hospital and they'll tell you everything you want to know.' She was neutral. She was just doing her job with her clipboard. I can't remember her name - she was just a professional. She came back to say that there was a waiting list for this bath thing so I'd have to have bed baths for three months from the carer. Finally this thing arrived, none of us knew it was coming, it came with a man in a van - a lovely, friendly man with this contraption - but it didn't fit. We got to 'breaking rule time' then which meant 'blow what they said'. My friend and my carer got these two boards and they made a slide system to the bath. The OT didn't help one bit. When we told her the contraption wouldn't work she said,

'Well, that's that then, it will have to be bed baths.' She never came again.

Kevin objects to going through occupational therapists for the equipment he needs:

If you want a spade to dig your garden you don't go to an OT do you? You go down the hardware shop and buy a spade, the one that suits you. So why can't I go down to my local hardware shop and buy a buttonhook, or buy a stick, or buy anything? – a tool is a tool.

For assistance to be given with housing issues, the organisation and the professional must first recognise that these issues need addressing. In Barbara's case this was not recognised and this lack of recognition may reflect both her age and her impairment:

I never had advice. The only thing that I was asked was if I had a magnifying glass. Well there are hundreds of different types but you have to find out for yourself what suits you. I was a bit disillusioned when all they said was 'Have you got a magnifying glass?' It's not very substantial is it?

We will end this section with some advice from disabled people. This begins with some good experiences with occupational therapists. When there is choice and control on the part of the home user and a true working partnership with the occupational therapist, creative and satisfactory ideas emerge giving a very positive experience. For Dawn and David this was when occupational therapists recognised their agendas and took their side. Dawn thinks the occupational therapist who is working with her son at present is constrained by finance, but, nevertheless, she backs Dawn rather than the system.

She makes recommendations that are clearly based on what she believes to be right and she listens and she's prepared to alter according to family circumstances. An example of that would be when she originally looked at our old house for rails around the house, she made the recommendation, came back for comments, and took on board what I had to say, and made some alterations. She's also got off the fence and written to local authorities, complained and pleaded with them to alter curbs, pavements, roads around the house. It is not part of her brief really but she is prepared to do that.

David has had similar experiences of occupational therapists joining forces with him.

When I was being offered accommodation by the local authority and the housing association it was very useful to have the OT there who could say 'Well no, that's not actually suitable for this person'. That I found useful because I felt very pressured to just take somewhere to live whenever I was offered somewhere. I was in crisis and I was thinking 'No this isn't right, this will not work' and I was really worried that I wouldn't be able to get out.....I found that they reassured me and fought my corner, which was to say 'Don't you worry, stop in that short-term accommodation as long as you need to, until it's right for you, don't feel pressured to take something that's 75% of the way towards something you are after if you physically can't cope with it'.....So I think they give you psychological support as well because of their expertise when everyone else was saying, 'Well it's a disabled flat so just get yourself in there.'

Arlene and Dawn offer advice to occupational therapists which emanates from the central theme of choice and control and emphasises the need for active listening. The first quotation is from Arlene who puts a particular emphasis on the need to recognise that it is the client's home environment. Dawn then underlines the importance of recognising the particular values adhered to by the family.

Remember that the person you are going in to, it's their home environment and it's never an extension of the hospital ward. You are not in control. You have got to respect the person that you are going in to. Treat them with dignity and listen to what they say because the disabled person is living the disability and they are the experts.

To listen. To do as much listening and understanding as possible. Not to take your own agendas into your workplace, and your own personal experiences. We all have a perception of what is a good family life, what constitutes acceptable levels of access, but just because an OT feels that they know what's right for a client, doesn't mean it's going to work. . . . Even the ones that have good practice, there's still the underlying attitude that the best thing for the child is to be independent and it comes down to what independence is all about. Independence for my child, as far

as I am concerned, is not being able to walk up and down stairs by himself. Independence is choosing whether or not he ever wants to go up the stairs again. It is not about getting the best out of somebody physically, I am not aiming to produce an Olympic champion, I want a content, well rounded child.

## **CONCLUSION**

Esmond et al (1998) undertook a three year research project which kept at its centre the views of disabled people. They concluded that housing cannot be examined in isolation as it is linked to appropriate assistance and access to all community facilities. They provide a range of principles which can be applied regardless of the particular housing scheme adopted. These include:

- \* An understanding of what independent living means in practice
- \* Participation and control by disabled people
- \* Access to independent advocacy support
- \* Security of tenure
- \* Financial control over services if that is what disabled people want
- \* Size of housing scheme appropriate to the tenants' choice, control, independence and privacy
- \* Accessibility of the local and wider community
- \* Good liaison among agencies – housing departments, social services, health authorities and disabled people's groups
- \* Flexibility and a range of housing to take account of disability and change
- \* Accessible and adaptable housing

- \* Promotion of disability equality at all levels of organisations
- \* Sensitivity to the needs of people from ethnic minorities
- \* Housing which is integrated into the community rather than being grouped together as 'special needs' housing.
- \* Flexible support which is not tied to any one building.

They conclude that:

.....disabled people want the same as non-disabled people, the opportunity to live in their own homes, with whom they choose or by themselves, to participate in their local communities and to have a reasonable quality of life. (1998:31)

Imrie goes further when he states:

One of the most significant problems for disabled people relates to physical obstacles and barriers within the built environment. Many commercial and public buildings are inaccessible to wheelchair users, while few buildings provide appropriate design features to enable people with a range of sensory impairments to move around with confidence and ease. Accessible public transport is a rarity while most housing lacks basic adaptations or design features to facilitate independent living for disabled people.....As some have argued this is tantamount to an infringement of disabled people's civil liberties. (in press)

Macfarlane and Laurie (1996) provide a long list of recommendations which include the need for professionals to acquire a full understanding of the social model of disability, the need for organisations of disabled people to be adequately funded to enable their full involvement in planning and consultation, and a move away from the notion that disabled people have 'special' housing needs.

Until there is sufficient political will to make society inclusive to all disabled people, it is naïve to imagine that accessible private dwellings will be anything more than a nominal gesture. Similarly, If the impact of occupational therapists is to move beyond

tokenism, they need to heighten their awareness of disability from the perspective of disabled people, work in partnership with disabled people to remove disabling barriers, recognise the expertise of disabled people, and use their professional power to assist disabled people in their struggle for full participative citizenship.

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