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Research report 114

# The housing experiences of disabled people in Britain

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# Executive Summary

## Key findings

- Our qualitative research with disabled people demonstrates several key factors for successful independent living: accessibility features such as adapted kitchens and bathrooms; a feeling of safety and security; being in a good location with access to shops, transport and public services; support from friends and family; good neighbours; and freedom from harassment.
- When searching for accessible homes, common challenges faced by participants were: a lack of availability across all tenures; housing providers' and local authorities' failure to understand their needs and communicate properly; accessibility difficulties with housing application forms; frustration with allocation systems; and deterioration in mental wellbeing caused by the stress of living in unsuitable accommodation and facing an uncertain future.
- Although many participants were living in an accessible home at the time of interview, some had lived in unsuitable properties for long periods of time – in some cases, years. This was primarily because appropriate housing was either unavailable or unaffordable.
- Obtaining home adaptations often took a long time, and some participants found it challenging to acquire the changes they required. The interviews indicated that social housing tenants tended to find it easier than private tenants or homeowners to obtain adaptations. This is likely due to the support and assistance offered by housing associations.
- Well-managed local housing and support services, whether voluntary or statutory, had a positive impact on participants' housing outcomes. However, participants' experiences of these services varied significantly.
- Participants' financial resources, level of confidence and

communication skills played an important role in securing appropriate and adequate housing. Wealthier, more confident individuals had more success in navigating these services and acquiring the home they wanted.

- Finding appropriate, accessible housing helped transform participants' lives for the better. Positive consequences included improved health and wellbeing, and enhanced prospects for employment and study.
- Our evidence review (Appendix 1), supports the findings from the qualitative research about the disadvantages disabled people face in the housing market.

## About this report

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This report contains findings from two pieces of research undertaken in 2017 into the housing experiences of disabled people in Britain. The main piece of research involved in-depth interviews with 51 households containing disabled individuals in the Bristol area, Central Scotland and South Wales. Interviews were with disabled individuals or, if the disabled person was a child, their parent. Participants were identified by contacting housing and disability organisations, which excluded by definition those unknown to key agencies.

The 51 households covered a diverse range of characteristics, but were not intended to be representative of disabled people living in Britain today. We sampled areas in England, Scotland and Wales to examine if there were any reported differences based on the various local and national policy frameworks. The themes and main findings were broadly similar across the three geographic areas and no notable differences were found, but we remain cognisant of the limits to conclusions generated by small sample sizes.

The secondary piece of research involved a review of data from the Census of Population, separate national housing and house condition surveys, and academic and policy/practice literature published in the three years prior to the research. This review is summarised briefly below and in more detail in Chapter Two. Its main purposes are to set the scene for, and inform the development of, the qualitative research, and provide context for the interview findings. The evidence review is included in full in Appendix 1.

## Interview findings

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### The long road to an accessible home

Our research with disabled people and parents of disabled children found that their housing aspirations were often no different from those that might be expected of non-disabled people. In general, those interviewed valued safety and security, good transport links and friendly neighbours. However, other preferences emerged that related specifically to the participants' disabilities: for example, accessible kitchens and bathrooms were particularly sought after. Proximity to support networks was also important to those we interviewed, with many people stating that this had influenced their choice of housing location.

Many participants had eventually found housing that met their needs but some interviewees had spent long periods of time in unsuitable properties. Disabled people in the private and social rented sectors were more likely to have experienced poor housing than disabled homeowners. Although homeowners overall had more choice and control over their housing, many had experienced considerable difficulty purchasing accessible homes, particularly within an affordable price range. Several participants had had to decide whether or not to buy a particular property in a very short space of time. Also, the acquisition of an impairment had forced some participants to make sudden changes to their living arrangements.

Multiple participants stated that they had felt forced to accept inappropriate housing if it was the only option offered. These participants described becoming 'stuck'; the local authority no longer considered them to be in priority need. Several people with impaired mobility had moved from inadequate private rental accommodation to a succession of upper-floor council-run hostels or flats before finally obtaining the right accommodation.

The interviews uncovered a range of experiences that further demonstrated the impact of living in unsuitable housing. Inappropriate housing increased the risk of accidents, led to stress and ill-health and imposed costs on health services. Several people reported having falls or struggling with their breathing when climbing the stairs or walking a long distance to their car. Poor housing also had a significant impact on carers, who often reported stress and subsequent health problems. The poor, run-down condition of properties, a lack of social support, financial constraints and anti-social behaviour from neighbours were seen as particularly harmful to participants' sense of wellbeing. Such problems had often resulted in deterioration in

health. The added stress of trying to move house often increased these negative effects.

Most of the individuals in our sample were resourceful, articulate and felt that they had good negotiating skills. Despite this, they had generally had to battle for a long time to gain accessible housing. Individuals who do not have similar advantages are likely to face even greater challenges in finding adequate housing.

### **Installing home adaptations**

Many participants had carried out adaptations to their homes. Some adaptations were necessary to deal with current problems, and some were in anticipation of a disability becoming more severe. Participants reported diverse experiences of the process of obtaining adaptations. Many spoke positively of experiences with Care & Repair services (organisations that support older and disabled people to adapt their homes).

Housing associations tend to offer support with the process of applying for an adaptation, which meant that residents of social housing reported finding it easier to have adaptations installed than private tenants or homeowners. The interviews also indicated that private landlords are sometimes resistant to making changes because of the perceived inconvenience and expense, and homeowners often lack awareness of the support available. Despite comparable ease, the process of acquiring adaptations for social housing was described as lengthy, and participants often struggled to get the changes they needed.

### **The importance of local housing and support services**

Interviews across the three study areas revealed a mixed picture of housing services. Participants reported finding it difficult to find out who to contact and needing persistence to get results. Many remarked upon a difficult and lengthy process to obtain appropriate housing, describing how they had felt trapped in unsuitable housing with minimal chance of being able to relocate.

The coverage and quality of local services often had a significant impact on participants' housing outcomes. Access to appropriate social housing, clear choice-based lettings schemes, good quality advice and support, and the constructive involvement of other organisations (such as estate agents and letting agents) all positively contributed to participants' ability to find an accessible home. Participants who had accessed voluntary sector support and advocacy noted its significant

benefits, but participants also described the provision of this support as uneven and limited.

Participants' financial resources, level of confidence and communication skills influenced how successfully they were able to identify, and access, appropriate housing. Several of the people interviewed for this research were well-educated, articulate and confident. These advantages did not prevent them from struggling to find their way through complex services and obtaining appropriate housing.

### **The effects of independent living and appropriate housing**

For the people we interviewed, the ability to live independently was informed by several factors: adequate disability benefits, appropriate social care, self-directed support (SDS), and support from occupational therapists, assistive technologies and Care & Repair services.

Participants who had been rehoused into appropriate, accessible homes stated that they felt settled and, in many cases, reported improvements in their physical and mental health. Some participants cited reduced dependency on alcohol, and others reported taking up study and business development opportunities.

### **Case studies**

Most of the participants in our research had managed to find a resolution to their housing problems. However, they had needed to overcome considerable obstacles along the way, as the following cases highlight. More detailed case studies can be found at the end of Chapters Three, Four, and Five.

- Simon, a young man with autism, epilepsy, learning difficulties and little verbal communication, required housing with adequate space and specialist support workers who could ease his transition from living with his family. Simon was told by his social worker that he could not 'pick and choose' where he lived. The inadequacy of support offered by their local authority led Simon's family to consider re-mortgaging their house to buy Simon a flat, but he was finally offered a place in a housing association by the local authority.
- Several participants had struggled with stairs. Struan, a wheelchair user and home owner, had been unable to find an accessible, affordable bungalow in his local area. The affordable options for Struan were too small and had corridors too narrow for his wheelchair. As a result, he had lived for seven years in his previous home, navigating the stairs on his hands and knees. Leon, a young man who had cared for his terminally ill mother, had also experienced housing without

appropriate adaptations. Before hospice staff assisted Leon to obtain adaptations, he had needed to carry his mother up and down the stairs to her bed and the toilet.

- Avril, a wheelchair user living on her own, had wanted to find an accessible home near her support networks. Avril reported that the estate agents she had encountered had no knowledge or awareness of disabled people's needs. The limited options in a competitive market led her to obtain a home that had adequate space to navigate her wheelchair but which required extensive further adaptation. Avril spent her own savings on home adaptations rather than face a potentially lengthy wait for a disabled facilities grant from the local authority.
- Brooker, a wheelchair user living on his own, was told by his local authority that his application for housing might be de-prioritised as a result of turning down offers of accommodation that he did not feel were suitable for his disability requirements. Brooker had experienced hate crime from a local family and the housing association did not respond to his concerns. He finally settled in an adapted home after living in unsuitable housing for an extended period of time.
- Emma, mother to a disabled child using a wheelchair, gave up full-time employment to care for her daughter and was unable to afford adaptations to meet her daughter's needs. Emma discovered that suitable private rental properties were scarce and buying another property would be too expensive. Emma reported that, despite being allocated a higher priority status (as a single mother with a disabled child and another non-disabled child living in an inaccessible property), she had waited for five years on the social housing waiting list.
- Fiona was left with nerve damage, scoliosis and difficulty walking after the removal of a spinal abscess. She remained for 10 months in a rehabilitation hospital and realised that her privately owned flat would not meet her accessibility needs. Fiona made the decision to move to an accessible sheltered social housing development, but had to remain in hospital for a further two months until a suitable property became available. Fiona recognised that buying a home would jeopardise her right to free social care, and decided to remain in a sheltered accessible social housing development so that, in the event of her death, her money would go directly to her children and help them get onto the property ladder.
- Quinton, a wheelchair user, found himself housebound in an inaccessible home for 12 years. During this time, Quinton lived in a single room of his wife's property due to the house's stairs and lack of space for internal circulation of his wheelchair between rooms. An assessment carried out by an architect and an

occupational therapist concluded that the physical structure and layout of the property were unsuitable for adaptations. Quinton described a 'very difficult fight' with the local authority to move into accessible social housing and gain independent living. After exploring the option of shared-ownership under the guidance of Housing Options Scotland (HOS), Quinton secured a property which was adaptable to his housing needs. Quinton described his experience of obtaining an appropriate level of social care that met the needs of his household as an extensive 'battle'.

## Evidence review findings

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The following highlights from the evidence review touch on themes similar to those raised by the interviewees in our research:

- Disabled people were less likely to own their own home in the period 2012–14 than non-disabled people (62.6% to 76.2%). People with mental health conditions were far less likely to be owner-occupiers than the general population (EHRC, 2017b).
- About 2% of households in Britain include a disabled person who does not live in appropriate housing. Most problems in inappropriate housing could be tackled by making low-cost alterations.
- Across Britain, disabled people are more likely to be dissatisfied with their housing than non-disabled people. Younger disabled people express the lowest rates of satisfaction. These households, and households with disabled children, face the poorest housing conditions (EHRC, 2017b).
- Finding an accessible home is not straightforward. A survey of 200 young disabled people and 12 focus groups across Britain showed that respondents were waiting years to find accessible housing (Trailblazers, 2012).
- Even if good local authority policies exist, and accessible homes have been built, it remains difficult for disabled people to access information about them (Chaffin-Edwards, 2015).
- Accessible housing registers are often regarded as the solution to a supply shortage. A survey of local authorities across Great Britain in 2014 revealed that 83% of councils did not have a register (Leonard Cheshire Disability, 2014b). Only 16% of councils could provide any data on the number of homes in their area that were wheelchair accessible, and only 10% could provide data on the number of homes built to Lifetime Homes Standards. Registers are expensive to establish; they usually involve an extensive survey of properties that most local

authorities cannot afford to carry out. Tax and welfare reforms in the period 2010–17 had a more adverse impact on disabled than non-disabled households. On average, tax and benefit changes relating to families with a disabled adult has reduced income by about £2,500 per year; for families which include a disabled child, the reduction has been over £5,500 per year. This compares to a reduction of approximately £1,000 for non-disabled families (EHRC, 2017c).

# Chapter One

## Introduction and Methodology

### 1.1 Introduction

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This report presents findings from a study commissioned by the Equality and Human Rights Commission ('the Commission') in 2017. The study was designed to provide supporting evidence for an inquiry into housing for disabled people. The inquiry examined the extent to which the right of disabled people to independent living is supported by the provision of accessible and adaptable housing and tenancy support services.<sup>1</sup>

This study sought evidence to answer two overarching questions:

1. What does the evidence indicate about the housing needs and experiences of disabled people in England, Scotland and Wales (hereafter, 'the three nations'), with particular reference to the extent of any shortfall in the availability of accessible and adaptable housing, and in the availability of tenancy support services?
2. What views and experiences of housing provision in the three nations do disabled people have? We sought evidence correlated to the inquiry's terms of reference; namely:
  - How the provision of accessible and adaptable housing and tenancy support services has enabled disabled people to fulfil their right to independent living
  - The consequences of not having accessible or adaptable housing or tenancy support services for disabled people's right to independent living
  - How well systems are performing for applicants in relation to determining applications and administering grants for housing adaptations.

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<sup>1</sup> The work reported here was accompanied by other evidence-gathering activities to inform the broader inquiry by the Commission. The full inquiry report can be found on the Commission's website at: <https://www.equalityhumanrights.com/en/publication-download/housing-and-disabled-people-britains-hidden-crisis>

The first question is answered by our evidence review (included in full in Appendix 1 and summarised in Chapter Two below). The second question is answered by our research findings, summarised for each of the three nations (Chapters Three, Four and Five). The conclusion in Chapter Six reviews the principal findings.

## 1.2 Methodology

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The study's methodology was based on a rapid evidence review and semi-structured interviews with tenants and homeowners who were disabled or who had disabled children. Advice and guidance on the research was provided by a Peer Advisory Panel (PAP).

### **Rapid evidence review**

A rapid evidence review of the literature investigated research, policy and practice regarding disabled people's experiences of suitable accessible or adapted housing. Smith *et al.* (2011) define a rapid review process as using methods to accelerate or streamline the traditional systematic review processes, due to an urgent need for the results or because of project resource constraints.

Time constraints did not allow for a systematic search of multiple databases; the evidence review was conducted online using standard search engines and the Google Scholar database for academic materials. Appendix 2 shows the thematic search strings that were carried out.

### **Peer Advisory Panel (PAP)**

The PAP was set up to review the project sampling strategy, offer feedback on research tools, assist with the recruitment of potential participants (including providing guidance on ethics) and provide feedback on the plans for disseminating the findings. PAP members included representatives from nine disability and housing related organisations in the three nations.

### **Semi-structured interviews with disabled people**

Overall, 51 disabled households (including families with disabled children and carers) took part in semi-structured interviews across three broad areas within Britain: 20 from Bristol, 21 from Central Scotland and 10 from South Wales. The participants' identities remained confidential and are anonymised in this report for

ethical reasons (pseudonyms are used throughout). The topic guide (see Appendix 3) and the project information and consent sheet (Appendix 4) were approved by the commissioner and PAP, and given to participants. Appendix 5 summarises the characteristics of the interviewees.

Face-to-face interviews were carried out with 18 Bristol participants and 18 Scotland participants. For logistical reasons, telephone interviews were conducted with all of the Wales participants, one of the Bristol participants and three of the Scotland participants. Skype was used with one of the Bristol interviewees, at their request, and to facilitate participation.

## Chapter Two

# Background

This chapter summarises the main points from our review of evidence (see Appendix 1 for the full review).

Since the UK economy's recovery from the global financial crisis of 2007–9, many parts of Britain have shown rapid house price inflation and significant pressure on the supply of social rented housing (Office for National Statistics, 2017; Wilcox et al., 2017). The consequences of inflation and pressure on social housing are the increasing difficulty to own a home or waiting extended periods for social housing. Under these conditions, private rental supply and concerns about the affordability of such housing have grown. Disabled people, especially those with specific accessibility requirements, have experienced challenges securing housing that meets their needs.

Disabled people were less likely to own their own home in the period 2012–14 than non-disabled people (62.6% to 76.2%). People with mental health conditions continued to be far less likely to live in owner-occupied accommodation. English Housing Survey data show that 1.9 million households contained someone with a 'long-term limiting disability' who required adaptations to the home (unchanged since 2011–12). Scottish data on housing and disability show higher levels of social renting and overcrowding among disabled people compared with non-disabled people. There was a decrease in local authority wheelchair-adapted housing in the period 2006–15 (EHRC, 2017b).

In England, evidence suggests that 9% of households have a long-term disabled member, and a fifth of these disabled members (2% of the population of the country) are living in unsuitable, mainly rented, housing. The types of adaptation needed to make housing suitable are generally small, inexpensive items like grab rails (Department for Communities and Local Government, 2017). Scottish data show younger disabled people are more likely to be missing the required adaptations to their homes than older people (Scottish Government, 2016).

Across Britain, disabled people are more likely to be dissatisfied with their current housing, with younger disabled people expressing the lowest rates of satisfaction (Habinteg and Papworth Trust, 2016). However, survey data for the three nations show that households with a disabled member are less likely to live in overcrowded housing than the population as a whole (Department for Communities and Local Government, 2016; Scottish Government, 2016; Welsh Assembly Government, 2009). These data suggest that factors other than overcrowding are driving dissatisfaction.

The 2017 housing white paper for England (Department for Communities and Local Government, 2017) aimed to increase the supply of new and accessible housing, but failed to specify how these ambitions will be met. The Right to Buy may be extended to housing associations reducing the overall availability of social housing and further limiting the prospects for disabled people searching for an affordable, accessible home. Two Green Papers due out in 2018, one on Social Housing and another on Social Care for Older People, should provide greater detail.

In Scotland, the Right to Buy ended in 2016. Government regulations encourage, but do not require, 10% of new council housing to be accessible (Scottish Government, 2017a). All social housing funded by Housing Association Grant has to meet 'general' Housing for Varying Needs Design Guidance, which does not ensure the housing will have sufficient space standards and features to make it wheelchair accessible.

Adapting existing houses is crucial to providing appropriate housing for disabled people. Dedicated funding streams (the Disabled Facilities Grant in England and Wales, and grants under the Housing (Scotland) Act, 2006) are vital to making sure essential adaptations are made. In England, central government funding has increased considerably, but, across Britain, disabled people face delays getting work done, and difficulties in accessing information about relevant funding streams produces a further potential barrier (Mackintosh and Leather, 2016).

Across Britain, welfare reform continues to have significant consequences for disabled people's personal and household budgets. The social-rent spare room subsidy (the 'bedroom tax') has affected over half a million households across Britain, almost two-thirds of which include one or more registered disabled people (Wilcox, 2014). These households have found it difficult to find alternative housing. Those opting to remain in their housing have often had less money for essentials such as heating and food. The tax has also had negative impacts upon households which were using 'spare' rooms for carers (Wilcox, 2014; Moffatt et al., 2016).

Discretionary housing payments have mitigated some effects in Scotland and Wales and some parts of England (Scottish Government, 2017b).

Young disabled people and families with disabled children experience high levels of inadequate housing (Beresford and Rhodes, 2008; Cavet, 2009). Evidence suggests that the housing needs of people with visual impairments and cognitive impairments such as autism are not recognised as readily as those with physical impairments (Thomas Pocklington Trust, 2013). A shift in policy towards personalised care over the 10 to 15 years prior to this report is undermined by reductions in social care budgets, which threaten to hinder disabled people's ability to live independently and access the support they need (Age UK, 2017).

# Chapter Three

## Findings from Bristol

During May and June 2017, we interviewed 20 households in Bristol. The participants had a range of backgrounds and impairments (both in type and severity), and covered a range of ages, from disabled children through to retired individuals.

This chapter provides an overview of the interviews, focusing on the key themes that emerged from the participants' testimonies. The ability of adequate and appropriate housing to transform the lives of disabled people and their families is uncovered through the course of the chapter, via discussions of the adaptations and support required by participants, the difficulties and long-term effects of living in unsuitable housing, and the experiences of the interviewees in obtaining adequate support.

The chapter closes with case studies that offer an in-depth examination of some of the themes explored within the chapter's main parts.

### 3.1 The importance of housing

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Many of the participants lived in accessible housing and emphasised the benefits this had brought. Some interviewees stated that their home had positively transformed their lives. A disabled woman on the autistic spectrum with a mobility impairment and mental health conditions had previously struggled to find suitable housing, but reported that the housing association flat she moved to a few months before the interview was the best housing she had experienced.

Interviews indicated that having adequate, accessible, and appropriate housing can affect the whole family. We interviewed a family with five children, two of whom were disabled. The older son (sixteen years old) was a wheelchair user with no verbal communication and a hearing impairment. The young disabled daughter (two years old) had the same condition and would also eventually be in a wheelchair. The family had previously lived in a council-owned home to which the council had delivered significant adaptations. The family realised the house was becoming too small after

the birth of their second disabled child and with their son in need of a bigger wheelchair.

The family remained on the council waiting list for three years before they were relocated. The new home was already adapted and had space for further adaptations as the disabled daughter's needs increased. The family had anticipated needing to wait for the right home, in recognition of the scarcity of appropriate housing. They reported improvements to their mental and physical health following the move, including a reduction in the rate at which the youngest daughter had been admitted to hospital with chest infections.

### 3.2 Adaptations

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Many participants had carried out adaptations to their homes. Some adaptations were necessary to accommodate current accessibility issues; others were to prepare for the possibility of requiring greater accessibility in the future. Winston had bought a dormer bungalow in a rural area outside Bristol with his partner five years ago. He fit an extra bannister on the stairs to meet his current requirements, but even this simple job proved to be difficult due to non-structural plasterboard on the inner walls (a common feature of new, well-insulated homes). Winston had started to consider longer-term needs, and anticipated needing a wet room and a stair lift in the future.

Thomas, a single homeowner with epilepsy and subsequent health complications, highlighted the time it had taken to get adaptations through the local authority's official channels. Thomas had seen negative financial effects from being forced to take early retirement. He needed handrails in the bathroom, on the stairwell and over the garden steps, and he estimated that these had taken four years to arrange. Thomas's seizures were getting worse and he expected to need more adaptations in the future.

Overall, social housing tenants reported that specialist services had provided a relatively quick and responsive service to carry out adaptations. If involved, occupational therapists appeared to be instrumental in improving people's housing. West of England Care & Repair had also played an important role for some participants, helping them with occupational therapy advice, builders' lists, and giving practical help with building work. However, not all participants knew about Care & Repair or disabled facilities grant (DFG) services (see Appendix 1).

Several homeowners had tackled adaptations without any specialist advice. Some reported difficulties obtaining simple adaptations, and had instead conceived their own solutions (for example, designing and commissioning wardrobes for storage). Katarina had tried to 'future-proof' her home, but reported having already fallen over in her new shower. She had not looked for advice or support. She had assumed that there was little help available for disabled homeowners.

Hyacinth was a home owner with mobility issues and long-term health conditions that caused her early retirement. Her previous career as a social worker helped her navigate the system, but she still found it difficult to obtain support to get her bathroom converted and a disabled parking bay provided. When the adaptations were finally completed they increased her independence sufficiently to give her daughter freedom from caring duties and the opportunity to go to university. Mariah, a younger person with a hearing impairment, had bought her first home with her partner shortly before our interview with her. She reported no knowledge of how to access advice or support with adaptations.

Avril spent her own savings on installing adaptations, rather than waiting for a disabled facilities grant, and reported encountering an easier and cheaper process because she knew people in the trade. Katarina's adaptations had a significant cost, but she made the decision not to apply for a grant. She stated:

One of the things that I'm really conscious of is that disabled people, particularly those who are excluded from work because they are too ill to work or too disabled to work, are some of the poorest, most impoverished people in the country, and so what grants are available have to go to those who are in most need.

A few home owners said they had received disabled facilities grants. The mother of Simon, a profoundly autistic young man, reflected upon the grant application process as 'very long-winded and very cumbersome', but emphasised that the outcome was a bathroom which works 'very well' for Simon.

Other homeowners in our sample had sought support and advice, and several participants had received help from West of England Care & Repair. A participant who worked in the disability field reported using Care & Repair's advice service to consider a through-floor lift for his new home. He also tried to find a specialist builder from their builders' list, but discovered he would face a wait of at least three months as specialist contractors are in high demand. One participant was a first-time buyer and wheelchair user. He reported that the original developer of his new-build property had failed to design an appropriate bathroom, despite being specifically

asked to do so. He turned instead to Care & Repair's occupational therapist for design advice which in the end gave him a better outcome.

Leon (25 years old), cared for his mother who had a terminal illness. He had not known there was any help available and prior to adaptations to his home, he had been carrying his mother up and down stairs to get to her bed and the toilet. Hospice staff were instrumental in obtaining adaptations to their home.

### 3.3 Unsuitable housing

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Although many participants reported currently having accessible housing, some had experienced long periods of time in unsuitable properties.

Some of those people interviewed had previously been housed by their local authority in upper-floor accommodation with either no lift or unreliable ones, even when authority staff knew that they were unable to manage stairs (see case studies 1 and 2). Interviewees who had been housed in upper-floor accommodation reported an increased risk of accidents, increased stress and ill health, and additional costs imposed on the health service. Several people reported having falls or struggling with their breathing when having to use stairs, steps or long walks to their car. These problems also had a significant impact on carers, who were put under additional pressure and often suffered from health problems themselves. In one case, a young carer's multiple relocations led to a repeated change of schools, negatively affecting her education. She developed alopecia from the stress of living in inappropriate housing.

Katarina took early retirement due to her mobility issues. Her home had various adaptations, including to the bathroom, but due to fear of falling she would not shower unless her partner was there. Katarina reported feeling as though she constantly needed to make compromises and was considering moving to a bungalow or another more accessible home where she could feel safer. Norma, a disabled older woman with chronic obstructive pulmonary disease, was living alone in a council bungalow. She had experienced frequent falls, leading to periods in hospital. Norma's landlord had recently moved her disabled parking bay further away from the front door, and her shortness of breath made it hard to reach the car. As a result, Norma was leaving her house less often and relying on a friend to bring her shopping inside the house, which she could no longer do unaided.

### 3.4 Moving house

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Most of the people we interviewed were trying to make the best of their situation and were determined to maintain their independence. Struan, a homeowner and wheelchair user, had struggled for a long time before deciding to move house. He liked his former property and had friendly neighbours, but realised that his situation had become unsustainable:

Probably for the last three years there I was using a wheelchair more often than I was the steps and ... for the last probably seven years or so, I was on my hands and knees going up the stairs.

Interviewees in the owner-occupied sector reported having limited housing choices, even for those with adequate equity. Struan stated that bungalows in his area within his price range were far too small, with corridors that were too narrow for a wheelchair. Struan spent a year unsuccessfully looking for a suitable home, losing two buyers in the process. When he finally found a property through an estate agent, he was obliged to make a rapid decision to buy, and did so without being fully aware of the property's limitations.

Avril, a wheelchair user living on her own, had wanted to find a new home near her support networks. With limited funds, finding a home in a competitive market was difficult, and the one she bought had been the only affordable possibility. The house had adequate space for Avril to navigate her manual wheelchair, but she had not accounted for the space the stair lift would occupy. She had since adapted the property and reported feeling lucky to have had a positive resolution.

Winston, a wheelchair user, had searched for an affordable home in his preferred area. Deciding it would be difficult to find an accessible home, he focused instead on finding a property that could be adapted. He eventually bought a dormer bungalow with his partner.

Manny, a wheelchair user, bought a new property thinking it would be more straightforward to obtain built-in accessibility than converting an older property. Although Manny bought the property off-plan, he experienced significant frustration trying to obtain basic changes that catered for his needs (see case study 4).

All the homeowners interviewed reported that the estate agents they encountered were ill-informed about issues important to disabled people. Avril had tried to rent privately, but stated that her choices had been extremely limited. She was critical of letting agents, and reported that those she had encountered had no knowledge or

awareness of accessibility issues. Only one participant offered a positive experience of dealing with agents, stating that once his estate agent fully understood his needs he was very helpful.

Participants reported that, when they were eventually rehoused into accessible homes, their lives improved hugely. Several people commented on how settled they felt and how their physical and mental health conditions had lessened.

### 3.5 Support needs

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The interviews revealed that advocates and support workers were often vital to achieving proper housing for disabled people, particularly those with mental health conditions or learning disabilities as well as physical disabilities. Paulette submitted complaints to her local authority that she felt bullied by the other residents in her house, but was only helped to move from her upper-floor flat when her psychiatrist intervened.

Jordan had a good support worker who helped him move out of an upper-floor council flat into an accessible housing association property on the ground floor. Shawn and his young daughter (his main carer) received support from the Carers' Support Centre, a local voluntary sector organisation, to find a level-access home nearer their support networks. They reported finding the occupational therapy and accessible housing team extremely helpful.

Others reported frustration with obtaining support. Hyacinth eventually turned to Citizens Advice after spending time making multiple phone calls and writing letters to different local authority departments, and being passed from person to person.

Some disabled people we interviewed were concerned about the increased care and support they would need as they aged. Paulette expressed that she was unsure how much longer she could remain in her current home due to the deterioration in her physical health. She also expressed that she did not know how to proceed with finding a new home or who she could ask for advice.

We spoke to two families with autistic children who had reached an age at which they needed their own home. These families were well-educated, well-connected and able to research the options available, but still found it difficult to find appropriate housing for their children. Both families had needed to be persistent to reach a housing solution, but the eventual outcomes transformed their sons' lives.

One of the families had originally identified a flat for their son that was owned by the local authority and managed and supported by an autism charity. The flat was in a rural area with no transport links, and unsuitable for Chay, a young man who liked to watch live music and who was developing his own card business. Chay's mother stated that 'getting the flat was fairly simple, but getting the right support, getting people who understood [him] was really tricky'.

Chay's family emphasised that they believed their ability to purchase a second home had opened up more choices and possibilities for their son. At the time of interview, Chay's family were in the process of buying a small home for him in Bristol. A care package, including accompaniment for Chay at night in case of emergency, was to be provided by Bristol City Council. Chay's family felt that they had received substantial positive support from the local authority. For example, in a recent phone call from the local authority Chay had been told: 'You are a young man; you've got your whole life ahead of you. Let's get this right now and find you a place where you can thrive and contribute.'

The other family were dealing with the same local authority but expressed that the support they received was ineffective. Their son, Simon, was profoundly autistic, with epilepsy, learning difficulties and little verbal communication. He had outbursts of frustration and would damage the house. He held a job on a farm that he enjoyed and which involved caring for animals and doing odd jobs, and had reached the age where he needed his independence. Ideally, the family would have liked to find him a supported home in a farm setting, but waiting lists were extremely long. The local authority suggested various other options that did not meet Simon's requirements for adequate space and specialist support workers to ease his transition.

Simon was told by his social worker that he would not be able to 'pick and choose' his accommodation. According to Simon's mother, the whole family was under stress:

My son ... started to act out even more. We went through a period of about 18 months where things became pretty, pretty dire, he wasn't just damaging property he was pushing us.

The family had almost reached the decision to remortgage their house to buy Simon his own flat when they heard, by word of mouth, about a housing association supported living option that met Simon's needs. The City Council agreed the funding for his care. The family reported relief at the solution but frustration that it had taken so long and that they received minimal practical help.

### 3.6 Housing support for carers

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Our research revealed considerable housing consequences for carers in social housing after the death of the person they are looking after. For example, Leon was given notice to leave his property just two weeks after his mother's death. Leon, who had dyslexia and mental health conditions, had lived with his disabled mother in the same council house for his entire life.

Leon received support from the Carers' Support Centre and, at the time of the interview, had received the right to remain in his home. As a result of his mother's death and the prospect of losing his home, Leon had become ill and had to resign from his job. Leon's support worker asserted that the additional strain on health services as a result of individuals losing their homes results in a greater overall cost to the state in the long term.

### 3.7 Local housing services

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The previous sections of this chapter reveal a range of experiences with housing services. Participants reported having difficulty identifying who they should contact and needing persistence to get results, and described the way in which disabled people could become trapped in unsuitable housing with limited opportunities to move.

Participants revealed problems across all tenures. Social housing tenants reported difficult housing experiences involving repeated moves from one unsuitable dwelling to another. Many of the disabled tenants who were interviewed had persevered for a long time to find accessible housing. Those who were unable to use stairs (and had made this clear to relevant authorities) reported being housed by their local authority in upper-floor accommodation with no lifts.

Participants stated that the limited options offered by their local authority often led to them feeling forced to accept inappropriate housing. Once they had accepted, they were no longer considered in priority need, which reduced their chances of being granted more suitable housing. Participants also emphasised a perceived tendency by local authorities to de-prioritise those who turned down offers of accommodation.

Several people had moved from inadequate private renting to a succession of upper-floor council hostels and flats before finally obtaining suitable accommodation. One participant, Brooker, highlighted systemic difficulties, stating:

I got a lot of offers for stuff that weren't suitable and had to turn it down, and the people that were ringing me weren't too happy about it and saying, "Oh, it might affect your banding", and I was saying, "Well, if I don't bid, that's going to affect my banding." So, the system was a little bit crazy ... In the whole time, I only bid on two flats that were actually suitable for my needs and one of them was this one, and I was very lucky.

Participants revealed difficulties that can emerge when disabled people wish to move across local authority boundaries. Saffron, a resident of North Somerset, believed that Bristol represented the largest source of employment in the area, but said that she did not want to risk moving there and losing support from her existing authority. As a result, Saffron felt that her job prospects were limited.

In other contexts, local authority boundaries led other participants to feel they could not move to cheaper housing areas outside Bristol. Avril explained:

Now there is a cash shortage on health and social care, we cannot move out of [the] area. I'd moved temporarily to South Gloucestershire because I couldn't get anywhere in Bristol that was remotely accessible. I notified them that I'd moved out...but that I was intending to move back into the area. Because of staff shortages they didn't get onto it so that worked out perfectly. It could have been a nightmare because my direct payments come from Bristol for me to employ my support worker ... otherwise I would have to be reassessed again and that whole process can take a really long time.

### 3.8 Location

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While the focus of our research was on the accessibility of disabled people's homes, several participants highlighted the significance of location. Some said that they liked living in Bristol, and described the city as easy to navigate, especially for those living near the centre. Several participants emphasised that steep gradients in some parts of the city affect access into and out of people's homes and can make it harder to move around the city. Older parts of the city were described by participants as harder to navigate. Avril stated that her brother lived close to her, but narrow pavements made it a challenge to reach his house. She faced similar accessibility issues when trying to access local shops.

Participants reported that the poor design of built environments in newer developments had a negative effect. Levi, a disabled man with chronic obstructive

pulmonary disease who could only walk for a maximum of 25 metres, reported that the area outside his housing association home had been developed as a mixed-use outdoor space for pedestrians, cyclists and cars. He regarded the design of this area as dangerous; the risk posed by cars passing through at speed prevented Levi and his partner going out at certain times of the day.

Support networks were emphasised by participants as important, and several people stated that these had influenced their choice of location. Shawn and his young daughter had twice been placed in housing away from their family, but were finally relocated nearer their support network. Several homeowners, especially those using wheelchairs, mentioned the importance of nearby support from friends, neighbours and relatives, and how this had narrowed their search when they looked to relocate.

Two people reported experiencing disability hate crime in their neighbourhoods. Hyacinth had experienced abuse from a shop keeper who was allowing other people to park in her disabled parking bay. Brooker, a wheelchair user who lived on his own, had finally settled in an adapted home after being in unsuitable accommodation for a long time. He had experienced hate crime from a family nearby. Although several local residents had complained, the family continued to act aggressively. The son of the family had spat at Brooker's front door and a downstairs window had been broken. The housing association did not respond to Brooker's concerns. He felt very vulnerable and was worried he might have to move again. He expressed concern that he, a disabled person requiring adaptations, might be asked to move from suitable accommodation, rather than the other family being told to move.

## Case study 1: the transformative effect of good housing

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Paulette had hemiplegia, causing paralysis on her left side. She had lived in a flat managed by a housing association near the city centre for eight years. She was in full-time paid work and lived alone.

### Previous housing experience

Paulette spent eight or nine years living in an upper-floor flat. The stairs were difficult; she was not able to carry shopping because of the paralysis on one side of her body. She was unable to obtain a downstairs flat in the building and she said that the landlord had been unhelpful. She also felt bullied by the building's other residents. Paulette's home environment caused her substantial stress and, as a result, her work deteriorated and she developed depression and alcoholism.

### Finding an accessible property

Paulette was on the housing waiting list but only received a housing association flat after her psychiatrist intervened by writing letters to the council.

Paulette moved into a new apartment block. Her flat was on the second floor, but contained within one level, and the building's lift made the location easy to manage. Paulette lived alone and was therefore afraid to use the bath upon moving in. She approached the landlord and within a month they had replaced the bath with a shower. The landlord was also quick to fix the lift when it broke down.

### The impact of independent living

Paulette affirmed that she loved her new location's easy access to the city. She reported significant improvements in her mental health and her feeling of safety. Paulette stated that she no longer smoked or drank, and ascribed this to her improved housing situation. Speaking about her life as a result of these positive changes, Paulette described herself as a 'different person'.

## Case study 2: the difficult process of finding suitable housing

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Jordan was a man of working age with mobility issues and a history of mental health conditions. Although not a wheelchair user at the time of the interview, Jordan anticipated using a wheelchair in the future. Jordan lived alone in an adapted

housing association bungalow, but had faced a long and difficult process to reach the point of feeling settled.

### **Previous housing experience**

Jordan's story started two years prior to the interview, when he separated from his wife and lived in his car for approximately four months. He had passed Personal Independence Payment (PIP) assessments, had been allocated a blue badge, and was officially recognised as disabled. The police were concerned about him and visited him nightly. Jordan was not eating properly and was using a local swimming pool's facilities to wash.

Jordan was eventually housed in emergency accommodation. Despite having been told that he would not be given an upper-floor dwelling, Jordan was allocated a second-floor property. Jordan requested relocation at the housing office but felt he was being treated badly and became agitated. As a result of his agitation, Jordan was arrested and experienced a seizure in the cell where he was held. The police assumed he was faking the seizure and Jordan was held in prison for 24 hours without any of his medication. After appearing in court, Jordan was released to find that he had lost his accommodation and that all his possessions were in storage. Jordan was forced to move back into his former partner's home while she moved out to her mother's house.

Jordan was finally housed by the council, but in a second-floor flat that did not meet his mobility requirements. He was forced to move again and, although the council had promised to meet Jordan's needs by placing him on the ground floor, he found himself on the top floor of a block of flats.

### **Finding an accessible property**

Finally, after approximately three months of requesting assistance from the council, and with the help of a support worker, Jordan moved to a ground-floor council flat. Although the flat was not adapted, it represented an improvement and Jordan felt unable to refuse the offer. Jordan received some furniture and began to settle. The council stipulated that he would be housed in the flat only for a few months, but he remained there for a year.

During that time, Jordan continued bidding for properties and, after reaching the top of the priority list, he finally received the flat he wanted.

### **The impact of independent living**

Jordan's eventual relocation represented a long-term solution to his housing problems. The building had a ramp at the front door and all the doorways were wide. The flat was fully accessible and could be easily adapted to meet Jordan's changing needs; for example, the kitchen units could be lowered. At the time of the interview, Jordan had lived there for nearly six months and, pending a review, was hopeful of securing a long-term assured tenancy. Jordan stated in the interview that his new accommodation had allowed him to begin to settle and relax.

### **Case study 3: the impact of housing on carers**

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Shawn was a disabled man of working age with mobility issues. He was a veteran diagnosed with Post Traumatic Stress Disorder (PTSD) who had trouble sleeping. He used crutches inside his home and a wheelchair to go out. He lived with his main carer, his 14-year-old daughter. At the time of interview, Shawn and his daughter were about to move to their third home in three years.

#### **Previous housing experience**

Shawn and his daughter lived for approximately a year in a council flat and were regarded as low priority by the local authority, as they had already been housed, despite the fact that their flat was not accessible. After a fall which saw Shawn rushed into hospital, he was seen by an occupational therapist. The therapist asserted that Shawn could not remain in the same housing. Shawn and his daughter waited five months to be moved and, during this time, Shawn was exposed to considerable danger navigating the steps to his home.

At the time of the interview, Shawn and his daughter had moved to another unsuitable house. The house had a stair lift but Shawn's daughter had to carry his wheelchair down several steep steps to the front door so that Shawn could leave. Although it was not ideal, Shawn's daughter felt that the new house was an improvement and had given her father more freedom; for example, Shawn was able to leave the house via the back door and sit in the garden while she attended school. However, the house was situated on the other side of the city from members of their extended family who could provide support. The stress caused by the situation had resulted in Shawn's daughter developing alopecia.

#### **Finding an accessible property**

Shawn and his daughter had asked the council to have a driveway installed to replace the steps, but after an assessment the occupational therapist decided that they ought to move again. Shawn and his daughter found it difficult to attain priority, but members of the local Carers' Support Centre took photos of the steps and lobbied on their behalf. At the time of the interview, plans were in place to relocate Shawn and his daughter to a council bungalow in an area of the city nearer their family. They would be moving within four to six weeks and the process had been less stressful than the last time.

### **The impact of independent living**

Although both Shawn and his daughter were very positive about the imminent move, Shawn's daughter had been obliged to join a new school again – her third school in three years. She would also have to join another young carers' network and give up her acting group. Shawn stated that he felt his daughter was missing out on important parts of life.

## **Case study 4: moving to a newly built home**

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At the time of interview, Manny had recently bought his first home – a ground floor flat in a newly built block. He chose a new property believing it would be more accessible than an older house. The flat he chose was not far from the city centre in an area that had recently been developed.

### **Previous housing experience**

Manny found it difficult to search for housing because estate agents did not understand or prioritise his accessibility needs. Once Manny had finally found a suitable, ground-floor apartment, he was not anticipating further problems. Manny was a confident communicator and had significant knowledge about accessible housing from his full-time work alongside planners and architects. Despite this, he faced a long and difficult process to ensure his new home was genuinely accessible.

### **Finding an accessible property**

Manny bought his home 'off-plan' prior to build and asked the developers for a shower to be fitted instead of a bath. He was informed that this would require building regulations approval and was therefore impossible. After confirming with his colleagues that a change in building regulations was not in fact needed, Manny

returned to the developer to insist on the change. When the apartment was nearly finished, Manny viewed the flat and discovered that a bath had been installed. After discussion with the developer, Manny received a reduction of £2,000 to the asking price, but had to arrange for the shower installation himself with the help of West of England Care & Repair. He anticipated the final cost to be up to £4,000.

Manny discovered another problem with the flat when he visited to discuss bathroom alterations with the occupational therapist. When he tried to leave, Manny found that the latch on the heavy front door was very small and located too high, leaving him trapped in his own flat. The site manager agreed to change the fittings but the work had not been done at the point of completing the house purchase. Manny was concerned that other disabled people in the building could also have an issue with lock placements. No one Manny spoke to in the development company appeared to know about Part M Building Regulations relating to accessibility or the requirement to fit locks, catches and switches so that someone who is disabled can reach them.

### **The impact of independent living**

At the time of the interview, Manny was nearly ready to move in. He expressed his excitement at having a property suited to his accessibility needs, but also noted his trepidation at living alone.

## **Conclusions**

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The interviews in the Bristol area highlighted a wide range of experiences. Some of these – such as securing adaptations – touched on the advantages and disadvantages of different tenures, with homeowners often being unaware of the support available to them. Nearly all the interviews demonstrated the importance of support networks, whether informal ones made up of family and friends or formal networks of professional service provision. The interviews also emphasised the importance of supportive advocates and estate or lettings agents. The strengths and shortcomings of local housing services were revealed to have major impacts on the lives of disabled people and their carers. Personal factors such as resilience and resourcefulness had a powerful part to play in the housing outcomes for the interviewees.

## The interviewees

Table 3.1 summarises characteristics of the people interviewed. All names are pseudonyms.

**Table 3.1 Interviewee characteristics in Bristol**

Name	Location	Tenure	Type of House	Age Group
Avril	City	Homeowner	House	Disabled adult middle years
Brooker	City	Housing association	Ground flat	Disabled adult middle years
Chay	Rural	Housing association	Upper flat	Disabled adult younger years
Hyacinth	City	Homeowner	House	Disabled adult middle years
Jordan	City	Housing association	Bungalow	Disabled adult middle years
Katarina	City	Homeowner	House	Disabled adult middle years
Leon	City	Local authority housing	House	Former young carer
Levi	City	Housing association	Bungalow	Disabled adult older years
Manny	City	New homeowner	Ground flat	Disabled adult middle years
Mariah	City	Homeowner	House	Disabled adult younger

				years
Norma	City	Local authority housing	Bungalow	Disabled adult older years
Paulette	City	Housing association	Upper flat	Disabled adult middle years
Saffron	City	Housing association	Upper flat	Disabled adult middle years
Shawn	City	Local authority housing	House	Disabled adult middle years
Simon	City	Living with parents	House	Disabled adult younger years
Struan	City	Homeowner	House	Disabled adult middle years
Thomas	City	Homeowner	House	Disabled adult middle years
Winston	Rural	Homeowner	Bungalow	Disabled adult middle years

# Chapter Four

## Findings from Central Scotland

This chapter presents information gathered by interviews conducted in Central Scotland. The chapter offers insight into the range of participants' opinions about positive aspects of appropriate housing and their negative experiences of unsuitable housing. The cumulative scope of these negative experiences highlights the mental and physical stresses placed upon disabled people when they face significant barriers to accessing suitable housing. Benefit reductions, and associated eligibility assessments, often had negative consequences for those with mental health conditions. They were also seen as adding significant complexity to the pursuit of adequate housing. The consequences of financial barriers, unavailability of housing, and inadequate support are shown through the course of the chapter to have been harmful to participants' wellbeing.

The chapter closes with case studies that offer an in-depth examination of some of the themes explored in the main sections.

### 4.1 The importance of housing

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The interviewees described a range of positive aspects of their housing. They generally valued accessible kitchens, private gardens, downstairs bathrooms and secure entrances. Location was highlighted as important; both urban and rural inhabitants expressed the desire to live in a pleasant, safe area with good transport links. Some interviewees also emphasised the importance of being a tenancy holder and expressed a preference to live alone rather than share a property.

Interviewees also shared a range of negative housing experiences. A few interviewees noted the contrast between aspects of their housing at the time of interview and those of previous accommodation. For example, some interviewees had lived in homes that were expensive to heat, had inadequate storage for

equipment for their health needs, and had waited for long periods of time for repairs to, and essential maintenance of, their property.

Our research in Scotland revealed four main categories of negative effects on the families involved. The first category covers the physical restrictions inaccessible properties pose to independent living. Some interviewees noted that their housing did not suit their family's needs. For example, Carrie, the mother of a disabled child, stated that her house's layout posed a risk to herself and her child and had resulted in falls on the stairs and in the bath. The second category covers the anxiety caused by dealing with private, rental, short-term tenancies. Interviewees emphasised the insecurity attached to short-term leases and noted that they feared being asked to leave if the landlord decided to sell their home. One participant stated that it was difficult to feel settled because of worries about being forced to move against her will.

The third category covers the stress caused by existing or anticipated deterioration of health conditions that necessitate a more accessible home, either immediately or in the future. Deterioration in health caused some participants to seek alternative housing or to make adaptations to their current property. Harry, a social housing tenant, and Geana, a tenant in the private rental sector, stated that deterioration in their mobility made it difficult to use stairs. Both were aware of the future risk of becoming housebound if alternative suitable accommodation was not found. Fiona acquired new accessibility requirements when the removal of a spinal abscess left her with nerve damage, scoliosis and difficulty walking. She remained for 10 months in a rehabilitation hospital and realised that her privately owned flat would not meet her accessibility needs. Fiona made the decision to move to an accessible sheltered social housing development, but had to remain in hospital for a further two months until a suitable property became available. Quinton, a wheelchair user, was housebound for 12 years while waiting for a suitable property.

The fourth category covers financial concerns prompted by housing issues. Ken had made financial sacrifices to privately rent an adequately spacious home with a garden that was suitable for him and his guide dog. Ken was concerned that he would not be able to afford anything similar if the landlord decided to sell the house. Emma had given up full-time employment to care for her disabled daughter and the resulting stress caused a breakdown in her relationship with her husband. Emma struggled to pay the mortgage on her reduced income and was unable to afford adaptations to the home to meet her daughter's needs. Emma discovered that suitable private rental properties were scarce and buying another property would be too expensive. Beth, a private renter with deteriorating health, emphasised her repeated experience of being informed by letting agents that flats were not available

to those on housing benefit. Beth expressed the belief that disability should be accounted for when considering a person's earning potential.

## 4.2 Adaptations

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Many interviewees reported installing adaptations to meet their needs. The adaptations described by interviewees included a low breakfast bar for a young wheelchair user, adapted kitchen units, remodelled bathrooms, and installing useable garden paths. Many interviewees had struggled to secure adaptations, mainly due to their cost, and interviewees reported that getting work done could be time-consuming and stressful.

Quinton's experience of locating an adaptable home is one example of the tenacity and personal resilience exhibited by many of the research participants. Quinton lived in the lounge of his wife's property for 12 years due to the house's stairs and lack of space for internal circulation of his wheelchair between rooms. An assessment carried out by an architect and an occupational therapist concluded that the physical structure and layout of the property were unsuitable for adaptations. Quinton described a 'very difficult fight' with the local authority to move into accessible social housing and gain independent living. Quinton gained support from his doctors and local MP. After exploring the option of shared-ownership under the guidance of Housing Options Scotland (HOS), Quinton secured a property which was adaptable to his housing needs.

## 4.3 Unsuitable housing

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The interviews uncovered a range of experiences demonstrating the effects of living in unsuitable housing. The poor, run-down condition of properties, a lack of social support, financial constraints and anti-social behaviour from neighbours were described as particularly harmful to participants' sense of wellbeing. For many participants, these problems had resulted in deteriorating health and the added stress of needing to move house.

Alice, a wheelchair user, had a teenage son with a mental health condition. Alice was only able to access the ground floor level of her family's two-storey property, and her social housing landlord therefore converted two downstairs rooms into a wet

floor shower room. Despite this adaptation, Alice was unable to supervise her son's behaviour upstairs and as a result he caused significant damage to his bedroom.

Jill, who was disabled and had family members with a range of impairments, was also living in unsuitable housing, and described her frustration that her landlord and social services were not willing to fund the installation of an accessible bath. Jill explained that she was on the social housing waiting list because of persistent damp in the property. Harry had similar problems; he had been a tenant in an upper-floor, damp and draughty flat, and the housing provider did not provide sufficient financial support to allow him to carry out necessary renovations.

#### 4.4 Support needs

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The interviewees highlighted several aspects of housing provision that facilitate independent living for disabled people: adequate disability benefits, appropriate social care support, self-directed support (SDS), formalised boundaries between personal care tasks and family relationships, support from an occupational therapist, assistive technologies, and Care & Repair services.

Fiona recognised that buying a home would jeopardise her right to free social care. She decided to remain in a sheltered accessible social housing development so that, in the event of her death, her money would go directly to her children to help them get onto the property ladder. All the participants highlighted that disability-related benefits such as Personal Independence Payments (PIP) or Employment Support Allowance helped to cover housing costs.

The interviews revealed the connection between suitable accessible housing and appropriate social care. Participants with learning difficulties or mental health conditions had experienced rigorous benefit assessments, which often led to a reduction in their support hours. During an assessment for PIP, Liz was told by her housing support worker that she did not have learning difficulties, despite her diagnosis at the age of two.

Sarah, who had a mental health condition and physical impairments, was refused home support by the council, despite needing assistance from neighbours to perform basic tasks. Harry, who also had learning difficulties, received six hours of support per week, which he felt did not meet his needs to live independently in his flat. Harry explained that he had refused two studio flats from social landlords due to the

inability to separate sleeping from everyday activities and the lack of privacy if he had guests. Harry explained that he took this decision to protect his mental health.

Interviewees with learning difficulties or mental health conditions also emphasised the importance of living close to social networks and support. Liz remarked that the two weeks she spent in a private let, away from her social connections, prior to moving into a supported housing development were very difficult.

Participants who received self-directed support (SDS) expressed satisfaction with the control they had over the support they needed to live independently in their homes. Interviewees reported SDS budgets being delivered through social work departments with recipients choosing their hours and support worker(s). Quinton advertised for, and then recruited, his own support workers and Rob accessed support provided by a housing association that specialised in independent living for people with learning difficulties.

Some interviewees remarked that there was a need to formalise boundaries between personal care tasks and family relationships. Housing providers and other services routinely assumed that family members were willing and able to support disabled tenants and homeowners. Quinton described his experience of obtaining an appropriate level of social care that met the needs of his household as an extensive 'battle'. Emma asserted that it had been difficult to obtain support workers with the necessary skills; her daughter required a stair lift and support workers tended to lack the training necessary to use the equipment. Isobel also noted that low wages resulted in a high turnover of support worker employees, in turn leading to long periods of time teaching new staff routines and personal preferences.

Participants also talked about the importance of other sources of support such as occupational therapists, assistive technologies and Care & Repair services. Donna described her occupational therapist's person-centred approach towards her needs following a hospital discharge. Beth enlisted the help of a Care & Repair service to carry out small tasks such as changing the light bulbs in her private rental flat. Both Fiona and Isobel used assistive technologies to support their independence at home; both had emergency community alarms that would ensure, for example, that the community alarm would be activated through a bracelet in the event of a fall. These interventions, although small, were highly valued by participants.

## 4.5 Local housing services

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The participants in our research highlighted a number of negative issues relating to local housing services including: a lack of accessible housing, housing providers' misinterpretation of accessibility standards or property categories, inadequate allocation systems, difficulties completing applications and viewing properties, a lack of housing options, and poor communication between housing providers, tenants and other services.

Participants commented upon the shortage of accessible housing. Quinton remarked that he felt the 10% allocation of social housing for disabled people in new developments was 'too low', and that he saw no reason why all houses could not 'be geared up to suit disabled and able-bodied people at the same time'. Donna felt that accessible housing provision needed improvement across all tenures. She pointed out a consistent lack of housing planning that considered future health-related problems for all individuals, and noted that an increase in properties adhering to accessible design standards could allow more individuals to remain in their own homes if unexpected health conditions emerged.

Many participants had been placed on a housing waiting list for years as a result of the shortage in accessible social housing. Geana was on the council housing waiting list for 18 years before her father decided to buy her a flat and become her landlord. Isobel was informed that she would need to wait for 10 years if she applied for a wheelchair-accessible property in her area. Emma reported that, despite being allocated a higher priority status (as a single mother with a disabled child and another non-disabled child living in an inaccessible property), she had waited five years on the social housing waiting list. Harry, who had learning difficulties and deteriorating mobility, had been on the social housing waiting list for a period when a ground-floor flat became available in his block. He approached the housing provider to enquire about transferring there from his upper-floor flat to meet his mobility needs. This ground-floor flat was designated as mid-market rent, making the tenancy unaffordable for Harry.

Some participants were of the view that housing providers' interpretations of accessible properties were often narrowly focused on wheelchair use and did not take into account other needs. Tina remarked that she encountered difficulties when installing a walk-in shower because the local council had a policy not to adapt any flats with internal stairs, even if they were on the ground floor. Sarah recounted that her occupational therapists had refused at least two houses without consulting her because they considered these properties to be inaccessible for a wheelchair user.

Sarah's experience demonstrated that a flexible approach towards accessibility should take a long-term view of how a property can be adapted.

Alice, on the other hand, was positive about the approach taken by her housing provider. She required a three-bedroomed wheelchair-accessible property, a type of property scarce in her area. The housing association allocated her a five-bedroom detached house that exceeded her needs for space but which allowed her to access a ground-floor bedroom and gave her children their own bedrooms and a separate bathroom upstairs.

Tina and Victor expressed concerns about housing providers' understanding of their accessibility requirements. Tina experienced difficulties seeking the installation of a spending pen (an enclosed slabbed area to accommodate the toilet needs of her guide dog) by a housing association. The Guide Dogs' Association became involved in order to provide advocacy for Tina. Victor described looking for a house in the private rented sector, noting that the accessibility needs of guide dog owners were not always recognised. Victor encountered one letting agent who knew about appropriate legislation and was helpful, but encountered others who did 'not have a clue'.

Ken and Beth discussed the ways that social housing allocation systems failed to recognise disabled people's diverse needs. Ken said that the points-based social housing allocation system in one local authority area did not give priority to issues related to visual impairment. Ken required a new property within a familiar location, and a property in a different area would not have met his visual impairment needs. Beth also recounted her experience of applying for top priority in a choice-based letting system. During the assessment, she was penalised because she could climb a flight of stairs, even though this took her a long time due to her physical impairments. Beth suggested that the allocation system should consider the challenges involved with the performance of a task and not focus solely on the completion of that task.

Participants outlined challenges they had met with the housing application process across sectors. Donna commented that the lack of a shared housing application form in an area with multiple social housing providers could lead to confusion about which applications were active or required renewal. Participants with a visual impairment said that application forms for social housing and letting agencies should be provided in alternative formats, and that cross-tenure organisations needed to assist visually impaired prospective tenants to complete their application. Some visually impaired interviewees reported that friends, family or care agencies provided ad hoc support

to fill out necessary paperwork, but that this approach infringed upon personal privacy. Alice described how she was in hospital and stressed during her housing application process and stated that the housing association should have delivered additional support for her to fill out forms and draft correspondence.

The participants emphasised how property viewings could pose challenges. Ken, who was visually impaired, encountered a housing officer who described specific properties to him during the choice-based letting process. Victor commented upon the importance of viewing a potential new home to properly assess if it would meet his needs, but noted that he had on one occasion relied upon his family to make the decision on whether the property would meet his needs when he was unable to attend a viewing.

The interviewees' accounts of their engagement with local housing services highlighted the range of options they had explored to try to resolve their housing issues. Alice's positive experience as a housing association tenant for 20 years meant that she felt more comfortable exploring a down-sizing scheme operated by her housing provider. By contrast, Tina obtained a suitable accessible flat through a home-swap scheme without any guidance from her housing association. Beth decided to look into the private rental sector due to the long wait for social housing, but her status as unemployed and her receipt of housing benefit led to difficulties in applying for suitable privately let properties.

Isobel and Quinton described their experiences of a shared-ownership scheme named Lift.<sup>2</sup> Both felt that it was expensive to buy an accessible property spacious enough for a wheelchair user and in a convenient location for local amenities and public transport. Quinton explained that the Lift scheme provided help to first-time buyers, disabled people and veterans in Scotland to divide the costs of ownership with government funding. The Scottish Government usually purchases 50% and receives back their share of the investment with any profit if the property is sold. Quinton remarked that, 'It is a simple enough scheme and it is great that it is there. It is just a pity that more people did not know about it. It should be publicised more.'

Donna indicated that having a named contact in a housing organisation to arrange repairs had helped to ensure that any issues were dealt with effectively. Sarah discussed the importance of having communication tailored to meet the needs of tenants who have mental health conditions. Many interviewees cited the importance of regular communication and coordination between housing and other services and organisations. For example, Orla stated that, as a parent and the main carer for her

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<sup>2</sup> For more information see: <http://www.gov.scot/Topics/Built-Environment/Housing/BuyingSelling/lift>

disabled son, the local centre for carers was an important source of advice and support to help her maintain independent living at home. The centre's services included help with filling out forms, welfare advice, social events and relaxation techniques such as massage therapy.

Housing Options Scotland (HOS) was frequently mentioned by interviewees.<sup>3</sup> Carrie, the parent of a disabled son who required a wheelchair-accessible property, was initially refused planning permission by the local authority to extend her home. Carrie described how HOS acted as advocates to insist that the local authority examine the extension plans due to the unlikelihood of suitable social housing becoming available in the near future and the fact that other local authorities had set a precedent by making exceptions in similar cases. As well as providing intensive advocacy, HOS managed to secure an agreement for an accessible extension that would be jointly funded by the local authority and HOS.

Emma, a homeowner with a disabled daughter in a wheelchair, reflected upon the challenges presented by other family members, social workers and housing providers. Emma's family home was not wheelchair accessible, but her estranged husband wanted to sell the house and would not provide consent for the adaptations. The shortage of alternative suitable accessible social housing and affordable, accessible, privately let accommodation meant that Emma was left in an inaccessible home. Social services considered the situation to be potentially harmful to Emma's daughter:

Currently, we have a really serious situation with [social services] because they are fully aware that the house is not suitable for my daughter, yet they are unable to do anything about it because my husband will not allow the adaptations. So, their response has been to refer my daughter to the Children's Reporter on the grounds of lack of parental care ... even though they are telling me it is not to do with me, it is more to do with my husband, it is still a very difficult situation.

Disabled social housing tenants also highlighted that additional assistance may be required during repair or maintenance work. For example, Jill described that her housing provider expected her to re-paint the ceiling after her bathroom was flooded. As a triple amputee, Jill was unable to perform such a task and needed assistance to arrange support for redecorating.

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<sup>3</sup> This was partly due to the fact that the organisation provided some of the sample of interviewees.

## Case study 1: the importance of independent living

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Nina is a young disabled adult. She is a wheelchair user with limited mobility and requires 24-hour care support.

### Previous housing experience

Nina lived with her father in a wheelchair-accessible property until a flood forced her to move to a residential setting run by the Red Cross. The housing was a transitional residential unit delivering 24-hour support to people with disability support needs. In 2015, the Red Cross made the decision to close the unit. The different local authorities involved had four months to find suitable accommodation for the 21 permanent residents.

Nina's social worker assumed that she would return to living with her father in his fully accessible property. After having lived independently for seven years, Nina in fact wanted to move to an accessible house in the local community. Her social worker failed to understand her desire to live independently, focusing instead on the accessibility of the home. Nina said:

[All] they were seeing was the fact that my dad's house is accessible. They weren't seeing the bigger picture; that I would lose everything that I've worked for.

Nina discussed her need for independent living with her father, and he expressed his support for achieving the housing situation that would best fit her needs. Nina stated that she felt the signalling of transitional housing as a temporary bridge to moving into appropriate housing with community support was misleading. She asserted that moving back in with her father would result in local authorities choosing to believe her situation had been resolved.

### Finding an accessible property

Nina enlisted the assistance of a local councillor to make her voice heard. Initially, social services and council housing departments offered the alternative option of residential care within a local nursing home. The day after a story about Nina appeared in the media, the housing department found an adaptable property for her. The property required the installation of ramped access, necessitating a six-week stay for Nina in a nursing home during the installation. A full six months later, Nina viewed the property with her local councillor and discovered that the entrance had a ramp but that the rest of the ground-floor flat remained inaccessible.

Nina reported that the housing department's response had been to claim that they had been told she would be receiving 24-hour care. She returned to the nursing home and set up meetings with her social worker and the housing department to deal with her access needs. Nina's local councillor provided invaluable advocacy throughout these meetings. Nina revealed that the social worker had said that installing an automatic front door would make the property liveable, despite the fact that Nina would be required to ring a community alarm to receive the support necessary for her to conduct the most basic tasks, such as turning lights on and off.

When Nina pointed out the failure in logic in moving her into a house with the goal of increasing her independence while in fact making her more dependent, the social worker had no response. Nina's local councillor approached the head of the local council and the necessary adaptations were carried out the following week.

### **The impact of independent living**

At the time of interview, Nina was living in an accessible house and receiving care and support to assist with everyday tasks. She reported feeling much happier and more independent as a result.

After the completion of her education, Nina created an organisation to share with others her experiences and provide support to improve disabled people's rights to independent living.

## **Case study 2: the transformative effect of good housing**

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Quinton has quadriplegia and further health conditions as a consequence of being a wheelchair user. He is retired and lives with his wife in a shared-ownership, accessible house in rural West Scotland. It took many years for Quinton to secure this accommodation.

### **Previous housing experience**

In 2003, following a relationship breakdown, Quinton was temporarily housed in a nursing home. After six months, the local authority and social services were no closer to finding a suitable property for him. The quality of care in the nursing home was poor. The local MSP informed Quinton that he could obtain a predetermination from the local authority allowing him to rent privately until an accessible dwelling that met his needs became available.

Quinton moved into his new wife's home, a two-bedroom terraced house with steps up to the front door. The property had no wheelchair access nor did it have enough space inside for Quinton's wheelchair. He found himself housebound in the lounge, where he slept, ate, socialised and received care for 12 years.

### **Finding an accessible property**

Housing Options Scotland (HOS) helped Quinton apply to the Lift scheme. Quinton explained that the Lift scheme seeks to help first-time buyers, disabled people and veterans to get on to the property ladder. Lift uses Scottish Government funding to purchase 50% of a suitable house which, for Quinton, was a three-bedroom house with ramped access and spacious rooms to allow the internal navigation of his custom-built wheelchair.

### **The impact of independent living**

Quinton's new home had transformed his life. Quinton's wife appreciated having private space upstairs away from the support workers delivering 24-hour support to Quinton. Quinton and his wife felt that it was important to separate caring from an intimate relationship.

Quinton and his wife had been invited to become church elders and their accessible house provided a good venue for meetings and social gatherings. Quinton completed an honours degree in Law. At the time of interview, Quinton was in his penultimate year of a second degree in Criminology and Psychology, providing advice on the law to charities, and considering a doctorate in Juvenile Crime. Quinton observed that the time and patience required to complete his studies was equally important in his quest for an accessible home.

## **Conclusions**

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The Central Scotland interviews highlight the positive consequences that suitable and accessible or adapted housing can have for disabled people. Many participants reported long waiting periods when seeking a new property or trying to install adaptations to an existing one. These waiting periods caused emotional and physical distress. Effective communication between and within different agencies, advocacy, appropriate funding for adaptations, good housing options advice, and adequate welfare benefits were emphasised by interviewees as vital in securing the right home.

The participants’ testimonies brought to light the negative effects of being inadequately housed. Interviewees with sensory or cognitive impairments, in particular, found challenges in navigating social housing allocation processes that betrayed a lack of knowledge of the diversity of disabled people’s accessibility needs. Families with disabled children and disabled home-seekers with spouses often felt that the allocation system did not recognise the needs of all household members and tended to assume that non-disabled members were carers.

## The interviewees

Table 4.1 summarises characteristics of the people interviewed. All names are pseudonyms.

**Table 4.1 Interviewee characteristics in Central Scotland**

Name	Location	Tenure	Type of House	Age Group	Child's Impairment
Alice	City	Housing association	House	Disabled parent with teenage disabled child	Mental health condition
Beth	City	Private rent	Ground flat	Disabled retired	
Carrie	City	Owned	House	Family with disabled child	Indoor wheelchair user
Donna	City	Housing association	Ground flat	Disabled retired	
Emma	Rural	Owned	House	Family with disabled child	Indoor wheelchair user
Fiona	City	Council housing	Bungalow	Disabled retired	
Geana	Rural	Private rent	Upper flat	Disabled adult middle years	
Harry	City	Housing association	Upper flat	Disabled adult	

				middle years	
Isobel	City	Shared-ownership	Ground flat	Disabled young adult	
Jill	City	Housing association	Bungalow	Disabled retired	
Ken	Rural	Private rent	House	Disabled adult middle years	
Liz	City	Housing association	Ground flat	Disabled adult middle years	
Max	Rural	Housing association	Upper flat	Disabled adult middle years	
Nina	City	Council housing	Ground flat	Disabled young adult	
Orla	City	Council housing	Bungalow	Family with disabled adult	Indoor wheelchair user
Peter	City	Council housing	Bungalow	Disabled retired	
Quinton	Rural	Shared-ownership	House	Disabled retired	
Rob	City	Housing association	Upper flat	Disabled adult middle years	
Sarah	City	Council housing	Ground flat	Disabled adult middle years	
Tina	City	Council housing	Ground flat	Disabled adult middle years	
Victor	City	Private rent	House	Disabled adult middle years	

# Chapter Five

## Findings from South Wales

This chapter presents the views and experiences of interviewees living in South Wales at the time of interview. The 10 participants from South Wales were a variety of ages, with a range of backgrounds, family circumstances and geographical locations. They had diverse social and disability issues.

The interviewees confirmed themes that emerged from participants' testimonies in England and Scotland. The chapter considers the positive effects of successful adaptation and, in its course, considers a range of barriers to achieving accessible and appropriate housing for disabled people. Participants highlighted the failure of services to adequately provide for needs related to the search for housing, such as the need for accessible property viewings for people with visual impairments and the need for clearer assistance through the benefits system.

The case study at the close of the chapter explores the intersection between disability and domestic abuse in one participant's experiences seeking adequate housing.

### 5.1 The importance of housing

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Most interviewees were living in social housing, with one individual living in an owner-occupied property and three living in privately rented homes. Those living in social housing had availed themselves of the local accessible homes scheme, which meant their disability needs were taken into consideration when they were offered a property, although this process did not always proceed smoothly. As a result, all those interviewed were living in homes which were generally suitable for their or their family's accessibility needs at the time of interview. This had most frequently resulted from the installation of adaptations to their existing home rather than their move to different housing. The adaptations were reported to have had positive effects for the participants and they felt that their needs had been met. Mike reported that having

his own home had made him feel more independent and more positive about life. However, the participants revealed that positive outcomes had not been easy to attain, and arranging the necessary adaptations had taken considerable time and effort.

The participants described a lack of tenancy security in the private rented sector. Zack, for example, was worried about becoming homeless again if his landlord decided to sell the property. Kim was turned away because private landlords would not accept tenants in receipt of housing benefit. She visited the landlord's office in the hope that she would be more likely to receive support in person. Kim found an individual who sympathised with her situation and as a result she viewed a property from which she had previously been excluded due to being on housing benefit. By contrast, an earlier landlord had been receptive to Kim's needs and had allowed her additional time to find a new place when the time came to sell.

The interviews indicated that the choice of privately rented accommodation was limited. Will reported that moving from one private rental to another involved significant upheaval. He had resolved to remain in his privately rented home and wait for a council house, despite the 'dreadful' state of his housing. Other interviewees attested to little choice of social housing. Wendy described perceiving that if she did not take the housing offered to her she would be removed from the waiting list. Kim stated that the fact she was not homeless led to her being deemed as low priority by the council, in spite of the fact that she faced imminent homelessness. Mary described an experience in which social landlords had exhibited more concern for rent being paid than a recognition of the fact that her ex-husband was in hospital and unable to pay. Interviewees reported that a major barrier in social rented housing allocation was local authorities' failure to understand the needs of disabled people and their reasons for turning down housing offers. Will, for example, was told that the standard accommodation for one person was a one-bedroom dwelling. Will's visual impairment meant a one-bedroom property would have been unsuitable: he required an additional room for specialist aids, such as a computer and scanner to access written information, and adequate storage for food and other necessary equipment related to having a guide dog. Will insisted that the council make an exception to meet his needs and was subsequently offered a suitable two-bedroom ground-floor flat.

Some participants described realising that they needed to register with the correct system to gain access to the social housing appropriate to their needs. Once Alex

had registered with Cardiff Accessible Homes<sup>4</sup> he received support with the housing application process and managed to obtain a suitable flat.

Several participants revealed the barriers and prejudice facing disabled people in attempts to access suitable housing. Unity, a retired, disabled woman with a guide dog, faced difficulties when attempting to purchase a flat due to a clause in the management company's rules that forbade pets. When challenged, the leaseholders agreed to make an exception for a guide dog. Will asserted that local authority staff tended to assume that disabled people were not in employment. Zoe, who is deaf and moved into her home from a women's refuge, stated that she perceived discriminatory attitudes towards disabled people regarding housing choices, and towards those on benefits as a consequence of disability. She said she had felt treated 'like scum'.

## 5.2 Adaptations

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Our interviews revealed that home adaptations did not always meet the requirements of disabled people. Zack, for example, moved into an accessible home with his young disabled son but found that the adaptations were unsuitable for his son's needs: the kitchen was designed for an adult wheelchair user and Zack needed to have the facilities replaced with ones his son could use.

Both Zack and Alex reported that adaptations were installed in a timely manner, and Alex stated that the adaptations met his needs.

## 5.3 Support needs

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The interviews revealed that participants could not always resolve their housing issues alone and sometimes required the support and assistance of others. One participant reported that her sister had located her accommodation for her and that she paid for additional personal support. Interviewees emphasised the importance of being housed close to family and friends, and close to services such as general practitioner surgeries.

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<sup>4</sup> Cardiff Accessible Homes is an organisation that was set up in 2003 to help those wanting to move from their current property into a property that suits their needs. Accessible Homes is supported and funded by Cardiff City Council and six housing associations.

Interviewees reported that social landlords and service workers such as occupational therapists had a supportive attitude, but noted limited accessible information available from these service providers. For example, participants with a visual impairment reported that written materials were often unavailable in alternative formats. Obtaining the quality of service expected took persistence.

Two interviewees discussed being unable to recognise areas of disrepair when viewing potential new properties. Will, who is visually impaired, viewed his accommodation with a partner who also had a visual impairment. He felt that the letting agent had neglected to bring to their attention areas in disrepair. Will reflected that, to his knowledge, there were no support services available to make property viewings accessible, such as impartial sighted guides to accompany visually impaired people. Zoë had difficulty navigating the benefits system. She felt demoralised by its complexities and was only able to resolve her problems by drawing on the support of others. She stated that she 'totally understood' how people could become trapped on benefits, unable to see a way out – particularly disabled people requiring additional support to access advice and services.

Two interviewees asserted that they had overcome negative experiences by drawing on their own resourcefulness and personal connections when accessing services. One participant had a daughter who was a manager in the NHS who helped her get the care she needed, and stated that she was offered 'no official help'.

## 5.4 Location

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Although interviewees generally viewed their accommodation as suitable for their needs, all the participants described location as crucial. Will, who was registered blind, noted that he would feel vulnerable living in an area of high crime.

### Case study: the long road to independent living

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Zoe, a profoundly deaf adult of working age, described her experience of entering a women's refuge to escape domestic abuse and then finding a home in social housing.

#### Previous housing experience

Zoe had been a joint tenant with her ex-partner in a private sector rental. A friend of Zoe's advised her to seek help from Women's Aid for the domestic abuse she was experiencing.

When Zoe sought help she realised the vulnerability of her situation. After approximately six weeks, during which Zoe slept on a friend's couch, a housing officer offered Zoe a place in a local Women's Aid refuge. The refuge wanted to help Zoe immediately find a permanent solution, rather than the temporary housing more common for women in her situation. Zoe felt that the staff were taking her deafness into account and attempting to deliver appropriate support.

At the refuge's intake house, Zoe underwent a two-week assessment period alongside seven other women. From there, Zoe joined approximately 30 women and their children in a transitional unit directed towards rehousing in the community. Zoe found it difficult to communicate with others in the unit; there was a high turnover of women and Zoe had significant residual hearing loss.

The refuge staff made adaptations, provided some direct support, and sign-posted Zoe to relevant organisations. The refuge installed a flashing fire alarm with a vibration pad in the transitional unit, provided a case worker to assist with Zoe's transition to living in the community and pointed Zoe towards additional assistance from other organisations, such as local charities. Zoe's hearing impairment made phone calls to local services and organisations a challenge. Her refuge case worker assisted where possible but encountered difficulties; for example, when navigating data protection protocols adhered to by banks and credit card lenders.

### **Finding an accessible property**

During this period, Zoe experienced several challenges finding accommodation that suited her needs. She reported feeling as if local officials were looking down on her and her confidence suffered as a result. After moving into an unfurnished and dirty housing association flat, Zoe was left with minimal support from her housing officer. She requested the installation of a video-entry system due to concerns that she would be unable to confirm the identity of callers by their voice and that her ex-partner might try to visit. Zoe's request was refused by her housing officer and she was told she would have to pay for an installation herself, which she could not afford.

### **The impact of independent living**

Eventually, Zoe found a long-term, affordable, social housing flat that was suitable for her needs. She finally felt able to live independently. Working part-time and

meeting a new partner had helped her to rebuild her life and she had plans at the time of interview to further develop her career. Zoe asserted that basic human kindness from friends and strangers had provided her with more support than the professional services on which she had relied.

## Conclusions

Overall, the interviewees in South Wales reported positive housing situations, although these had commonly been achieved with support from key individuals. The participants had had different experiences of securing adaptations to their homes; many delivered positive reports but others detailed processes that had negative effects. Many participants reported having found the welfare benefit system confusing and frustrating.

## The interviewees

Table 5.1 summarises characteristics of the interviewees. All names are pseudonyms.

**Table 5.1 Interviewee characteristics in South Wales**

Name	Location	Tenure	Type of House	Age Group	Child's Impairment
William	City	Private rented sector	Ground flat	Disabled adult middle years	
Zack	City	Housing association	Ground flat	Family with disabled child	Physical
Unity	Rural	Owned	Bungalow	Disabled person retired	
Zoe	City	Housing association	Upper flat	Disabled adult middle years	
Wendy	Rural	Council	Bungalow	Disabled adult	

				middle years	
Alex	City	Housing association	Upper flat	Disabled adult middle years	
Diane	City	Private rented sector	Upper flat	Disabled adult middle years	
Mike	City	Housing association	Room in shared flat	Disabled adult middle years	
Kim	City	Private rented sector	Ground flat	Family with disabled child	Physical
Mary	City	Housing association	Ground flat	Family with disabled partner	Physical

# Chapter Six

## Conclusions

The people we interviewed had a wide range of impairments – physical impairments, learning difficulties, autism, visual and hearing impairments, and mental health conditions – and included people with deteriorating conditions. The qualitative research conducted for this report is not representative of all disabled people, but rather offers insight into themes emerging from the housing experiences of disabled people in Britain.

Ensuring access to appropriate, decent housing for all is a fundamental right provided under the UN Convention on the Rights of Persons with Disabilities. Our research suggests that disabled people are not always afforded this right. Our interviews uncovered the human cost of inadequate housing. Disabled interviewees were forced to navigate the stairs on their hands and knees, or had been confined to one room for periods of many years. Carers had no choice but to carry their physically disabled family members from one room to another, while parents of autistic children were often told the local authority could do little to help them. A common theme that emerged from the interviews was a feeling of being ‘trapped’ in unsuitable accommodation.

Many of the people we interviewed had reached a point of contentment with their housing, feeling that their current and anticipated needs were met. However, the interviews revealed an overarching theme of disabled people investing a lot of time and effort to achieve satisfactory outcomes. Whether participants were adapting their own home, buying a new one, or seeking a social or private rental property, they reported experiences in which they needed to show tenacity and patience, and often needed to accept shorter-term unsuitable accommodation to reach more suitable options in the long term. Many interviewees were articulate, confident people who had nevertheless faced barriers to accessing information, navigating services and accessing appropriate help and support. Disabled people who face additional vulnerability through not holding these advantages are likely to experience even greater social obstacles to successful housing outcomes.

Our research engaged disabled people known to voluntary and statutory agencies who, overall, exhibited a high level of resourcefulness and empowerment. The research findings highlight important questions. What are the housing experiences and outcomes for disabled people who are unknown to these agencies? What are the housing circumstances faced by those disabled people who are ‘hard to reach,’ don’t know to whom they can turn and are therefore less empowered? Undertaking further research with such people is an important task.

The interviews and case studies in this report demonstrate the importance of personal resilience, support from family and friends and, to a lesser extent, support from local authorities, housing associations and other local organisations. The long delays that our research participants faced often placed a considerable strain on their mental health. Participants spoke about their frustration and helplessness and the negative effects these feelings had on their lives, including their ability to work, socialise and take part in normal activities. For some participants, the stress of trying to resolve their housing problems emerged as more debilitating than their pre-existing impairment. This conclusion highlights the high social and economic costs of preventing disabled people from accessing appropriate housing in a timely fashion.

The findings indicate that the housing system seems to accommodate people with certain impairments more effectively than others. The interviews suggested that housing professionals were typically familiar with the needs of wheelchair users and those with physical disabilities. Housing professionals tended to be less familiar with the requirements of those with learning disabilities, autism, mental health conditions or sensory impairments. Several participants described experiences of local authorities that included ineffective support for families with disabled children

The evidence review preceding the empirical work demonstrated that Scotland, England and Wales have different housing policies. However, national strategic frameworks in the three nations share the ambition to improve the supply of appropriate housing and ensure sustainable communities in which disabled people’s organisations are effectively integrated and involved in decision-making. Research evidence of specific disability-related housing issues was uneven, with most of the evidence collected by charities and voluntary organisations that have a particular interest in the area.

In our research, the impact of different policy regimes in the three nations was not emphatic: more significant was the beneficial effect of key individuals and agents, and pilot initiatives of different forms. These agents and initiatives contended with a lack of joined-up thinking about how adequate and suitable housing could reduce

care and health costs. This suggests that aspirations for housing need and provision to be included in health and social care planning at local and national level have not, as yet, been realised.

How much difference does housing tenure make? Different outcomes emerged, largely reflecting divergent rights and responsibilities in the different sectors. Homeowners felt a greater sense of ownership and control over their circumstances, but this was tempered by worries about the affordability of making adaptations or buying a more suitable home in the future. Those in social housing tended to find it easier to have adaptations installed than homeowners and those in private lets. These individuals nonetheless often faced delays and obstacles.

The research revealed that problems such as poor property conditions and discrimination against tenants were experienced across the private rental and social housing sectors. Across all sectors, supporting disabled people to continue with work, education and social activities – enabling disabled people to be independent – emerged as of central importance. Appropriate housing for all disabled people, regardless of location and tenure, and regardless of form of disability, is essential for those benefits to come to fruition.

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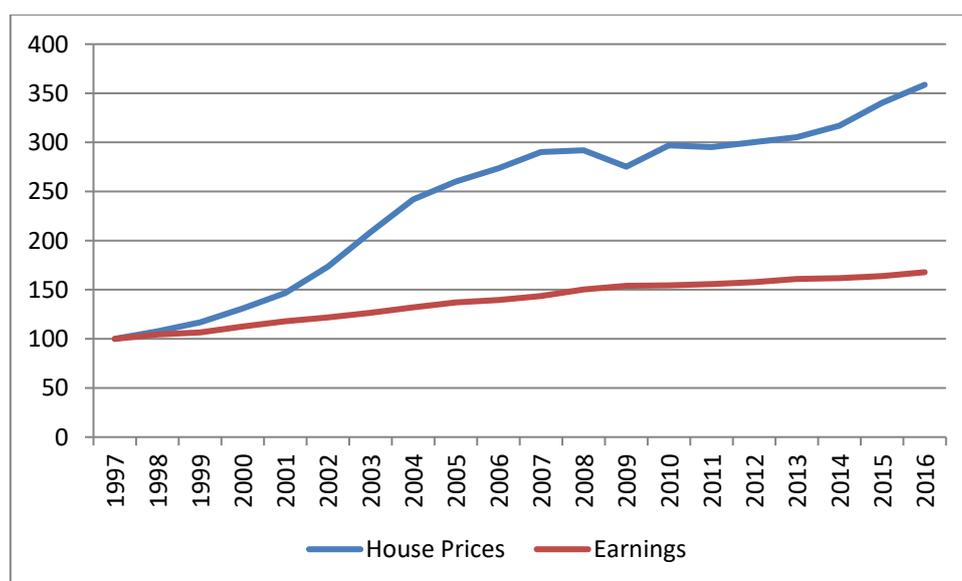
# Appendix 1

## Housing and disabled people – evidence review

### Introduction

After the recovery of the British economy from the global financial crisis of 2007–9, many parts of Britain saw rapid house price inflation alongside significant pressure on the supply of social rented housing. These resulted in individuals facing increasing difficulty accessing homeownership and facing long waiting times for social housing. Figure 1 below shows how price increases outpaced earnings since 1997 in England and Wales. Private rental supply grew in this environment, with concerns in different areas about rent levels (Wilcox *et al.*, 2017). Disabled people faced particular challenges in this context.

**Figure 1: Median price paid for property and annual earning indices**



Source: House Price Statistics for Small areas and Annual Survey of Hours and Earnings, Office for National Statistics (2017)

Housing tenure is a common marker of wellbeing, with homeowners perceived to enjoy greater rights than renting. The Commission has drawn on the Life Opportunities Survey, a large-scale longitudinal survey of disability in Britain, to report upon disabled people's experiences. Disabled people were less likely to own their own home in 2012–14 than non-disabled people (62.6% to 76.2%). The gap between ownership among non-disabled people and those with a mental health condition decreased by 1.9 percentage points between 2009–11 and 2012–14, but people with mental health conditions remained far less likely to live in accommodation that was owner-occupied (EHRC, 2017b, p. 81). English Housing Survey 2014–15 data show that 1.9 million households contained someone with a 'long-term limiting disability' who required adaptations to the home, and that this has not changed since 2011–12 (ibid, p. 82). Scottish data on housing and disability show higher levels of social renting and overcrowding, and a decrease in local authority wheelchair-adapted housing (ibid, p. 84).

## Housing stock

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Our knowledge of housing stock across England, Wales and Scotland varies due to data availability. The Ministry of Housing, Communities and Local Government (formerly the Department of Communities and Local Government) and the Scottish Government produce house condition surveys on a rolling basis. The relevant data here come from findings of the English Housing Survey (EHS) and Scottish House Condition Survey (SHCS), published in 2016 by the respective Governments from fieldwork carried out in 2014/15 (Department for Communities and Local Government, 2016; Scottish Government, 2016a). The data for Wales come from the Living in Wales Survey (Welsh Assembly Government, 2009), a cross-sectional survey carried out from 2004 to 2008 that is repeated on an annual basis. The survey includes some questions about housing quality, but these are not as detailed as a housing survey.

For the three nations, census data show that overcrowding (having at least one room under the room standard) tends to be less common among households within which at least one member is disabled (Table 1).

**Table 1: Rates of overcrowding and disability in Britain**

	England (%)	Wales (%)	Scotland (%)
Long-term health problem or disability: All categories:	11	7	11
Long-term health problem or disability: Day-to-day activities limited a lot	8	5	11
Long-term health problem or disability: Day-to-day activities limited a little	8	5	9
Long-term health problem or disability: Day-to-day activities not limited	12	7	11

Note: percentage refers to the proportion of people in that disability category living in overcrowded housing. Source: Census of Population, 2011

### Housing stock in England

The 2016 EHS analysis (Department for Communities and Local Government, 2016) included a specific focus on adapted homes for disabled people, and ageing within the home. The analysis found that 9% of households included an individual with a long-term disability that required an adaptation. Of these households, 81% felt their housing was suitable. Of those households including an individual with a long-term disability who felt they were in unsuitable housing, 32% were renting privately, 22% were in social rented accommodation and 15% were owner-occupiers. Within this context, 75% of households with the oldest resident over 55 are owner-occupiers, with 62% of these households owning outright; by comparison, 53% of households with the oldest resident under 55 are owner-occupiers, with only 9% owning outright.

Most of the adaptations required were straightforward (for example, grab-rails or adapted toilet seats). Households including an individual with a long-term disability where the oldest member was under 55 were less likely to have suitable adaptations (55% without) than where the oldest person was over 75 (55% to 36% without adaptations). Of those households without adaptations, 24% had not carried them out because they did not have time; 21% because they could not afford them; 10% because their landlord would not allow it; and 10% because they could not get a grant (a two-percentage-point increase from 2011–12). Of those households with a person with a long-term disability, 10% wanted to move to more suitable accommodation.

Data from the EHS show the positive impact that building regulations on accessibility can have. In England and Wales, Part M of the Building Regulations, *Access to and*

*Use of Buildings*, began to have an impact from 2001. This was demonstrated across four areas in newly built homes:

- Level access: 68% of homes (13.5% before 2001)
- Flush threshold to main entrance: 77.5% (19.9% before 2001)
- Wide doorways and circulation space: 80% (22% before 2001)
- WC at entrance level: 93% (61% before 2001)

These four categories make a home 'visitable' by someone with a physical disability. The EHS survey showed that across the whole housing stock 28% of homes could not be adapted to provide these four visitability elements. The data breaking down how visitable properties are by type showed 20% of flats were visitable, although this proportion declined if a lift was required. Less than 10% of all types of houses were visitable and over 50% of terraced houses could not be made visitable. Analysing by tenure shows that 18% of housing association homes were currently visitable; compared with 5% of owner-occupied homes, 8% of local authority homes and 7% of privately rented homes.

The hidden housing market by Habinteg and Papworth Trust (2016) included a survey of approximately 2,000 adults aged over 15 across Great Britain. The survey showed that more than 50% of the adult disabled population are under the age of 65 and 25% of disabled people of working age do not have the accessibility features they need. Disabled people were significantly more likely to be dissatisfied with their current home than non-disabled people (14% compared with 8%). Findings demonstrated:

- Working-age people living in inaccessible homes were four times more likely to be unemployed than those from other households, indicating the impact of housing on ability to work.
- Satisfaction levels were lowest among disabled people under 45 and those renting from a private landlord.
- 50% of people interviewed stated that they would favour remaining in their current home with some adaptations to achieve independent living. Even higher rates of disabled people (60%) and older people (63%) stated that they would prefer to stay in their current home to achieve independent living.
- 19% (9.8 million people across Great Britain) of people interviewed would favour moving to a different property that was specifically designed or adapted.
- 700,000 (39%) of households with a need for accessible housing had incomes in the top half of income distribution, indicating a market for accessible housing that was not being fulfilled.

## Housing stock in Scotland

The data from the Scottish House Condition Survey (SHCS) are less detailed. The SHCS found that 36% of households contained someone who was long-term disabled or ill, and 14.4% of all households believed they required adaptations to their properties. The data revealed that, of households containing at least one person who was long-term disabled or ill, 52% lived in owner-occupation; 22% in local authority housing; 16.5% in housing association properties; and 7% in privately rented accommodation.

Focus on those requiring an adaptation revealed that 45.6% of households lived in owner-occupied properties; 28.5% in local authority housing; 18.7% in housing association properties; 4.6% in private rented accommodation; and 15.1% of households lived in homes built after 1981. Of those households requiring an adaptation, 19.5% felt their home was not very suitable, or not at all suitable, and 50.6% were missing at least one adaptation. Younger disabled people (aged 16 to 24 years old) were more likely to be missing one or more adaptations in their household compared with households in which the oldest person was over 75 (60.7% compared with 39%).

Over 17, 000 wheelchair users in Scotland were estimated to have unmet housing needs in 2012 (Horizon HA and the Chartered Institute of Housing, 2012). In 2015, the Scottish Household Survey showed that 67,000 households in Scotland had great difficulty cooking or could not cook in their own home; 40,000 households included individuals who could not get in and out of their own home; and 38,000 households had great difficulty using or could not use their own bathroom or toilet.

Unlike in the EHS, there is not a break in the SHS data before and after accessible building regulations. However, focusing on the age of dwellings among households requiring an adaptation reveals 16.2% of those living in homes built after 1982 believed their home to be very or not at all suitable, compared with 18.7% of homes built pre-1919, 19% of homes built between 1919 and 1944; and 23.2% of homes built between 1945 and 1982. The higher percentage in the 1945-82 period is likely to reflect the high number of homes built by local authorities over those years.

## Housing stock in Wales

At the time of this report, the Welsh Housing Conditions Survey was last published in 1998. While a new housing conditions survey was being planned for 2017–18, the most recent source of detailed data came from 1998 (National Assembly for Wales, 1998). These data showed 56% of homes with at least one adaptation, and 10% of

homes requiring one or more adaptation, with broad trends similar to those in England and Scotland.

## Policy context, housing supply and adaptations

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In the following sections, we address the constituent nations of Britain in turn. Welfare reforms enacted since 2010 have had a significant effect upon the ability of vulnerable households to access housing. These reforms are reviewed in the England section, as welfare benefits are largely not devolved. Specific mitigation measures by devolved administrations are noted within relevant sections. A significant amount of the research evidence is from a British perspective. Much of this is reported in the section on England, because sample sizes and relative population sizes mean that British research is most likely to reflect the experience of disabled people in England as opposed to those in Scotland and Wales.

## England

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This section provides an overview of the legislative and policy context affecting housing for disabled people in England over the three years prior to the writing of this report.

Data from the Family Resources Survey (2014–15) show an estimated 10.7 million people (20% of the population) with a long-standing illness, disability or impairment causing substantial difficulty with day-to-day activities. For these individuals, mobility was the most prevalent impairment (53%), followed by stamina, breathing, or fatigue issues (39%) and dexterity (29%). Of the same group of people, 20% had a mental health condition (Department for Work and Pensions, 2016).

The data also show that the number of people with a disability increased with age, particularly after the age of 80, in which category 60% of people have a long-standing illness or disability. There were distinct regional variations, with levels of disability higher in the North East and the North West. Some rural areas also had higher levels of disability, which may reflect their older age profile compared with cities. In tandem to these findings, research suggests that the figures in official surveys may be an underestimate of true levels of disability by failing to account for households with disabled children and because disabled people do not always realise the extent of their needs (Provan, Burchardt and Suh, 2016).

## Housing supply and policy

At the time of writing, housing policy in England has been dominated by debates about housing supply, particularly in London, major urban areas and the south of England. The Housing White Paper *Fixing our broken housing market* was published in February 2017, and focuses on ways to stimulate the housing market by building faster and increasing the number of homes for rent since homeownership is out of reach for most new households (Department for Communities and Local Government, 2017).

The White Paper contains little specific information about housing for disabled or older people, only general assertions such as the following:

We propose to strengthen national policy so that local planning authorities are expected to have clear policies for addressing the housing requirements of groups with particular needs, such as older and disabled people. (p. 24)

We will explore ways to stimulate the market to deliver new homes for older people. (p. 63)

[We will] help older people to live independently for longer while relieving pressure on the adult social care system. (p. 64)

There is no indication of how the goals outlined above might be attained, other than a suggestion about providing improved information and advice about housing choices and adaptations. Solutions may also include support for custom-built, community living, innovative models of housing with support, supported housing, and sheltered, step-down or extra care housing (p. 64), but no details are provided by the paper. There is support in the White Paper for off-site development and modular housing but it is unclear to what extent, if at all, these will conform to accessibility standards. The White Paper is unlikely to deliver a substantial increase in 'last-time' homes for older people, or accessible homes for disabled people of all ages, particularly when the emphasis is on building at speed.

In parallel to the publication of the White Paper, at the time of writing The House of Commons, Communities and Local Government Committee was carrying out an inquiry into housing for older people in England, examining the provision of homes for older people and the challenges people face in accessing housing which meets their needs. It also considered: the adequacy of current planning policy; whether more housing specifically for older people was needed; whether specialist housing provision in England could improve people's health and wellbeing and deliver savings in public expenditure; if the right financial products were available to help

older people move home; and whether there needed to be a national strategy to support housing provision specifically for older people. The results will feed into a Green Paper in 2018 considering the entire range of care and support for older people in England.

In 2016, NHS England announced that it was aiming to work with 10 Healthy New Towns to improve health through the design of the built environment. It was not clear if this would include building more accessible homes, but it is hoped that accessibility will be a key factor in the planning guidelines for new housing in these locations.

The social housing sector is vital for disabled people. Households with disabled people tend to have low incomes, and a third of disabled people are in the social housing sector, where housing stock is more likely to be accessible, rents more affordable, and tenancies more secure. The number of new affordable homes is continuing to fall for three reasons: reductions in housing association income due to falling rents and benefit cuts, the reduction in the strength of planning obligations, and the more commercial nature of the housing association sector as government grant allowances are cut. A reduction in rents of 1% for the following four years was introduced in April 2016 (Department for Communities and Local Government, 2016a). The cap on housing benefit and the continuing roll-out of universal credit were, at the time of writing, leading to higher levels of arrears due to rents no longer being paid directly to landlords.

A report by the Joseph Rowntree Foundation in 2015 showed that the number of new homes being delivered through planning obligations (Section 106 agreements) in England had halved (Brownill *et al.*, 2015). In 2006–7, 32,000 (65%) of all affordable homes were completed through S106 agreements but, by 2013–14, this had fallen to 16,193 homes (37%). Right to buy for housing associations was rolled out on a voluntary basis and through regional pilots from April 2017. This may further reduce the supply of affordable, accessible housing. A survey of the 50 housing associations completing the highest level of development in June 2016 showed a 20% fall in overall provision of new homes, and a shift away from new affordable and social rented homes towards market sale and private rent products (McCabe, 2016). In 2014/15, only 8% of homes completed by the largest associations were for sale on the open market, but this had reached 15% by 2015/16. Although in many cases housing associations complete private sales to cross-subsidise affordable housing, this further restricts choice for households containing a disabled person.

The Housing White Paper does little to alleviate the problems in the private rented sector. The emphasis is to encourage 'build to let' by private companies, rather than

a further expansion of social housing. This may allow some homes to be let on longer tenancy agreements, but the rents may be beyond the level that people on the lowest incomes can afford.

### Adaptations and the supply of accessible and adapted homes

In England, the main funding source for adaptations is the disabled facilities grant (DFG). Table 2 below gives details of its use by tenure.

**Table 2: Disabled facilities grants in England**

Tenure	Means-tested grant	Non-means tested discretionary grants
	DFG provides adaptations up to a maximum of £30,000 in England. There is a test of resources for adults, but not for families with children and young people under 18. There is no duty for housing authorities to fund more than £30,000, but social care may top up funding in some cases.	Flexibility in use of the DFG is allowed under the 2008 Regulatory Reform Order, but authorities must have an approved, written policy. Only about half of authorities have developed these plans and not all give non-means tested grants.
Owner-occupier	Yes Means-test does not take account of mortgage payments, so the test of resources is less generous to younger owners who may not be able to afford to contribute to costs.	Yes
Private tenant	Yes Proves difficult to deliver if the landlord does not agree to the work being carried out, if adaptation is expensive but there is no security of tenure, or if the landlord insists on the local authority agreeing to remove the adaptation when the tenancy changes hands.	Yes

Local authority tenant	<p>No</p> <p>Use the DFG criteria, but funding usually provided through the Housing Revenue Account not the DFG. Sometimes delivered by a separate team but often combined with DFG teams. Some adaptations were also done as part of Decent Homes work but this was not a requirement of the Decent Homes legislation and not always well-co-ordinated. Most decent homes work has now finished.</p>	No
Registered landlord/housing association (either tenant or landlord can apply)	<p>Yes</p> <p>RLs used to have their own direct funding in England but this was removed incrementally and ceased in 2008. Most RLs do their own minor adaptations (usually up to a cost of £1000) and a few also fund major adaptations, but most refer tenants for a DFG for work over £1000. In some places, adaptation agreements with local authorities mean there are contributions to DFG funding ranging from 20–50% of the costs, but these are the exception rather than the rule, and are becoming less common.</p>	Yes
Former council tenant (Large Scale Voluntary Transfer Organisation)	<p>Variable</p> <p>LSVTs should have set aside money to pay for adaptations for disabled tenants, but early transfer associations did not do this. Even when a budget existed, it may have only been</p>	Variable

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for the first five years. Some adaptations were also done as part of Decent Homes work, but this was not a requirement of the Decent Homes legislation. Some LSVTs have excellent adaptation policies and a few even employ their own occupational therapists (OTs); however, others make considerable demands on DFG budgets.

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The most significant impacts on home adaptations in England have been the inclusion of the DFG funding in the joint health and social care budget (the Better Care Fund) from April 2014, and the increase in central government resources that came into effect in April 2016. At the time of writing, DFG funding was due to rise each year until 2019/20, from £220 million in 2015/16 to £500 million in 2019–20. This was intended to double the number of grants completed to 85,000 by the end of the decade and prevent 8,500 people from needing residential care. However, the central government contribution is only one component of the broader picture. Many local authorities contribute their own money and some housing associations contribute funding, although these amounts have varied, particularly since 2010 (Mackintosh and Leather, 2016). The proportion of local to central government funding has dropped from roughly an equal share in 2004/5 to approximately 25% from local councils and 75% from central government in 2014/15. This change reflects wider pressure on local council budgets.

Mackintosh and Leather (2016) show how funding and grant delivery evolved up until 2014/15. The grant has not always been delivered effectively; key parts of the customer pathway are dealt with by different services. Occupational therapists are in social care (at county level in two-tier authorities), but casework and technical teams are usually based in housing (at district level in two-tier authorities), or in home-improvement agencies. Delays and lack of communication have been the most common problems and several reports have highlighted the substantial difficulties this has caused for disabled people (Local Government and Social Care Ombudsman, 2016; Muscular Dystrophy UK, 2015).

Mackintosh and Leather (2016) report that most people appear to find out about the grant through word of mouth, which means that more isolated disabled people may

not be aware of its existence. A report by The Muscular Dystrophy Campaign showed that only 50% of 200 young disabled people surveyed had heard of the grant (Trailblazers, 2012).

Even prior to the development of the Better Care Fund and the increase in DFG resources, some local authorities had begun to make substantial changes to services. Diverse areas such as Wigan, Cornwall, Leicestershire and Ealing are developing more effective and joined-up models of DFG delivery (Mackintosh and Leather, 2016). The most integrated service identified so far is Knowsley, where extensive consultation with older and disabled people has resulted in a 'one-stop-shop' through which all services for older and disabled people are provided under one roof, and the DFG is only one strand of a much broader, holistic housing service.

Some authorities in England provide innovative solutions, such as home from hospital services, or dementia grants, often using a 'fast-track' approach without a test of resources. Foundations (the coordinating body for home improvement agencies and handyperson services in England) has established a DFG Champions' network and is providing training and roadshows to pass on good practice and encourage other authorities to improve and streamline services.

The integration of health and social care services in England, and in some devolved areas such as Greater Manchester, could have a significant effect on services for disabled people. Sustainability and Transformation Plans were produced for 44 health regions in late 2016, but detailed discussion about housing remained absent from most plans. A Memorandum of Understanding was signed in 2014 by a number of government departments along with health, social care and housing organisations to ensure that housing issues are part of the health and social care agenda (Department of Health and Public Health England, 2014). Social prescribing by health centres and GPs might be a way of targeting the DFG at those most in need.

A major source of practical help with adaptations and repairs has been from Home Improvement Agencies (HIAs). Many had core funding from the Supported People fund, which has been substantially reduced. In the few years prior to the time of writing, several HIAs had been taken in-house by authorities or had closed. Only a small number of independent HIAs remain (Mackintosh and Leather, 2016).

The loss of HIAs is likely to have a negative effect, as they provide non-statutory services that are often not available elsewhere. HIAs help people raise funding to improve their homes, provide access to reputable builders and can support project management. HIAs also offer handyperson services, small scale repairs and home security, and help with energy efficiency, decluttering and housing options advice. If

these services are unavailable, disabled people who do not qualify for the DFG service have nowhere to turn. The Care Act 2014 requires suitable housing to be taken into account and for people not eligible for local authority services to be effectively signposted elsewhere, but there is currently a gap in HIA services in many areas.

Since 2004, the London plan (Mayor of London, 2016) has required that:

- 90% of new housing meets Building Regulation requirement M4 (2) 'accessible and adaptable dwellings'
- 10% of new housing meets Building Regulation requirement M4 (3) 'wheelchair user dwellings'; that is, designed to be wheelchair accessible, or easily adaptable for residents who are wheelchair users.

At the time of writing, a revised London plan was being produced, but there was no indication that the accessibility requirements would change under the new mayor. In 2012–13, 95.1% of completed homes in London were built to Lifetime Homes Standards and 9.5% were built to wheelchair accessible standards; 84.5% of homes given building approval met Lifetime Homes Standards, and 8.4% were wheelchair accessible (Leonard Cheshire Disability, 2014a). It is unclear if developers' viability calculations have affected the number of accessible homes that have been built subsequently. Space standards are often central to enabling the adaptability of homes. The Housing White Paper (Department for Communities and Local Government, 2017a) mentions 'pocket homes' or 'micro-homes' (flats that are only 400 square feet, rather than the 500 square feet minimum) and states that the London mayor has accepted a 400 square feet space standard for some new build developments to boost housing supply for younger people. This is likely to hinder accessibility and adaptability.

Elsewhere in England, policies to build accessible homes are not as robust. The Building Regulations Category Two standard (equivalent to Lifetime Homes Standard) is optional, not mandatory. Habinteg is campaigning for all local authorities to make Category Two the default standard, and has produced an accessible housing toolkit to help planners assess the need for accessible housing in their area (Habinteg, 2017). A freedom of information request by Habinteg (returned by 82% of English local authorities) showed that, excluding London, only 3% of local authorities had policies to deliver and monitor the number of accessible homes built.

A survey of local authorities across Great Britain (Leonard Cheshire Disability, 2014b) revealed that, despite councils' legal responsibility to 'periodically review the housing needs of its area' and to 'have regard to the special needs of chronically sick

or disabled persons', nearly one third of councils (32%) either did not mention disability at all in their housing plan or mentioned it only in passing. Of those councils with a housing plan, less than one fifth (17%) had plans to build disabled-friendly homes in the year ahead. Only 5% of housing authorities had carried out any analysis of the additional costs to health and social care of inadequate housing.

Finding an accessible home is not straightforward. The results of a survey of 200 young disabled people and of 12 focus group meetings across Britain showed that respondents were waiting years to find accessible housing (Trailblazers, 2012). Estate agents exhibited little or no understanding of accessible property, and websites in all housing sectors did not provide the right information to determine whether properties were disabled-friendly. Many respondents stated they had been forced to search through thousands of properties individually in the absence of easy ways to locate suitable homes on leading property websites. Leonard Cheshire Disability surveyed over 2000 adults aged 18 and above across Great Britain in 2014 and found similar issues (Leonard Cheshire Disability, 2014a). More than half (54%) of those who had mobility problems, and who had looked for accessible homes, stated that they were difficult to find.

Even when good local authority policies exist, and accessible homes have been built, it is not always easy for disabled people to access information. A mystery shopping exercise on London development sites revealed that marketing personnel did not have information about which properties were built to Lifetime Homes or wheelchair standards, and often did not understand what those terms meant (Chaffin-Edwards, 2015).

Accessible housing registers are often regarded as the solution to housing provision. London has an accessible property register, but this only operates in a small number of boroughs. A survey of local authorities across Great Britain in 2014 revealed that 83% of councils did not have a register. Only 16% of councils could provide any data on the number of homes in their area which were wheelchair accessible, and only 10% could provide data on the number of homes built to Lifetime Homes Standards (Leonard Cheshire Disability, 2014b). Registers are expensive to set up as they usually involve an extensive survey of properties that most local authorities cannot afford to carry out.

Choice-based letting (CBL) systems for social housing should have mechanisms to give priority to disabled people when bidding for an adapted property. Some councils take this mechanism further, providing a service to match disabled people to adapted properties. Councils should also make reasonable adjustments to ensure that

disabled people are not disadvantaged when using CBL systems and that they are given extra time to bid. However, the way CBL systems operate appears to be inconsistent and it is difficult to move between different areas (Galbraith, 2017).

Some local authority adaptation services offer help with rehousing for people eligible for a DFG. These usually operate across all tenures to help people to find a more appropriate property. The DFG can be used to pay for adaptations to the new home if required (Mackintosh and Leather, 2016). However, a freedom of information request in 2016 by Foundations found that across England only 283 people were helped to move in 2015/16. Home Improvement Agencies also offer housing options advice and help with searching and moving, but it is difficult to develop these services further without secure, core funding.

For older people wanting to move, the FirstStop website and telephone helpline provide housing advice and offer lists of available properties. In the period 2013–15, eight out of every ten clients helped had long-term health issues or were disabled, and, of all users, 37% wanted to move and 38% needed adaptations (Cooper, 2015).

In 2016, Aspire produced a report illustrating the difference adapted and accessible housing makes to people's lives (Smith and Caddick, 2015). The report considered the experiences of people with spinal cord injury, demonstrating that an accessible home provided an environment in which people could have a good quality of life, manage their physical health effectively, be happy and sustain relationships. By contrast, non-adapted homes had a negative impact on wellbeing, often leading to the benefits of rehabilitation being lost and physical and mental health being jeopardised. Depression, loneliness, stress, and feelings of worthlessness were shown to be common and the non-adapted home also adversely affected family relationships. Long conflicts with local authorities to get adaptations, or to move to alternative housing, made situations worse. The report concluded that savings could be made in health and social care with better discharge planning; more accessible housing (both in the private and social sectors); a faster process to obtain adaptation grants; and appropriate care to allow people to live independently.

### **Impact of welfare reform**

A briefing paper produced in 2016 demonstrates the importance of welfare benefits to disabled people (Kennedy, Murphy and Wilson, 2016). In 2013/14, 83% of families in Britain with at least one disabled adult and no disabled children were in receipt of benefits, and 38% claimed an income-related benefit. Rates were even higher for

families with disabled children – 95% of families with a disabled child (and no disabled adult) received benefits, and 37% received an income-related benefit.

In October 2016, the Work, Health and Disability Green Paper covering Britain was published (Department for Work and Pensions and Department of Health, 2016). The paper showed that, overall, 4.6 million disabled people and people with long-term health conditions were not in work, and that there was a considerable difference in the employment levels of disabled people compared with non-disabled people (48% to 80% in work)<sup>5</sup>. The 1.2 million disabled people with five or more conditions had an employment rate of only 23%, indicating that low incomes are likely to affect a high proportion of disabled people.

Since 2008, the following welfare changes have affected disabled people's incomes and their choices in the housing market:

- Incapacity benefit was replaced by Employment and Support Allowance (ESA) to cover day-to-day living costs for people with a health condition or disability who are unable to work
- The 'spare room subsidy' was removed for those on housing benefit in social housing
- Council Tax Benefit was replaced by localised support
- Disability Living Allowance (DLA) for people of working age was replaced by Personal Independence Payment (PIP)
- Means-tested benefits and tax credits for working-age families gradually replaced by universal credit
- Lower rates of housing benefit for under-35s
- Lower rates of Local Housing Allowance for people in the private rented sector
- Service charges for disability aids and adaptations were no longer reimbursed through housing benefit.

The removal of the spare room subsidy (RSRS) (commonly known as the 'bedroom tax') affected approximately 559,000 working-age households. The Department for Work and Pensions (DWP) made an initial equality impact assessment that estimated almost two-thirds of these households would contain one or more registered disabled persons (Wilcox, 2014). Research has shown that it has been difficult for disabled tenants to find suitable alternative accommodation, particularly if they had been living in a specially adapted home (Wilcox, 2014; Moffatt *et al.*, 2016). Remaining in their current home often resulted in financial hardship and reduced

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<sup>5</sup> These data are drawn from the Labour Force Survey and refer to full- and part-time employment among those aged 16 to 64. Full-time students are excluded.

expenditure on food, heating and clothing for disabled people. The impact for some disabled people and their families was severe; the additional room was often revealed as necessary for partners to be able to sleep, a carer to stay overnight, disabled children to sleep separately from siblings, or essential equipment to be stored. Claimants could be referred for Discretionary Housing Payments (DHPs) but the application of these payments is subject to significant variation. A number of disabled tenants challenged the RSRs in court, eventually resulting in an extra bedroom being allowed if a child with severe impairment is unable to share a room.

An evaluation published by DWP in 2015 found that most affected tenants did not consider themselves to be 'over accommodated' and that only about 8% of those affected have downsized (Cambridge Centre for Housing and Planning Research and Ipsos MORI, 2015). Moves were more likely in the south and east of England where rents were high and there were more smaller properties available, although less likely in London where the opportunities to increase earnings may have been higher. In the north, particularly North West England, a lack of smaller properties made it more difficult for people to move. Moves were least common in Wales and Scotland due to a lack of smaller stock and DHPs being more readily available.

New guidance was published by DWP in 2017 (The Secretary of State for Work and Pensions, 2017). The guidance stipulated that, from April 2017, some categories of household needing an extra room did not have to pay the additional costs. Allowances also were made for a bedroom for a non-household carer who stays overnight to look after a child or other person in the household, and separate bedrooms for each member of a couple who cannot sleep in the same room due to disability. The guidance only mentions physical health problems and it is not clear if it also covers claimants with mental health conditions.

In a report for Habinteg, Kane, McGill and Halliwell (2013) looked at the impact of benefit cuts on tenants and concluded that 'the government's programme of benefit cuts' would not only 'further impoverish disabled people', but also posed a threat to disabled people's ability to 'live independently' and to their 'human rights' (Kane *et al.*, 2013, p. 7). This research was carried out only six months after the major changes to welfare benefits began. The authors highlighted that their analysis did not take account of the cumulative effect of the cuts over a longer period or the impact of higher fuel costs, and that there was a clear 'trend towards greater inequality and poverty' (*ibid.*, p. 27).

Many disability organisations have expressed concern that the new benefits are more restrictive than the ones they replaced, and that there have been long delays in

payments being received. The Work Capability Assessment process has been criticised for not taking account of mental health conditions or fluctuating conditions, and for delays in payments and lack of support towards employment. Several high-profile cases have involved problems with contractors carrying out assessments. In 2015, PIP overtook ESA as the number one problem dealt with by Citizens Advice services (Citizens Advice, 2015). A high proportion of cases have gone to appeal, where decisions are often overturned. Following a review, a UK Government Green Paper (Department for Work and Pensions and Department of Health, 2016) suggests a simpler assessment system that draws as far as possible on information which has been gathered from the NHS, the adult social care system or other benefit applications.

Research for the Joseph Rowntree Foundation considered the impact of changes to welfare benefits across the English housing association sector (Power *et al.*, 2014). The research found that tenants who had previously been 'unseen' (their rents were paid directly) now required support to prevent arrears and evictions. Tenants had serious concerns about poverty, with associations needing to provide more advice on jobs and benefits, and deliver a stronger focus on work, training and skills. Associations needed to help tenants budget to meet rent, council tax payments, and food and energy bills. They were also supporting food banks. New tenants were being assessed more carefully before property allocation, with more tenants being rejected. Housing associations had to reconcile their own financial viability with their commitment to house low-income tenants and vulnerable groups, made even more difficult by the 1% reduction in rents and the benefit cap. Not all these changes were directly affecting disabled tenants; many were exempted from reductions in welfare benefits.

The challenge to the viability of housing associations means they may have to cut-back on discretionary services for disabled tenants. The reliance of disabled people on housing associations suggests that they are likely to be negatively affected by the pressures on the sector in England.

### **Pressures on social care**

Alongside benefit changes, local authority budgets were reduced considerably after 2010. Analysis by APSE suggests that social care budgets were prioritised over other service areas, although these budgets still failed to rise with increased demand from an aging population or with inflation. Research by Age UK (2017) showed:

- There was a £160 million cut in total spending in real terms to older people's social care in the five years prior to 2015/16.

- Funding transferred from the NHS to social care grew from 2% of the total public spend on older people's social care in 2006/07 to 16% in 2015/16.
- In 2017, there were nearly 1.2 million people (1,183,900) aged over 65 who were not receiving the help they needed with essential daily living activities. (This represented a 17.9% increase from the previous year and a 48% increase since 2010.)
- Nearly one in eight older people were living with some level of unmet need.
- The percentage of older population receiving social care support fell from 15.3% in 2005/06 to 9.2% in 2013/14.

A survey of young disabled social care users commissioned by Scope in 2014 showed that, between 2010 and 2014, a quarter of social care users had experienced no change in services, a fifth stated that services had improved, and over a third (36%) stated that services they used had become less effective at supporting them (Grayston, 2015).

Estimates of the number of people who provide unpaid care vary from more than 6.5 million people (Carers UK, 2016) to over 9 million (Age UK, 2017). Hours of care provided are increasing in line with an ageing population exhibiting more complex health and care needs. Approximately 20% of carers are aged 65 and over and full-time carers are twice as likely to be in bad health themselves as non-carers (Carers UK, 2016).

Age UK gives even higher figures for England alone (Age UK, 2017). It estimates that:

- Of an estimated 9 million carers, an estimated 2 million are aged 65 and over, and 417,000 are aged 80 and over
- 37% of carers aged 80 and over are providing 20 hours or more of care a week, while 34% are providing 35 hours or more
- Nearly two-thirds of older carers have a health condition or disability and 72% report feeling pain or discomfort, which rises to 76% among those who provide 20 or more hours of care a week.

Almost three million people combine paid work with providing informal care, while an estimated two million people have given up paid work to provide care (Department for Work and Pensions and Department of Health, 2016).

Most carers are in the owner-occupied sector and face the challenge of adapting homes to make them suitable for their caring role. A survey by Carers UK found that 20% of carers were waiting for home adaptations in 2014, with 9% of carers stating

that their home was in poor condition (compared with 15% in the private rented sector). Fuel poverty was highlighted in the survey; many carers have high utility bills as a consequence of keeping a house warm for someone who is unable to regulate their body temperature or is immobile for long periods (Carers UK, 2016).

### **Experiences of disabled people and intersectional experiences**

There has been minimal research into the housing issues facing children, young people and their families since the mid-2000s. Families with disabled children and young people are the worst housed of all disability groups, with almost half of all disabled children living in housing that is not suitable for their needs, and are the group most likely to want to move home (Beresford and Rhodes, 2008; Cavet, 2009). Research by Contact a Family showed that families with disabled children are often on low incomes, feel very isolated, spend a lot of time trapped in their own homes, and find services poorly co-ordinated and difficult to navigate (Contact a Family, 2011).

In 2015, Demos examined the experiences of families and children living with life-threatening and life-limiting conditions (Paget and Cadywould, 2015). In total, the number of disabled children aged 0–16 in Great Britain in 2011–12 was 800,000. The authors estimated that there were 49,000 children and young people aged 0–19 across Britain with life-threatening and life-limiting conditions that might require palliative care. The report showed that progress had been made since research 10 years earlier, with more personalised care and support being delivered, but families with severely disabled children have very high costs and low incomes. The report mainly focuses on health, social care and education services, with no mention of housing. A lack of services coordination is a common theme throughout the report, and accessing care and support are revealed as a continuous challenge. The research also identified that services varied geographically and identified the different approaches taken in each jurisdiction in Britain. The authors pointed out that the gains made for these families are in danger of being lost because of cuts to local authority services and welfare reforms.

Children with autism spectrum disorder require a safe home environment; it can be difficult to manage harmful behaviour in a home without adaptations. Research by occupational therapists showed that, because the condition does not confer physical disabilities upon autistic children, their families have sometimes been unable to access, or faced long delays in accessing, the DFG (Boyle *et al.*, 2014). The research recommended that the management of grants be improved to meet the needs of autistic children and their families.

Families with children are now the biggest group in the private rented sector and half a million children live in unsafe private rented homes (New Policy Institute, 2015). Concerns exist that, under universal credit, many families with disabled children will suffer financially, and families whose caring responsibilities prevent them from working will lose more than £1600 per year (Contact a Family, 2017).

The housing needs of people with sight loss and dementia have received increased profiles. One in five people in Britain over the age of 75 are living with sight loss, rising to half of all people aged over 90. Dementia is increasing and may also lead to impaired vision and visual disturbances. Better design can improve people's health, wellbeing and ability to manage at home (Thomas Pocklington Trust, 2013; Dementia Services Development Centre, 2013). At the time of writing, these designs had mainly been applied to care homes or extra care settings, but expertise should be extended to the adaptation of ordinary housing and the development of new, accessible homes. A few local authorities are starting to offer DFGs tailored for people with dementia.

Specific health conditions are more prevalent in certain communities. Rates of dementia appear to be higher in ethnic minority groups, but lack of understanding and stigma are attached to the condition. Culturally appropriate services are required to raise awareness and provide community-based support and appropriate housing services (Truswell, 2013). The Demos report on children with disability suggested that ethnicity is the most poorly researched area of disability, but the incidence of life-limiting illness is greater in some ethnic minority communities, and, 'to deliver an equitable service, practitioners need to adapt to different cultural and religious beliefs and attitudes towards disability, caring, illness, death' (Paget and Cadywould, 2015, p. 63).

The Thomas Pocklington Trust (2013) conducted research into the lived experiences of housing for visually impaired people. Many younger adults with sight loss do not need ongoing care or support (although some require it), but most need intensive time-limited support to find a suitable property, move into it, make minor adjustments and learn new routes around the local area. Some people receive support from family and friends but support can be difficult to obtain from formal services. The research found that young visually impaired people relied upon the private rented sector. Independent living was facilitated by: the location of housing in relation to public transport, essential amenities, accessible road crossings and support networks; a property in good repair; sufficient space for equipment and guide dog; and security of tenure. Barriers to accessing properties in the private rented sector included: affordability; blanket restrictions on those claiming benefits; limits to the

amount of rent covered by housing-related benefits; and direct and indirect discrimination by landlords and their agents. Some research participants reported reasonably positive experiences in the private rented sector, while others described challenges in sharing with strangers, getting landlords to agree to even simple adaptations or needing to move again at short notice.

A common theme in the research was that visually impaired people did not have enough points while on council and registered social landlord (RSL) housing lists and some had been waiting for years. Available properties tend to be in less desirable areas and some people described feeling particularly vulnerable to attack and abuse as a result of their visual impairment. Choice-based lettings systems presented challenges for people with sight loss, due to the difficulty of making a quick decision about whether a property would be suitable and bidding for it online. Some respondents stated that they felt under pressure to accept any offers, even if they were unsuitable. There are very few housing advice services or resources available for younger adults with sight loss who are seeking to move to independent living, and many used social networking sites, friends or parents to investigate their housing options. More advice and information is available for those facing a housing crisis or who have lost their sight since acquiring their own home.

## Wales

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The 10 to 15 years prior to the time of writing this report saw several reviews and inquiries being undertaken in Wales to investigate home adaptations (Jones 2005; Bibbings, *et al.*, 2015). This section summarises the effects of these reviews and inquiries on Welsh Government and local authority policy regarding housing adaptations, and considers other evidence and policy changes to provide a Welsh perspective on housing and disabled people.

### Housing supply and policy

In Wales, the Government's guidance and expectations are progressive. The Government desires "'barrier free" housing developments' (Welsh Government, 2016, p. 131); all new homes in Wales should be being built to the Lifetime Homes Standards of good value, sustainability, adaptability, accessibility and inclusivity. The focus on planning does not mark a failure to recognise the need for adaptations in existing or new build properties. The Welsh Government's housing quality guidance for social landlords (Welsh Assembly Government, 2008) emphasises that, if tenants

with specific needs are to be accommodated, their homes should be adapted and all necessary aids and equipment provided. The Housing (Wales) Act, 2014, has similar principles of sustainability in housing to those seen elsewhere in Britain (Welsh Government, 2015).

The Welsh Government also insists that all planners of housing should ‘ensure that development plan policies are based on an up-to-date assessment of the full range of housing requirements across the plan area over the plan period’, and that ‘local authority planning and housing staff should work in partnership with local stakeholders, including private house builders’ (Welsh Government, 2016, p. 132).

The Welsh Government principle of ‘progressive universalism’ (Drakeford, 2006) has resulted in policy initiatives such as free prescriptions and bus passes. Means testing is not generally regarded as compatible with progressive universalism, but DFGs continue to be means-tested. Welsh Government policy at the time of writing was to carry out a Wales Audit Office audit of the adaptations system in light of six reviews between 2004 and 2015 (Bibbings *et al.*, 2015; Boniface and Morgan, 2017). The Welsh Government is aligning its strategies (for example, *Together for mental health* (Welsh Government, 2012) and its legislation (for example, the Social Services and Wellbeing Act 2014 and the Wellbeing of Future Generations (Wales) Act 2015), and identifying how strategies and legislation interact.

### Adaptations and the supply of accessible and adapted homes

Mandatory disabled facilities grants (DFGs) are available to disabled people to help them adapt their home, with top-up discretionary grants also available in different local authorities up to differing levels. Legislation stipulates that disabled facilities grants are available to eligible individuals regardless of housing tenure, but in practice there are different funding routes for different housing tenures in Wales (summarised in Table 3 below).

**Table 3: Disabled facilities grants in Wales**

Tenure	Disabled facilities grant (DFG) up to £36,00 with discretionary grants available – provided by local authorities (means tested)	Physical Adaptation Grant (PAG) – provided by the Welsh Government (requires three quotes for the work to be carried out)	Rapid Response Adaptations Programme – up to £350 provided by the Welsh Government, delivered by the various arms of
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			Care & Repair Cymru after referral by a professional, e.g. Occupational Therapist (OT)
Owner-occupier	Yes	No	Yes, but only if over 60 years old
Private tenant	Yes	No	Yes, but only if over 60 years old
Local authority tenant	Yes	No	No
Registered social landlord/housing association	Yes	Yes	No
Registered social landlord/housing association tenant	Yes	No	Yes
Former council tenant (Large Scale Voluntary Transfer Organisation)	Yes – but LSVT should have set aside money to pay for adaptations for disabled tenants	No	No

At the end of 2016, the Welsh Government introduced a new enhanced adaptations system titled ‘ENABLE’ as a result of the most recent review of independent living adaptations (Bibbings *et al.*, 2015). The goal of the ENABLE system was to make it as simple as possible for those needing adaptations to request and acquire them. ENABLE aimed to identify and resolve blockages in the system. The Welsh Government allocated £4m to the programme, creating three broad adaptations categories – very small, small, and large (Community Housing Cymru, 2016; Breeze, 2017).

Legislation concerning home adaptations is complex, evolving in the wake of welfare changes and Welsh Government reviews. Perhaps most overtly, legislation is dependent on the housing tenure of the disabled person. At the time of writing, the most recent influential pieces of legislation in Wales were the Social Services and Wellbeing Act 2015 and the Wellbeing of Future Generations (Wales) Act 2015. A

specific memorandum in Wales, the Disabled Facilities Grants (maximum amounts and additional purposes) (Wales) Order 2008 (National Assembly for Wales, 2008), introduced the highest maximum sum for DFGs in Britain of £36,000. The order clarified that local authorities had the power to reclaim DFG funding where the grant had been over £5,000 once individual circumstances had been considered.

The same order made provision for a DFG to be paid to a disabled applicant to facilitate access to a garden, or to make a garden safe for a disabled occupant. The Physical Adaptations Grant (PAG), directly funded by the Welsh Government, is only available to registered social landlords (Warren, 2017). As a result, those living in Large Scale Voluntary Transfer (LSVT) housing may not receive adaptation provision if their landlord has not taken full notice of the expectation that it is their responsibility to fund adaptations on transfer.

As is the case in England and Scotland, money is taken back upon sale of the property if the DFG adaptation grant has exceeded £5,000, but there is no specified maximum charge in Wales and the charge is left to the discretion of the local authority once it has taken individual circumstances into account (Age Cymru, 2016). Equipment provision and payments are also at the discretion of each local authority and sometimes equipment is available from health sources.

Research into the experiences of families with a disabled child of the adaptations process in Wales (Morgan, Boniface and Reagon, 2016; Boniface and Morgan, 2017) found that families felt excluded from the process of adaptation. The research concluded that this sense of exclusion was due to the following factors: the needs for adaptations to meet the disabled child's needs and those of the wider family were not met; professionals did not always work in partnership with families; a paucity of information about adaptations related to children existed; families would have liked a single point of contact to guide them through the process; and families did not realise the part they can play in increasing delays in the adaptations process.

A Welsh Government (2013a) review of accessible social housing found that 'all local authorities in Wales have a process for allocating disabled people to accessible housing' (p. 16), but that only 14 local authority areas (of 22) had an accessible housing register in the local area. At the time of the review, accessible housing registers were therefore not universal in Wales, but local authority processes were in place for matching disabled people with suitable housing, and other registered social landlords offered a mixture of provision. The emerging picture is of disparate policies, which is reflected in the way that the accessible housing registers that do exist are run (Welsh Government, 2013a).

## Impact of welfare reform

The changes to the welfare system discussed earlier in this review apply equally to Wales. Disability Wales's 2013 report expressed concern that reform to the general welfare system would adversely affect all but severely disabled children in relation to the under-occupancy rule and housing benefit. A review of these changes concluded that 'the majority [of studies] do not provide recommendations that relate to housing policy and few identify actions to be taken by the Welsh Government' (Williams and Carter, 2015, p. 13). Rather, most suggestions for action were being directed at local authorities or housing associations to deal with in a localised manner.

Tax and welfare reforms in the period 2010–17 had a more adverse impact on disabled than non-disabled households. On average, tax and benefit changes on families with a disabled adult would reduce income by about £2,500 per year; if the family also includes a disabled child, the reduction would be over £5,500 per year. This compares to a reduction of approximately £1,000 for non-disabled families (EHRC, 2017).

## Experiences of disabled people and intersectional experiences

The housing needs of lesbian, gay, bisexual and transgender older people in Wales were considered via a 2009 literature review funded by the Welsh Government (Addis *et al.*, 2009) and used to inform a Welsh Government strategy for older people (Welsh Government, 2013b and 2017).

There is some evidence that, while required adaptation provision for physical issues is routinely considered, adaptation provision 'for developmentally challenged individuals' such as those with autism is 'rarely considered' (Mostafa, 2010, p. 37). In a narrative study of people with motor neurone disease, Sakellariou (2015) identified the potential disparity between disabled people's housing wishes and what were regarded as their housing needs.

## Scotland

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After devolution in 1999, housing policy in Scotland diverged considerably from that in the rest of Britain. Since 2016, control over some welfare benefits has been devolved to the Scottish Parliament and Scottish Government. This section provides an overview of these changes.

## Housing supply and policy

*Homes fit for the 21<sup>st</sup> century* (Scottish Government, 2011) set out the Scottish Government's housing strategy for the decade following 2011. The strategy encouraged local authorities to build at least 10% of new properties to accessible standards (Housing for Varying Needs, which was first adopted in the late 1990s) and provided funding to develop a Scottish Accessible Housing Register (now called Home2Fit) for disabled house seekers, in partnership with Glasgow Centre for Inclusive Living.

Social housing in Scotland is regulated through the Scottish Housing Charter, which is enforced by the Scottish Housing Regulator, with RSLs required to report annually in their Annual Return on the Charter (ARC). Outcome 1 specifies that:

Every tenant and other customer has their individual needs recognised, is treated fairly and with respect, and receives fair access to housing and housing services. (Scottish Government, 2017, p. 2)

In their ARC, all RSLs must state how many tenants, staff and board members are disabled; describe which of their stock has been adapted; and outline when they provide specialised housing with additional care.

Under the Housing (Scotland) Act 2001, local authorities have a statutory requirement to produce a Local Housing Strategy (LHS) that sets out the local authority's five-year approach to tackling housing demand, with attention to affordable housing, homelessness services, community and care support, sustainability, fuel poverty, cross-tenure property condition, and the role of the private sector. Policies and practices adopting a co-production approach were supported by the revised Scottish Government guidance in 2008, which outlined the role of co-production in LHS development. Co-production is widely recognised as the most intensive form of user involvement.

The Scottish Government's disability delivery plan, 2016 is part of the Fairer Scotland programme (Scottish Government, 2016b). The programme contains an ambition to improve disabled people's rights to places, including increasing housing that is accessible for everyone. Action 62 recognises the role that accessible housing plays in facilitating independent living for disabled people. The plan asserts the intention to 'work with local authorities, disabled people, and other stakeholders' to ensure realistic targets are set by each Local Housing Strategy for the delivery of wheelchair-accessible housing (Scottish Government, 2016b). Action 65 emphasises the importance of adaptations.

Since 2012, housing policy in Scotland has been part of a legal framework for the integration of health and social care services, including the Social Care (Self-directed Support) (Scotland) Act 2013 and the Public Bodies (Joint Working) (Scotland) Act 2014. Local authorities must prepare and produce a three-year Strategic Commissioning Plan (SCP). The plan should set out the strategy of service provision, service delivery, and resource allocation to support the achievement of national and local health and well-being outcomes. Part of the SCP involves each integrated authority producing a housing contribution statement.

The Scottish Government policy statement on architecture and place, *Creating places* (Scottish Government, 2013), and NHS Scotland and Architecture and Design Scotland’s ‘Place Standard’ tool (A&DS *et al.*, 2015), aim to create high-quality places that maximise physical and social benefits and produce good health and wellbeing. This initiative emerged from ‘Good Places, Better Health’, an ongoing initiative launched in 2008 as the Scottish Government’s strategy on health and the environment. Good Places, Better Health recommended a Scottish Neighbourhood Quality Standard, and *Creating places* called for the development of a place standard to deliver quality, sustainable places across Scotland. While these policies may affect new developments (a very small part of the built environment) they have little impact on the existing built environment.

**Adaptations and the supply of accessible and adapted homes**

Scotland does not have a disabled facilities grant. Instead, disabled people (or households which include a disabled person) are eligible to apply to their local authority for financial support (outlined by Table 4).

**Table 4: Support for adaptations in Scotland**

Tenure	Eligibility	Grant
Home owner	Eligible	Mandatory for adaptations deemed essential: prioritised but includes fitting or changing standard amenities and some structural changes. 80% grant for essential adaptations; 100% grant for those receiving Income Support, Income Based

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		<p>Jobseeker's Allowance, Pension Credit (guarantee element) or Income Related employment and Support Allowance. Some local authorities will 'top up' the 80% grant to meet more of the costs of the work.</p> <p>No cash limit, but work must be deemed essential by the local authority.</p>
Private tenant	Eligible; private landlord has to consent	
Social housing tenant	Eligible; work normally led by landlord who must agree it is essential; budget limited	<p>Disabled people are entitled to seek financial assistance from the local authority, but council tenants are directed to their landlord and their landlord is expected to fund the adaptations from rental income.</p> <p>Housing association tenants are directed to their landlord, who in turn can either pay from rental income and/or claim a central Scottish Government grant.</p>

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The Housing (Scotland) Act 2014 increased landlord discretion for lettings policies, subject to 'reasonable preference categories'. The housing needs of disabled people are not specifically identified as a reasonable preference category, but are categorised under 'people who are living under unsatisfactory housing conditions and who have unmet housing needs'. The Housing (Scotland) Act 2014 enshrines the priority for disabled people in allocations of adapted and accessible social housing. The Act allows for the use of temporary tenancies and broadened

possession grounds to ensure adapted properties can be effectively used for disabled people.

In 2014, guidance on new approaches in England, Wales and Northern Ireland to social housing allocation was published by the Chartered Institute for Housing (CIH). While the guide excluded Scotland, the Housing (Scotland) Act shows some similarity in direction. The CIH guidance highlighted current practice and examples to explore how RSLs can develop their allocation systems and policies to meet local needs and deliver the best use of homes. For example, allocation system reviews should assist in making optimal use of housing stock, including ensuring properties are allocated to the most appropriate person and freeing up properties adapted for disabled people if households no longer require the adaptations.

Anderson, Theakstone and Jago (2017) note that a considerable amount of research for or by the Scottish Government has focused on particular areas of housing and excluded others. Attention has been paid to disabled people's pathways into accessible housing and to adaptations made to existing properties to meet needs. However, less attention has been paid to the roles of allocations and new housing supply in meeting the needs of those who do not need or want housing with integrated support.

MacLean and Guy (2015) were commissioned by the Scottish Government to explore disabled people's housing pathways into accessible housing. The research uncovered the following key barriers to disabled people's access to suitable housing: financial or economic status (whether or not people could afford to buy a home or afford adaptations); supply or availability of appropriate accessible housing; and household composition (whether or not people lived with a partner, children or parents). However, the study did not present detailed evidence on the process of matching disabled housing applicants to suitable vacancies.

Discussions with practitioners suggest that some councils have developed their own adaptation services, building on care and repair services and supporting people across all tenures. This work is being facilitated through partnership working between agencies and aims, for example, to reduce delays in discharging people from hospital.

Anderson, Theakstone and Jago (2017) examined the application and allocations processes for disabled house seekers. The findings provide an in-depth illustration of key issues. None of the housing applicants in the pilot study knew of the Home2Fit register of accessible properties and housing staff reported uncertainty about using Home2Fit for the allocation of adapted social housing. Housing applicants valued the

role of a named housing professional to help access and engage with housing allocation systems. This worked to help housing applicants understand next steps; coordinate communication; minimise time delays through verification processes; and avoid applicants having to repeat complex life situations to a range of agencies.

The same research suggested the need for improved coordination across and within groups of social landlords and other services to better facilitate effective allocations. For example, housing data recorded by occupational therapists could provide landlords with up-to-date property details and could work to harmonise needs assessment across services. Disabled housing applicants affirmed that they would welcome housing options advice to explore all available opportunities. This advice would need to acknowledge that health conditions can fluctuate over time, and identify the best solutions for the whole household (not just a sole disabled main applicant). The research indicated that disabled people need to be supported when using choice-based letting systems, particularly applicants with cognitive impairments. Interviewed applicants reported challenges with using the online bidding process, for example, due to a lack of IT skills or difficulties with memory. The research found more broadly that housing allocation systems may fail to adequately recognise the support needs of people with cognitive impairments as housing difficulties can exasperate or trigger emotional stress for applicants. One recommendation from the research was that social landlords could build in inclusive design during cyclical maintenance and modernisation projects to enhance the accessibility of properties.

### **Impact of welfare reform**

The Scottish Government has the authority to mitigate the effects of Housing Benefit reductions in Scotland. From 2013, the Scottish Government has given local authorities extra funding for Discretionary Housing Payments to make up for any reductions in Housing Benefit caused by under-occupancy rules. Tenants have to apply for DHP following any reduction to their Housing Benefit.

The Scotland Act 2016 devolved a limited number of some social security powers to the Scottish Parliament. These include benefits for carers, disabled people and those who are ill (currently covered by Personal Independence Payment (PIP), Disability Living Allowance (DLA), Attendance Allowance (AA) and Carers' Allowance). Between July and October 2015, Citizens Advice Scotland (CAS) gathered the views of bureau advisers and clients across Scotland on how devolved social security powers could be used to develop a Scottish system of benefits for disabled people and carers (Citizens Advice Scotland, 2016). The data identified key needs,

including: for trust, respect and dignity; for the use of positive and inclusive language; for the benefit system to promote independence, participation and equality; for raising awareness of entitlements to disability and carer benefits; for universal entitlement for disability benefits; for a person-centred assessment process with face-to-face assessment as only absolutely necessary; and for carers' benefits to recognise their contributions and enable the pursuit of education or employment opportunities.

### **Experiences of disabled people and intersectional experiences**

At the time of writing, the Scottish Consortium for Learning Disability was conducting a literature review and fieldwork in the housing needs of people with learning difficulties. Research from a 2016 investigation by the Mental Welfare Commission Scotland examined hospital discharges and discharge planning, and the legal basis for treatment and any restriction on people's freedom. The research also explored the perspectives of service users and their support workers, showing that a third of people with learning difficulties across Scotland experience delayed discharge from hospital. The main causes for delays were lack of funding, unsuitable accommodation or care provision, or a combination of these elements.

### **Housing needs of people with sensory impairments**

In March 2017, the Thomas Pocklington Trust published an evaluation of a pilot housing brokerage service for younger adults (aged 16 to 44 years old) with visual impairments. The housing brokerage service was operated by Housing Options Scotland (HOS) from August/September 2015 until March 2016, and assisted 22 visually impaired people across 14 of the 32 local authority areas in Scotland. Brokerage outcomes ranged from individuals moving to a new housing solution to the delivery of housing options advice. The evaluation identified key components for effective brokerage services, including:

- using connections to gain the trust of local authorities and social landlords as a source of expertise and practical assistance, helping them to provide housing opportunities for younger adults with visual impairments
- building and sustaining long-term relationships with community based organisations that support people with visual impairment to build 'bottom up' knowledge and understanding of how to access different housing options
- being able to demonstrate how meeting the housing needs of younger adults with visual impairment can assist organisations to meet statutory obligations as well as other national or strategic objectives; in the Scottish context, this could include

achieving the National Health and Wellbeing outcomes and supporting delivery of the See Hear strategy (Scottish Government, 2014).

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## Appendix 2

### Themes and search strings

Theme	Search String
General issues – levels of disability – regional differences, tenure split between different regions	Housing Condition Survey/disabled people tenure
Social housing – choice-based letting, allocation systems, conditions on tenancies, void times, bidding issues	disabled people and choice-based letting/disabled people housing allocation/disabled people social housing
Social housing – fewer new accessible homes – loss of government grant, rising land/construction prices, viability issues, having to cross-subsidised affordable housing by building for market rent/outright sale/shared ownership	disabled people shared ownership/disabled people accessible housing/disabled people adapted housing/disabled people housing affordability
Adapted housing registers, matching systems – variation between local authorities and jurisdictions	accessible housing register/adapted housing register
Welfare reforms and the impact on housing – housing benefit cap, bedroom tax, universal credit, benefit assessments, payment delays, rising service charges, use of discretionary housing payments	disabled people welfare reforms/disabled people housing benefits
Private rented sector – rise of this sector among all age groups, future trends, impact of recent reforms in Scotland compared with England and Wales, house conditions, security of tenure, adaptation issues, urban versus rural issues	private rent disabled people/private rent adaptations
Homelessness – hostels, move-on accommodation, increasing levels of homelessness – regional differences	disabled people homelessness/disabled people domestic abuse
Housing issues for specific groups – LGBT, ethnic minorities, dementia, mental health, learning difficulties, spinal injury, sight loss, other specific conditions, refugees	sight loss housing/housing mental health/housing learning difficulties/housing disabled LGBT/housing sensory impairment/housing dementia
Design issues – co-production, co-housing	co-production disabled people/disability co-production housing

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Cross-tenure adaptations – differences in the way adaptations are delivered and funded between tenures and between the different jurisdictions	private rent adaptations/social housing adaptations
Housing for later life – staying put versus moving, lack of choice to move, last-time homes, sheltered housing, extra care housing (ECH), step-down housing, housing options advice	housing options disabled people/housing advice disabled people/housing support disabled people

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# Appendix 3

## Housing and disability research: topic guide for interviews with disabled people

(Alternative formats and languages were offered)

### **Current housing**

Check: is interviewee an owner/sharing owner/ LA or HA tenant/ PRS tenant?

Can you tell me about living in this home/where you are living at the moment?

- Is it a house or flat?
- Is it specialist or general needs, supported or independent living

How long have you lived here?

How did you find this house? Were any agencies (such as the Council or Housing Association) involved?

Prompt if needed:

- How long did you have to wait?
- How did you find the process? Were you supported by the council or HA?
- Could you get information from the LA in an accessible format? (e.g. text phone services, BSL interpreters, easy read, etc.)

How do you feel about living here?

What things do you like about your current home? And what don't you like?

In what ways does your current home meet your needs? In what ways does it not?

Prompt if needed: Are you able to get to all the rooms in your home or are there any important areas you can't get to?

- What do you feel about this? Do you have sufficient space for any specialist equipment you may need?

- Can you get in and out of your home easily – to the street and to any garden area or parking place? What do you feel about this?

Have you had changes to the house to make it more suitable?

Prompt if needed – What sort of changes were these? Have they improved things? Did you get any help in planning changes? And any say on finishes?

- Did you get a Disabled Facilities Grant?
- What was the application process like? Were you waiting long?
- Did you get full or partial approval? Was the funding granted enough to meet your needs, or did you have to top it up with your own funds?

What more needs to be done? What barriers do you face in making these changes?

How easy do you find it to get by on your income and any benefits?

What about keeping the house warm enough?

(If tenant) How helpful has your landlord been in helping you to make sure your home is suitable for you?

And what about the neighbourhood you're in: what are the good things about it?

Prompts: is it accessible? Do you feel safe? Friendly neighbours? Good transport? Shops/schools in easy reach? What are the downsides?

Do you get any help in the home from family, friends, a personal assistant, or any other carer? Has this changed lately and what effect has this had on you?

Have you had any tenancy support?

- If yes, what type of tenancy support do you receive?
- Has it helped?
- What issues have you had to face in getting it?

### **Previous experience**

Can you tell me about the other places you have lived since you became an adult?

How does your current home compare to other places you have lived?

What makes it better or worse?

How did those places affect how you felt?

### **The future**

Do you think your current home will meet your needs in the future?

If not: what would need to change?

Are you looking to move to a better/more suitable house?

Would you like to live in another area?

Do you think you have enough housing options?

Do you have enough say about your housing choices?

Do you know people who can help you with those choices if you need?

# Appendix 4

## Interviewee information sheet and consent form



Faculty of Social Sciences  
University of Stirling  
Stirling, FK9 4LA Scotland

'The housing experiences of disabled people'

### **Information sheet for potential interviewees**

We are a team of researchers from the Universities of Stirling, the West of England and Cardiff. We are currently undertaking a research project funded by the Equality and Human Rights Commission (EHRC) looking at the views and experiences of disabled people in relation to housing. You have been chosen from records of contact of local housing and disability organisations as we think you can help with our study. Before you decide whether to take part, we would like to provide a bit more information about the research and what it might involve for you. You have the opportunity to discuss this information with the project team and to ask them any questions you may have.

### **What is this research for?**

The EHRC is conducting an inquiry into housing for disabled people across Britain. It will make recommendations to Governments and housing providers on how to improve things. Our research will be providing evidence for this inquiry.

### **How can you help us?**

You are being invited to take part in an interview in which we would like to ask you about your housing experiences. We would like to talk about your housing situation. The interview will take place face-to-face, by phone or online (e.g. Skype). We can choose the format which is most convenient for your circumstances. The interview will last for about one hour. Your participation is entirely voluntary, can be withdrawn at any time and will not affect your housing. Any information you provide will be kept in confidence to the research team and neither it nor your name and contact detail provided to anyone without your express consent.

### **What will happen to the information that you provide?**

We would like to audio-record the interviews, but we will ask for your consent to do this. If you would prefer not to be recorded, we will respect this and we will ask to take notes instead. We will analyse information in the recording. The recordings and interview notes will be kept on secure University servers. The recordings will be deleted upon completion of the study. Interview notes will be kept for ten years in line with the University's data protection policies.

### **How will the research benefit you?**

The research may not benefit you directly, but we hope that our findings will provide a better understanding of the issues in housing provision for disabled people and lead to positive change in the long-term.

### **Further information**

Should you wish to discuss the study further prior to making a decision, the team can be contacted via e-mail or telephone:

Principal Investigator: Dr Madhu Satsangi, [Madhu.satsangi@stir.ac.uk](mailto:Madhu.satsangi@stir.ac.uk)

Tel: 01786 467986

If at any time you have other concerns or issues regarding the research or the way in which it is being conducted you can discuss these with Professor Isobel Anderson, Associate Dean, Faculty of Social Sciences, [Isobel.anderson@stir.ac.uk](mailto:Isobel.anderson@stir.ac.uk).

Thank you for taking the time to read this information sheet. Can you let the person who gave it to you know whether you are willing to take part and we will get in touch to make arrangements.



Faculty of Social Sciences  
 University of Stirling  
 Stirling, FK9 4LA Scotland

‘The housing experiences of disabled people’ – Interviewee consent form

Please initial the boxes in the right column if you agree with the statements below:

1. I confirm that I have read and understood the information sheet.	
2. I confirm that I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
3. I understand that my participation is entirely voluntary and that I am free to withdraw at any time without giving any reason.	
4. I understand that some statements I give may be anonymised and included in a report on the study and publications originating from it, but I will have the opportunity to see drafts of these.	
5. I understand that my interview will be <b>recorded and transcribed</b> , but that these will not contain my name or any other identifiable information. I give permission for interviews to be <b>recorded</b> .	
6. I understand that some interviews may be video-recorded and that my consent will be sought if this applies to me.	
7. <b>IF APPLICABLE:</b> I consent to my interview being <b>video-recorded</b> . The recording will exclude any mention of my name.	
8. I understand that any information I provide, including any recording of interview, will be kept anonymous and stored securely under password and used exclusively for the purposes of this project. No information will be passed to any third party without my consent.	
9. I agree to take part in the above study.	

Participant Name:

Signature:

Date:

Researcher Name:

Date:

Please keep this copy for your records. We will either ask you to sign another copy or ask you to confirm each of the statements prior to your interview.

# Appendix 5

## Interviewee characteristics

Characteristic	Bristol	Central Scotland	South Wales
<b>Tenure</b>			
Council housing	5	6	1
Housing association	5	7	5
Private rent	0	4	3
Owner occupation	9	2	1
Other – local authority property, managed by autism charity; shared ownership	1	2	0
<b>Type of home</b>			
House	12	6	2
Bungalow	3	4	4
Ground-floor flat	2	7	3
Upper-floor flat	3	4	1
Room in shared house	0	0	0
<b>Design of housing</b>			
General needs (may have subsequently been adapted)	16	11	6
Built as wheelchair housing or Lifetime Home	3	6	3
Specialist housing (e.g. sheltered)	0	1	0
Supported housing (i.e. care on site)	1	3	1
<b>Length of time in home</b>			
1 year or less	6	6	4
1–5 years	4	4	5
5–10 years	2	7	0
10–20 years	6	3	1
20 years or more	2	1	0
<b>Housing needs met?</b>			
Yes	5	12	4

Partially – can manage	3	1	4
Needs met now – but needs likely to change	6	1	1
No – need adaptations	1	3	0
No – need to move	3	4	1
<b>Age group</b>			
Family with disabled child or young adult	2	4	3
Disabled – young adult	1	2	0
Disabled – middle years	13	9	6
Disabled – later life or retired	3	6	1
<b>Specific groups</b>			
Ethnic minorities	3	0	0
Young carers	2	0	0
<b>Disability issues</b>			
Physical disability (not wheelchair user indoors)	9	17	1
Wheelchair user (at least some of the time indoors)	6	9	3
Sight or hearing loss	1	3	3
Mental health issues	0	1	0
Learning difficulties or autistic spectrum	3	6	3
Other	1	0	0
Any experience of residential care (self or other household member)	0	2	0

# Contacts

This publication and related equality and human rights resources are available from the Commission's website: [www.equalityhumanrights.com](http://www.equalityhumanrights.com).

Questions and comments regarding this publication may be addressed to: [correspondence@equalityhumanrights.com](mailto:correspondence@equalityhumanrights.com). The Commission welcomes your feedback.

## Alternative formats

For information on accessing a Commission publication in an alternative format, please contact: [correspondence@equalityhumanrights.com](mailto:correspondence@equalityhumanrights.com).

## EASS

For advice, information or guidance on equality, discrimination or human rights issues, please contact the Equality Advisory and Support Service, a free and independent service.

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Textphone 0808 800 0084  
Hours 09:00 to 19:00 (Monday to Friday)  
10:00 to 14:00 (Saturday)  
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