

Unaddressed

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**The housing aspirations of young disabled people
in Scotland**

Jo Dean

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Summary

This report explores the housing aspirations of young disabled people in Scotland. It draws on interviews with 30 young disabled adults and 13 parents of young disabled adults. What emerged was the importance of good housing and the difficulties that young disabled people face in accessing suitable housing. The principal barrier identified by young people was not having information about housing choices.

Three groups of young disabled people were identified:

- those who had left the parental home
- those who lived with family and were aspiring to leave
- those who lived with family and were not aspiring to leave.

Young adults in the three groups did not noticeably differ in terms of type and severity of impairment, age distribution, daytime occupation, family income, educational achievement, gender or other characteristics. These characteristics did not appear to act as predictors of housing aspiration or experience.

Young people who have left the parental home

Ten young people were interviewed who were living away from the parental home. They had taken one of three pathways to leaving.

- *Chaotic*: left in crisis, made several moves in the first few years of independent housing. These young adults had most contact with formal support services and least control over the house moves that they made, compared to those in other groups.
- *Student*: left for education with parental support. Their first move was softened by moving to university accommodation and repeated returns to the parental home. Like

those on chaotic pathways, students made several moves in the first few years but this was understood as a normal part of student living.

- *Planned (not student)*: left with the support of parents because they wanted to move. This move was carefully planned and those in this pathway continued to live in their first home. They were older when they left than those who left on chaotic and student pathways.

All were generally satisfied with their housing but four expected to move to better properties in the near future and only two thought that they would never move. Those who thought that they would move in the future imagined living with a partner and having children and they aspired to family housing like their parents' home. Half aspired to owner occupation because of the sense of ownership and as an investment. The remainder rejected the tenure because it was perceived as unaffordable, too much responsibility and because mortgages were imperfectly understood.

Young people aspiring to leave the parental home

Nine young people were living in their parental home and aspiring to leave. Four had already lived away from their parents and returned.

A desire for independence was the main reason for seeking to leave the parental home. A number of more specific push and pull factors were also identified. Push factors were those aspects of living with parents that created or reinforced the desire to leave. They included tensions within the family, restrictions that parents placed on behaviour, a lack of privacy and encouragement by parents or siblings to move away. Pull factors were the attractors – how young people imagined life would be when they had left the parental home. These were the desire for independence, the belief that leaving home signifies adulthood and a desire to be like peers.

Those in this group expressed a preference for and expectation of living in the social rented sector at first but owner occupation was an aspiration. Those who had taken action had applied to social landlords with the active support of parents and professionals. Those without parental and professional support had taken no action to leave home.

The young people had found it difficult to access information about the range of choices available to them and relied on parents' advice and guidance. There was confusion about the processes used by social landlords to allocate housing and those on a waiting list did not know when they could expect to receive an offer.

Young people not aspiring to leave the parental home

There were 11 interviews with young people in this group. None had ever lived away from their parents.

Staying in the parental home was a positive choice for a minority but for most it was the default position. Four expected to live in the parental home for ever. The remainder aspired to leave at some time in the future, although the timescale and conditions for doing so were not clear.

Most expressed several reasons for staying in the family home and no one reason predominated. These included the importance of their relationship with family, the need for care and support that was provided by parents, home comforts and a fear of alternatives. A few were concerned about the effect that their leaving might have on remaining family members. They did not know that they could have support to live away from their parental home.

Before being interviewed, only one young adult in this group had been asked to voice their housing aspirations. Others had not discussed the future with their parents or with care professionals. All had little general awareness of housing issues.

Housing satisfaction

The reasons young disabled people gave for satisfaction or dissatisfaction with their housing were similar, regardless of whether they were happy living with parents, aspiring to leave or presently living in their own housing. Four aspects were identified:

- *location*: feeling safe, having access to facilities and being known
- *independence*: having freedom and control over their life
- *property features*: accessible design features and the type of property
- *house contents*: audio-visual equipment and consumer goods.

Being satisfied or dissatisfied with housing did not predict whether the young person was aspiring to move. Those already living away from parents wanted to improve their housing without, necessarily, being dissatisfied with where they were living. Those aspiring to leave the parental home were motivated by non-housing reasons, primarily the desire for greater independence and the status of adulthood. Those not aspiring to leave the parental home were choosing to stay not because of housing, but because of people – affection for family and what household members did for each other.

Parents' perspectives

Thirteen parents participated in the research. All had a disabled adult living with them and most had adapted their home to make it suitable.

With respect to future housing, the parents fell into three groups.

- active supporters of independent housing
- passive supporters of independent housing
- rejecters of independent housing.

Those most committed to a future move saw leaving home as a normal aspect of adult life. Those most opposed to a move often had little trust in formal service provision. They saw housing and care as inextricably linked and believed that family care was the best for their adult child.

Parents acknowledged that they were largely ignorant of the housing options available. Those who had discussed future housing with professionals were no clearer about the range of potential options or what actions to take to help their son/daughter access housing. Those who had begun to pursue housing spoke about how complicated and difficult it was to find out about housing, support and benefits for their adult child.

Talking about the future

Throughout the report, the distinction is made between expectation, aspiration and preference.

- *Expectation* is the individual's belief about what will happen, regardless of what they would like to happen.
- *Aspiration* is choice that is not restricted by availability or accessibility.
- *Preference* is a choice between the various options thought to be available.

Largely, the young people expressed preference – that is, they referred to what they would like, but restricted their options to what they believed to be attainable. Desire and actions were being shaped by young people's beliefs about housing. Often these beliefs were inaccurate or, at best, partial. Parents largely expressed their expectations. Again, these were often based on inaccurate or partial understandings of housing options.

Conclusions

The majority of young adults who participated in this research wanted to leave their parental home in their teens or twenties. This was seen as a normal progression to adulthood. The majority of parents also support this aspiration to a greater or lesser extent. This implies that housing providers and social care agencies should focus on supporting young people to achieve their aspirations, before a crisis develops. Helping young people to voice those aspirations is the first step.

There were high levels of ignorance and confusion over what housing choices might be available. This implies that parents and young people should be provided with accessible information that can inform their decisions. This needs to:

- be available before the child is of an age to leave and raised regularly thereafter
- assist the individual and their supporters to think about what represents good housing for them
- explain how to find out about local options
- indicate which agencies would be able to answer questions, provide support and advocate if required
- consider all living options – staying with parents, living alone, living with a partner, sharing with friends and group living
- cover all tenure options – mainstream and specialist social housing providers, private renting and owner occupation.

Finally, the underlying assumption of much policy in this area is that young disabled people leave in a planned way because of readiness and will continue to live in their first home for a considerable period of time, if not for life. This is

the experience of some. Those leaving for education and in crisis follow different housing careers and their needs must also be taken into account. Further, there is an inequity in the assumption that, for young disabled adults, a first home is a home for life. This may delay leaving the parental home

while perfect housing is sought. Moving house while young, including returning to parents, is common for both disabled people and non-disabled peers. It usually enables people to improve their housing position whether this is within or between tenures.

1 Introduction

For many young people, one of the markers of becoming an adult is attaining independent housing. In policy and popular discourse, leaving the parental home is a desired and 'normal' part of growing up. How this is achieved – the readiness of the individual to leave their family and the expectations of family and young person – is influenced by gender, class, age, culture, ethnicity and, perhaps, disability. This report is based on research into the housing aspirations, beliefs and experiences of young disabled people in Scotland.

This chapter focuses on what is known about young disabled people and housing. It starts by examining the literature on young people's housing careers, noting that this rarely acknowledges whether being disabled has an impact on young people's choices. It then assesses what is known about housing for disabled children and disabled adults, drawing on literature about people with physical/sensory impairments or learning difficulties. Finally, it offers an overview of the key social policies that influence young disabled people's housing choices.

Young people and housing

Becoming adult is a process, a transition, which may be drawn over a period of years. Definitions of adulthood are complex. Markers might include the age of criminal responsibility, rights to confidential medical care and to consent to treatment, the vote, leaving school, entering paid work, differing benefit entitlements, sexual activity and parenthood. Living away from the parental home is another of those markers.

It should be noted that 'becoming adult' has different meanings to different groups in society. In some families, the expectation may be to continue living in the parental home until, or indeed after, marriage. In particular, young people from some minority ethnic communities may not see leaving home as a necessary part of achieving independence and adult status (Bignall and Butt,

2000). This does not mean that the status of adult is not achieved.

There is a substantial amount of published research into the housing circumstances of young people. This often explores the social and economic factors that influence a housing career. However, it rarely explicitly considers disability. This section considers what is known about young adults and housing, drawing on research that presumably included some disabled people but did not separately identify their experiences.

Moving to independent living

The age at which half of young people live away from home in the UK is 21.2 years for women and 23.5 years for men (Iacovou, 2001). A recent survey of 16–25 year olds found that 53 per cent had lived away from the parental home at some time and 47 per cent were currently living independently (Ford *et al.*, 2002). One-fifth had been living in independent housing before the age of 18.

Of those living in independent housing, the majority live in the private rented sector (44 per cent), a third in social rented housing and almost a fifth (18 per cent) in owner occupation (Ford *et al.*, 2002). The majority, 83 per cent, expect to live in owner-occupied housing within ten years.

Returning to live in the parental home after leaving is common for young people, although it is not clear if we know whether this is an increasing trend. Of a sample born in 1958, a fifth had returned to the parental home at least once by age 33 (Di Salvo *et al.*, 1995). A survey in 2000 found that 40 per cent of young people aged 16–25 had returned to the parental home since first moving into independent housing (Ford *et al.*, 2002). The main reason for graduates returning to the parental home was to live cheaply while paying off student debt (Pavis *et al.*, 2000).

Around a fifth of 16–24 year olds have experience of homelessness (Ford *et al.*, 2002). The incidence of youth homelessness has risen steadily since the 1970s and the number of young people

leaving the parental home because of family tensions is said to be increasing (Jones, 1995).

Influencing factors

The housing career of young adults – including the age they leave the family home – is influenced by a range of factors that relate to each other in complex ways. Gender, ethnicity, family structure, employment status and rurality have been shown to make leaving the parental home more or less likely.

Typically, young women leave the parental home earlier than young men and are less likely to return (Ford *et al.*, 2002). Women are more likely than men to move away from the parental home in order to live with a partner (Iacovou, 2001). Asian and black women are less likely to live away from the parental home than white women. Young black men are more likely to live away from the parental home than young Asian or white men (Heath, 1999). Stepchildren leave the parental home earlier than those living with their natural parents (Heath, 1999). Young people who grow up in rural areas are more likely to be living in the parental home than those raised in urban areas (Ford *et al.*, 1997).

Young adults who were ‘looked after’ by the local authority during their childhood are more likely to live independently at a young age, and more likely to experience homelessness (Wade, 2003). Disabled children are more likely to be ‘looked after’ than their non-disabled peers (Gordon *et al.*, 2000), but their housing experiences in adulthood do not appear to have been explored.

Financial independence or the prospect of such independence is an important influence on young adults’ choices. Young people who are unemployed are twice as likely to be living with their parents than those in paid work (Iacovou, 2001). Young disabled people are less likely to be employed than their non-disabled peers: 55 per cent of disabled people aged 20–24 are in paid work compared with 73 per cent of their non-disabled peers (Office for National Statistics, 2002; Smith and Twomey, 2002).

The kinds of statistical analysis that inform our understanding of young people’s housing careers are not available for young disabled people. Assertions are made, but we do not know when young disabled people leave the parental home, their primary reason for leaving, the likelihood of returning to live with parents, or the tenure they move into. We do not know whether having specific impairments influences housing careers. Nor do we know how factors such as gender and ethnicity affect the housing careers of young disabled people.

Higher education

The pursuit of higher education makes a considerable difference in the housing careers of young people. Fifty per cent of young Scots are currently in full-time higher education, but young disabled people are much less likely to participate in higher education than their non-disabled peers (National Audit Office, 2002). It is not known whether disabled students follow broadly the same housing careers as their non-disabled peers.

Those leaving the parental home to study typically leave younger, and are more likely to return (Heath, 1999), not least because of rising levels of student debt (Ford *et al.*, 2002). They are also more likely than non-students to be living in the private rented sector (Rugg *et al.*, 2000). Around a quarter of all students live in accommodation provided by their educational institute (halls) (Rugg *et al.*, 2000).

Of those aged 18–35 leaving home for reasons other than education, most leave to owner occupation (46 per cent of males and 54 per cent of females) or the private rented sector (43 per cent of males and 31 per cent of females). A minority (12 per cent of males and 16 per cent of females) leave to social renting (Iacovou, 2001).

Housing pathways

A number of authors have suggested models of housing routes that young people take in leaving the parental home.

Ford *et al.* (2002) found five typical housing pathways. The pathways were influenced by young people's ability to plan for a move, their ability to control the move and their motivation for seeking independent housing. The five pathways are:

- *Chaotic*: no planning, no family support and considerable constraints on the affordability of and eligibility for housing. Young people in this pathway often experience episodes of homelessness and frequent moves within the private rented sector. They often cannot return to the family home.
- *Unplanned*: no planning and substantial constraints, but with some family support. Young people in this pathway may be forming a new household following pregnancy and often access the social rented sector. They then move within this sector, towards better housing.
- *Constrained*: a planned, voluntary move with substantial constraints and family support. Typically, the first move is into the private rented sector and further moves are made as the opportunity arises.
- *Planned (non-student)*: a planned voluntary move with family support, which may be delayed to manage constraints. The move may be into the private rented sector and thence into owner occupation or into social housing.
- *Student*: planned to coincide with the move to higher education, using student accommodation or the student segment of the private rented sector. There are serial returns to the parental home, during study and after graduation.

Jones (2000) has identified four intermediate household types that young people may move between before settling into a family of destination. Returns to the parental home may also occur. The intermediate household types are:

- *one person*: living alone
- *peer*: living with friends
- *kin*: living with relatives
- *surrogate*: living with others not previously known to each other, with the accommodation dependent on a course of study or a job.

Families of destination may be living with a partner, with or without children, or living as a lone parent.

As Jones (2000) notes, it is important to ask whether these four household types truly are intermediate or whether they are seen by young people as long-term preferred alternatives to the families of destination which are more traditional household types. Heath (1999) makes a similar point, suggesting that wider participation in education is changing patterns of housing preferences for young people. He suggests that students' experience of shared living is making this a more appealing housing arrangement post-graduation, by choice rather than financial necessity.

There is a need to beware the assumption that young people do and should aspire to particular forms of housing. While social policies, housing availability and the local labour market may constrain young people's ability to leave the parental home, living with parents may be a positive choice for some (Heath, 1999). Parental homes now are more likely to have the space to comfortably accommodate an additional adult and changing social mores mean greater freedom and privacy for many.

Housing aspirations

Research with Scottish teenagers (aged 14–16) has found that their 'ideal home' is a two-storey detached house, with a back and front door and a garden. They aspire to own their homes in the future, seeing owner occupation as an investment,

cheaper in the long run and a legacy for future generations (Homepoint, 1995). This was the case regardless of the kind of house or tenure they currently lived in. Similarly, Ford *et al.* (2002) found that most young adults aspire to owner occupation in the long term even if this is not immediately achievable.

The immediate housing aspirations of young adults in rural areas are influenced by the perceived availability and affordability of housing, the local labour market, income, access to leisure and social opportunities, access to larger centres of population, benefit restrictions and the desire to establish life as an independent adult. In other words, a range of non-housing issues impact on housing choices (Ford *et al.*, 1997).

Young adults rely heavily on the advice and guidance of family and friends when seeking housing (Ford *et al.*, 1997). The Homepoint (1995) study found that teenagers' understanding of housing tenures other than their parents' tenure was sketchy. There is a danger, therefore, that families' problematic housing experiences may reproduce themselves and that those growing up in rented housing will not easily enter owner occupation.

Jones (2001) has argued that myths and misunderstandings about housing are as important as the objective reality. Beliefs about the local housing market and about social landlords' allocation policies affect the house search behaviour of young people:

The accuracy of their judgements is thus less important than what they say.

(Jones, 2001, p. 48)

Disabled people and housing

As shown above, the research on young people's housing careers does not often explicitly address young disabled people's experiences, although some disabled people must be included in the studies.

However, a wealth of qualitative material on the housing experiences of disabled children and adults does offer insights into what young disabled people can expect. In particular, there is consistent evidence on the barriers that disabled people face in accessing suitable housing and on their generally disadvantaged position in all tenures.

The starting point is:

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 have a reasonable quality of life.

(Esmond *et al.*, 1998, p. 31)

Beresford and Oldman (2002) explored the housing experiences of families that include a disabled child. They found more housing problems than in families where there is no disabled child. Most had moved house at least once to improve their child's housing circumstances, often without professional advice or assistance. Although the families had an assessment of needs under the Children Act, this rarely considered housing needs. It was noted that professional practice was marked by a lack of clarity about the roles of practitioners and departments, and that typically no agency takes lead responsibility for assessing and meeting housing needs. Bevan (2002) found that families of disabled children do not generally know what help is available with housing or who to approach for help.

Families from black and minority ethnic communities with a disabled child report similar types of unmet needs to those of white families, but the extent of these needs is greater. It is apparent that black and minority ethnic families are more disadvantaged than their white counterparts (Beresford and Oldman, 2002; Chambra *et al.*, 1999).

Morris (1999) found that disabled adults of all ages living with their parents had particular difficulties in accessing appropriate housing in

order to leave the parental home. Housing allocation policies typically interpreted these people as being adequately housed, and they were therefore not a priority for scarce resources.

Disabled people are much more likely to live in the social rented sector than non-disabled people. Almost two-thirds of households containing a person with a physical/sensory impairment live in the social rented sector (60 per cent), as do over two-thirds of households containing a person with a learning difficulty (67 per cent). The majority of the remainder live in the owner-occupied sector (35 per cent and 27 per cent respectively) (Scottish Homes, 1996). It should be noted that these figures relate to households containing a disabled member, not necessarily headed by a disabled person. Disabled people living with parents are therefore included.

In part, this is because disabled people face barriers to accessing the private sector. Financial barriers to private renting include the need to raise a deposit and rent in advance, and the housing benefit regulations that restrict the kind of housing young people may live in and the cost of that housing. People wishing to access owner occupation must usually raise a mortgage and find a deposit, and there are barriers to both for disabled people (Burns, 2002). It is possible to buy a home using benefit income but this route is not common (King, 2000).

Reliance on social renting may also be related to the assumptions that disabled people, their families and care professionals make about what is possible for disabled people. Finally, housing and support have been inextricably linked in the past, through funding mechanisms and service culture, making it difficult for disabled people to live independently in housing that was not specially designated.

The policy environment

This section briefly sets out the key policies that impact on young disabled people's housing choices in Scotland. Since the establishment of the Scottish Parliament, Scottish social policies have been diverging from those implemented by Westminster. Housing, community care, social work and education are devolved policy areas. Social security policy, including housing benefit and disability legislation, is reserved to Westminster.

No one agency or professional body takes lead responsibility for supporting young disabled people to identify their housing choices and access the most appropriate housing for them. Three key pieces of legislation, however, could provide a starting point for exploring housing need. These are the Education (Scotland) Act 1980, the Community Care Act 1990 and the Children (Scotland) Act 1995.

Under the Education Act, teenagers who have a record of needs must have a future needs assessment (FNA) at around age 14. This should be the starting point in planning for adult life and held early enough to give young people, parents and professionals every chance to find out about choices, make decisions and implement them.

The FNA is led by the local authority education department but should be multi-agency and cover all aspects of transition planning, including ongoing educational provision, daytime activities, social activities, the transition to adult services and housing. The guidance emphasises listening to the views of the young person and presumes that young people can participate in the process. The FNA is in the process of being changed, but the multi-agency approach remains, as does the consideration of all aspects of a young person's life.

A fundamental plank of the community care agenda has been the right of people with community care needs to live in their own homes with the support they need to do so. The Community Care Act requires that social work

authorities assess people who may be in need of support and ensure that the required services are provided. Community care policy has espoused choice and independence, although some have questioned whether this has been achieved by the community care reforms.

Under the Children Act, disabled children are considered 'children in need' and parents may request an assessment of the child's needs from the local authority. Guidance says that these assessments should be undertaken collaboratively and coordinated with the assessments made by other public bodies for other purposes. The act focuses on the need to listen to the views of disabled children and young people, and on developing an effective partnership between families and professionals.

But housing is rarely considered in a Children Act needs assessment (Beresford and Oldman, 2002). The investigation of housing needs in Children Act assessment is highlighted by Bevan as good practice, not common practice (2002). Thus, while Children Act assessments could be a tool for supporting families to identify and meet their housing needs, and that in turn could be a springboard for identifying and meeting the changing housing needs of young disabled adults, it does not appear to be happening.

In addition to this legislation, there have been two important reviews under the auspices of the Scottish Parliament.

The Same as You? A Review of Services for People with Learning Difficulties (Scottish Executive, 2000a) summarises the findings of a wide-ranging review of services for people with learning difficulties. Its recommendations included:

- the preparation of partnership in practice documents (joint health and social work learning difficulty service plans)
- the employment of local area coordinators to act as brokers for people with learning difficulties

- the use of personal life plans in place of future needs and community care assessments.

The review notes that most children and adults with a learning difficulty live with their family and housing is a key theme of *The Same as You?* (Scottish Executive, 2000a). It sees hospital closure as the immediate priority but also emphasises the importance of supporting people to reach the best solution for their housing need and of recognising that housing needs will change over time.

Implementing Inclusiveness: Realising Potential – known as the Beattie report (Scottish Executive, 1999) examines the needs of young people who require additional support to participate in post-school education or training. It is part of several government initiatives to encourage lifelong learning and widen participation in education. Key recommendations include a focus on improving transitions from school to post-school provision, an enhanced role for careers service companies and closer links between the FNA process and the support offered to young people.

Direct payments may be an increasingly important route for young people to achieve independent living. Direct payments are money provided in lieu of the community care services that the individual has been assessed as needing. They enable a disabled person to employ their own personal assistants or purchase other services of their choice. They are a mechanism by which disabled people may control their own care. It is argued that this is a particularly appropriate way of meeting the needs of people from black and minority ethnic communities, as it allows for the close matching of user and staff (Hasler *et al.*, 1999). Current requirements are that the individual is aged over 16, eligible for community care services, and willing to accept direct payments and able to manage them alone or with help. Under the Community Care and Health (Scotland) Act 2002, the scope of direct payments was extended in June

2003. This should increase the take up of this option.

About the study

This was a qualitative study based on 30 interviews with disabled people aged 18–34. They all had a physical/sensory impairment or learning difficulty; some had both. Thirteen parents of young disabled adults were also interviewed.

Of the young people interviewed, 11 described themselves as having a physical/sensory impairment, 16 as having a learning difficulty and three as having both. Of the parents, two described their son/daughter as having a physical/sensory impairment, six described them as having a learning difficulty and five as having both.

The research was conducted in three areas of Scotland: two urban and one rural. To protect participants' anonymity, the three locations are not named in this report.

Interviewees were approached through a variety of statutory and voluntary agencies operating in the areas. The most successful routes of recruitment were through educational establishments and adult training centres. The least successful were through specialist and mainstream housing providers.

Further details of research methods and of the sample characteristics are given in the Appendix.

Note to the report

Throughout this report, the term 'young disabled people' is used to describe people aged 16–34 who have a physical/sensory impairment or a learning difficulty. Specific impairments are identified only where this has a bearing on the housing or support need discussed.

Where referred to in a family context, the term 'adult child' is used, to distinguish between the generations.

All names have been changed, as have minor details that may identify individuals.

Report structure

The remainder of this report is concerned with the findings of the research. It is structured as follows.

Chapter 2 explores the attitudes and experiences of young people who are living away from their parents. It identifies three pathways to independent living and shows that satisfaction with housing is based on location, property features, tenure and being independent.

Chapter 3 considers young people who were aspiring to leave their parental home. Increased independence was the most important reason for seeking to leave. An important finding was that young people's expressed desire and their actions were being shaped by their beliefs about housing. Often these were incomplete or inaccurate.

Chapter 4 reports on the young people who were not aspiring to leave the parental home. Of these, some were actively choosing to stay while others had never considered alternatives. Most expected that they would move away from their parental home in the future but there was little knowledge about housing.

Chapter 5 is concerned with parental perspectives. Three groups were identified: those actively supporting a move, those offering passive support for a future move and those who rejected the idea. Where the adult child required 24/7 care, the parents' preference was for them to continue to live in the parental home, but most did not expect this to be achievable.

Chapter 6 concludes by drawing together the similarities and differences between the three groups of young people and parents. It identifies where this study fits alongside other research and offers implications for policy and practice. The most important message is that awareness of the range of housing options needs to be increased

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among young disabled people, parents and professionals. This will enable young people to formulate housing aspirations and be supported to achieve them.

2 Young people who have left the parental home

Ten interviews were conducted with young people no longer living in the parental home. Of these, five had a physical/sensory impairment, four had a learning difficulty and one said they had both. They ranged from age 19–34. The majority lived alone, although two were living in shared university accommodation and one woman's mother lived with her. No one was living with a partner and no one had children.

Housing careers

The age at which people had left the parental home ranged from 16 to 27. The apparent pattern from a small sample is that those who were younger when they left home were more likely to experience several house moves. Three types of leaver can be detected: those who left the parental home in crisis, those who left in a planned way for education and those who left in a planned way for reasons other than education. Following Ford *et al.* (2002), these have been termed chaotic, student and planned (not student) pathways.

Chaotic

Three young people had left their parental home in crisis. One was homeless after his family asked him to leave, one was imprisoned and not welcomed back to the parental home on release and one had lived in a care home as a teenager. They left the parental home young – aged 16 or earlier – and all had lived in supported group housing.

At the time of interview, all were living alone with their own tenancies. They had all lived in at least three houses since leaving the parental home and found it hard to chronologically relate their complex housing careers. Compared to the others reported in this chapter, these young people appeared to have had most contact with support services, particularly social work, for housing and other help. They also appeared to have had least

control over the house moves that they made. This was true not only for the first crisis move but also for future moves. They referred to being 'given', 'placed', 'put into' and 'chucked out' of housing:

I was just put there – it was shoved onto me.

This did not mean, however, that satisfactory solutions had not ultimately been secured.

Andy was asked to leave the parental home aged 16, he says because of his behaviour. He spent eight months in a hostel for homeless people before being offered a flat through his social worker. He lived there for around one year before moving to his current local authority flat. This move was prompted because Andy had problems in the area. Andy is now happy with his flat, which is spacious and has supportive neighbours. He does not want to move at the moment.

Student

Four young people had left their parental home to pursue higher education. All spent at least one year living in university accommodation and regarded this as a gentle introduction to independent living. They left the parental home young (aged 17–18) and experienced several moves over the course of study.

Their leaving was softened by parental support and the opportunity to plan. All returned to the parental home over long university holidays and one woman who had completed her education was in the process of returning to the parental home while job hunting. As she was expecting to move to her ideal job, she did not feel she should seek a house of her own either in the university town or her parents' town. Further, her student debt provided an incentive to return to live cheaply with parents.

Unaddressed

The housing experiences of these disabled students appear to reflect the common experiences of all students, although little has been written on this.

Warren left his parental home aged 17 to go to university. His first year was in catered university halls of residence and he then moved through a series of university-owned and private rented flats, which he shared with friends. In his final year of study, he decided that he did not want to return to the parental home and applied for local authority housing. He moved into a two-bedroom flat and sublet one room to a friend for a while to help with the rent. Warren continues to live in the flat and does not expect to move in the near future.

Planned (not student)

The remainder left their parental home in a planned way for reasons other than education. They were still living in the same housing association property they had first moved to and

had been living there for between three and nine years. Two had a learning difficulty and were in their mid to late twenties when they first left their parents' home. One had a physical impairment and was aged 20 when he moved into his own home after spending a short period in an assessment flat.

All had had the support of their parents to move home, which was expressed in practical ways (such as furnishing and equipping the new home) and emotional ways. The two women with learning difficulties did not report the involvement of care professionals in organising and making the move from their parental home, although, as they had ongoing support in their homes, some social work involvement is indicated. The man with a physical impairment had problematic experiences with care professionals giving him inaccurate advice about funding eligibility. He has since sought advice from other disabled people to avoid reliance on social workers and uses direct payments to fund the employment of personal assistants.

The pattern of housing careers experienced by young people in the three groups is set out in Table 1. It is apparent that, in this small sample, those

Table 1 Housing careers since leaving the parental home

	C	C	C	Reason for leaving			S	P	P	P
				S	S	S	S	P	P	P
				Age left						
	16	16	16	17	18	18	19	20	25	27
				No. of moves						
	3	4	3	2	3	3	4	1	1	1
Type of accommodation										
Student halls				xx	x	x	xxxx			
Shared private rented sector						x				
Group	x	x	x							
Furnished social renting		xx								
Social renting	xx	x	xx			x		x	x	x
Owner occupation					xx					
Key to pathways:										
S = student, C = chaotic, P = planned (non-student)										

with chaotic and student pathways experienced more house moves than those who took a planned (non-student) route. It could be argued that the greater number of house moves by these two groups is a function of leaving home younger and hence having more time in which to make these moves. However, in this sample, this was not the case. Rather, they were staying in housing for shorter periods of time.

The reasons for frequent moves were different for those in chaotic and student pathways. Those in chaotic pathways moved because their housing was transitional/ move-on housing or because they had accepted tenancies in problematic areas and were seeking to improve their housing situation. Those in student pathways followed a typical student pattern of annual moves through university halls and tenancies in the private rented sector. They saw frequent moves as a normal part of student life.

Young people who left in planned (non-student) ways appeared to find pleasanter, more suitable properties first time, and were more satisfied with these houses. This may be because they were able to wait and choose housing that would suit them or it may be related to the influence of parental support and parents' more practised judgement in assessing potential properties.

Past housing

As reported above, young people in two of the three groups had experienced several house moves in their independent housing careers. This section explores their experiences of and attitudes to past housing. It considers living with parents, in university accommodation, in supported accommodation and sharing with friends. Jones' (2000) typology of intermediate households is drawn on where appropriate.

Parents' housing

Almost everyone used their parents' housing as a yardstick against which to compare their current housing. The exception was a person who lived in care as a teenager.

For a minority, parents' houses had not met their housing needs. This was either because parents faced financial constraints in choosing housing or because they must meet the needs of all family members and a compromise was made. For example, one wheelchair user could not independently go in and out of his parents' home because of steps:

I had to wait for somebody to help me ... sometimes I'd get home from college and I had to sit and wait outside for about two hours.

But, for most, the parental home represented good housing that was accessible and comfortable. Young people referred to building design, to the contents of their parents' house and to the care and support that parents provided. Several looked forward to living in a house similar to their parents in due course:

They have a big garden and it's just really nice to be able to go out and sit in the garden in the summer and it's nice to live in a house, especially a detached house, because you don't get the noise from neighbours.

Yet, while the home comforts offered by the parental home were identified and valued, the young people were not interested in returning to live with parents. Living independently was more important than living in better, larger, more comfortable housing with parental support:

There comes a time in your life when you need to kind of move ... now I'm kind of independent and made up my own mind about things and it's very strange going home and it's even to the point that my parents and I don't even eat the same food.

Most students returned to the parental home during university holidays and some had returned or expected to do so after graduation. This was seen as a necessity and a short-term solution to housing need rather than a preference:

I don't mind going back home but I'm not looking forward to it cos you can't play your music loud or anything. You're restricted to what you can actually do.

University accommodation

Those on the student pathway had all lived for at least one year in university halls of residence. Living like this was seen as having both advantages and disadvantages.

University halls were seen as a low-cost, high-quality option compared with the alternative of living in the student-oriented private rented sector. It was a gentle introduction to living away from the parental home, particularly for students living in catered halls. They said that the provision of meals had helped them to adjust to independent living and budgeting for themselves:

I would recommend it to any student cos it softened the move greatly because, as long as you turned up for breakfast, you got fed. Turned up for dinner, you got fed. And once kind of being fed's taken care of, everything else sort of – you can live with.

Almost all had moved to a new city to pursue their education and living in university halls in the first year took away the need to search for housing in an unknown area. The university was also seen as a reliable landlord and students valued not having to take responsibility for repairs and maintenance:

If something breaks down, if the light goes out, if the electricity goes off, there's always a back-up there and you don't have to worry about getting new light bulbs or getting your shower fixed.

The students who lived in halls had all been allocated to rooms designed to be accessible to wheelchair users, regardless of their own impairment or access needs. This meant larger rooms and bathrooms with particular design features. Generally, this was seen as more desirable than standard student accommodation. However, the students – none of whom was a wheelchair user – did question whether their rooms would truly be accessible to wheelchair-using students.

Universities provide security in the person of wardens, which several students described as reassuring. Wardens' presence and their first-aid expertise were highly valued by one woman with epilepsy who said that she would not be happy living without such support. Further, halls offered an easy way to make friends and be with people. The social side of this kind of housing was highly valued:

There's always constant company. It's not like you have to go very far.

On the negative side, living in halls means living in shared accommodation. Consequent problems of noise, personality clashes and petty theft had arisen. One woman felt unsafe sleeping with her door closed in case she needed medical attention but also felt unsafe leaving the door open because access to the building was not tightly controlled.

Shared accommodation may always mean a lack of privacy, but some disabled students felt that they were more visible than their non-disabled peers:

Everybody knows what's going on. So it's a bit like being in a goldfish bowl a little bit, especially if you've got a disability because everybody knows if you sneeze, just about.

University halls are 'surrogate households' in Jones' (2000) typology. Those on student pathways did see halls as a transitional or intermediate form

of housing. Most spent long holidays in the parental home and they did not see halls as 'home'.

Supported housing

Those following a chaotic pathway had all experienced group living in supported housing. This term is used to mean housing where support is inextricably linked, which is shared with others who have support needs who were not chosen as flatmates by the individual. Experiences include a homeless hostel, a long-stay group home that was also used as a respite facility and a transitional/move-on project. All of these young people have since moved on to live alone in their own tenancy.

Living in shared accommodation was not much liked. The young people did appreciate the support and company of staff, but did not like living with others who they had not selected. Problems with co-residents included tensions over lifestyle (such as loud music), resentments about differing abilities (for example, with shared cleaning duties) and a rejection of the stigma that they attributed to co-residents' behaviour. As the examples below show, there were evident tensions between the judgement of individuals and that of support staff over individuals' readiness to move out of supported housing.

Tara moved from a care home to a supported living project aged 16 and stayed there for eight years. She liked being with the staff and appreciated the help that they provided with cooking, cleaning, laundry, etc. However, she did not always like the other residents, who were mostly older than she was. There were disagreements over lifestyle, particularly playing music, and activities on group holidays were not to Tara's tastes. Despite these tensions, she wanted to stay in the supported project, but says she was made to leave.

Gordon moved to a supported living project after leaving prison. He was moved through a series of shared flats and then into a satellite flat alone but with ongoing staff support. In total, he lived in this project's accommodation for four years. The project enabled him to develop independent living skills, such as keeping himself and the flat clean. He did not like sharing with others and did not always agree with decisions taken by project staff or with the rules of the project. Gordon felt that he was ready to leave the supported project much earlier than he did but the project held him back.

Supported housing is also an intermediate household type in Jones' (2000) typology. However, in contrast to the perceptions of university halls, the young people did regard this housing as 'home' for the time that they lived there. This may be because they had nowhere else to go, no alternative place to call home.

Shared living with friends

Those following the student pathway all had experience of shared living with friends/chosen flatmates. Those following chaotic and non-student pathways had not lived with friends. Shared living was mostly experienced in private rented accommodation, but had also been experienced in social rented and owner-occupied properties. In the latter cases, the householder had brought flatmates into their current housing for a period in order to help defray housing costs.

The implicit belief that shared housing is a normal component of a youth housing career is underlined by the experience of a man following a planned (non-student) pathway. He moved from the parental home into an individual tenancy in the social rented sector. He now regrets missing the experiences of his peers who lived in shared housing:

I would have loved to live in a flat with flatmates ... I didn't get the chance. I suppose now it's alright because I'm 25, but one thing I did miss was sharing a flat. Especially my PAs [personal assistants] were living in flats and the things they got up to – it made me a bit jealous.

Jones (2000) terms this shared living 'peer' households. Most who had shared with friends had enjoyed the experience, but saw such a household as a temporary stage in a young housing career rather than something you would do long term. This tends to confirm Jones' (2000) suggestion that peer housing is transitional housing.

Current housing

The length of time that the young people had lived in their current housing ranged from less than one year to almost a decade. There is an association here with age. Those who had lived in their current home for less than two years were all aged under 23. Those over age 23 had all lived in their homes for three years or more. Too much cannot be read into a small sample, but it is intuitively true that those who took chaotic and student pathways left the parental home young and had several years to trade up into housing that suited them, while it has been shown that those who took planned, non-student pathways left later and did not move on.

Current housing was mostly in the social rented sector, including local authorities, mainstream/general needs housing association and a specialist housing association working with community care groups. One woman was an owner occupier and two students were living in university halls. No one was renting privately.

Interviewees were asked to identify what was important about their current housing – both positive and negative aspects. In doing so, many drew on their experiences in previous housing or on others' experiences. Four main themes emerged:

location, property features, tenure and independence. These are discussed below.

Location

The area in which they lived was important to young people and affected how satisfied or dissatisfied they were with their housing. A 'good' location was one that was near to important people (mostly family), where young people felt a sense of belonging, where they felt safe and where there was easy access to the kinds of facilities that young people wanted to use and a desired ambience.

The majority lived in housing that was near to their parents' home, although perceptions of 'nearness' must depend on how easy it is to move between the two locations. Very few drove or talked of using public transport, so nearness was conceived of as being the distance that the young person could comfortably walk or travel in their wheelchair.

Those on the student pathway had all moved from their home area to another town/city to study. For each, their decision to attend a particular institution was partly a decision about the kind of town/city they wanted to live in. However, having taken the decision to live in halls, the neighbourhood they lived in – whether on campus or off – was allocated by the university, not chosen by the individual.

The presence of good immediate neighbours was important to all, as was feeling part of the local community. This was both knowing people who live close by and being known by others:

I've always wanted to live in an area that has people that you know. Because, if anything went wrong, there's just someone you know that'll help you out.

Although 'being known' was raised by most, the sense of being in the right place was particularly important to young people living in rural areas or small centres of population. Those still living in the area where they grew up also

talked about the importance of having a history in the area:

I was brought up here and I went to school here.

Two lived in a housing development that was purpose built for disabled people. Both highly valued living alongside other disabled people as well as the amenity of an accessible environment. In particular, the presence of disabled neighbours who have children, partners, cars and jobs was valued for showing what disabled people can achieve. They also valued the opportunity to provide assistance and care for neighbours, which gave them a sense of being needed and useful.

No one talked of feeling excluded from the wider community although many did express a sense of personal loneliness. A few had experienced tensions with neighbours. This included both perpetrators and recipients of noisy behaviour:

The neighbours are a bit older than I am and they don't like it when I play my music loud ... sometimes they get the polis in.

I didn't really feel safe living in that flat ... my neighbours were exceptionally noisy and I really couldn't get any peace and quiet to study.

Feeling safe or threatened in the local area was a very important feature of whether young people liked their housing. Many reported feeling unsafe in their current or previous housing. A number had been victims of crime or had witnessed assaults. Young people placed a sense of safety high on their list of priorities:

It's quiet, you don't have any disturbances ... it's not like an area for vandalism or whatever and, although you're not supposed to walk home alone at night, I have done on several occasions and it's quite safe.

The fighting. All the time ... I can hear it.

Having easy access to desired facilities or services was also an important factor in satisfaction with

location. What was important naturally varied from person to person, but included space to exercise a guide dog safely, being near to shops, pubs, cinemas and so forth. People in employment, education or who regularly attended day centres highlighted the importance of being able to get there:

I've got my little routine. I know exactly where every shop is. It's got everything you need. You've got the cinemas, you've got the pictures, you've got the pool.

The ambience of the area, closely linked with both a sense of safety and with local facilities, was the final aspect of location that affected satisfaction:

I like [this area] ... ye can sort of [dress] dead smart an' people won't look at ye, cos ye meet business people an' that. So I sort o' quite like that. I've always liked [this area]. I've always done my shoppin' there so it's a lot easier – an' it's a lot easier tae get tae yer work from there.

It's kind of mainly young families and young professionals that live here. It's nice and quiet. It's good for studying and things and I feel safe here.

Property features

Particular aspects of the house or flat were also a very important feature in satisfaction with housing. Partly, this related to the importance of accessible design and specific features for meeting disabled people's needs. For example, several interviewees, not all wheelchair users, lived in housing designed for wheelchair users. They all valued the features that this meant: greater space standards, wet-floor showers and lower kitchen units.

The house is nice. I like the houses. The way they're built for wheelchairs.

Problems of disabling design included dimly lit communal areas, heavy fire doors and the presence of steps and stairs. One wheelchair user who lived in a supposedly wheelchair-accessible flat still had problems with the property:

I can only just get through [the doors] with this chair. I would say that it's just the light switches and the taps and the wet-floor shower that make it a disabled flat. Apart from that it's just normal.

Young disabled people also referred to property features that were not related to accessibility or disabling design. They valued spaciousness, that the property is structurally sound and that the lifts work. No one mentioned problems of damp, poor insulation or other issues of poor quality as affecting their housing satisfaction. It is assumed, therefore, that they did not and had not lived in housing that was poorly maintained housing or of unsatisfactory build quality.

Tenure

Tenure was not, in itself, important in young people's satisfaction with their housing, but aspects linked to tenure were raised. Most of the young people were tenants of social landlords or living in university accommodation. Having a landlord means that you are not responsible for repairs or for the maintenance of the property. This was said to be reassuring:

I would rather rent it. It's just if anything went wrong they would be responsible to sort it out.

No one had had a problem with their current landlord and most regarded their landlord as a good landlord, citing experience with repairs as evidence of this:

They've been really good. I had to get my washing machine replumbed and they did that for me. I've had a few problems with taps and they've done them and they've come out and did the things that I asked them to.

Living in a socially rented house was seen as providing both stability and security. The tenancy provided a home for life if they chose, but there was also freedom to move at short notice. Tenants were also aware that the social rented sector

provided comparatively cheap and high quality housing. Many, even those on full housing benefit, referred to the reasonableness of their rent:

The tenancy is secure ... the value for money is phenomenal compared to student type flats ... and we get a living room and it's ours and we can put things on the wall and use drawing pins.

Only one young person was an owner occupier. She saw a number of benefits of the tenure. She said that owning her house allowed her to make it a home, because there were no restrictions on her use of the flat or on changes she could make within the flat. It was also seen as an investment, compared to the waste of spending money on private renting:

It's a little bit silly to actually pay rent to a landlord every month for accommodation that I probably wouldn't be all that happy in.

Independence

The independence conferred by creating a household separate from parents was very important to the young people in all pathways. Being independent was a factor that influenced satisfaction with housing. However, the term 'independent' was not expanded on as the young people seemed to feel it was self-explanatory.

Two aspects of independence emerged from analysis of the interviews: specific freedom from the control and influence of parents/care staff and, more generally, the freedom of living alone:

I like to feel I'm independent – I get to do what I want and go to bed when I want, get up when I want, watch what I want when I want.

It is notable that, with a few exceptions, the list of important positive and negative aspects of housing identified by young disabled people living independently does not differ from problems that non-disabled people may identify with their housing. Studies of housing satisfaction typically

highlight the importance of specific property features and of locality with particular reference to feeling safe (Spark Research, 2002).

Support

The research was not directly concerned with investigating the support that enables people to live away from the parental home. However, for many disabled people, support is essential for independent living.

The majority of interviewees with a physical/sensory impairment did not have contact with formal support services, although one was using direct payments and another was in the process of investigating support options available to her. She was doing this through the university and believed that she would not be eligible for support from the local authority. The remainder managed without formal support, often drawing on friends where assistance was required.

An unexpected finding was the role that internet shopping could play in enabling independent living. Two disabled people used a supermarket web site to select items, which were delivered for a fee. This fee was acceptable because the service made life easier. One visually impaired man pointed out that the taxi fare home with shopping bags would be about the same cost, and the supermarket web site was accessible to him as the shop itself was not.

All but one of those with a learning difficulty were in receipt of some support to help them live independently. Most commonly referred to was support with paperwork such as benefit claims and paying bills: often the individual was dropping into a local support service for this help as the need arose. These interviewees also referred to support that was primarily social and leisure oriented. Having somebody to talk to was highly valued – it is notable how many disabled young people were lonely and talked about a desire for more friends and more social activities.

Gordon had lived in his flat for three months. He had regular contact with his social worker and staff from a supported living project. When he moved into the flat his social worker arranged for the property to be redecorated and his support worker shopped with him for furniture and household goods. This initial support was welcome but Gordon has since settled and would prefer to see less of the support staff as he felt he was coping without their interventions.

Future housing preferences

Future housing preferences were identified by a number of these interviewees. Four expected to move in the near future or were open to the idea if the opportunity arose. They all had their name on the council or a housing association waiting list, or had investigated other housing options. As would be expected, people's future housing preferences corrected the negative aspects that they had identified in their current housing. So people who discussed concern over safety talked about moving to a better area. Others wanted to move to a better house design or prioritised property features that would better suit them.

New-build developments by specialist housing associations were attracting interest in two separate areas of the rural authority. The attractions of these new developments were that support would be provided and that interviewees knew others who intended to move into the development. It may be that the high profile of the building in small communities was stimulating latent demand to move that would otherwise not have been expressed.

Looking further into the future, people described ideal housing that would represent a change to a more settled lifestyle. This often incorporated hopes of living with a partner and having children, termed 'family of destination' by

Jones (2000). Ideal housing for this imagined family of destination was typically larger than current housing, a house rather than a flat and with a garden. Only two people, both living in specialist housing association accommodation, expected to continue living in the same house for the rest of their lives. Neither expected to have a partner or children.

Tenants were asked their views on owner occupation. Four wanted to own in the future, because 'it would be mine' and because buying a house was perceived as making financial sense. Those who were happy with their current home thought they would like to exercise a right to buy:

I would buy it in a minute if I could afford it. As an investment.

Tenants who aspired to owner occupation all expected that they would buy in the future.

They had two key reasons for delaying entering home ownership. These were financial considerations and an unwillingness to make a long-term commitment to living in a particular neighbourhood, city or country:

Just now I wouldn't because I'm young and I don't want to be tied down. I can leave on four weeks' notice. Just now I don't want that commitment.

The remainder (five) rejected the tenure as not right for them. This was because owner occupation was perceived as too expensive, but also interviewees liked landlords to be responsible for the upkeep of the property. Buying a home was understood to be a responsibility, to tie you to one property for the duration of a mortgage and to be a commitment to a particular locality:

It's just like 15 years to pay off a mortgage and ye might no' like that house in 15 years. I wouldn't know the legal arrangements if you wanted in seven years to move and ye're still payin' off the mortgage and things like that. I don't know. I don't think so.

Summary

This chapter has identified three pathways by which young disabled people have left the parental home: chaotic, student and planned routes. The three groups have had identifiably different housing experiences. But they were similar in what was important about that housing. Satisfaction was linked with location, property features (including accessible design), tenure and independence. Although they were generally happy with their home, half expected to move in the near future and only two expected never to move.

It is worth noting that no one had left their parental home because of a job, to live with a partner, or to start a family. Those who left in planned pathways because of 'readiness' left after a considerable wait to find the right housing and support. Most had left through education routes or through 'chaotic' or 'crisis-driven' moves. This is different to the patterns of leaving identified in the review of literature presented in Chapter 1 and is particularly notable because young disabled people living at home talked about 'feeling ready' to leave *without* a crisis having arisen or the incentive of a job, partnership or pregnancy to make the move. The views of these young people are reported in the following chapter.

3 Young people aspiring to leave the parental home

This chapter is based on interviews with young disabled people who had taken action to leave the parental home or who expressed a strong preference to leave. Research participants who were ambivalent or unclear about their future housing are discussed in the following chapter, along with those who expressed a preference for staying in the parental home.

Nine interviews were conducted with young people who aspired to leave their parental home. Of these, three had a physical/sensory impairment and six had a learning difficulty. They ranged from age 18 to 28. Aspiring leavers with a learning difficulty were older than those with a physical/sensory impairment.

Current housing

All of the aspiring leavers were living with parent(s) and most with siblings also. Four had already lived away from the parental home for a period of time: variously in student accommodation, shared supported accommodation and tied housing. Two had left on a student pathway and returned to the parental home at the end of their course, two had left on a planned (non-student) pathway but returned to the parental home after crisis in their own homes. This fits with Jones' (2000) idea of transitional households and the common pattern of returning to live with parents.

Interviewees were asked to identify what was important about their current housing: both positive and negative aspects. Four main themes emerged: location, property features, house contents and independence. These are discussed below.

Unlike those who have already left, aspiring leavers did not mention tenure as an aspect of satisfaction. Many did not know whether their parental home was in the social rented, private

rented or owner-occupied sector. The basis on which parents occupied their house was not considered important by the young people.

Location

The area in which they lived was important to young people and affected how satisfied or dissatisfied they were with their housing. The positive aspects of location that emerged were about the people who live nearby and the amenity of the area, including access to facilities and ambience. Negative aspects that were raised were lack of amenity and feeling unsafe.

Most were very positive about the area they were living in. Generally, they had lived in the same neighbourhood – often the same house – for many years. They valued knowing neighbours and being known. This was true for those living in both rural and urban areas:

It's such a nice place. Everyone's just so friendly. If you've been living there all your life then you just know nearly everybody.

The young people also valued the amenity of the place – their access to facilities and the ambience. There was variation in the kind of amenity that was valued. Some liked easy access to shops and leisure facilities; others valued access to countryside and the lack of busyness:

It's nice. Nice neighbours. Nice walks ... I like to be near the country.

For a few, the lack of facilities was a problem. They noted that what they liked about their parents' neighbourhood had changed over time – as they grew older they wanted different things in an area. For example, one man had enjoyed growing up in the countryside but said that the very rural location of his parents' house was now a significant reason for his aspiration to leave:

You're kind of cut off from all walks of life ... the worst thing about it is the distance. I mean you're like five miles from anywhere ... you're out in the middle of nowhere.

Feeling unsafe in their home neighbourhood was a very important factor in dissatisfaction with current housing. Two of the aspiring leavers had witnessed assaults or frightening events, others knew through word of mouth or local media that violent crimes had happened in their neighbourhood. The young people did not talk about this fear affecting the way they lived their lives, nor was it a strong influence on wanting to leave the parental home, but it was a factor in how happy they were while living there:

Did you hear about a guy with a knife? And he stabbed another guy ... This was the place where I used to stay and [the town] was as frightened as ever after that.

Property features

The aspiring leavers described particular features of the building as making a difference to how satisfied they were with housing. Few described accessible or disabling design features of housing as important to them, although the sample includes wheelchair users and people with mobility problems. Perhaps these are taken-for-granted features of the home where young disabled people have grown up and inaccessibility has become accepted by long experience. Where the house design was causing problems, young people appeared resigned to this:

It's okay but I hit the door all the time.

Rather, the young people discussed their housing in more general terms. They described the external appearance of the property, its size and spaciousness, and the comfortableness, or otherwise, of their home:

It's medium. It's nice. Cosy.

It's cold and draughty ... because of the draughts, I need two heaters in my room to keep me warm ... because it's always dull, it's a bad house for daylight ... in one of the rooms there's a bit of a leak.

House contents

Not strictly an aspect of housing, the contents of their home were nonetheless the thing that many aspiring leavers chose to discuss in talking about where they lived. In particular, the young people spoke about the contents of their bedroom, which could perhaps be seen as the space within the home over which they had most control. Leisure-oriented items, such as audio-visual equipment, featured most strongly:

I've got a CD player. I've got my own telly. Own video.

For some, the important contents of their home were used to compensate for deficiencies in the location. For example, a man who lives in a rural area without independent transport reported:

We've set up a gym at home there and I go upstairs working in the gym.

Independence

Although all were aspiring to leave the parental home and believed that this would offer increased independence, several made reference to the independence that they already had living with parents.

For young adults with a learning difficulty, there was pride in having house keys or in staying alone in the house. This was a symbol of independence and adulthood:

I was about 16, 17 before I started doing stuff like that. And gradually my mum began to trust me being in the house by myself. It took her a wee bit of time though.

Others signified independence by reference to going out without parents or to making choices

within the parental home. Having their own bedroom was important. It was a space where they had control:

I can do what I want in my own room.

Some signified independence (and adulthood) by explaining that they were not dependent on parents. A few were making a financial contribution to the parental household, for example by using benefit income to pay 'dig money' to parents or buying their own food:

I give my mum money to buy food and she does it when she's doing her shopping. I give her £30 a week to go and buy my food and stock up the freezer with microwave stuff.

Others contributed to the household by taking responsibility for household chores such as cleaning, laundry and shopping:

I go down for my mum's paper and I do the shopping for her sometimes and I do the dishes for mum. Which is actually really good because it gives me something to do.

Reasons for aspiring to leave the parental home

Although the young people felt that they had independence within the parental home, a desire for greater independence was the overwhelming reason for seeking to leave:

I want to be on my own. Yes. Be independent... I said I want my own house. I said I want to be on my own. In my own house.

Reasons for wanting to leave were not always clearly expressed but typically participants talked about feeling it was time to move on, wanting to be more independent and the idea that they could not stay with their parents forever. Strongly expressed was the sense of ownership and control that they believed they would have in their own home.

Specific reasons for wanting to leave included both push and pull factors.

Push factors

Push factors were the aspects of the parental home that created or reinforced the desire to leave. Push factors were strongly linked to relationships within the parental home and to the tensions that living with family can create. No one in the sample referred to deeply problematic relationships with parents or siblings. But, as would be expected, there were disagreements and dissatisfactions within the family. Young people saw moving as a way of resolving those tensions:

We're always arguing about things. And I think it's mainly to do wi' me being blind, I always say – especially me and my sister.

Mum and dad always argues. Argue with me. Not tidying my room. And money. It's all the time.

Restrictions that parents placed on their adult child's behaviour were another push factor. For example, one woman resented her parents' attempts to protect her against financial exploitation by others:

If my friends need help, I can give them away my money. When I do that now mum and dad shout about getting it back.

A lack of privacy in the parental home was a third distinct factor in the aspiration to leave. Implied but unstated was the difficulty of developing sexual relationships while living in the parental home:

You've not really got a choice when you live with people. Like mum will come in and you don't want her to come in.

Finally, some young people were experiencing pressure from parents or siblings to leave the parental home as a normal part of growing up. No one was being asked to leave urgently, but several

were being encouraged to make plans to do so. Additionally, a few had been encouraged by a care professional to think about leaving:

[Siblings] say you should get a house of your own. They think I should leave my mum and dad on their own as well now. Because they think, well, they've got their own houses, I should have my own house as well now.

Pull factors

While most aspiring leavers made reference to one or more push factors, pull factors appeared more strongly implicated in the aspiration to leave. Pull factors were attractors – how young people imagined life would be once they had left the parental home.

Perhaps the most important pull factor was the desire to be independent. In these interviews, 'independence' was a term frequently used but infrequently explained. As noted above, independence for young adults can include having house keys, choosing to stay in or to go out, making choices about behaviour within the home, paying your own way and taking responsibility for running the house and household chores. Young disabled people largely took the meaning of independence for granted and saw leaving the parental home as intrinsically increasing their independence.

It gives me my own independence. I can come in when I want.

A second, important, pull factor was the idea that leaving the parental home is a signifier of adulthood. Put simply, the aspiring leavers believed that young people should leave the parental home as they get older because adults do not live with their parents. So the aspiration to leave is an assertion of adulthood:

I can't live with my mum all my life ... because you love her to bits but really, if you want a place of your own, then you should try to get a place of your own.

You don't get any younger. I mean I'm not saying I'm old like but time goes on and bits and pieces like that and things. I think if they offered me a house tomorrow I'd be over the moon. Honestly. I would be over the moon.

These young adults also looked forward to being like peers who already had their own homes. Visiting friends who had their own homes reinforced the desire to leave the parental home as it modelled what is possible for disabled people. It made a dream look achievable:

I've been told by my other friends that have got their own houses that they've got to keep their houses tidy, so I said 'right, if I get a house, I'll keep it tidy as well'.

Types of housing desired

It is worth noting the difference between expectation, aspiration and preference.

- *Expectation* is the individual's belief about what will happen, regardless of what they would like to happen.
- *Aspiration* is choice that is not restricted by availability and accessibility.
- *Preference* is a choice between the various options thought to be available.

Largely, the young people here were expressing preference: that is they were referring to what they would like, but restricting their options to what they believed to be attainable. Jones' (2001) point about myths and misunderstandings is therefore highly relevant. Expressed desire and actions were being shaped by young people's beliefs about housing. Often these beliefs were inaccurate or, at best, partial.

Three aspects were mentioned when talking about the types of housing desired: tenure, location and design. These are discussed below.

Tenure

All of the aspiring leavers expected, in the first instance at least, to move to a property in the social rented sector. Any moves that had been made towards leaving the parental home were applications for a local authority or housing association tenancy.

Before interview, the private rented sector had not been considered by aspiring leavers as a way to move out of the parental home. When questioned about the sector, they said they felt that such housing was likely to be expensive and of low quality. Often, they drew on siblings' experiences of student renting in formulating their opinions. The possibility of using the private rented sector to gain fast access to independent housing did not outweigh what were understood to be the negative aspects of the tenure:

It's never occurred to me to rent off a landlord, but I don't know what it's like to rent up here because I've never rented anywhere ... [my sister] it was a poky wee place she was renting but she said it's extortionate.

By contrast, owner occupation had been considered and was an aspiration. However, buying a property was believed to be unattainable at present. The rejection of the tenure was largely because the young people were dependent on benefit income or working only a few hours each week:

I haven't got the finances to buy a house. I haven't – because I'm not working I'm not bringing in a wage every week. I wouldn't be able to buy a house on the money what I get off the social.

While it is possible (though by no means straightforward) for disabled people to buy a house using benefit income (King, 2000), the young people were not aware that this was even an outside possibility. Yet, if more people do not go down this route, it will continue to be difficult.

Location

Moving to a house that was reasonably near to the parental home was important for most of the aspiring leavers. They saw a continuing relationship with parents as very important, both emotionally and for practical support:

I would need to stay close to mum and dad because I don't want to be completely independent, but a bit more.

As discussed above, many liked the neighbourhood where they lived with parents and they wanted to stay there. Those who lived in the rural area generally wanted to stay in the same centre of population, or move to the next nearest larger centre. Urban dwellers were prepared to think about moving a little further – perhaps a bus ride away from the parental home. Just two wanted to move completely away from the parental neighbourhood, in both cases to different areas of Scotland. Neither family was supportive of a long distance move:

I do prefer the East coast, but I know what my mum would say – she doesn't want me to go that far. She said that it wouldn't be easy for the rest of the family to visit and that, and she says that I wouldn't be able to cope.

A quiet, safe neighbourhood was also important. None of the aspiring leavers had a driving licence, although several expressed a wish to learn to drive. This meant that easy access to facilities and leisure opportunities was required.

Design

Everyone wanted to live in a self-contained home alone, or with a friend or a partner. No one wanted to live in shared supported accommodation. Many expressed a preference for a house rather than a flat. This is similar to the teenagers whose aspirations were reported in the Homepoint (1995) study.

Only one of the aspiring leavers was seeking wheelchair-accessible housing, although several expressed a preference for housing that did not have external steps or internal stairs. This was because of their mobility or respiration problems.

The need for an extra bedroom for a carer to live in or stay in occasionally was repeatedly referred to. The young people also wanted space for guests; they referred in particular to visits by their younger siblings.

Carl aspired to move to a two-bedroom house near to his parental home. He had identified a new housing association development several streets away, which he thought would be ideal. He preferred not to live in a flat, partly because stairs and dust aggravate his condition and partly because he would be frightened to live in a home with communal access. Although Carl wanted to live alone, and was looking forward to the privacy his own home would give him, it was important that he had an extra bedroom in case he had a period of illness and needed a member of his family to stay with him. He did not like the thought of depending on non-family carers.

Types of support needed

Most believed that they would need support of some kind to enable them to live away from the parental home. The extent of this perceived support need depended on both their existing skills and capabilities and also on the confidence that the individual had in themselves. Four of the aspiring leavers had already lived away from the parental home and so had a clearer idea of the help they would need. The remainder estimated the help they would need, using the help parents already provided as a baseline. Reported support needs ranged from 24/7 to daily visits and ad hoc help in

response to particular events. Many anticipated that their support needs would decline over time as they became more practised at independent living:

It will take a bit of getting used to at the beginning but I would gradually get there.

One of the main reasons for the aspiration to remain close to the parental home was the assumption that parents would continue to provide care and support. For those with learning difficulties in particular, parents were the preferred source of support once they had left the parental home.

Other pre-existing sources of support were expected to be important once the aspiring leaver had made their move. Interviewees with a learning difficulty were all in contact with a training provider or specialist employment agency and trusted that their key workers in these agencies would provide support in the future. Issues that they thought they would seek help with included bills and paperwork, money management and shopping. The support that would be sought did not always fit agencies' remits, as a few young people recognised:

I don't know if that's their job or not? I don't know. I mean, since I've worked with [employment project staff], they've always helped me out with filling in forms, doing bits and pieces ... They've helped me quite a lot in here.

Two of the three aspiring leavers with a physical/sensory impairment had no contact with formal support services. The other was funding daily visits by home care staff through Independent Living Fund money. This support would follow her when she left her parental home. No one anticipated that they would access new sources of support when they left their parents' home.

Actions taken

The aspiring leavers fall into two groups: those who had acted to find alternative housing and those who were expressing a desire to leave but were unsure how to access independent housing. The latter group had taken no steps because they did not know what to do or were being discouraged by parents.

Forming and voicing aspirations

One of the nine aspiring leavers had not discussed their housing aspiration with either their parents or care professionals prior to interview. This is termed 'private aspiration'. Eight had talked to their parents about future housing. This is termed 'privately voiced aspiration'. Seven had talked to care professionals, including college staff, key workers at support agencies, social workers and occupational therapists. This is termed 'aspiration voiced to professional'. Only one had in any way had contact with a specialist housing advice service about their aspiration and this contact had been made by his mother.

Two patterns were identified. In the first, the young person formed the private aspiration to leave, discussed this with family, then with care professionals. Those with parental and professional support had then taken action to seek housing. In the second, the care professional asked whether the aspiration to leave was present and encouraged the young person to consider moving on. The young person then discussed the issue with parents and, if they did aspire to leave, voiced that aspiration back to the original care professional who supported action to seek housing.

In this small sample, there was no indication which factors might influence whether the young person initially formed a private aspiration or was encouraged by professionals. No examples were found where parents raised the notion. Awareness of other young people leaving the parental home – disabled peers, non-disabled peers and siblings – appeared to support the aspiration to leave.

Pursuing aspirations

Six aspiring leavers had applied to one or more social housing providers. They had all relied on the guidance of parents and care professionals to find out about potential sources of housing providers and to make the application. There was some surprise about the number of social housing providers and the difficulty of navigating through what might be available.

Perhaps to make sense of the task, most had restricted their consideration to one or two potential providers. This strategy has the effect of reducing the likelihood of obtaining housing:

There was other ones as well as the [chosen housing association] I could have tried but I picked [chosen housing association]. Maybe I could go back to the other ones.

Others tried a scattergun approach, making applications to all known housing providers in the area:

I'm on a few waiting lists. There's a lot of forms to fill out ... I think we're applying for [local authority] and these various housing associations. As many as you can to get a house.

Whether single or multiple applications were made appeared to depend on the advice of parents. It is not known what influenced parents to select either strategy.

Most knew that, having made the application, they could expect to wait before receiving an offer. Few knew the likely length of that wait. They did not understand how applicants were prioritised or how housing providers decided who would be offered a property. They did not know that housing providers apply criteria for assessing the size and type of property that will be offered. They had not asked housing providers or other professionals these questions and it seems that explanations had not been offered, were misunderstood or had been forgotten. Sometimes applicants had expectations

that were unlikely to be met by social housing providers. Others were resigned to waiting:

I was in there a few weeks ago asking [housing association] how long I was on the list. I have to say, I'm down at the bottom. So maybe when you're as far down as that you've got a long, long wait to get a house.

Most had made some preparation for a new home. These included saving money, creating a 'bottom drawer', obtaining furniture and developing skills for independent living. For those with a learning difficulty, college courses that focused on nutrition, cooking and money management were an important source of confidence building and skills development, which they believed had prepared them for leaving the parental home. There was an apparent gender split in the preparations made for leaving. Only women referred to buying furniture, pots and pans, linen, etc. or being given such items by friends and relatives. Men appeared to have made fewer preparations for creating a new home.

Few expressed any real idea about the costs of living away from their family. This may be because they were young and those who had always lived with parents did not have experience of the kinds of costs that householders incur. It may also link to the fact that the group are largely benefit dependent and could expect to have their ongoing housing costs met in full by housing benefit.

Most believed that social renting was the cheapest housing option available to them. However, they did not refer to housing attributes that may affect the rent charge, nor did they seem to understand the different rents charged by different social housing providers. Private renting was thought to be more expensive, but, again, aspiring leavers did not have a clear idea about costs.

Two had received offers of housing that they had rejected. Their stated reasons for rejecting the offer related to location and to features of the

property such as stairs, number of rooms and size. It is not clear whether the application procedure had not enabled adequate specification of their needs or whether the allocation procedure had resulted in offers of properties that were inherently unsuitable. There was some indication that the two young people were unsure about leaving the parental home when the offers were made:

I've been offered houses and I just turned them down. I don't know why. I just turn them down ... I will move but it's just I have to think about it first before I want to move.

Those who had rejected offers noted that it was difficult to view an empty house and imagine what it might be like furnished:

I'm all confused. I don't like going into houses without furniture.

This was also raised by one person who had recently moved into his first independent flat. Unfurnished houses are not attractive prospects for novice house hunters. This may be particularly the case for people with a learning difficulty searching for their first home.

Not pursuing aspirations

Three of the nine aspiring leavers had, at the time of interview, taken no steps to pursue a home of their own. They were a disparate group, as their stories, below, illustrate.

Cathy had discussed her desire to leave her parental home with her parents and with care professionals. The response of both was to discourage her. She was told that she must wait for five years before she could apply to a social housing provider for a house of her own. Cathy was frustrated but believed that she had no other choice than to continue living with her parents.

Geoff had previously lived in shared supported accommodation and returned to live with his parents over a year ago. He wanted to move closer to the employment project that he attended in the neighbouring town. He had not yet discussed this aspiration with anyone but expected to talk to his mother in the near future.

Isabel was single but wanted to live with a boyfriend in their own home. No one had ever asked her about her housing aspiration and she had not talked to anyone. Isabel was shy and did not think she would voice her aspiration unless she was asked how she felt.

Summary

This chapter has shown that those who wanted to leave their parental home were generally positive about their housing. The desire to leave was not about dissatisfaction with housing per se. Rather, it was linked to tensions within family relationships (push factors) and to how young people imagined life away from their parental home would be (pull factors).

A distinction has been made between aspirations, expectations and preferences, and it was noted that both expressed desire and actions were shaped by beliefs about housing. There was a reliance on parents and care professionals to provide information and guidance, and this was, on occasion, misleading. Young disabled people were not aware of expert housing advice agencies.

The following chapter considers the views of young people who lived in the parental home but did not want to leave.

4 Young people not aspiring to leave the parental home

This chapter is based on interviews with young disabled people who expressed a preference to stay in the parental home, or were ambivalent or unclear about their future housing preferences.

Eleven interviews were conducted with young people expressing these preferences. Of these, three had a physical/sensory impairment, six had a learning difficulty and two had both. They ranged from age 18 to 28. None had ever lived away from the parental home.

Satisfaction with current housing

Satisfaction with current housing was related to location, property features and property contents. Issues of independence did not feature in these interviews, other than in occasional mentions of having their own bedroom. Tenure did not feature at all. This group, like the aspiring leavers, often did not know the tenure of their parents' home and they did not consider it important.

Location

For some, the location of their parents' home was simply the place where they belonged. They had always lived there and knew their neighbours. They liked being known in the area and could not imagine living elsewhere. Where they lived was a part of who they were:

I'm used to [village] so I don't know about anywhere else.

Living in a quiet, safe area with good neighbours was important to the young people:

It's one of the best areas round this bit ... The neighbours. They don't bother you and there's no vandalism really round here or anything.

Feeling safe or unsafe in the area emerged as an important aspect of satisfaction with housing. Two had recently moved with their family from difficult

neighbourhoods where they had been witness to and victims of crime:

Alcoholics, drug dealers, rapists, people peeing in the front gate ... before we moved I got jumped. I was attacked.

Both said that they felt liberated in their new area, away from crime, anti-social behaviour and bullying:

Being getting to go out everyday and not being called muppet and spazzy.

Others continued to live in difficult areas. Some were frightened while others claimed to be inured to what they saw:

Sometimes people fight about here. That's sometimes. But it's sometimes quiet. I'm no' scared to see it.

Less pressing dissatisfaction with the neighbourhood related to young people feeling that there was little to do locally. Either this was about a lack of facilities or not having local friends. Many reported spending most of their free time inside the house, alone or with family. Few spent time with friends in the local area. Staying in was not linked by the young people to feeling unsafe. Rather, it was because the neighbourhood had little to offer:

There's a shop and the beach. I don't go there very much. Mainly at home either collecting or playing on the computer.

Property features

Compared to aspiring leavers, this group focused far more on accessible and disabling design. Several noted particular features of the house or adaptations that helped them. Everyone who had difficulties with stairs had lifts installed or lived in housing on one level. Only one had outside steps that caused a problem, although this had been

partly alleviated by handrails. Adaptations to bathrooms were highlighted by a number of the young people:

They put a walk-in shower in cos I cannae get in an' out the bath ... It is easier for me. I've got a chair put in the shower as well cos I can go for tae have a shower an' sit in the chair.

Not everyone had all of the adaptations that they would like in their parents' home. One was in the process of having a hoist installed; another had been refused a hoist by an occupational therapist. Two wheelchair users had particular difficulties in their parents' house: one got around on her knees because the house was not accessible; another used his wheelchair, but doorways were too narrow and turning space inadequate. Both had injured themselves because the design of their home was not appropriate. Others were restricted in how they could use their parents' home by its design. For example, two very short women could not comfortably use the kitchen.

Property features also more generally formed part of the satisfaction with housing. Those whose siblings also lived in the parental home almost all wanted a larger house with more rooms. Having plenty of space was important to everyone:

Very comfortable. It's very spacious even though we've got lots of stuff, so there's quite a bit of mess.

Having moved into a property with a main door, rather than a communal entrance to the flat, was a source of some pride for one young man:

My ma always wanted a back an' front door. She wanted a house wi' stairs in it. ... Aye. Liked the houses wi' back an' front doors were nice.

This reference to parents' views was typical in these interviews. The young people had formed less definite opinions about housing than those in the other groups.

Contents

There was, though, definite opinion about the contents of the house, in particular about consumer goods and audio-visual equipment. For many in this group, the best thing about their housing was the television, stereo or computer. As noted earlier, this group spent the majority of their time inside the house, so sources of entertainment were important:

Watching the football ... That's about it. ... And eating the food.

Reasons for staying

Most expressed several reasons for staying in the parental home. No one reason predominated. For some, the aspiration to stay appeared to be a positive choice. For others, staying with parents was the default position – the aspiration to leave had not formed:

I've no really thought about havin' a place o' my own.

Relationships with family were an important reason for choosing to stay. This was primarily expressed as affection for parents, but there was also reference to siblings and family pets. The home was the site of important relationships and living together reinforced bonds:

There's nothing I don't like living there. I love living there. It's just I'm near the people I care about – my mum, my stepdad and my brothers and sisters ... It's nice to be with the family.

Family also provided company and entertainment. These young people enjoyed spending time with their parents. Although there was some reference to family disagreements, this was markedly less than the tensions described by aspiring leavers. Whether the quality of family relationships was different between the two groups or whether aspiring leavers placed greater emphasis on tensions is not known.

Nathan lived with his mother and siblings in a local authority flat. The building was due to be demolished in the next few years, so he had thought about where he might live in the future. But he had not formed aspirations to live separately from his family. When his mother is rehoused he will move with her. He hoped this would be in a nice, quiet, not posh neighbourhood and that the next house would not be damp. Nathan really enjoyed the company of his family and could not imagine living away from them.

Oliver lived with his parents and brother. He attended college four days a week and spent the rest of the time with his family. He had no friends and participated in no activities outside college. Oliver's parents did not work so he was never alone in the house. He saw this as a positive thing as he liked being with people rather than being alone.

Parents were an important source of care and support related to the young person's impairment. For some, this had been most needed following illness or operations; for others, it was an ongoing need. The young people valued the care provided by their family and could not imagine what would happen if parents were not available to provide that support:

I can't imagine livin' without my mum. I can't imagine – what I would do if she's no there, I don't know what I'll do ... I don't care how old I'm are. If I take no well an' my mum's not there, I can't imagine it.

Other reasons given for choosing to stay living in the parental home included satisfaction with home comforts and an awareness that, by living with parents, they were living cheaply. Some

expressed fear of alternative living arrangements and did not believe they would be able to cope living away from the parental home. No one in this group was in receipt of care services in their parents' home and they did not know that they could have support to live away from their family:

I can't do everything myself. I'm not used to doing the ordinary things like arranging the plans, like paying the bills, keeping track of everything ... I'd prefer living with my mum and dad.

Finally, a few were choosing to stay because of the effect that they thought leaving would have on remaining family members. They said that they were needed by their family – to provide company, care or practical domestic help. Two believed that being disabled had helped their family access better housing, by increasing their points. One was concerned that her parents would be evicted from the adapted parental home if she left:

If I turn round and say 'I don't like it, I don't want it'. But then they could turn round and say, well they could say to my mum and dad 'you will have to get another house'.

Aspirations for the future

Although the young people reported in this chapter expected to stay in the parental home for the foreseeable future, only four expected to live there forever. The remainder expected to move eventually. The timescale for this was uncertain and the conditions for doing so unclear.

No one had taken steps to investigate their housing options, voiced an aspiration to parents or professionals, or made applications in preparation for a future move. Just one had been asked by a professional about future housing and no one had been asked by parents. The young people did not know that there might be a long wait after applying for a house before a property was offered to them.

Summary

The young people whose views are reported in this chapter had the least well developed ideas about their future. The desire not to leave was not related to satisfaction with housing. Rather, it was about the relationship with family. The family provided love, company, care and support, which the young

people thought they would have to manage without if they left the parental home. These young people were also conscious of their own important contributions to the household, providing company and practical help to family members.

Parents' views about their adult child's future are reported in the next chapter.

5 Parents' perspectives

This chapter is based on interviews with parents who had a young disabled adult living with them. Thirteen interviews were conducted. Two of the interviewees were parents of young adults with a physical/sensory impairment and 11 were parents of adults with a learning difficulty, many of who also had a physical/sensory impairment.

The majority of parents provided personal care to their son/daughter as well as physical therapy and other assistance. These parents were experienced in supporting their child and in dealing with the various agencies that impact on the lives of disabled children and adults.

Current housing

The tenures of parents were evenly split, with seven owner occupiers and six living in social rented housing. Two had moved house in response to the particular housing needs of the disabled son/daughter and five had adapted their homes. Adaptations included: extensions, ramps, hoists; installation of showers, toilets and aids for their use; changes to garden design; and reorganising living space to use a downstairs room as a bedroom. Parents reported that the need for adaptations had changed as their child grew older. Partly this was because of the child's increasing weight and size, and partly because of the child's growing need for privacy and independence.

The majority who had adapted their homes had received guidance from occupational therapy staff and many had had the adaptations funded in whole or in part. Most felt that their housing was now suitable for the needs of the whole family, although a few had further adaptations planned.

Current support

All the parents had contact with non-family sources of support, including carers' groups and social work services. Carers' groups were highly valued for providing emotional support, practical help and

information on what services might be available. Parents connected to carers' groups saw them as reliable sources of advice and guidance. Social workers were also valued sources of advice, although the relationship with social work services was not always easy. Three families reported that there had been difficulties when their son/daughter made the transition from children's services.

Eight of the 13 young adults were attending day services (resource centres and employment/training projects), four were at school or college and one had no external structured activity. Parents were in touch with key staff in these services and said that they had sought advice on wider issues from these sources.

Four adult children attended respite services, two parents had rejected offers of respite and two had unsuccessfully sought respite. Three were in receipt of home care services and one had rejected the offer of home care. Parents did not report seeking advice from respite or home care staff.

No parent mentioned using health service staff for anything other than medical needs. Health services were not seen as places that provided signposts to other potentially useful agencies.

Housing expectations and preferences

The main focus of interviews with parents was their hopes and fears for their adult child's future. With respect to future housing, the parents fell into three groups. Again, there was a distinction between expectation, preference and aspiration, although parents mostly restricted themselves to discussing expectation and preference.

- *Active supporters of independent housing:* had acted to support their adult child to seek alternative living arrangements. They expected and preferred that their adult child would live away from the parental home in the future.

- *Passive supporters of independent housing:* were willing to support their adult child to leave the parental home in the future and expected this to happen. Some were positive about this future move, while others preferred that their son/daughter lived in the parental home for life.
- *Rejecters of independent housing:* preferred and expected their adult child to live in the parental home for life.

Where expectations and preference differed, this was because parents believed what they wanted for their son/daughter could not be achieved. The tensions between expectation and preference arose when parents became aware that they would not always be able to care, when their adult child expressed their own preference to leave and when care professionals suggested that parents consider the future. Where the adult child had expressed a preference to leave, parents expected that the child would leave.

Their expectation for whether their child would leave home shows no apparent connection with either the child's age or with the level of care and support needed. Table 2 shows the distribution of parental expectations according to their son/daughter's age. No one with a child under age 18 was actively supporting a move and no one with a child over 21 was rejecting the possibility of a move. Parents were evenly split between those whose preference was for their child to live with parents for life (6) and those whose preference was

for their child to move away in the future (7).

Apart from parents who had taken action to support their adult child to leave home, most were unclear about the housing and care options available to young disabled adults (several requested information from the researcher). Some knew of local sheltered housing schemes or specialist housing associations. Others saw the council's housing department as the best route. As with young people, no one was considering anything other than social rented housing as an option. Not all knew that support could be provided to an individual in their own home – they only knew about supported group housing.

Several had considered adapting their property so that their son or daughter could live more independently but still within the parental home. One family had thought seriously about converting the garage and another believed that their home could be partitioned into two separate but interconnected residences. The families considering such changes were all owner occupiers.

Parents were asked to assess the level of support that their child needed. These have been grouped into those who needed:

- full-time care and support, with waking or sleeping night-time cover (termed 24/7)
- support on a daily but not full-time basis (daily)
- support on a less frequent basis, ranging from weekly checks to several times a week (popping in).

Table 2 Housing expectations according to age of adult child

	16–18	19–21	22–25	26+
Active supporter	–	2	1	–
Passive supporter – future proponent	3	1	–	–
Passive supporter – reluctant	1	–	2	1
Rejecter	1	1	–	–

Only one parent, whose daughter had just turned 16, could not assess the level of support needed by her child. No one thought their child could manage with no support.

Table 3 shows the distribution of parental expectations for the future according to their assessment of their adult child's support needs. It is notable that the rejecters believed their adult child needed the highest level of care, but other parents who believed that their adult child required similar levels of care did see a future for them away from the parental home. However, the majority of parents whose adult child required 24/7 care said that they would *prefer* their son/ daughter to live with them for life.

Parents' assessment of support needs is not necessarily a good predictor of the type and level of support that the young adult would need, particularly as people often develop capacity once they live independently. However, the focus here is on parental beliefs, as their beliefs form the basis of their preferences and expectations. Furthermore, the expertise of parents should be respected. Their judgements are based on a relationship with their

adult child, knowledge of their successes and difficulties, and long experience of providing care and support to that individual. It cannot be assumed that professionals, without this knowledge and experience, could predict support needs any more accurately.

There was some association between the kinds of living situation that parents thought would best suit their adult child and the level of care and support that they thought was needed (see Table 4).

No one who thought that their son/ daughter needed 24-hour support thought that living alone would suit them best. Shared living – with family, friends or in a group – was believed to offer a better quality of life. One mother argued that living alone with 24-hour care would be an observed life and that, paradoxically, her daughter could have more privacy living with others. Parents talked about the need for company and stimulation, and thought that living alone with care staff would be lonely:

It would be terrible for [her] to be living in a house on her own with just staff coming in ... she'd be bored with a small group of people I think, cos she's limited in what she can do and she loves to see other people.

Table 3 Housing expectations according to adult child's support needs

	24/7	Daily	Popping in	Don't know
Active supporter	1	1	1	–
Passive supporter – future proponent	–	2	1	1
Passive supporter – reluctant	4	–	–	–
Rejecter	2	–	–	–

Table 4 Household type expectations according to adult child's support needs

	24/7	Daily	Popping in	Don't know
With family	2	–	–	–
Alone ¹	–	2	1	–
With friends ¹	1	1	1	–
Group living ²	3	–	1	–
Don't know	1	–	–	1

Notes:

1 With individual support as necessary.

2 Used here to mean living in a shared environment with others not necessarily chosen by the individual.

Parents of young adults needing 24/7 care also saw living with others as providing protection. This was in part protection from abuse, with the sense that the young adult would be more vulnerable living alone. It also stemmed from parents' experiences with unreliable care staff:

If she lived in a kind of flat and was waiting on carers coming in on shift – four hours here, four hours there – you don't know whether they're going to be held up ... I don't know if she'd be left on her own till they could get there.

The parents who hoped to see their son/daughter move in with friends all had specific individuals in mind who their adult child had identified as a potential housemate. In each case, the son/daughter had expressed a preference to live with their friend(s). Several parents expressed the hope that their son or daughter would live with a partner in the future but no one saw this as a first move from the parental home.

Perhaps the only unexpected situation is the mother who believed her daughter needed only intermittent support – popping in – but expressed a preference for group living. However, on closer examination this seems to be because of ignorance of alternatives from which to choose:

That was the only thing the social worker had ever mentioned where she would have a room of her own and she would get help with meals and things and have a communal living room and stuff. Aye. She could live there.

The kind of area where their adult child would live in future was important to parents. Of those currently living in very rural areas all but one felt that a move to a centre of population would be preferable. They felt that living in a town or city would offer their adult child more opportunities and greater independence:

She'll be in town for a start, which means she can actually go out and do things without me having to

take her and collect her – that will probably be the biggest thing for her.

The exception was a mother who believed that living in a very rural community offered her son more freedom than he could have in a more populous area. In the place where he grew up he was known by all the neighbours, safe and did not need to be restricted. She felt that traffic and 'stranger danger' in a more urban environment would require greater limitations on his activities.

All parents – rural and urban dwellers – emphasised the importance of a safe, pleasant neighbourhood for their adult child:

A pleasant ambience to the place ...[she] likes shopping, she likes lights, she likes music, she likes noisy things.

There were fears that disabled people needing social housing are often offered properties in the worst areas. Parents expressed a determination to protect their adult children from such offers:

There are needles lying about. There are street fights, there's vendettas, there's dreadful stabbings. It's the only place in town where there's trouble – and that's where they want to put them ... over my dead body. He ain't going there.

Active supporters

Parents termed active supporters had taken steps to help their adult child find alternative accommodation. Three parents have been termed active supporters. They saw leaving the parental home as a normal part of growing up, and compared their disabled child's life to that of siblings and peers. They wanted their disabled son or daughter to achieve what non-disabled young people do. These parents were playing an active role in helping their son/daughter to leave the parental home, for example making applications for social rented housing or pursuing funding for a care package.

All were providing high levels of care and support to their adult child. For one mother, her own advancing ill health and the emotional stresses of caring formed an important additional motivation for supporting her son to move. Her admission to hospital had acted as a catalyst for looking into alternative housing. The remaining two parents, while able to continue to care, were looking forward to a time when they no longer had to. They wanted to develop a different kind of relationship with their adult child and were looking forward to developing interests of their own.

The parents were at different stages in their search for independent housing on their adult child's behalf. Debbie's daughter will move house in the next few months, Caroline has applied on her son's behalf to several social housing providers and Molly has obtained application forms. They had used a variety of sources of advice in finding out about their adult child's options, including their child's social worker, disabled people's organisations, social housing providers, housing advice agencies and other parents. More support in the search and application process would have been welcome:

I think he should have more points. But I didn't have anybody to help me fill it in ... I didn't fill the form in very well. I know I didn't.

Molly had sought information on housing options from her daughter's social worker who provided her with an application form for a specialist housing association. However, she had been unable to complete the application. Both Molly and the housing association wanted to include her daughter in decisions, but she was unable to understand the concept of time or plan for the future:

[If] I had to say to her, 'look, there's people coming to see about housing for ye, but it's a long long time in the future' – she would go ballistic. She would think I was wanting rid of her.

Passive supporters

Parents termed passive supporters expected their son/daughter to leave home in the future but had taken no steps towards this. Eight parents were passive supporters.

Half were future proponents of a move. Their adult children were teenagers and parents believed that this was too young to move away. Like the active supporters, future proponents saw leaving the parental home as a normal, desirable part of growing up. It was likely that future proponents would become active supporters when their adult child reached the age where peers and siblings were moving on:

You've not really succeeded as a parent if your child is still living with you. It's the whole point, isn't it? You're supposed to get them up to a certain stage where they move on and have their own life.

Half were reluctant supporters of a future move. They preferred that their adult child would continue to live in the parental home, but expected that this would not be possible forever. These parents may have been rejecters in the past but circumstance had changed. In contrast to active supporters and future proponents, reluctant supporters saw their son/daughter as different from peers. They focused on what their adult child could not do and placed greater emphasis on the need to protect their son/daughter.

Amita was finding it increasingly difficult to cope with her daughter's care needs. She would prefer that her daughter continued to be cared for within the family, but recognised that this was not possible as her daughter's siblings would not take on the responsibility. Amita was Muslim and required services that were culturally appropriate, but she did not trust care agencies to deliver these:

continued

I can't decide myself what to do ... I think all her life she needs somebody with her ... The more I'm getting older, the more hard for me to keep her.

Rejecters

Two parents have been termed rejecters. They expected their disabled son/daughter to live at home forever and anticipated that extended family or siblings would continue to care after the parents' death. Both were parents of young men who required 24/7 care.

For both families, the duty of care was strongly grounded in religious principle. One family rejected any support from external agencies following a series of bad experiences with care staff. The other had only recently accessed social work support for their son, having spent several years after he left school with no support.

Both argued that their sons could never cope outside the parental home and expressed a strong fear of abuse, seeing their sons as particularly vulnerable. These parents wanted to protect their sons from the behaviour of other people with learning difficulties, from inept or unkind care staff and from an unwelcoming wider community.

They also wanted to protect their sons from themselves. They felt that their sons were not competent to take decisions about their future. The parents felt that decisions about their sons' lives must always lie with them as parents. They said that they would not welcome professionals raising the question of their adult child leaving home. Discussion about the future with their adult children was ruled out as this would raise unrealistic expectations or create fears.

Harriet wanted her son to live in the family home forever. She had a strong sense of family duty and had refused offers of respite or home helps. Harriet had a confrontational relationship with formal support services who she felt did not respect her expertise as a parent of a disabled person. She planned that her son would live with his sister or an aunt after her death. She did not think that her son should be asked what he would want:

[He] will be here with me and then hopefully, when we go, my sisters will take him. I don't want him going into a home ... doesnae know what he wants. Now, ye could say to [him] 'do ye want to move into a house on yer own?' But [he] would turn round and say 'aye'. Of course he would.

Summary

This chapter has shown that the majority of the parents expected their adult child to move out of the parental home in the future. However, the degree of enthusiasm that they had for such an event differed. Those most committed to a move – termed active supporters and future proponents – saw leaving home as a normal and desirable aspect of adult life. For them, housing and care were issues that may be considered separately. Those most opposed to a move – termed rejecters and reluctant supporters – saw family care as the best possible for their adult child and had often had experiences that damaged their trust in formal service provision. For them, housing and care were inextricably linked and family care was the best for their adult child.

Parents acknowledged that they were largely ignorant of the housing options available to their adult child. Those who had discussed future housing with professionals were not much clearer about the range of potential options or what actions to take to help their son/daughter to access housing.

6 Conclusions

In the review of literature presented in Chapter 1, it was noted that little is known about the housing experiences and aspirations of young disabled adults. Throughout this report, it has been shown that their experiences and aspirations do not really differ from their non-disabled peers. Most young disabled people wanted to live away from the parental home as adults. The routes they took to do so did not differ from routes taken by other young people. What they said was important about their housing was similar to what has been found in wider studies of housing satisfaction.

This concluding chapter reviews these similarities and identifies where this research has found differences between disabled and non-disabled young people. Finally, it offers suggestions for action, focusing on the need for information provision. The intention is to support young disabled people to achieve their realistic housing aspirations in a reasonable timeframe.

Similarities and differences

The young people who participated in this study did not diverge from the models that Ford and Jones had identified. Those who had left their parental home – ten living independently and four who had left and returned – followed chaotic, student or planned pathways (Ford *et al.*, 2002). One-person, peer and surrogate households were found (Jones, 2000), where surrogate households included accommodation dependent on care as well as on study or employment. The young disabled people did generally see these as *intermediate* household types and aspired to create a ‘family of destination’ in the future and move to ‘family’ housing. There were indications that their ideal home would be like that described by Scottish teenagers: owner-occupied, detached and with a garden (Homepoint, 1995).

Various aspects of housing were identified that affected satisfaction. These were: location, property features, tenure, property contents and

independence. Tenure did not emerge as an important issue for those living with parents; property contents were not significant for those living away from parents. It was noted that independence could be achieved while living within the parental home, but most of the young people felt that they were or would be *more* independent living away from parents. Living away was felt to signify adult status.

The importance of feeling safe in the home and local neighbourhood emerged very strongly as a theme. Those interviewed had often witnessed or been victims of violent crime. Their stories confirmed previous research findings about the extent to which disabled people are threatened in and around their homes (Williams, 1995). It is known that young people, particularly young males, are most at risk of being a victim of violent crime (Scottish Executive, 2000b).

Suggestions for action

Young people and parents indicated that a lack of information about local housing options, not knowing who could help and not having the opportunity to voice aspirations were the main barriers to leaving the parental home. Other issues – such as whether there is appropriately designed affordable housing in the right location and whether support is available – do matter and have been comprehensively covered in other studies of disabled people and housing. These other issues must be resolved. Here, the focus is on how young people and parents can be better informed about housing and helped to seek out what is needed.

Young disabled people did not know a great deal about the housing system, about the possible advantages and disadvantages of different tenures, or about what was realistically attainable in what timescale. Their lack of knowledge and misunderstandings related directly to the preferences and aspirations they expressed, and the actions they had taken. Previous research on advice

services suggests that four stages of information and support need to be addressed (Dean *et al.*, 1996). These are:

- *awareness* of what is possible
- *information* about all local options
- *advice* about what might best suit an individual and how this can be accessed
- *advocacy* to support particular individuals where there is conflict between them and funders, providers or parents.

Awareness

It has been apparent throughout this report that aspirations are limited by what people know to be possible. Seeing peers or older disabled people living in independent households is one route by which awareness of possibilities might be raised. Schools and colleges also have a role to play here, perhaps in the citizenship strand of the curriculum.

In Chapter 1, it was noted that no single agency or professional body takes lead responsibility for supporting young disabled people to identify their housing choices and access the most appropriate housing for them. The various assessments and planning tools could be useful starting points for ensuring that housing aspirations are taken into account. These assessments should always consider housing – even if the current situation is apparently stable and happy. This will both encourage professionals, parents and individuals to plan for the future, and ensure that there are opportunities to develop and voice aspirations that can then be met.

Information

There are a range of local and national sources of information on housing options, but young people and parents found it difficult to ascertain what is available.

Local authorities in Scotland have a statutory duty to provide housing information and advice

services. The Scottish Executive is reviewing what these should comprise with respect to particular groups such as asylum seekers. The Executive could usefully extend this review to disabled people.

Information about local housing options needs to:

- be available before the child is of an age to leave and be repeated regularly
- assist the individual to think about what represents good housing for them
- explain how to find out about local options
- indicate which agencies would be able to answer questions, provide support and advocate if required
- consider all living options – staying with parents, living alone, living with a partner, sharing with friends and group living
- cover all tenure options – mainstream and specialist social housing providers, private renting and owner occupation.

Because young people relied on parents for information and advice when leaving home, it is important that the information should reach parents as well as their adult children. Parents in this study were not well informed about the range of choices that their son/ daughter could have.

Advice

As noted above, young people relied most heavily on parents for advice on housing. They also turned to care professionals in different agencies including social workers and educational and day service staff. Parents sought information and took advice from other parent carers and from social workers. At the point of applying to particular social housing providers, housing staff were consulted. Generic housing advice services and disabled persons' housing services were not used by the

interviewees in this sample. There was little awareness of their existence or of the help that they could provide.

This implies that housing advice experts should be seeking to raise their profile with young disabled people and their supporters. It also implies that non-housing professionals in a range of agencies should be encouraged to develop greater housing expertise, including knowledge of when to refer housing problems to housing advice agencies. However, profile raising will be problematic if housing experts do not have the resources to meet increased demand for advice.

Advocacy

No one in this study had used independent advocacy services to help them leave the parental home or move to better housing. No one reported any awareness of independent advocacy agencies. However, there was an indication that support services with other remits – such as employment projects – were informally advocating on their users' behalf. This study did not explore their housing expertise or their capacity to provide such help to their users.

Future directions

This research has offered important insights into the housing aspirations and experiences of young disabled people. By taking a broad and inclusive definition of who is disabled, it has highlighted some of the common barriers faced by young people regardless of the type and severity of their impairment. This approach has highlighted similarities between young disabled adults and their non-disabled peers in terms of what they want and how they begin their housing careers.

However, this study has indicated differences between the experiences of young adults with learning difficulties and those who have physical and sensory impairments. For example, fewer young people with learning difficulties had taken

the student pathway. There were also differences between those who could live with lower levels of support and those who needed 24-hour care in terms of what is aspired to and the routes to independent housing. There is therefore scope for further consideration of youth housing careers that investigates the interactions between specific types of impairment and housing.

Further, the design of this study has meant a concentration on young people who have lived with family. Disabled children and teenagers are more likely than their non-disabled peers to be 'looked after' outside a family environment. Young people who have lived in residential schools, local authority care, hospitals, residential/nursing homes or supported group housing may have particular insights and patterns of experience.

In this study, rurality did not appear to affect the experiences and aspirations of young disabled adults, but studies of non-disabled young people have shown a rural/urban effect. This implies that a closer look should be taken to see whether there is a similar effect for disabled young adults.

Questions also remain about how factors such as gender, ethnicity, educational attainment, and employment and income influence housing careers and about how these factors interact. There is the potential for the reanalysis of large scale datasets such as the Scottish Household Survey to begin to address some of these issues. Over the longer term, the deliberate inclusion of disabled people in studies of youth housing careers and of young people in studies of disability and housing are indicated. This will begin to replace some of the assumptions about young disabled people's housing experiences with some truths.

All research uncovers new areas to be explored and this final section has indicated areas that could usefully be addressed. This study has found young disabled people follow similar housing pathways to their non-disabled peers and they hold similar aspirations, although they sometimes have limited horizons. Knowing more about what affects

aspirations and experiences will assist the development of policy that supports young people to achieve the community care ideal of an independent life – whether this is as a tenant or as a home owner, living with a partner, children, friends, parents or alone.

Finally, for disabled young people – indeed, for everyone – this study has shown that housing means more than bricks and mortar. Housing is a

symbol of who we are and what we have achieved. It is a signifier of adulthood and a site of independence. The rhetoric of community care has for years supported the right of disabled people to live outside of institutional care or away from the parental home. Yet the evidence from this research suggests that much more is needed to inform and advise young disabled people of the options they have if this rhetoric is ever to be made real.

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Appendix

Research methods and sample characteristics

Interviews were conducted in three areas of Scotland: two cities and one rural local authority. Potential participants were contacted through local services in the three areas. Most organisations passed a letter to those who fitted the study's age criteria; a few chose to explain the study to their users face to face. A range of organisations were used, including housing providers, educational institutions and social care agencies.

Consent

Research with potentially vulnerable subjects can be contentious. There is a tension between the desire to enable people to make their own decisions and the desire to protect people when they may not be aware of the consequences of participating.

An opt-in system of consent was used. During initial telephone contact, the reason for the research was explained and the kinds of questions that would be asked were indicated. At the beginning of interviews, this process was repeated, with the added information that participants' words may be used in a book but no one would be able to identify

them. Everyone agreed to the use of a tape recorder.

In a small number of families, both the disabled young person and their parent were interviewed. This was always with the consent of the young person. Such participants were assured that their responses would not be compared and care was taken to maintain the confidentiality of each individual during the interview. These double interviews have not been identified in the report and details have been altered to prevent comparisons.

Sample characteristics

This was a qualitative study. Participants were not selected for particular characteristics, other than the study criteria: being disabled and between 18 and 35; or having a child who fitted those criteria.

Both physically disabled people and people with learning difficulties were included in the research. Those who participated included people with visual impairments, mobility impairments, epilepsy, restricted growth, autism, cerebral palsy

Table A1.1 Age and gender of young people interviewed

	16–18	19–21	22–24	25+	Total
Men	1	4	5	4	14
Women	2	3	5	6	16
Total	3	7	10	10	30

Table A1.2 Housing of young people interviewed, by age

	16–18	19–21	22–24	25+	Total
Living away from parents	–	1	5	4	10
Aspiring to leave parental home	1	2	2	4	9
Not aspiring to leave parental home	2	4	3	2	11
Total	3	7	10	10	30

Table A1.3 Age and gender of adult children of parents interviewed

	16–18	19–21	22–24	25+	Total
Men	2	3	–	1	6
Women	1	2	3	1	7
Total	3	5	3	2	13

and speech impairments. Of the 30 young people, 11 said they were physically disabled, 16 said they had a learning difficulty and three said they were both physically disabled and had a learning difficulty.

Of the 13 parents, two described their son/daughter as physically disabled, six as having a learning difficulty and five as both physically disabled and having a learning difficulty. Two fathers and 11 mothers were interviewed.

Efforts were made to include black and minority ethnic (BME) young adults and parents in the research through contacts with specialist organisations that support disabled people and carers from BME communities. In the event, only two carers from BME communities participated in the research. No young adults from BME communities chose to participate.

Interviews

Interviews lasted between 20 minutes and two hours. Typically, they were about an hour long. Interviews with young people who did not aspire to leave the parental home were shorter than interviews with other young people.

Questions were adapted to suit the individual's way of communicating, their concentration and the stories they had to tell. The basic research questions were simply outlined at the beginning of each interview. For interviews with young people, the topics covered were:

- satisfaction with current housing
- previous housing experiences
- preferences for future housing

- whether they had received advice and help on housing.

For interviews with parents, the topics covered were:

- feelings about the son/daughter leaving home
- parents' preferences for their son/daughter's future housing
- parents' understanding of their child's future housing preferences
- parents' knowledge of local housing options
- whether they had received advice and help on housing
- parents' advice for other parents with disabled children.

Several participants used communication aids during the interview. Two used Makaton sign language in addition to speech.

Analysis

Full transcripts were produced from audio tapes in all but one instance where notes were taken during the interview. The quality of these transcripts was variable: noisy environments, quietly spoken interviewees and the participation of people with speech impairments contributed to gaps in the record. In real-world research, this is inevitable.

Transcripts were read repeatedly searching for common themes and different experiences. As like groups emerged, these transcripts were read together and against those of other groups. The

intention has been to allow research participants to speak for themselves, with their stories emerging from the rich data collected.

The housing histories provided by interviewees with a learning difficulty require some caution. These interviewees found it more difficult to tell their story chronologically and the interpretation of

the author may be incorrect. Further, painful memories were uncovered for a few and the interviewee's comfort was always placed before the desire to learn more. However, no attempt was made in the research to confirm the housing history of interviewees with others. The intention was to hear the individual's voice.