Improving outcomes for people with learning disabilities: Opportunities and challenges for housing

Rachel Ormston, Jane Eunson and Gareth McAteer
Ipsos MORI Scotland

**October 2017**

SCLD

Ipsos **Ipsos MORI**

Contents

Foreword

The Scottish Government wants to improve the lives of people with learning disabilities. This report is one of a series commissioned by the Scottish Commission for Learning Disability on behalf of the Scottish Government to understand how we can achieve that change.

Scotland's learning disability strategy, The keys to life, seeks to improve the quality of life for people with learning disabilities so that they live longer healthier lives, participate fully in all aspects of society and prosper as individuals.

Where people live can play a significant role in improving the lives of people with learning disabilities. A house is much more than bricks and mortar. It provides people with a sense of place and belonging. It is the starting point from which people can engage and participate in their local community and wider society. Housing contributes to better health outcomes and getting it right has potential to narrow inequalities.

However this research tells us that people with learning disabilities are not always empowered to understand their options or make informed choices about where they live, who they live with and the type of support they receive. And it also suggests that they do not always get accessible advice.

This report was commissioned to explore the extent to which housing is currently delivering positive outcomes for people with learning disabilities. It draws on the experiences and perspectives of people with learning disabilities and professional stakeholders in housing and learning disability services.

We hope it will provide a platform for dialogue and action for all those who share a commitment to improving the lives of people with learning disabilities in Scotland.

Chris Creegan,
Chief Executive, SCLD

Acknowledgements

Executive summary

Aims and methods

The study is one of a series of research projects, requested by the Scottish Government Learning Disability policy team and commissioned by the Scottish Commission for Learning Disability (SCLD). Its remit was to **explore the current housing landscape for people with learning disabilities in Scotland**. In doing so, it aims to **assess the extent to which housing can (and does) contribute to positive outcomes** for people with learning disabilities, with specific reference to 'The keys to life' strategic outcomes and to **identify key challenges** that need to be addressed to realise these more effectively.

It draws on data collected using mixed methods, including:

- A **rapid review of key research** on housing and learning disability (focusing primarily on evidence from Scotland)
- **Analysis of available quantitative data** on housing for people with learning disabilities in Scotland
- A **review of local authority housing documents** (Local Housing Strategy (LHS), Strategic Housing Investment Plan (SHIP), Housing Contribution Statement (HCS), and Local Development Plans (LDPs))
- **Qualitative interviews with 17 people with learning disabilities and 4 carers**, and
- **Qualitative interviews with 23 professional stakeholders** involved in the housing sector in Scotland.

A shifting housing landscape

There are some significant limitations to, and gaps in, the available quantitative data on housing for people with learning disabilities in Scotland. However, the data that is available highlights some clear patterns:

- People with learning disabilities are much **more likely to live in social housing** (52% compared with 21% of the population as a whole) and much **less likely to live in a home they or their family own** (39% compared with 66%)

- While **most people with learning disabilities live in 'mainstream' housing**, 17% of those known to local authorities live in supported accommodation and 7% in registered adult care homes

- While many adults with learning disabilities live on their own, **over a third (35%) of those known to local authorities live with a family carer**.

The available quantitative data indicates that there is **considerable variation across local authorities** in the housing and living circumstances of people with learning disabilities – for example, there are wide variations in the proportions living in different accommodation types, and the proportions living with a family carer. The reasons for these variations are unclear. However, they raise questions about what such differences mean for the degree of choice people with learning disabilities are able to exercise over their housing options.

- The housing landscape for people with learning disabilities in Scotland has changed dramatically in the last 15 years and is continuing to evolve. Although new commissioning of housing for people with learning disabilities appears to favour a supported accommodation model, **care homes remain a significant part of the current accommodation mix** for people with learning disabilities

- While some argue that care homes should continue to be an option, **concerns** have been raised over:

  o The number of people with learning disabilities being housed in **care homes aimed at older people**, and

  o Reported instances where local authorities have suggested people who are currently living independently may be **offered a care home place for cost reasons**

- **'Supported accommodation' covers diverse specific models**. There is a lack of data on the balance of specific models of supported accommodation in Scotland

- There appears to be a trend across a number of local authorities towards a '**core and cluster' model** of new supported housing for people with learning disabilities. Interviewees described examples where they believed this model was working well in delivering independence and community participation. However, there are also questions over whether the size and structure of some 'core and cluster' developments may recreate 'institutional' aspects to accommodation for people with learning disabilities

- Housing Associations and support providers interviewed for this research expressed concern over a perceived trend back towards **shared tenancies** for people with learning disabilities in particular local authorities. While this was described by commissioners as aimed at enhancing social connections, there was concern that it was primarily motivated by cost-cutting and was narrowing the options of people with learning disabilities

- While there has been a **dramatic reduction in the number of people with learning disabilities in hospitals** or NHS settings, there are **ongoing challenges** in ensuring that people with learning disabilities do not enter or remain in such

settings when there is no clinical need for them to be there. There is also concern that the number of people with complex needs who are in this situation has increased in recent years, although the way data is recorded means it is difficult to establish an accurate figure

- In 2016/17, 698 people who presented as homeless were recorded as having 'a learning disability'. There has been an **upward trend in recent years in the proportion of homeless applicants assessed as having support needs** relating to 'basic housing management and independent living skills'.

Delivering on housing for people with learning disabilities

Key factors that can or do help maximise the contribution housing makes to achieving 'The keys to life' outcomes for people with learning disabilities include:

- **Expanded choice of housing options**, supported by a **housing options approach to advice** to ensure that people are aware of, and able to navigate, the diverse options available to them
- **Advances in accessible design**, to help people with learning disabilities and co-existing physical conditions live healthy, independent lives
- **Person-centred planning**, to ensure that the needs and aspirations of people with learning disabilities are at the centre of decisions about their housing and support
- **Support for community participation**, in combination with housing in the 'right' location, where people feel safe and are close to support networks and local amenities.

Challenges and barriers

While there are many examples of good practice with respect to the factors identified above, there are also significant challenges to implementing these equally for all people with learning disabilities in Scotland. Key barriers include:

- Significant challenges around the **current supply of housing in general**, and of **accessible accommodation** in particular
- **Lack of consistency in access to advice** about housing options
- Major challenges around the **funding of housing support**, which are impacting providers' ability to deliver effective, person-centred support for people with learning disabilities
- Negative impacts and uncertainties arising from the UK Government's programme of **welfare reform**, including: the 'bedroom tax'; restrictions to housing benefits for under 35s; the introduction of a cap on housing benefits to Local Housing Allowance rates for social housing; and reassessments of entitlements to disability benefits
- **Legal barriers**, particularly relating to a perceived increased insistence on Guardianship Orders before people with learning disabilities can have their 'own' tenancies
- **Attitudes to people with learning disabilities** among social workers, landlords,

and support workers, and aspirations among people with learning disabilities themselves, which can be limited by experience, awareness and confidence.

Planning housing for people with learning disabilities

The review of local authority documents and interviews with professional stakeholders conducted for this report indicates **considerable variation in the level of detail around identifying and planning for the needs of people with learning disabilities** within local authority housing documents. Professional stakeholders interviewed for this study also indicated that there is **variation between local authorities in the quality of planning and joint working** around housing for people with learning disabilities.

Poor planning can lead to:

- The options available to people with learning disabilities being constrained
- Long delays in finding accommodation that meets their needs, and
- People being placed in inappropriate accommodation or out of area, away from family and friends.

Lack of resources and **lack of information** are both barriers to improving planning for people with learning disabilities. However, stakeholders suggested that there are **opportunities to improve planning** in spite of these challenges, from allocating dedicated local leads, to simply 'getting the right people in a room' to discuss individual cases.

Progress, risks and opportunities

There are mixed views on whether housing for people with learning disabilities is continuing to progress towards more positive outcomes, or whether progress has stalled. Overall, the picture appears fragmented, with variations across different areas of Scotland and differences in experiences and outcomes for different individuals with learning disabilities.

This report identifies a number of **key risks** to the ability of housing to contribute effectively to 'The keys to life' outcomes, including:

- The **UK policy context** and the negative and **uncertain impacts of welfare reform**
- **Demographic change** (an ageing population of people with learning disabilities) and rising expectations (particularly among younger people with learning disabilities) – positive trends but which create pressures within housing
- **Availability of suitable housing stock**, and
- A challenging climate for **housing support funding and staffing**.

It also identifies **potential opportunities** to influence positive change, including:

- The **devolution of supported housing funding**, which presents an opportunity for Scotland to do things differently
- Opportunities to **extend and enhance the housing options** approach
- Opportunities to **think creatively about housing support provision and funding**
- **Health and Social Care Partnerships as vehicles** with the potential to enhance joint working around housing for people with learning disabilities, and

- Scope to further **increase access to owner occupation** and to **enhance the sustainability of private renting**.

Recommendations

SCLD should:

1. Initiate a national conversation on how to achieve better housing related outcomes for people with learning disabilities

The **Scottish Government** should:

2. Identify a local authority test site to review data collection, information sharing and evaluation to improve strategic planning and delivery

3. Develop an implementation framework to prevent people with learning disabilities being accommodated in health care settings unnecessarily

The **Scottish Government and local planners** should:

4. Develop more specific guidance to ensure Local Housing Strategies (LHS) more effectively address the needs of people with learning disabilities

Local planners should:

5. Give greater consideration of 'The keys to life' outcomes within strategic planning and commissioning processes

Housing providers and professionals should:

6. Develop joint protocols between local authorities and other Registered Social Landlords (RSLs) around the provision of housing and achieving positive outcomes for people with learning disabilities

7. Develop a 'hub' for sharing good practice in housing planning and practice for people with learning disabilities

8. Provide greater transparency in housing allocation decisions and ensure people with learning disabilities receive appropriate advice and support to make an informed choice on their housing.

1 – Background, aims and methods

Background and aims

'The keys to life' is Scotland's learning disability strategy. Published in 2013, it was developed by the Scottish Government with COSLA and a wide range of statutory and third sector partners, together with people with learning disabilities and carers. It is underpinned by a commitment to human rights for people with learning disabilities and to the principles of choice, control and independence. The implementation framework for 'The keys to life' includes four strategic outcomes relating to the United Nations Convention on the Rights of People with Disabilities:

- **A healthy life**: people with learning disabilities enjoy the highest attainable standard of living, health and family life
- **Choice and control**: people with learning disabilities are treated with dignity and respect, and protected from neglect, exploitation and abuse
- **Independence**: people with learning disabilities are able to live independently in the community with equal access to all aspects of society, and
- **Active citizenship**: People with learning disabilities are able to participate in all aspects of community and society (Scottish Government, 2015).

The study is one of a series of research projects, requested by the Scottish Government Learning Disability policy team and commissioned by the Scottish Commission for Learning Disability (SCLD). Its remit was to **explore the current housing landscape for people with learning disabilities in Scotland**. In doing so, it aims to **assess the extent to which housing can (and does) contribute to positive outcomes** for people with learning disabilities, with specific reference to 'The keys to life' strategic outcomes and to **identify key challenges** that need to be addressed to realise these more effectively.

In this introductory chapter, we introduce key features of the wider historical and policy context that form the backdrop to this research, before summarising the methods we used.

Historical and policy context

In the 20th century, housing for people with learning disabilities in Scotland (and elsewhere in the UK and further afield) was underpinned by a **policy of institutionalisation** that left many people isolated from family and community, deprived of freedom, and vulnerable to abuse. In their 2014 report, SCLD and ENABLE Scotland estimated that, by the 1960s, over 7,000 children and adults were permanently housed in over 20 long-stay hospitals in Scotland. Large institutions, such as Lennox Castle outside Glasgow, were home to over 1,000 people. Some people entered these hospitals as children and stayed for the rest of their lives. SCLD and ENABLE Scotland describe this policy of institutionalisation of people with learning disabilities as "a policy that isolated people, separated them from their families and communities and, for a long time, left them without a voice and vulnerable to emotional, physical and sexual abuse" (SCLD/ENABLE Scotland, 2014: 14). This view is borne out both by research on the experiences of those who lived in long-stay hospitals, and by the number of scandals around standards of care and the prevalence

of abuse in such institutions from the 1960s onwards.

Initial resistance to using hospitals as a long-term or permanent housing option for people with learning disabilities began in the 1960s, with families initiating a movement to close these institutions and place more emphasis on disabled people as equal citizens. Gaining independence from institutional living was also a focus from the outset of the **Independent Living Movement** in the UK. The Independent Living Movement originated in the USA, but has since become a worldwide movement of disabled people coming together to advocate for their rights to the same freedoms, choice, dignity and control as non-disabled people.

In Scotland, people with learning disabilities and their families continued to lobby for the closure of long-stay hospitals into the 2000s. At the time **'The same as you?'**, the Scottish Executive's first learning disability strategy, was published (2000), an estimated 2,450 people with learning disabilities in Scotland remained in hospital across 25 sites. A key recommendation of 'The same as you?' was that all remaining long-stay hospitals should close, with the exception of a small number of places for people with learning disabilities who required assessment and treatment or those on statutory orders. The vast majority of residents moved into community-based facilities or their own tenancies by 2005 or shortly after.

The accelerated move away from long-stay institutions in the 2000s was underpinned by an increased policy focus on disabled people's **empowerment** and **human rights**. The United Nations Convention on the Rights of Persons with Disabilities[1] was formally adopted in 2006, and requires that governments "ensure and promote the full realisation of all human rights and fundamental freedoms" for disabled people. In relation to housing specifically, it emphasises:

- **Accessibility** – that disabled people should have access "on an equal basis with others, to the physical environment, including housing (as well as schools, medical facilities and workplaces)"

- **Independent living and community participation** – stating that disabled people should have the "opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement", and

- The role of housing in securing the right to **"an adequate standard of living"** for disabled people and their families.

In a Scottish context, recognition of disabled people's human rights has been accompanied by increased recognition that they are themselves best placed to determine what services and support will enable them to realise these rights in practice. Since the closure of large-scale institutions, there has been a growing recognition of the need for **personalisation** of services – that they should be planned around people's individual needs and aspirations, and not around institutional or organisational priorities. At the same time, a growing recognition that traditional approaches to public service development and delivery have not delivered the 'transformational' change Scotland needs to tackle significant inequalities in health and social outcomes has led to an increasing focus in recent years on the linked themes of

1https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

co-production, **assets-based approaches**, and **prevention**. The Christie Commission Report on the Future Delivery of Public Services (2011) focused policy makers and planners on the need to approach services differently in order to deliver them both better and more efficiently, including:

- Grounding approaches in people's lives and fitting services to needs, rather than the other way round (personalisation)
- Services and users work together to decide what is needed and how it should be delivered (co-production)
- Building the capacity of all those involved, including service users, acknowledging their expertise on their own lives (adopting an assets-based approach)
- Taking a long-term view, anticipating and preventing problems wherever possible (shifting to a more preventative approach to planning and delivery).

These core themes are apparent in many of the specific recent Scottish policies and strategies of relevance to the current and future housing landscape for people with learning disabilities, including:

- **Self-Directed Support**, which is one means by which the Scottish Government has tried to promote increased personalisation and to empower disabled people, including people with learning disabilities, to have more control and choice over their care and support. Since 2014, local authority social work departments have had a duty to offer people who are eligible for care a choice over how their support (including housing support) is provided, and to give them as much control as they want of their individual budget
- The **integration of Health and Social Care**, which is central to the Scottish Government's public service reform programme and which aims to reduce barriers to personalisation and preventative approaches by removing silos around the planning and funding of health and social care services. Integrated Joint Boards have a duty to produce Housing Contribution Statements, which set out how they intend to carry out the housing functions delegated to them
- The development of new **National Health and Social Care standards** for Scotland, which aim to "put human rights, dignity, compassion and wellbeing at the heart of all health, social work and social care services" (Scottish Government, 2016:13), and to focus on delivering person-led outcomes
- A duty on local authorities to develop **housing strategies** that address the needs of disabled people, including people with learning disabilities, and which set out the current and future need for accommodation and care or support services to help people live independently
- A duty on social landlords to meet the **Scottish Social Housing Standard**, delivering housing services so that regardless of disability, every customer and tenant has their individual needs recognised (linking to personalisation), is treated fairly and with respect (in line with their human rights), and receives fair access to housing and housing services.

The Scottish Government's strategies for housing and disability both draw on a human rights framework. The **Joint Housing Delivery Plan** (JHDP) states that the right to "adequate housing" should apply "regardless of social, economic or cultural status, including older people and those with disabilities" (Scottish Government, 2015: 2). The Scottish Government's recent plan for delivering the UN Convention on the Rights of Persons with Disabilities, **'A fairer Scotland for disabled people'** (Scottish Government, 2016) emphasises (among other priorities):

- Supporting independent living and increasing people's say over how that support is managed and provided (linking to personalisation)
- Increasing the involvement of disabled people in the design and delivery of services (co-production), and
- Empowering disabled people to participate as active citizen in all aspects of daily and public life.

Meanwhile, the four strategic outcomes for **'The keys to life'** have the human rights of people with learning disabilities at their heart. The full strategy makes clear that achieving these outcomes in practice will entail exactly the sort of transformational change envisaged by the Christie Commission. To maximise access to health, choice and control, independence and active citizenship for people with learning disabilities, public services - including housing and related support - will need to be designed with individual people with learning disabilities, tailored to their personal needs and aspirations, and recognising their unique skills and assets.

Yet at the same time as Scottish policies on both housing and learning disability have become increasingly grounded in the values of human rights, empowerment and personalisation, the financial context in which they are being implemented has become ever more challenging. Funding for **housing support is no longer ring-fenced**, since the Supporting People scheme came to an end in 2009.[2] The **financial crisis** of the late 2000s and the subsequent UK Government **policy of austerity** have led to a continued squeeze on local authority budgets, affecting both housing and social care. Meanwhile, the UK Government's programme of **benefit reform** involves far-reaching changes to the benefits people with learning disabilities are able to access to enable them to live independently.

It is within this broad historical and policy context that this research has been commissioned and should be understood. Almost two decades on from the closure of the last large-scale hospitals for people with learning disabilities in Scotland, what is the current role of housing in realising a healthy life, choice and control, independence and active citizenship for people with learning disabilities? What are the gaps and barriers? And how can these be overcome to maximise the contribution of housing to delivering 'The keys to life' strategic outcomes in the future?

---

[2]Supporting People brought together several funding streams into a single grant which local authorities could use to fund both accommodation-based and floating support services to help people live independently in the community (covering non-housing costs). Introduced in 2003, it provided a financial impetus for the shift to supported accommodation. Since the ring-fence around Supporting People funding was lifted in 2009, local authorities have been free to determine how much they spend on housing support.

Definitions

The report examines issues relating to 'housing' in the broadest sense – including not only the physical properties people live in, but also the advice they receive to help them access suitable housing and the support they receive to help them live in their home and engage with their communities. It is concerned with the experiences of people who live in owner occupied and privately rented properties, as well as those in the social rented sector.

The focus of the report is on housing for people with learning disabilities, although we hope many of the findings will have wider relevance. There is no single agreed definition of 'learning disabilities'. However, 'The keys to life' describes people with learning disabilities as having:

> "a significant, lifelong, condition that started before adulthood, which affected their development and which means they need help to: understand information; learn skills; and cope independently." (2013: 6)

As 'The keys to life' points out, this definition does not capture the whole person – people with learning disabilities will vary in myriad different ways. At the same time, there is also a wide spectrum of need among people with learning disabilities – some people will need 24-hour care and support to be able to live their lives, while others with mild learning disabilities may not require any regular support.

Methods

This report draws on data collected using the following methods:

- **A rapid review of key research on housing and learning disability**. This was not intended to be a comprehensive review, but rather to identify what is already known about the landscape for people with learning disabilities. It focused on recent research on this subject in Scotland, although some key publications from elsewhere in the UK were also included

- **Analysis of quantitative data on housing for people with learning disabilities in Scotland,** including data from Learning Disability Statistics for Scotland, the Census, and the Scottish Household Survey

- **Review of local authority housing policies.** For each of Scotland's 32 local authority areas, we searched for the most recently available online version of their Local Housing Strategy (LHS), Strategic Housing Investment Plan (SHIP), Housing Contribution Statement (HCS), and Local Development Plans (LDP). We then searched within each document for any mentions of 'learning disability', 'learning disabilities' or 'learning difficulty' in order to examine the ways in which learning disability is currently incorporated into housing planning at a local level

- **Qualitative interviews with people with learning disabilities and carers**. We interviewed 17 people with learning disabilities about their housing experiences. The interviews all took place face-to-face, with participants recruited through a variety of organisations who work with people with learning disabilities

and their families (primarily but not exclusively, organisations that provide housing and/or housing-related support or advice – see Appendix A for details). Interviews were structured around a rough topic guide, designed to explore participants' 'housing journeys' and identify what had helped or hindered them in finding housing that met their needs and aspirations.

In addition, we interviewed 3 family carers and 1 paid carer about the housing journeys of the person they supported. In these cases, the person supported had particularly complex needs, including challenging behaviour or communication difficulties, and we were not able to arrange an interview with them directly.

Interviews included people with learning disabilities living in social-rented, private-rented and owner-occupied properties, and people living in both supported accommodation and mainstream accommodation. A more detailed breakdown of the sample structure is provided in Appendix A.

- **Interviews with professional stakeholders.** We interviewed 23 professional stakeholders involved in the housing sector in Scotland, including 17 telephone/ face-to-face discussions and 6 who participated in a focus group. These included:
  o Housing Associations and one private rented sector organisation providing tenancies and, in most cases, also support to people with learning disabilities (n = 9)
  o Staff from third sector organisations providing housing support (not attached to specific housing associations) (n = 2)
  o Representatives from local authority housing teams (n = 3)
  o Managers from social work/Health and Social Care Partnerships (n = 2)
  o Managers/staff from advice services and charities working for people with disabilities and their families (n = 5), and
  o National stakeholders, including the Scottish Government, the Scottish Association of Landlords, and the Scottish Federation of Housing Associations.

Again, interviews were qualitative, structured around a broad topic guide aimed at exploring the current housing landscape for people with learning disabilities in Scotland and how this might need to change to better meet their needs and aspirations. Additional informal conversations with a number of other housing professionals, including those involved in the Advisory Group for this project, have also informed this report.

Scope and limitations

As the Joint Housing Delivery Plan acknowledges, "our housing system is diverse with multiple impacts" (Scottish Government 2015: 6). The social rented sector alone is incredibly diverse, with different providers and allocation structures operating in different areas of Scotland. In addition to council-provided housing, there are 161 registered social landlords in Scotland according to the Scottish Housing Regulator's current register.[3] The number of private renting options are even more numerous. There

[3] http://directory.scottishhousingregulator.gov.uk/Pages/register.aspx

are also many people with learning disabilities living in owner-occupied properties.

Meanwhile, as noted above, we are not only interested in housing provision, but also in the support available to enable people to live in their homes. Again, there are numerous organisations involved in providing social care to people with learning disabilities, with the possible options further extended by Self-Directed Support.

The aim of this research was ambitious and broad – to explore the overall housing landscape for people with learning disabilities with a view to understanding how it enables progression of 'The keys to life' strategic priorities. While this report covers a wide range of issues, it does so in varying levels of detail - many of the topics discussed could easily be subjects of standalone reports in themselves.

As discussed above, we used multiple methods to address the research aims. However, in terms of mapping the key issues, our approach was primarily qualitative. The aim of qualitative research is to map the range of views and experiences of an issue, rather than to quantify how many people hold a particular view or have had a particular experience. Sampling therefore aims at diversity rather than representativeness, with samples typically much smaller than those involved in surveys. We believe that the interviews we carried out with people with learning disabilities, carers, and professional stakeholders, in combination with quantitative data and the rapid literature review, identify many of the issues surrounding housing for people with learning disabilities in Scotland. However, it must be acknowledged that there may be other perspectives and issues that are not captured by this research.

The focus of this report is on issues across Scotland, which may occur to a greater or lesser degree within particular local authorities. Stakeholder interviews included representatives from 3 specific local authority areas. These were selected to include different geographies (large city, rural and mixed urban-rural) and to include authorities that appeared to make more or less detailed reference to people with learning disabilities in their strategic housing plans (based on the review of local housing documents). Interviews with national stakeholders and with Housing Associations, support providers and charities who worked across different local authorities indicated that many of the issues identified are unlikely to be unique to individual areas. However, the diversity of Scottish local authorities in terms of their geography, population, housing stock, approach to managing social housing allocations and so on means that we cannot robustly assess the extent to which housing is contributing to meeting the outcomes of 'The keys to life' within particular local authorities.

Finally, this report is intended as a start point rather than an end point. We hope that people will use it to reflect on their own examples of how housing is or is not contributing to meeting 'The keys to life' strategic outcomes, and to share learning about how to overcome challenges. The final chapter includes a number of recommendations for actions to maximise the scope for housing in Scotland to contribute to positive outcomes for people with learning disabilities. We hope readers will add their own to these.

Reporting conventions

This report is organised thematically – findings from the different methods described above are interwoven rather than being presented separately. The data source for each finding is made clear in the text.

Where findings are based on qualitative interviews with people with learning disabilities or stakeholders, we avoid using quantifying language such as "most", or "a few" as far as possible (as discussed above, the purpose of qualitative research is to map the range of views and experiences, not their prevalence).

When their views are quoted directly, professional interviewees are identified only by the broad type of organisation they work for, to protect their anonymity. Participants with learning disabilities are identified by pseudonyms. Boxed case studies of the 'housing journeys' of people with learning disabilities as well as case studies of particular examples of current practice are interspersed within chapters to illustrate key issues.

Report structure

The remainder of this report is structured as follows:

- Chapter 2 discusses what is known about the current housing circumstances of, and housing landscape for, people with learning disabilities in Scotland
- Chapter 3 explores views on what works in delivering in housing for people with learning disabilities
- Chapter 4 discusses key barriers impacting on the contribution of housing to positive outcomes for people with learning disabilities
- Chapter 5 discusses issues in planning for housing for people with learning disabilities
- Chapter 6 assesses progress in housing for people with learning disabilities in Scotland, and considers risks and opportunities that might influence future progress
- Chapter 7 presents our conclusions and recommendations.

2 – A shifting housing landscape

Introduction

As discussed in Chapter 1, the housing landscape for people with learning disabilities in Scotland has changed dramatically in the 17 years since the publication of Scotland's first learning disability strategy, 'The same as you'. This chapter considers what the current housing landscape looks like for people with learning disabilities in Scotland. It draws on available quantitative data to look at the current housing circumstances of people with learning disabilities and how this varies, particularly by local authority area. It also draws on qualitative data (primarily interviews with stakeholders and our review of local authority housing documents) to explore recent trends and issues in the housing landscape for people with learning disabilities in Scotland.

A partial picture

The quantitative data presented in this chapter are taken from a number of publicly available sources, including Learning Disability Statistics for Scotland (LDSS, collated from local authority returns by SCLD), the 2011 Scottish census, and the Scottish Household Survey (SHS). While these sources provide useful information about the housing circumstances of people with learning disabilities, there are a number of key limitations:

- **There is no up to date, large-scale data source that would allow us to examine in detail the housing circumstances of *all* people with learning disabilities.**
  - o The census covers the entire population, but is not particularly up to date (the last census was in 2011), and it only provides data on limited aspects of people's housing circumstances
  - o The SHS is the most up to date source of data on the circumstances of households in Scotland. However, it only includes a small sample of households that include someone identified as having 'learning or behavioural problems' (around 150 out of approximately 10,000 participating households each year)[4]
  - o LDSS is the data source that currently provides most detail on crucial aspects of the housing circumstances of people with learning disabilities, including the type of accommodation they live in and who they live with. However, it is based on data for individuals with learning disabilities held by local authorities and as such only covers people *known* to local authorities. It is therefore likely to be missing data for people with mild learning disabilities who are not in touch with statutory services, as well as others with higher levels of need, but who are currently supported by family.

- **There are a number of key aspects of the housing circumstances of people with learning disabilities in Scotland about which we were unable to find any publicly available data.** The Scottish Government's Housing Statistics for Scotland include figures for the number of supported housing units for people with physical disabilities and older people, but not those with learning disabilities.[5] Nationally collated data on the numbers of people on housing waiting lists is not broken down by disability.[6] There is no current publicly available data on the use of housing support by people with learning disabilities.[7] And, perhaps most importantly in terms of assessing progress towards meeting 'The keys to life' outcomes, there is a dearth of data on whether the current housing circumstances of people with learning disabilities in Scotland actually match their preferences and aspirations – do they feel they have choice, control and independence in their current housing situation?

[4] In order to increase the sample size to enable some analysis of the housing circumstances of households including someone with a 'learning or behavioural problem', we combined 3 years of SHS data (2013-2015), giving a sample size of 464 households. However, although the differences reported in this chapter are statistically significant, findings based on the SHS need to be treated with some caution, given the relatively small sample size for this group.

[5] http://www.gov.scot/Topics/Statistics/Browse/Housing-Regeneration/HSfS/SpecialNeedsHousing

[6] http://www.gov.scot/Topics/Statistics/Browse/Housing-Regeneration/HSfS/HousingLists

[7] The Scottish Government's figures on social care services (Scottish Government, 2017) reported on overall numbers of people using housing support for the first time in 2015, but these publications do not include a breakdown by type of disability.

- **The definition of 'learning disabilities' varies between sources and is not always consistent with current language or understandings of the term.** For example, the wording of the question on long-standing health problems and disabilities in the Scottish Household Survey refers to 'Learning or behavioural problems (e.g. autism, Down's Syndrome)', which does not reflect current language or definitions of learning disability and may mean that some people who do not have learning disabilities are included at this question. Findings based on the SHS can therefore only be considered loosely indicative of the experiences of households which include someone with learning disabilities.

These gaps raise questions about whether or not there needs to be changes to the data collected on housing in Scotland to allow a more detailed assessment of the circumstances of people with learning disabilities in the future. However, in spite of these limitations, the available data highlights a number of important aspects of the current housing circumstances of people with learning disabilities in Scotland, as discussed in the remainder of this chapter.

Tenure

People with learning disabilities are much **more likely than the population as a whole to live in social housing** and much **less likely to live in a home that they or their family own**. Analysis of 2011 census data shows that:

- 52% of people recorded as having 'a learning disability' lived in social housing, compared with 21% of the population as a whole (Figure 1)
- Just 39% of people with learning disabilities live in an owner occupied property, compared with 66% of the population as a whole
- Within the social rented sector, those with learning disabilities are more likely to rent from a housing association or other Registered Social Landlord (56% of social renters with learning disabilities compared with 45% of social renters overall) rather than a local authority (44% vs. 55%).

Figure 1 – Tenure of people with learning disabilities in Scotland (2011 Census)
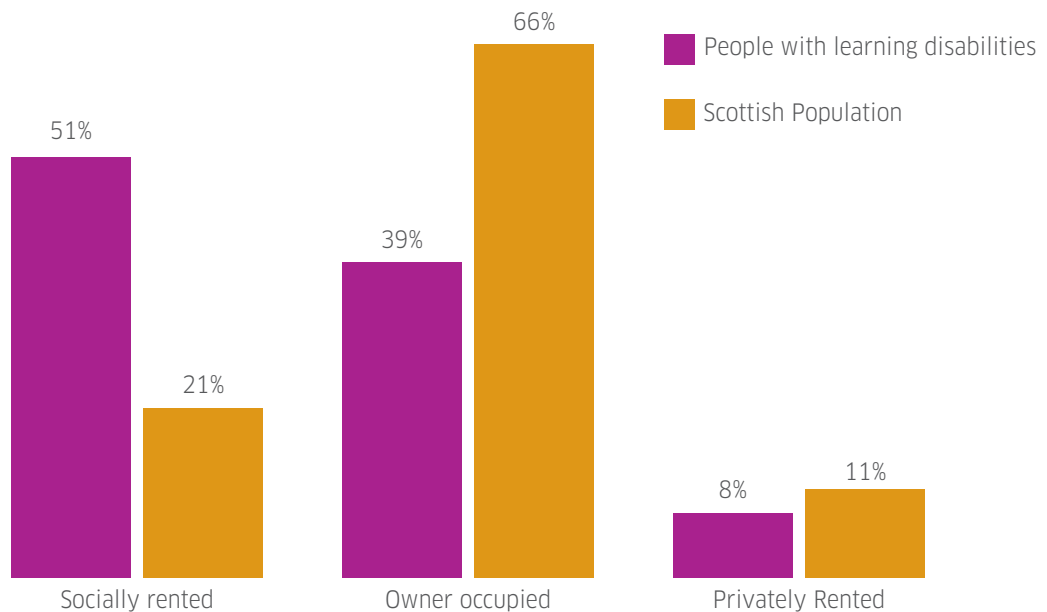
Notes to table: based on figures derived from Table DC3407SC, available from http://www.scotlandscensus.gov.uk/ods-web/home.html

Tenure does vary considerably with age, however. Younger people with learning disabilities are much more likely than older people with learning disabilities to be living in owner occupied properties (Figure 2). In many cases, this is likely to be because they are living at home with parents in a property that their parents own. Stakeholders interviewed for this study suggested that, while there are schemes which aim to make home ownership more accessible to disabled people in Scotland (examples of which are discussed in more detail in the following chapter), relatively few people with learning disabilities have accessed owner occupation for themselves.

Figure 2 – Tenure of people with learning disabilities in Scotland by age (2011 Census)
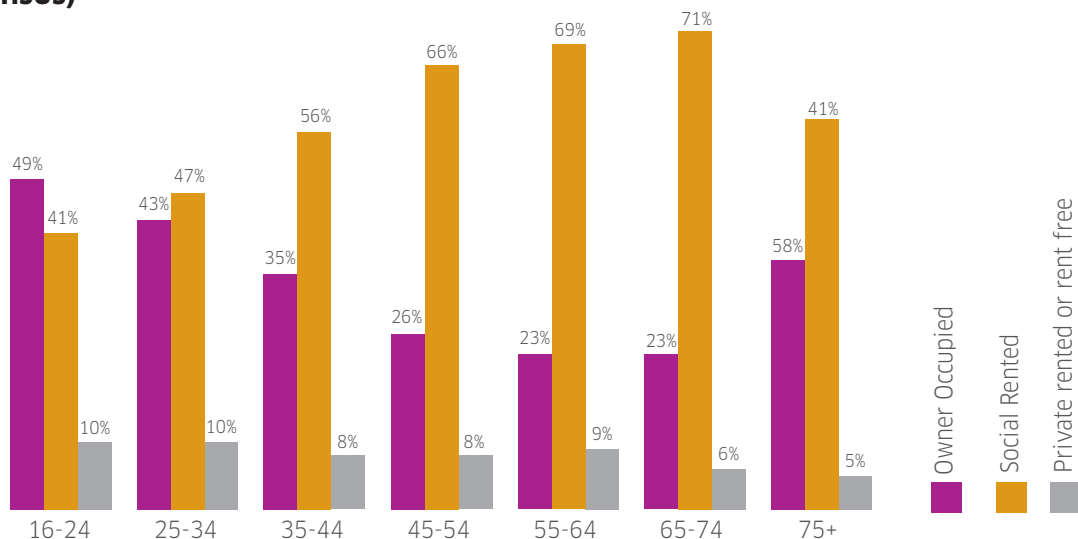
Bases: 16-24 = 3,877; 25-34 = 3,170; 35-44 = 3,377; 45-54 = 3,553; 55-64 = 2,197; 65-74 = 1,143; 75+ = 539

Accommodation type

Much of the focus of discussion around housing for people with learning disabilities in recent decades has been less about tenure and more about the type of accommodation available to them. LDSS (SCLD, 2016) shows that the **majority of adults with learning disabilities in Scotland who are known to local authorities (61%, 16,702 people) live in mainstream housing** – that is, in their own home or a family home which is not specifically adapted for their needs. However, in 2015:

- **7% (2,020 people)** of people with learning disabilities known to local authorities **lived in registered adult care homes** – that is, in a residential setting specifically for adults where a number of other people live, usually in single rooms, and have access to on-site care services

- **17% (4,622 people) lived in supported accommodation** – that is, a home to which external support is attached to help them live independently. A key feature of supported accommodation that distinguishes it from a registered care home is that residents have their own tenancy

- **4% (1,120 people) lived in other accommodation types,** including

  o special accommodation (424 people lived in a home designed or adapted for their needs, for example in terms of wheelchair accessibility)

  o sheltered housing (327 adults with learning disabilities lived in a group of self-contained homes linked to a warden)

  o hospitals or NHS facilities (218)

  o penal institutions (33)

  o registered childcare accommodation (29)

  o specialist rehabilitation units (12), and

  o mobile accommodation (10).

A continuing shift away from residential care homes?

In the initial period of hospital closures, from the 1980s to the early 2000s, there was an increase in the number of people with learning disabilities living in registered care homes (Scottish Executive, 2000). However, **since the early 2000s there has been a shift away from care homes to greater use of supported accommodation**.[8] This shift has reflected concerns about the 'institutional' nature of residential care. The National Development Team for Inclusion (NDTi) (2010) argues that while these should be an option, and there are good examples, care homes generally restrict the amount of choice and control people with learning disabilities have over their own home and how they are supported to live in it. At the same time, the introduction of Supporting People funding in 2003 provided a financial impetus for this shift.

However, **in spite of this reduction in use, care homes remain a significant part of the accommodation mix for people with learning disabilities in Scotland**. This includes both people living in care homes for people with learning disabilities, and people with

[8]The most recent Scottish Care Home Census (ISD, 2016) indicates that on 31st March 2016 there were 185 care homes for adults with learning disabilities, providing places to 1,603 residents. This compares with 4,462 occupied places in 635 homes at the start of 2002 (Scottish Executive, 2003).

learning disabilities living in care homes for older people. A recent report (LDAS, 2010) estimated that in 2010, 869 people with learning disabilities, including many who were aged under 55, were living in care homes aimed at older people. The report authors argued strongly that accommodating people with learning disabilities in generic care homes for older people was inappropriate, citing evidence that people with learning disabilities are less active in their community when they live in homes for older people rather than specialist homes for people with learning disabilities.

In terms of the future direction of travel, local authority housing strategy documents generally confirm that **commissioning of new dedicated housing for people with learning disabilities is focused on supported accommodation rather than a care home model**. However, in spite of this general trend, several professional stakeholders interviewed for this report cited recent cases they were aware of where people with learning disabilities who were living in their own homes had received letters from their local authority telling them that, if the support they required cost more than that of a place in a group home, then a place in a group home would be offered to them.

> So they're starting to talk now about limits on how much a package can be and that will mean that people may have to move from living in their own house to sharing with others. I don't have a lot of hard evidence of stuff like that, but it's certainly things that people have been told and I've seen letters from local authorities saying if you ask us for any more money basically … we'll only pay at the level of a group home.

(Charity working with people with learning disabilities)

Although one local authority concerned had subsequently withdrawn the letter (following complaints from people with learning disabilities and their families), it highlights the **potential for financial pressures within local authorities to restrict the choices that people with learning disabilities are offered**, even while the general trend apparent from local housing documents appears to be away from the commissioning of new group homes for people with learning disabilities.

Defining supported accommodation

At the same time as the number of people with learning disabilities living in residential care homes has declined, **there has been a very substantial increase in the numbers of people living in supported accommodation**, from an estimated 600 in 1998 (Scottish Executive, 2000) to 4,622 in 2015 (SCLD, 2016).

However, these figures do not show exactly what *type* of supported accommodation people with learning disabilities are now living in. **Within the supported accommodation sector there is enormous variety and diversity** in types of providers, scheme characteristics, client groups and models. NDTi (2010) outline 4 models of supported housing:

- **Shared supported housing**, where people share accommodation with others but have their own tenancy. NDTi describe this model as ranging from "services that look very institutional and give people little choice and control to those that look

like an ordinary shared house where those living there are in control." (2010: 14)

- **Extra care housing**, where people have their own flat within a wider development of flats for other people who need support, sometimes with additional communal space

- **Shared lives**, where a person with support needs lives in another person's home and gets support and accommodation from them, and

- **Community Living Networks**, in which a volunteer lives as part of the network and provides small amounts of support to each network member.

Within each of these models, there is also considerable scope for variation. For example, the Care Services and Improvement Partnership (2006) outline 9 models within 'extra care housing', varying depending on features such as: whether or not they include additional facilities (like activity centres); where support is based; and whether they are purpose built or adapted from a previous scheme (e.g. a residential care home converted into individual or shared flats).

Recent trends in supported accommodation

Our review of local authority housing documents indicates a **trend across a number of Scottish local authorities towards new supported housing developments being based on a 'core and cluster' model**. Core and cluster models involve a support 'hub', where staff supporting multiple tenants are based, with housing units clustered around it. The narrative among commissioners around the move to this model is partly one of supporting independence and community integration. For example, in outlining plans for a 7-unit core and cluster model for supported accommodation for adults with learning disabilities in Ayr, South Ayrshire Health and Social Care Partnership (2015) argued that the model offered benefits including:

- Increased independence and better outcomes for service users

- Greater flexibility of support provision, and

- Helping service users to develop good social networks.

However, achieving cost savings is clearly another perceived benefit – for example, Midlothian Council's SHIP states that moving to a 'core and cluster' model of supported accommodation for people with learning disabilities will "significantly reduce the costs of providing the appropriate level of support" (Midlothian Council, 2017: 41).

The scope for the 'core and cluster' model to achieve both sets of aims – increasing independence, control and community participation for people with learning disabilities, while also achieving efficiencies in care and support costs – is likely to depend on a wide range of factors, including development size, quality, location and level of support for wider community participation. Who such developments are aimed at may also be relevant. If targeted at people currently in group homes, this model may offer greater independence, flexibility and scope for personalisation. However, if aimed at people who currently live in their own independent tenancies with individual support packages, this is less clearly the case. In these circumstances, there is a risk that a

move to a 'core and cluster' development could in fact reduce some people's choice and control over their living situation.

The case study below highlights both perceived positives and some potential challenges in terms of the scope for a particular 'core and cluster' extra care housing development to fully maximise independence and active citizenship for its residents. It also highlights an appetite to learn more about what specific models of accommodation for people with learning disabilities work best – a theme which was echoed across stakeholder interviews and the local authority documents reviewed for this study.

CASE STUDY: An extra care housing development for people with learning disabilities

Professional stakeholders from housing and social work in one local authority discussed a recent Extra Care Housing (ECH) development in their area, comprising a number of individual flats with shared communal areas. The council own the building while the support is provided by a charity specifically providing services for people with learning disabilities. They described this development as a move away from the small group homes in which people with learning disabilities in their area had tended to be re-homed after the hospital closure programme. They believed the ECH model was helping people achieve *"that independence, that control"* that may have been missing when they lived in shared group homes. They also felt that it was a more effective model (in comparison with small group homes) for integrating people with their community and their family:

> *"what we have been finding over the years is that … people move into … the four person living situation and then become quite distant with their family. If you go to visit your relative, you're visiting your relative and three other people who you may or may not know and may or may not like … We find with (new development) it is much more natural that people are popping round to see their brother or their cousin or their son on a Friday night, and taking a pizza and watching the football".*

(Social Worker)

They reported that the flats had been tailor-made for the physical needs of residents, while staff had been trained to support people with complex learning disabilities and challenging behaviours, enhancing the quality of support they were able to offer.

However, while overall they felt the model was positive – "It's a fabulous building and a model that we like because of the independence for clients and the control for clients" (Housing Team) – they did question whether the scale of the development was ideal in terms of both the challenges of support provision and whether or not aspects of it might still be "institutional". At the same time, while they reported that residents valued and used the communal areas, they questioned whether this might mean they were less likely to go externally to meet their social needs – whether the model was potentially restricting the breadth of the 'community' they were accessing.

The local authority was strongly committed to evaluating and learning from this model for the future – they viewed the development as a learning model and had a group looking at evaluation and feedback to inform decisions about future developments.

One of the local authority professionals on whose interview the case study above is based suggested that they saw the future of supported accommodation for people with learning disabilities in terms of individual tenancies with shared support services – the fact that tenancies were *individual* was seen as key in promoting independence, personalisation of support, and family life. In contrast, other professional stakeholders interviewed for this report (from both housing associations and support providers) noted that they had **observed a recent shift back in particular local authorities towards requests for** *shared* **tenancies for two or more people with learning disabilities**.

While commissioners described this as aimed at enhancing social connections, there was concern that it was primarily motivated by cost-cutting and was narrowing the options of people with learning disabilities. In one case a stakeholder was aware of, he reported that:

> *"It was sort of presented as trying to make it more of a social thing, like people live together with people they'll probably get on with … but really it felt like 'the individual places were too expensive so we're putting them together'."*

<div align="right">(Housing Support provider)</div>

He felt that one of the tenants involved had been given limited choice over the decision, which had been justified in part on the basis that it would be *"distressing"* to go into the options before accommodation was firmly in place *"but once it's in place, they can't change it".* Another support provider reported that a commissioner at a recent conference she attended had indicated that *"the days of people with complex needs living in a home of their own with complex support were gone, and that the council was thinking of the development of 6-8 bedded units."* This clearly raises concerns – such a trend has the potential to undermine choice, control and personalisation of housing support for people with learning disabilities.

Moreover, while cost should not be the primary factor driving what options people with learning disabilities are offered, a recent paper from the Centre for Welfare Reform (Squire and Richmond, 2017) argues that neither residential care nor supported accommodation options where a number of people are supported together are necessarily any cheaper over the longer-term than supporting people in independent tenancies. Based on analysis of use of Individual Service Funds by Partners for Inclusion in Scotland, the authors found that, on average, people supported to live independently in their own separate tenancies became more independent over time with a consequent reduction in support costs (Squire and Richmond, 2017).

No one living in hospital without clinical need?

As discussed in Chapter 1, since the early 2000s there has been a dramatic reduction in the number of people with learning disabilities living in hospitals in Scotland. However, although the move away from housing people with learning disabilities in hospitals is rightly considered a major achievement, **it would be wrong to conclude that people with learning disabilities are no longer being accommodated in healthcare settings** when there is no clinical justification for them being there.

The Mental Welfare Commission (MWC) visited all 18 hospital units in Scotland for people with learning disabilities (excluding forensic units) in Autumn 2015. It found that 58 people were 'ready for discharge' but their discharge had been delayed due to a reported lack of funding, accommodation, or appropriate care provider, or a combination of these reasons. Although the numbers affected were small, they argue that "The implications for those awaiting discharge, who remain in hospital sometimes for significant periods for no clinical reason, and for those urgently requiring admission to a specialist unit, cannot be underestimated" (MWC, 2016: 21). Staff and carers described the impact on both individuals experiencing delayed discharge and on the service, highlighting the frustration, confusion and anxiety it caused.

Meanwhile, discussion with professional stakeholders for this study has highlighted the particular **challenges associated with accurately identifying the number of people with learning disabilities who are living in hospitals or NHS facilities**. While LDSS identifies 218 people in this category, several stakeholders believed the actual figure was significantly higher. Since 2013, a group of housing associations (the 'Good Life' working group) has been working with other key stakeholders to highlight this issue. The group was awarded ihub Improvement Fund monies in 2017, for a partnership project with City of Edinburgh Council to support people with complex care needs in Edinburgh who are currently living in hospital to live in a community setting. Initially, the project will be to support the 'Wayfinder Programme' (which targets people living in the Royal Edinburgh Hospital) and then develop an evaluation framework which can be used to transfer the learning to other parts of Edinburgh and Scotland as a whole.

In March 2015, there were more than 600 people with complex needs who had been in hospital for over a year – an increase of 21% (109 patients) on 2014 (ISD, 2015).[9] The figures show that 17% of these patients were being accommodated in learning disability healthcare settings. The fact that the 2015 figures were higher than the previous year highlights the need to avoid complacency about the numbers of people with complex needs accommodated in hospital when they do not need to be. There was a perception that there had been insufficient planning following the closure of large-scale hospitals for the *"next generation of people who eventually … may have the potential to end up in hospital"*, with several professional stakeholders citing cases they were aware of where young people with learning disabilities and complex needs had ended up in hospital after leaving residential school as a result of a lack of suitable alternatives.

This issue has been raised with Scottish Government Ministers, who have commissioned work to explore models of care for individuals who have complex needs, currently living within NHS provisions and/or out of area placement. This work will report in 2018. However, stakeholders expressed strong concern that unless pressure is maintained, it would be easy for people with learning disabilities in hospitals to be forgotten and for the numbers to rise again. This concern was exacerbated by a

---

[9]This figure was based on the number recorded by NHS Information and Statistics Division (ISD) at the time as being 'Category B' patients, who did not meet the criteria for NHS Continuing Health Care but who had been in hospital for over one year and for whom no estimated date of discharge had been set.

perception that recent changes to the way patients are coded within NHS Hospital Based Complex Clinical Care statistics[10] have made people with complex needs *"become a bit more invisible"* within NHS statistics.

Homelessness among people with learning disabilities

According to the most recent LDSS, 67 adults with learning disabilities who were known to local authorities were recorded as homeless at the time returns were submitted (SCLD, 2016). However, analysis of Homelessness Statistics for Scotland[11] suggest that many more people with learning disabilities will experience homelessness over the course of a year. In **2016-17, 698 households who were homeless or threatened with homelessness had 'learning disability' recorded as a support need**. While this figure remains small as a proportion of all households who are homeless or threatened with homelessness, it indicates that **substantially more people with learning disabilities may have experienced homelessness at some point**.

Moreover, although overall the proportion of households who become homeless or are threatened with homelessness has declined since 2012 (attributed by the Scottish Government to the impact of housing options prevention strategies across local authorities), **the proportion of those assessed as having a support need has increased as a proportion of the total**. In addition to 2.5% identified as having a 'learning disability', 20% of households who were homeless or threatened with homelessness in 2016-17 were identified as having support needs relating to 'basic housing management and independent living skills' (5,739 out of 28,247 applicants). This latter group has grown since 2007-8 both in terms of the overall numbers of people assessed as falling into it (4,300 in 2007-8, 5,739 in 2016-17) and as a proportion of the total number of homeless households (10% in 2007-8, 20% in 2016-17). Given that those assessed as having 'basic housing management and independent living' needs may well include people with low level or undiagnosed learning disabilities, this upward trend is concerning.

Who people with learning disabilities live with

Many people with learning disabilities can and do live on their own. However, some will need support to help them manage aspects of daily life. For a substantial proportion of adults with learning disabilities in Scotland, this support is provided by their family **- over a third (35%, 9,386 people) of adults with learning disabilities known to local authorities in 2015 lived with a family carer** (SCLD, 2016).[12] In most cases, those who live with a family carer live with a parent - **24% of adults with learning disabilities known to local authorities live with a parent**.

Across the population as a whole, the proportion of young adults who are living with their parents has increased in recent years (ONS, 2017). The 2011 Census indicated that 26% of adults in Scotland aged 20-34 were living with their parents (NRS, 2015). However, LDSS indicates that among young adults with learning disabilities who are known to a local authority, this figure is far higher - **69% of those aged under 35 lived with a family carer in 2015** (SCLD, 2016). There are also **significant numbers of adults**

10For example, the removal of 'Category B' for patients who do not meet the criteria for continuing care but have been in hospital for over a year.

11Available at: http://www.gov.scot/Topics/Statistics/Browse/Housing-Regeneration/RefTables. Additional analysis by the report authors. Tables available on request from SCLD.

12Forty-three per cent (11,804 people) did not live with a family carer, while for 22% (6,028 people) their living situation was unknown.

aged 45 and older living with a parent carer (n = 985, or 9% of those in this age group known to local authorities in 2015). As discussed later in this report, these figures raise challenges both about the options and choices available to young people with learning disabilities who currently live with their parents but may wish to live independently, and around transition planning for adults living with older carers, to avoid crisis situations arising when a parent dies.

LDSS also collects data on the number of people with learning disabilities who live together in the same accommodation. **Over half (53%, 14,517) of adults with learning disabilities were the only person with learning disabilities in their accommodation**, while 17% (4,729) lived with 1-3 other people with learning disabilities and **8% (2,060) with 4 or more other people with learning disabilities** (SCLD, 2016). The relationship between these figures and accommodation type is not clear cut – people with learning disabilities may live together as couples or in shared tenancies, and families may include more than one adult with learning disabilities. However, over half (53%) of adults who live with 4 or more other people with learning disabilities are living in a registered adult care home (SCLD, 2016).

Wider housing circumstances of people with learning disabilities

Beyond basic information about the kinds of accommodation people with learning disabilities live in and who they live with, there is a dearth of quantitative information about their housing circumstances. However, secondary analysis of the SHS (2013-2015) indicates that they face a number of additional challenges in this respect. First, households that include someone with 'learning or behavioural problems' are **more likely to experience difficulties paying their mortgage or rent** - 10% of households that include someone with 'learning or behavioural problems' compared with 4% of all households say they had difficulties paying their mortgage or rent in the last month. (Source: SHS 2013-2015[13]).

Households that include someone with 'learning or behavioural problems' are also **less satisfied with their property in general,** and with **its condition and size** in particular:

- 42% of households that include someone with 'learning or behavioural problems' compared with 56% of all households were very satisfied with their house or flat
- 62% of households that include someone with 'learning or behavioural problems' compared with 81% of all households rated the general condition of their house or flat as very or fairly good
- 14% of households that include someone with 'learning or behavioural problems' compared with 7% of all households were very or fairly dissatisfied with the overall size of their house or flat (Source: SHS 2013-2015).

This latter point is supported by evidence from the 2011 Census,[14] which shows that people with learning disabilities are slightly more likely to be living in a house with 1 or more rooms less than the recommended 'basic standard' for accommodation size based on household size (15% of people with learning disabilities compared with 11% of the population as a whole). This difference was most pronounced for older people

[13]Analysis by Ipsos MORI based on a combined dataset including data collected in 2013, 2014 and 2015.
[14]Analysis of additional table Batch 8 591_2011

with learning disabilities – while only 5% of those aged 55 and older in the population as a whole were living in accommodation with 1 or more rooms less than the recommended 'basic standard', this figure was 14% for people with learning disabilities in the same age group.

Housing support

The Scottish Government's website defines housing support as "services (that) help people to live as independently as possible in the community".[15] This could include, for example, assistance to help claim benefits, fill in forms, manage a budget, keep safe and secure in your home and the community, help accessing other specialist services, and help with shopping and housework. People with learning disabilities can have their needs for housing support assessed by social work. Support packages can range from around an hour a week to 24-hour a day residential support packages. Services may be provided by the local authority or commissioned from a charity or other support organisation, who may or may not also be the organisation from whom the person rents their home. Self-Directed Support means that people with learning disabilities have their support budget themselves, giving them greater choice over who provides them with this support.

As noted above, there is a lack of publicly available data on the use of housing support by people with learning disabilities in Scotland. The Scottish Government's figures on social care services reported on overall numbers of people using housing support for the first time in 2015, but these publications do not include a breakdown by type of disability. However, based on the types of accommodation included in LDSS, it can be estimated that **around half of people with learning disabilities who are known to local authorities receive some kind of formal support in their accommodation** – in addition to the 17% in supported accommodation and 7% in residential care homes, 21% live in mainstream accommodation with support, while 4% live in other types of accommodation where support would usually be provided (hospitals, special accommodation, sheltered housing) (SCLD, 2016). The Scottish Government's Social Care Services statistics also record that 1,230 people with learning disabilities were in receipt of Direct Payments (an option within SDS) in 2016, with a total value of £22.8 million.[16]

Appendix B provides further information on the size and cost of the supported accommodation sector for people with learning disabilities in Scotland. It highlights the relatively higher cost of providing support to people in supported accommodation in Scotland compared with the rest of the UK. This may in part reflect Scotland's particular geography and the challenges of providing support to people in rural areas.

[15] http://www.gov.scot/Topics/Built-Environment/Housing/access/housingsupport/supportpeople
[16] http://www.gov.scot/Publications/2016/11/8311

Variations between local authorities

There are some substantial differences in the living circumstances of people with learning disabilities across different local authorities in Scotland. Analysis of LDSS 2015 and Census 2011 data[17] shows that:

- While people with learning disabilities are less likely than the population as a whole to live in owner occupied properties across all local authorities, the **size of the 'owner occupation gap' varies**. The difference between the proportion of people with learning disabilities and the proportion of the population as a whole who live in owner occupied properties ranges from 20 percentage points to 36 percentage points

- Similarly, **the 'gap' in social renting** (which indicates how much more likely than the population as a whole people with learning disabilities are to live in socially rented accommodation) **ranges from 17 percentage points to 40 percentage points** across local authorities

- There are substantial **variations by local authority within LDSS in the proportion of adults known to local authorities who are living in different accommodation types**. For example, if those whose accommodation type is unknown are excluded, the proportion of people with learning disabilities known to local authorities who are recorded as living in supported accommodation ranges from 3% to 56%, while the proportion recorded as living in 'mainstream' accommodation ranges from 34% to 98%

- There is **wide variation in the proportion of adults who are recorded as living with a family carer**, with figures ranging from 27% to 73% (after those for whom this is unknown are excluded).

While some differences between areas in the housing circumstances of people with learning disabilities are to be expected, the degree of difference suggested by these figures is striking. It is of course possible that, at least in part, they reflect differences in how people's housing circumstances are recorded and defined. As discussed above, defining and identifying 'supported accommodation' in particular is known to be challenging, so there may be differences in how local authorities code accommodation as 'supported', 'mainstream' or 'other' (in spite of the efforts LDSS have made to clarify this in accompanying guidance). However, the extent of variation in tenure and accommodation type in particular does **raise questions about whether or not the balance of options open to people with learning disabilities in different areas of Scotland is appropriate**, and what impact it has on the degree of genuine choice they can exercise over their accommodation.

It is also worth noting that **some local authorities appear to know more about the housing circumstances of people with learning disabilities in their area than others**. There is a lot of variation in the proportion of 'missing' data, where the housing circumstances of people with learning disabilities known to local authorities is recorded as 'unknown' (because the local authority was unable to supply this data). As discussed later in this report, gaps in the data on people with learning disabilities at local level has the potential to substantially undermine the ability of local authorities to plan effectively for meeting their future housing needs.

[17]Detailed tables available on request from SCLD

Key points

- There are **significant limitations to, and gaps in, the available quantitative data** on housing for people with learning disabilities in Scotland. In particular:
    - o There is no large-scale, up to date source of information on the housing circumstances of all those with learning disabilities, including those who may not be known to local authorities
    - o There are gaps in information about the numbers of people with learning disabilities accessing formal housing support
    - o There is a no quantitative data on whether or not the current housing circumstances of people with learning disabilities match their preferences
- People with learning disabilities are **much more likely than the population as a whole to live in social housing**, and much less likely to live in a home that they or their family own. Although there are **schemes that aim to open up owner occupation** to people with disabilities, there is a perception that relatively few people with learning disabilities in Scotland to date have accessed owner occupation for themselves
- While **most people with learning disabilities live in 'mainstream' housing**, 17% of those known to local authorities live in supported accommodation and 7% in registered adult care homes
- Although new commissioning of housing for people with learning disabilities appears to favour a supported accommodation model, **care homes remain a significant part of the current accommodation mix** for people with learning disabilities
- While some argue that care homes should continue to be an option, **concerns** have been raised over:
    - o The number of people with learning disabilities being housed in **care homes aimed at older people**, and
    - o Reported instances where local authorities have suggested people who are currently living independently may be **offered a care home place for cost reasons**
- **'Supported accommodation' covers diverse specific models**. There is a lack of data on the balance of specific models of supported accommodation in Scotland
- There appears to be a trend across a number of local authorities towards a '**core and cluster' model** of new supported housing for people with learning disabilities. Interviewees described examples where they believed this model was working well in delivering independence and community participation. However, there are also questions over whether the size and structure of some 'core and cluster' developments may recreate 'institutional' aspects to accommodation for people with learning disabilities

- Housing Associations and support providers interviewed for this research expressed concern over a perceived trend back towards **shared tenancies** for people with learning disabilities in particular local authorities. While this was described by commissioners as aimed at enhancing social connections, there was concern that it was primarily motivated by cost-cutting and was narrowing the options of people with learning disabilities

- While there has been a **dramatic reduction in the number of people with learning disabilities in hospitals** or NHS settings, there are **ongoing challenges** in ensuring that people with learning disabilities do not enter or remain in such settings when there is no clinical need for them to be there. There is also concern that the number of people with complex needs who are in this situation has increased in recent years, although the way data is recorded means it is difficult to establish an accurate figure

- In 2016/17, 698 people who presented as homeless were recorded as having 'a learning disability'. There has been an **upward trend in recent years in the proportion of homeless applicants assessed as having support needs** relating to 'basic housing management and independent living skills'

- While many adults with learning disabilities live on their own, **over a third (35%) of those known to local authorities live with a family carer**

- Households that include someone with 'learning or behavioural problems' are **more likely to experience difficulties paying their mortgage or rent** and **less likely to be satisfied with their property** in general, and with its condition and size in particular

- There is **considerable variation across local authorities** in the housing and living circumstances of people with learning disabilities. This raises questions about whether such differences are appropriate, and what they mean for the degree of choice available to people with learning disabilities in different areas.

3 – Delivering on housing for people with learning disabilities – what works?

Introduction

This chapter considers some of the ways in which housing can and does contribute to health, independence, choice and control, and active citizenship for people with learning disabilities when it is working well. It draws primarily on interviews with people with learning disabilities and with professional stakeholders.

Expanded options

As discussed in the previous chapter, the housing options open to people with learning disabilities in Scotland – particularly those who would once have been accommodated in long-stay hospitals – have changed dramatically in recent decades, and are continuing to evolve. There remain questions over whether the precise mix of housing

options currently available locally or nationally is the right one. However, there was agreement among stakeholders that **the general expansion of options has increased the choices available to people with learning disabilities**, and made it more likely they are able to find housing that facilitates independence and positive health outcomes.

The case study below highlights how expanding the options being considered for and by one young man helped him find housing that far better suited his needs and aspirations. In Mark's case, the move from a care home to his own independent tenancy meant his support package could be far more personalised. At the same time, his support hours were gradually reduced as he gained independence (linking with asset-based approaches – by building on Mark's own strengths and abilities service providers were able to both save on resources and empower Mark to live as he wanted).

Case study: Mark

Mark is in his early 30s. As a child he lived in foster care before being moved into a residential home for people with learning disabilities in his late teens. He was not happy living there as he disliked sharing – "it wasn't the place for me, basically. It was like, they (other residents) just all got on my nerves". Around 10 years ago, C-Change, an organisation which supports people with learning disabilities, mental health issues and other additional support needs to achieve real positive change in their lives, started working with Mark to help him find a new home. With their help, Mark was able to move to a HA flat on his own. He is much happier living alone – "I like my flat on my own, it's good, my independence". The support he received was gradually reduced from 24/7 support to around 34 hours a week. Although Mark got on with his support workers, he was pleased about being able to drop his support on a Sunday as he liked being able to be "independently on my own on Sunday … I get to do what I want on Sunday".

Source: interview with Mark

Options for home ownership

As discussed in the previous chapter, people with learning disabilities remain much less likely than the population as a whole to live in owner-occupied properties. However, stakeholders nonetheless identified a number of **schemes that have sought to open up owner occupation** to people who might otherwise struggle to access it, including people with learning disabilities. Two specific examples are outlined in the boxed case studies below. Although the numbers of people with learning disabilities who have accessed these schemes was believed to be low (in the 100s), they nonetheless highlight the potential to make owner occupation more accessible, extending the choices available to enable people to live independently, in properties of their own choosing. A housing advice provider suggested that, although most people with learning disabilities and their families do not realise that owning is an option when they first approach them, it is actually now easier to help them find a mortgage, in spite of recent changes to the benefits system.

Case study: Shared Equity through the Open Market LIFT scheme

The Low-Cost Initiative for First Time buyers (LIFT) is a Scottish Government scheme aimed at allowing first-time buyers on low to moderate incomes to buy homes on the open market. Buyers must be able to fund at least 60% of the price of the property but the Scottish Government will fund the remainder, retaining an 'equity stake' in the property which is then returned to the Scottish Government when the home is sold.

A 2011 evaluation of the scheme (Scott et al, 2011) found that it had helped 157 disabled people purchase their own home (15% of all those purchasing homes through the scheme). Although there was no separate figure for the number of people with learning disabilities it had helped, the evaluation provides examples of this.

There are limits on the value of the homes that can be bought under the scheme. Although these vary according to house prices in different parts of Scotland, it was suggested by a Housing Association stakeholder that these caps might limit the scheme's usefulness to disabled people wishing to live in particular areas where prices were more expensive.

Sources: Scottish Government website and Scott et al (2011)

Case study: The Access Ownership scheme

Access Ownership is an open market shared ownership scheme provided from joint investment by Horizon Housing Association and Link Group, and delivered by Horizon in partnership with Housing Options Scotland. With an investment of £1.2 million by Link and Horizon and £1.25 million from the sharing owners, 18 disabled people and their families have purchased properties. The scheme's aims reflect all four of 'The keys to life' strategic outcomes. It aims to help people find or stay in homes that suit their needs (helping maximise outcomes relating to health and standard of living); gives them greater choice and control over where they live, by widening the options available to them; supports independent living (the scheme includes built-in support with home maintenance and adaptations); and enables them to access properties that might not otherwise have been available to them near support networks (supporting family life and community participation).

The scheme is open to all disabled people, including those with learning disabilities. It is available both to those looking to buy a more suitable home and those who already own a property but need to reduce their financial commitments. It is aimed at those who have access to lower levels of capital and who seek or need personalised maintenance and management services. As a shared ownership scheme rather than a shared equity scheme, it includes built-in support with maintenance and management (paid for via an 'occupancy fee'). It also offers flexibility around the value of the properties it will fund and the division of funding between the Access Ownership partners (there is generally a minimum of 25% and maximum 75% percentage that disabled people must contribute themselves but no fixed "tranche" between these, unlike traditional shared ownership). The scheme can, and has been, flexed, to support individual house purchase for rent.

An evaluation of the pilot scheme described a case in which a 51 year-old man with

severe learning disabilities was enabled to stay in his own home after his mother died when Access Ownership developed a bespoke shared ownership arrangement with his guardians (who were themselves too old to secure a mortgage). The end result was described as a 'seamless transition' for the man concerned, enabling him to stay in his house and be close to family support. Without the scheme, they believed he would otherwise have ended up in residential care with diminished quality of life.

The scheme has not as yet been actively marketed and is currently closed to new applications while its partners seek new funding. However, those behind the scheme believe that – with the right backing and infrastructure – it could extend its reach and support more disabled people with home ownership or with individual house purchase for rent.

Source: correspondence with Horizon and Evaluation report (Anna Evans (2016))

Options for sustainable private renting

Around 8% of people with learning disabilities live in **privately rented** properties (slightly lower than the 11% figure for the population as a whole, based on the 2011 Census). There was relatively less discussion of private renting among the stakeholders interviewed for this study, in part reflecting their particular professional experience (which tended to be in the social rented sector). However, the case study below provides an example of how private renting can be made both more accessible and more sustainable for potentially vulnerable tenants, including those with learning disabilities. Homes for Good, a social enterprise with no government funding, provides an enhanced, personalised housing management service, incorporating features that for other tenants might be provided by housing support providers, including preventative elements (such as help with financial management and benefits) to minimise tenancy breakdown.

Given the substantial increase in private renting in recent decades (up 10 percentage points since 1999, according to the most recent Scottish Household Survey figures), finding innovative ways of ensuring that private renting is a sustainable option is clearly another strand to enhancing choice for people with learning disabilities (and other tenant groups).

Case study: Homes for Good – opening up the private rented sector

Homes for Good consists of two related companies – a social enterprise letting company, which manages private rented properties on behalf of landlords across the housing spectrum (from low cost to high end), and Homes for Good investment, which buys affordable properties and renovates them, then rents them to people on lower incomes who might otherwise find it difficult to access the private rented sector. They own around 135 properties and manage around 160 more, primarily in Glasgow.

Instead of employing 'property managers', like a standard PRS letting agency, Homes for Good have a dedicated tenancy support team. Funded through management fees from their property portfolio, the team's role is to work with tenants to provide whatever support they need to help them maintain their tenancies. Examples include: making sure they are accessing the support they are entitled to, helping them access and navigate benefits (including attending appeal hearings), helping with difficulties with utilities and bills, and encouraging them to participate in their community. The tenancy support team work with people from their initial application for housing onwards, visiting at least every three months but often much more frequently depending on individual need.

The team are based in a tenancy support 'hub' which provides advice and support to tenants. They are currently looking at how to expand this support to provide a more social function, enhancing community links and participation among tenants – for example, running yoga classes, linking up with local allotments, and involving existing tenants in helping make decorations for new Homes for Good properties. Home for Good are also looking at developing a 'tenants' rights' course with Shelter, to educate tenants on their rights within the PRS.

Homes for Good were unsure how many people with learning disabilities they were currently letting properties to, since this was not something that was necessarily disclosed by their tenants when applying for properties. However, in working with us to recruit participants for this project they identified several tenants who, while not in receipt of any learning disability specific services or support, had attended special schools as children and appeared to have low to moderate learning disabilities. This highlights a key potential benefit of the Homes for Good model – providing enhanced tenancy support to PRS tenants with lower-level learning disabilities who might not be in contact with other services to enable them either to maintain housing or to support wider outcomes. Homes for Good believe that their business model could be replicated elsewhere in Scotland to help those who might otherwise struggle to access or maintain private tenancies access the PRS.

Source: Interview with Homes for Good

Enhanced advice

At the same time as stakeholders agreed there are now more options available to people with learning disabilities, there was also a consensus that having **access to high quality advice is a key factor in enabling people with learning disabilities (and their families) to access genuine choice** over their options. It was believed that overall the move to a housing options approach across Scotland has helped in this respect. Housing Options Scotland, a national housing advice charity which helps disabled people, veterans and older people 'find the right house, in the right place', was seen as having opened up this kind of advice to disabled people, including people with learning disabilities. Professional stakeholders also identified a number of local organisations that played a similar role in providing housing advice tailored to disabled people.

Housing options approach to advice

'Housing options' is an approach to advice that involves looking at an individuals' options and choices in the widest sense, including exploring all possible tenure options – council housing, housing associations, the private rented sector and owner occupation. It is intended to be tailored to people's personal circumstances, and to engage individuals' with other services they may need – for example, employability, health, money advice, family mediation – to avoid a housing problem becoming a crisis and to find a sustainable solution. The Scottish Government and local authorities have promoted this preventative approach to housing advice since 2010, when it was initially developed as a key tool in homelessness prevention and meeting the 2012 duty to resettle all unintentionally homeless households.

(Source: Scottish Government website)

The case study below highlights how housing options advice transformed the choices available for Ian and his family, enabling them to access housing that maximised his quality of life, independence and community involvement in a way that his family had not initially thought possible. In addition to housing advice, two other factors appear particularly key in achieving positive outcomes for Ian. First, the families' own resources and social capital – Ian's mother acknowledged that they had been lucky that they could afford shared ownership, while her own knowledge and connections (built over many years of tenacious campaigning for the rights of people with learning disabilities) were key in providing an initial link to appropriate advice. Second, having flexible funding for a 24-hour care package was also key. Ian was awarded this package in 2009, prior to many of the cuts to local authority funding discussed in the following chapter, and his family have been able to use the Direct Payments option within Self-Directed Support to choose who supports him and enable complete personalisation and consistency of support (Ian has had the same day-worker for 10 years). Without this, Ian may not have enjoyed the same quality of life and access to his community.

Accessible design

Case study: Ian

Ian is in his 40s and has severe learning disabilities. He lives in a shared house, close to his parents, with another man with learning disabilities. He has support 24-hours a day. Until he moved into this house, Ian lived at home with his parents. However, they wanted to make sure that he was settled and happy in his own home before they became unable to care for him, rather than waiting until that happened. His family began to look at different housing options themselves and, through a personal contact, were put in touch with Housing Options Scotland. Through their advice, they found out about a new shared ownership scheme (Access Ownership, described in chapter 2) and decided this was the best option for them – it gave them control over the type of property Ian would live in, as well as the location (allowing them to purchase somewhere close to them). They saw it as a more permanent option than renting.

Although the process of purchasing the house was slowed down by the need for his parents to obtain financial guardianship, they were extremely happy with the outcome. The location of the house meant Ian was close to family and in an area with good infrastructure and resources, while his support package also helped him to be active in his local community. He went for lots of walks in local parks and did his own food shopping as well as taking part in activities like trampolining and karaoke, all of which his mother believed gave him a community presence where he was "recognised and spoken to". The house, which was adapted for his physical needs, "felt like a home". His mother reported that both Ian and his family were now very happy with his situation and its sustainability for the future.

Source: interview with Ian's mother

Among a number of people with learning disabilities interviewed for this study, **a key factor that made their home either a good or bad place to live from their perspective was its accessibility for their physical needs**. As 'The keys to life' notes, people with learning disabilities can experience higher rates of both physical ill health and physical disability. At the same time, the population of people with learning disabilities in Scotland is ageing, along with the population as a whole. Studies from England predict that the numbers of older people living with learning disabilities will increase by over a third between 2001 and 2021 as a consequence of improving health and social care (Emmerson and Hatton, 2008). This in part reflects increases in the life expectancy of people with learning disabilities – although they still face significant inequalities in this respect, the British Institute of Learning Disability reports that "better social conditions and access to medicines like antibiotics have meant that more people are surviving beyond childhood and adulthood into older age."

While this increase in life expectancy is clearly to be welcomed, it means there are increasing numbers of people with learning disabilities experiencing mobility issues, dementia, and other common health problems of older age, all of which have implications for the kinds of housing and support they will need.

Professional stakeholders interviewed for this study felt that Housing Associations and Local Authorities were getting better at trying to 'future proof' new developments to be accessible for different and changing needs:

> *"I think what we are trying to do is improve the quality of overall provision in the city, but also improve flexibility and use in terms of being able to be utilised by the families where there are particular needs that have to be addressed."*

(Local Authority Housing Team)

They gave examples of new developments that were being designed to be both more accessible and more adaptable, so that people can stay in their homes as their needs change. For example, Blackwood Housing have designed new developments in Glasgow and Dundee that include a wide range of technological features to facilitate independent living, such as electric doors that slide open and shut at the touch of a button, rise and fall kitchen surfaces, stoves and sinks, and technology to support video calls with care providers.

The scope for well-designed accessible housing to meet people's health needs and facilitate independent living is illustrated by the case study below. Accessibility is not the only factor contributing to positive outcomes – for Lily, being in an area she liked, felt safe in and where she had friends was key to feeling happy with her housing situation, while having flexible, personalised and consistent support was also central to maintaining her independence and access to employment. However, accessibility was a key factor underpinning her access to all 4 'keys to life' outcomes.

Case study: Lily

Lily is in her 30s. She lives alone in a 2-bedroom semi-detached house in a Housing Association development for people with disabilities. Lily also has a physical disability and her house has been specially adapted - the doors are wider and the sinks lower to accommodate her wheelchair and the bathroom has been adapted too. Her second bedroom allows her to have an exercise room which helps maintain and maximise her mobility. Without these design features, she would not be able to live on her own, which was very important to her – she had previously lived with a friend, but moved out because she wanted to be more independent.

She has lived there for 16 years now and loves her house – the garden, the fact she has friends nearby, the local area which feels safe and has all the facilities she wants. Her support providers are linked to her Housing Association and are based just round the corner, which means she has people around to help her if she needs but feels they give her space and freedom when she wants it. They also help her travel to work. She is very happy living where she does, and could not think of anywhere better.

Source: interview with Lily

Person-centred support and planning

Ensuring care and support is person-centred is a key principle of 'The keys to life' – good health, choice and control, independence, and active citizenship are all enhanced by ensuring that people with learning disabilities are partners in planning their support, which is structured around their individual needs and aspirations. **Professional stakeholders believed that there had been a shift towards person-centred and outcome-focused planning over recent decades**. Overall this shift was believed to be resulting in people with learning disabilities being far more involved in planning for what they wanted to get out of both housing and housing support.

> *"(Social work) will do self-directed support assessments with everybody, and look at the outcomes that the person with the learning disability want to meet. Then they will support them, looking at support plans as to how they want to meet those outcomes … some of our young people will come through and immediately want to get their own place to live, or it's about supporting people to apply for relevant housing relating to their level of need, or to be aware or develop projects if people need that."*

(Social Worker)

> *"That's where we start from. We look to see what is it that the person wants? What is it that their aspirations are? … And put in the package of care that we felt, and that the person felt, would meet their needs … So it's all done using an outcome focus … And they would be allocated a key worker who would work with the person in making sure that the support plan was followed through on."*

(Housing and support provider)

The central importance of person-led support and planning is highlighted by a recent report by the Care Inspectorate (2017), which drew on two years of focused inspections of residential homes and care at home or housing support services aimed at assessing whether or not the principles of 'The keys to life' were being met. The report concluded that "where we saw strengths in services, overwhelmingly this related to the implementation of person-led practices which promoted choice and protected the rights of those using services." (2017: 4).

Interviews with people with learning disabilities for this study also highlighted the importance of housing support that is person-centred and over which they have control. This was not necessarily about having formal self-directed support (only a minority of those we spoke to were using SDS), but rather being able to decide what they do with their support workers, having support workers who knew them well and understood their needs and wants, and being able to decide when they do (and do not) get support – effectively 'co-producing' their support plans with their workers. They also highlighted the importance of having support that enables them to do things as independently as possible.

"So I said, 'well I've never been to Dundee or Aberdeen in my life', so we took a taxi down to the bus station … and went on the bus and it took us away up to Aberdeen and Dundee, Oban, Fort William, St Andrews, Perth … I would pick where I would want to go and I would pick places where I had never been."

(Helen)

"(Current support provider) staff was better (than previous provider).
INTERVIEWER: What was better about them?
Because they knew me, they knew me. Sometimes the council forgot to tell me to take my meds."

(Ben)

"I try to be as independent and deal with things in my way … but if I've got problems I do come round and say 'can I speak to you?'"

(Jane)

"I do my own cooking. I get the thing in the cooker, down to the bottom and (support worker) comes in and heats it up … I open the cooker and do it my own self and see if it's ready, and I say to (support worker), 'is that ready?' … I get it all my own self."

(Beverley)

The case study below highlights how high quality, personalised support – as well as the right house in the right location – has been a key factor in making independent living and active citizenship a reality for Lorraine, who had previously lived in long-stay hospitals with no independence or access to her community.

Case study: Lorraine

Lorraine has severe learning disabilities and physical disabilities. She spent much of her early adult life living in institutional settings, including Lennox Castle Hospital. C-Change, an organisation which supports people who have learning disabilities, mental health issues and other additional support needs to achieve real positive change in their lives, began working with Lorraine around 15 years ago to identify alternative accommodation that would enable her to live independently in the community. She had quite specific needs, both because of her physical disabilities and because traumatic past experiences meant that, although she was non-verbal, she often shouted out very loudly which could disturb close neighbours.

She was eventually housed in a cottage within a park, which has been specially adapted for her needs. Although her location might initially appear remote, in fact being within a park has enabled her to forge good relations with all her neighbours:

"She just loves being out … She is out in her community every day, she is very valued in her community, in the local shops, everybody in the park knows her."

At the same time, having a 24-hour support package was clearly essential to her being able to live there, and to being able to be out in her community. Consistency of support staff was also important in enabling Lorraine to control and direct her support. Her support worker, who had been with her for many years, described how Lorraine was able to direct them to do what she wanted even without verbal communication:

"Oh, she has got great communication so she has … (she) will take you to the cup for her tea, she will take you to the cupboard for her shoes, she will go to the door when she wants out."

(Source: interviews with support worker and other professionals)

Wider support for community engagement

The community and wider environment you live in, and your access to this, is key to everyone's health, wellbeing and standard of living. A few examples of specific initiatives available to help people with learning disabilities be active participants in their communities are shown in the box below. However, stakeholders stressed that there are many more – **supporting community participation was viewed as a central element of the professional practice of many Housing Associations and support providers**. Indeed, a number of Housing Associations interviewed for this study were keen to emphasise the role that Housing Officers play in this respect - the role of providing 'housing support', including supporting community connections, is not limited only to formal housing support workers. Several of the initiatives described below draw on asset-based approaches to involving people in supporting and helping each other in their community.

Examples of schemes that support people with learning disabilities to engage with their community

Loretto Community Engagement team – Loretto Housing Association have a Community Engagement team, which engages tenants with their own community and with inputting into how Loretto is run (for example, by having tenants as part of interview panels for recruiting new staff). There is a Community Engagement worker for each of their developments, including their specialist developments for people with learning disabilities. Workers help make sure tenants are plugged into statutory services (for example, supporting them to attend their GP), but also support and encourage them to join community groups and to get to know their neighbours.

ARK 'Active speak out' groups – Many ARK housing developments have 'Active Speak Out' groups, where tenants come together with a support worker to share ideas, support their involvement in local activities, and feedback ideas for improvements to housing and support to ARK. Volunteers from local 'Active Speak Out' groups sit on ARK's scrutiny group which has, for example, led to changes to the way in which they recruit new staff based on feedback from service users. This model thus supports both community engagement and increases people's control and influence over how their housing and support are provided.

Community Connectors – Community Connectors aims to connect people to information, local services and activities to improve health and wellbeing and to enable people to live a more independent life in their community. It offers signposting and referrals, one-to-one work, a buddy service, and support finding volunteering opportunities, depending on people's individual needs and aspirations. People with learning disabilities have both benefited from the scheme and acted as buddies to welcome others to their community. While the scheme is currently aimed at over 60s, there are aspirations to expand it. The scheme is delivered by Glasgow Council for the Voluntary Sector (GCVS) in partnership with Glasgow & West of Scotland Forum of Housing Associations (GWSF) and funded by Glasgow's Integrated Care Fund.

Blackwood Housing 'tenant ambassadors' scheme – Blackwood Housing Association are looking at developing a neighbourhood volunteering scheme, whereby tenants support each other by, for example, agreeing to grit areas outside in a development when it's icy, or check on neighbours with mobility problems to see if they need a hand with shopping. The scheme will thus draw on tenants' own assets in engaging them with each other. It will be open to all tenants, including those with learning disabilities, who will be supported to take part by Blackwood's Housing Officers.

(Source: interviews with Housing Associations and support providers)

Location, location, location

Interviews with people with learning disabilities and professionals highlight that having the right support is only one factor in enabling people with learning disabilities to be independent, active citizens. In fact, people with learning disabilities interviewed for this study generally placed greater emphasis on being **close to family and friends**, the **general amenities** available locally and in particular the **perceived safety** of the area as key to their feeling content with their housing and with their ability to be 'active' in their community.

The case study below highlights the different elements that can facilitate people with learning disabilities being 'active citizens' in their community. While Douglas did receive support specifically aimed at supporting community engagement, via Neighbourhood Networks, other factors were also clearly key – in particular, the location he lived in (which was near his family, felt safe, and contained lots of amenities and opportunities for involvement) and his own confidence and desire to give back to his community. The way in which Neighbourhood Networks works with Douglas is again an example of asset-based approaches – it makes the most of his own skills and enthusiasm, such that Douglas is both as independent as possible and is able to contribute as an extremely 'active citizen' in his own community.

Case study: Douglas

Douglas is in his 70s. He lives on his own in a flat which he lets from a Housing Association. He receives support from Neighbourhood Networks (a not-for-profit organisation that facilitates networks of mutual support for vulnerable people) with things like managing his budget (an issue he has had problems with in the past), but feels he does most things for himself – he considers himself to be very independent.

The location is the main thing Douglas likes about his flat – it is nearer to other family members than his previous flat, he likes the fact it is a *"quiet area", he knows his neighbours and other people in the community, and he feels very safe there – "I can go out late at night anytime and I never get any trouble … We look after each other, that's what we do"*.

He is very active in his local community – he volunteers for several different organisations locally, including the local park and a local charity for whom he did street collections several times a week. He was part of the tenants' organisation for his block, actively involved in Neighbourhood Networks and attended regular craft classes (which Neighbourhood Networks had signposted him to). He was much happier in his current flat in comparison with his previous flat (rented from a different Housing Association) as he did not know many people in the area he lived in previously.

Source: interview with Douglas

Professional stakeholders pointed out that, while some people with learning disabilities may need ongoing one-to-one support to be able to access the opportunities others take for granted in their community, for others it may just be a question of living somewhere with infrastructure that provides these opportunities for engagement. For example, a support provider described two men with learning disabilities he had worked with who had moved into *"really nice"* new Housing Association houses but did not know anyone in the local area:

> *"But what seemed to make a really huge difference was that there was a youth centre almost accidentally left in the middle … So they didn't just have a new place that was nice, they actually had some connection to the community."*

Key points

- The general **expansion of housing options** in recent decades has **increased the choices available** to people with learning disabilities. The move to a **housing options approach** and the development of advice services aimed specifically at people with disabilities has helped to open up these options to disabled people, including those with learning disabilities

- **Advances in accessible design** are helping people with learning disabilities and co-existing physical disabilities have a higher standard of living and enabling them to live healthy, independent lives

- **Person-centred planning** results in people with learning disabilities being more involved in planning for what they want to get out of both their housing and their housing support, enhancing the likelihood that both will contribute to 'The keys to life' outcomes

- People with learning disabilities highlighted the **importance of being able to decide** what they do with their support workers, having support workers who know them well, and being able to decide when they do (or do not) get support

- There are **many examples of initiatives among housing and support providers to support community participation** among people with learning disabilities. Such initiatives, in combination with housing in the **'right' location** – where people feel safe and are close to support networks and local amenities – can help facilitate people with learning disabilities being 'active citizens' in their communities.

4 – Challenges and barriers in housing for people with learning disabilities

Introduction

The previous chapter discussed 'what works' in housing for people with learning disabilities – the factors that appear to contribute most to positive experiences across 'The keys to life' strategic outcomes. However, while interviews with people with learning disabilities and professional stakeholders identified many examples of good practice, they also identified significant challenges to delivering equally positive outcomes for everyone with learning disabilities. This chapter discusses these barriers, drawing primarily on interviews with people with learning disabilities and professionals and on the rapid evidence review.

While our focus is on the potential impacts on outcomes for people with learning disabilities in particular, it is important to note that many of these barriers are not unique to people with learning disabilities. As a national stakeholder put it:

> *"I think that obviously people with learning disabilities are the same as the rest of the population. Their aspirations and needs are many and varied, and so it's an overall challenge to meet the needs of the population."*

Availability of suitable housing

While there are many more housing options available to people with learning disabilities in Scotland than was the case two decades ago, stakeholders identified significant challenges around the current supply of housing capable of meeting the diverse needs of people with learning disabilities.

The **level of funding available to build supported accommodation** was identified as a particular issue by local authority and housing association stakeholders. While it was acknowledged that the Scottish Government is currently looking at this and grant levels were reported to have risen recently, there was nonetheless uncertainty around future funding (in part relating to benefit reform, discussed below) which was having an impact on building of new supported accommodation:

> *"I think in terms of this area, from a housing perspective one of the key aspects to this is the uncertainty over housing support where we are providing specialist provision such as accommodation, where the cost, the revenue costs can't all be to rent, and the government suggested that there should be a budget or a grant set aside that can be dispersed in Scotland, that would be by the Scottish government. So, what we're finding is that with this uncertainty provision is going to lag behind need."*

> (Local Authority Housing Team)

This challenge is also reflected in a number of the Local Housing Strategies and other local housing documents reviewed for this report. For example, Edinburgh's City Housing Strategy reports that:

> *"the Edinburgh Learning Disabilities Plan Update 2011-2021 identifies a need for more core and cluster housing to help people to live independently. … However, funding constraints will make it difficult to find the required capital and revenue funding."* (Edinburgh City Council, 2011: 38)

Stakeholders commented that funding was having an impact both on the volume of new building aimed specifically at people with learning disabilities, and on the types and locations of accommodation they are building. One provider suggested that in their area budgets often limited them to building in areas that had a lot of social problems which were not where most people with learning disabilities and their families would choose to live. Another commented that if funding was higher they might build a wider mix of property types for people with particular needs, including single-story properties rather than just flats.

Challenges around availability are not limited to supported accommodation. There is a **general lack of wider social housing and affordable private lets**, both overall and in the right areas, and a particular lack of accessible properties.[22] As people with disabilities, including those with learning disabilities, are disproportionately likely to be living in lower income households,[23] they were seen as disproportionately affected by wider problems in the affordable and accessible housing markets. While several stakeholders welcomed the Scottish Government's commitment to build 50,000 affordable new homes by 2021[24], it was suggested that there had been a missed opportunity to consider what proportion of these homes should be accessible, or whether there should be targets around the proportion aimed at particular groups, including those with learning disabilities.

The impact of a lack of availability of suitable housing on people with learning disabilities cuts across 'The keys to life' outcomes. Choice is obviously reduced when desired or appropriate options are not available. Long waits for suitable accommodation can have a damaging impact on people's physical and mental health. A lack of accessible accommodation can limit people's ability to live independently and increase their reliance on formal and informal support. And a lack of affordable or appropriate options in the right areas can mean that people with learning disabilities are forced to live in areas where they do not feel safe, with negative consequences for community participation and mental wellbeing. Many of these negative impacts are illustrated in the case study below.

Case study: Derek

Derek lives with another man with mild learning disabilities in a private rented flat with no formal support. The flat is no longer suitable for Derek's physical needs. He needs a walk-in shower, ramp and wheelchair accessibility, none of which are feasible in his current flat. While his letting agents (Homes for Good, a social enterprise) are helping them with their search for a suitable property, they have been on a waiting list with a Housing Association for 2 years. Derek cannot leave the house at all easily and is reliant on his housemate for help with his physical needs (e.g. getting down stairs).

[22]These challenges have been documented elsewhere – for example, Watson et al (2012) used the 2009/10 Scottish House Conditions survey to estimate that 14.2% (17,042) of households including a wheelchair user had unmet housing needs.

[23]See for example analysis at: http://www.gov.scot/Topics/People/Equality/Equalities/DataGrid/Disability/DisabPov which shows that 23% of people in Scottish households containing a disabled adult were in poverty after housing costs, compared with 18% overall.

[24]https://beta.gov.scot/policies/more-homes/affordable-housing-supply/

His independence and ability to access services and amenities for himself were both constrained by his current accommodation, while the negative impact on his mental health and wellbeing were clear: "(I've been) getting depressed as well in here because I can't get out. That's nearly 2 years I've hardly got out (of) this house. It's a long time."

Source: interview with Derek and his housemate

Across the people with learning disabilities we interviewed, **feeling unsafe in the area they were living in was a key reason for either having moved or wishing to move**:

"It was horrible, because it was all drug dealers … you were scared to open your door … You couldn't leave your flat after 5 o'clock at night."

(Jane)

"Everybody was running about with knives and all that as well, and people were smashing windows and all that, and murders and stabbing … So I moved because of all that."

(Mark)

A joint People First/Capability Scotland event in 2010 with 28 people with learning disabilities identified a lack of housing in good areas as a key issue. This was seen as important to avoid harassment in particular – an issue around which people with learning disabilities felt there was not enough support (People First/Capability Scotland, 2010).

Difficulties accessing housing advice and guidance

Navigating the housing system is challenging for anyone: the range of options for renting or buying your own home can be bewildering. The additional options available to people with learning disabilities, and the various possible combinations of housing and support, make their options even more complex. In this context, having access to the right advice is key. As Mencap note, in their report on housing for people with learning disabilities in England:

"If individuals are not aware of their options, they will continue to live somewhere they would not choose to. Furthermore, many people with a learning disability are unaware of their right to live independently and how to get the housing and support they need to do this." (Mencap, 2012: 27)

People First and Capability Scotland's involvement event with people with learning disabilities found that social housing bidding systems and allocations policies were often difficult for people to understand, and that people wanted a right to advice and guidance on housing issues (People First/Capability Scotland: 2010).

Among professional stakeholders interviewed for this study, there was a perception that **although excellent advice and guidance is available, people with learning disabilities are not always referred to appropriate independent housing advice**. For example, an advice organisation that specialised in advice for people with disabilities reported that, in general, they got far fewer referrals from social work to support people with learning disabilities compared with referrals for people with physical disabilities. While she was not sure exactly why this was the case, she thought that one

reason was that social work often seemed reluctant to refer people for housing advice while they were trying to organise a support package:

> "There was a period that we were getting some referrals for people with learning disabilities, but social work were saying 'oh well, we've got them on our list, don't get them on the housing list separately … they'll get housed when we've got funding for the support package'."

She worried this meant that people with learning disabilities, particularly those with complex needs, were missing out on independent advice and the opportunity to apply for housing in their own right, rather than having it arranged for them. Other professional stakeholders suggested that there was no consistent application of advice for people with learning disabilities – that **access to advice is too dependent on which particular statutory or other support services you happened to be linked to**.

The importance of advice and guidance was also highlighted by professionals in the private rented sector. They suggested that people with learning disabilities may well miss out on private lets if they experience difficulties with application forms and are not able to apply as quickly as others.

Interviews with people with learning disabilities for this study generally confirmed that access to advice is inconsistent. At one end of the spectrum were people with learning disabilities and their families who had worked with housing advice or third sector support organisations to identify what they wanted from housing and help them access this. At the other end were people living in supported accommodation whose accounts indicated that they may have not have had any other options explained to them:

> "the social worker that put me in here … they just dropped me here and asked me if I wanted to stay in here." (Helen)

> "social work came and put me into my own flat" (Ben)

> "they couldnae find anything suitable in (area she preferred) so they found here … all they could find was just, here." (Rose)

In several of these cases, people had moved following a crisis – the death of a parent, becoming homeless, or experiencing threatening behaviour from neighbours or relatives. While they were not necessarily unhappy with where they now lived, the fact that they appeared to have been unaware of alternative options raises questions over the degree of genuine choice they had over their housing situation. When people move following a crisis, there may be a particular need to ensure they do not become 'stuck', without being empowered to consider other options that might suit them better.

Funding of housing support

As discussed in the previous chapter, interviews for this study identified examples where housing support was making a clear difference to the ability of people with learning disabilities to live independent, active lives. However, there was a strong perception among third sector providers of housing support that funding cuts were making the provision of person-centred and outcome-focused support much more difficult. Providers reported:

- **"Drastic" reductions in the hourly rates councils pay providers** - One provider indicated that 15 years ago some local authorities would have paid around £25-£30 an hour, but that now it was closer to £13 in some areas. This was seen as having a significant impact on the ability of providers to recruit and retain good support staff, which in turn meant that people with learning disabilities were not getting consistent, person-centred support:

    "Instead of getting the right carer for supporting that individual, sometimes it's just any carer" (Social Worker)

    It was suggested that funding was increasing the challenges around recruiting and retaining staff to support people with challenging behaviours in particular, reducing the scope for them to be able to live independently. At the same time, support providers gave examples where they had handed support packages for people with learning disabilities back to the council, because the level of funding available meant it was financially unsustainable to deliver it. This was reported to be a particular issue in rural areas, given the additional costs incurred in travel time. Again, this reduces the choice people with learning disabilities have over who supports them

- **Cuts to the 'size' of packages allocated to people with learning disabilities** – Support providers believed people with learning disabilities who might have been offered 10-15 hours of support 10 years ago were being offered as little as 2 hours now. Divergent views were expressed on who was most affected by these cuts – one view was that it was primarily (younger) people with learning disabilities who required a new support package to help them move who were finding it difficult to access packages that would enable independent living. Another was that people who had been in receipt of support for a long time were also seeing their hours cut "*just because of public sector funding cuts.*"

    Several providers of housing support and advice argued that those with more moderate support needs increasingly miss out on housing support. They reported that local authorities are increasingly concentrating support packages only on those with critical needs. At the same time, a housing support provider suggested that cuts to hourly rate for housing support meant it was becoming uneconomical for them to provide very small packages of support. As a result, they believed that those that needed perhaps a few hours a week or support to help them manage bills or to support community engagement had less choice over who provided them with this support than they would have had in the past.

Support providers felt that it was sometimes difficult for honest conversations to take place about the potential impact of cuts to support packages, as decisions about reducing packages were often framed by funders in terms of recognising or encouraging greater 'independence' among people with learning disabilities. Although support providers interviewed for this study gave examples where it had been possible to achieve this, facilitated by careful, person-centred planning for managing the reduction, they felt that this overall narrative made it difficult to argue that reducing support packages might have the opposite impact – that it might reduce someone's ability to live in their accommodation and access their community in an independent way

- **Greater inflexibility in how housing support is funded**, with a move away from 'block' funding of packages to fixed numbers of hours per week. Providers felt this restricted their ability to be flexible and creative in how they met outcomes for the people they worked with – for example, if someone was funded at 2 hours a week it was suggested that there was little scope to use support to encourage more social participation, whereas if they were able to use the funding more flexibly they could be more *"aspirational"* in the support provided

- **Barriers relating to funding streams** – an organisation that supports people with accessing and using Self-Directed Support gave an example of someone they worked with who had been told by the council that they would provide £47,000 a year for her to live in residential care, but only £21,000 for a care package in the community, because they came from different funding streams. The organisation had worked out that they could organise a package of care in the community that would fully meet her needs within £47,000, but this option was not available, so her independence and choices were being constrained by inflexibility over how funding from different streams can be spent.

Although the issues described above were recurrent across interviews with Housing Associations and support providers, among local authority interviewees there was not the same consensus that cuts to housing support were taking place:

"We're not planning to cut any services for people with learning disabilities … we have significant financial cuts to make, but we're not applying them to people with learning disabilities"

(Local Authority Commissioner)

However, research for the Housing Support Enabling Unit in 2012 found that on average funding for housing support (for all groups, not specifically people with learning disabilities) reduced by 3.49% from 2010/11 to 2011/12, and was predicted to fall by a further 1.7% by 2012/13 (HSEU, 2012). The overall picture of an extremely difficult funding climate is also supported by evidence from the more recent Coalition of Care and Support Providers' annual Business Resilience Survey – 65% of respondents, all of whom were third sector care and support providers, said they were less optimistic in 2016 than they were a year before, with low and decreasing funding levels a key reason for this declining optimism (CCPS, 2016). The trend for support services running

at a deficit is increasing, while a number of respondents to their survey also reported handing back services to commissioners because they were financially unsustainable.

Providers suggested that the situation around housing support was only likely to become more challenging in the future. As reported earlier, the population of older people with learning disabilities is expected to increase substantially, while professional stakeholders also reported rising expectations among younger people with learning disabilities and their families that they should be able to move out of the family home and live independently earlier, just as other young adults do. While increasing life expectancy and rising expectations of independent living are clearly to be celebrated, one professional stakeholder described the challenge of meeting the associated support needs as *"a ticking time bomb"* for services.

The case studies below illustrate some of the impacts that lack of the right support can have for people with learning disabilities.

- In the first case, Rose would really like to be able to go out regularly in the evening (as she used to, when she lived with her mother), but has been told there is no funding available for support to enable this. Her story reflects the view of professional stakeholders, that there is now less funding available to support and encourage social participation – access to **'active citizenship'** is being constrained by funding

- Ben reported having to lobby social work to be moved to supported accommodation. He was eventually allocated 30 hours of support, but thought the delay had been *'all down to funding'.* In the meantime, his physical and mental health had deteriorated – highlighting the negative impacts of inadequate support for **health and standard of living** for people with learning disabilities

- Finally, in John's case, from his father's perspective the key barrier to his son being able to **live independently** at least some of the time was a lack of support workers with the right skills and attitudes to support someone with challenging behaviour. As discussed above, professionals interviewed for this study believed that funding cuts were a key factor in difficulties recruiting and retaining the right staff for this kind of role.

Case study: Rose

Rose lives in a shared flat with two other women with disabilities. She has both physical and learning disabilities. She moved to this flat after her mother became unable to care for her. She takes part in various activities (including a walking group, attending the local community centre, and other activities like horse riding) and has a lot of support during the day. She felt she was able to control what she did with her day support workers – ""My community support workers take me where I want to go … me, I decide." However, she would really like to go out regularly in the evening (as she used to, when she lived with her mother). She has asked about this, but has been told there is no funding available for support to enable this as the other two women she lives with go to bed much earlier than she does. In the past, when she lived with her mother, she reported that she was "always out" in the evenings, whether at McDonald's or the local pub. Funding for support appears to be limiting her from being able to participate in her community in the way she would choose (and in the way other people are able to).

Source: interview with Rose

Case study: Ben

Ben is in his 30s. The block he lives in contains self-contained supported flats for people with learning disabilities, and is part of a wider housing development with mainstream tenants and some supported accommodation for homeless people. Ben initially lived here after becoming homeless as a result of experiencing abuse in his parental home (it was not clear why, as someone with learning disabilities and additional support needs, he had ended up in homeless accommodation). However, after 2 years in this accommodation, he had to move on (as the homeless accommodation was time-limited). He was housed in a flat on his own in another area of the town with 6 hours a week of outreach support.

He was very unhappy in this flat: the flat was damp and aggravated his asthma, and he had problems with neighbours who drank heavily and had parties: "(I was) coughing, coughing, and the building was stinking with alcohol … I had to go out every day and clean it." He reported that he was "bullied, big time" by his neighbours. His mental and physical health declined and he told his social worker and community care nurse that he wanted to move back to the development he had lived in previously, because he felt he had better support from the staff there. However, it took 6 months to achieve this, during which he said he was in contact with social work every day: "I was saying I want out of here, it's getting worse, it's getting worse". Eventually, after attending a hearing, he was allocated 30 hours a week of support and was able to move back to supported accommodation within his previous development. Ben believed the delay in being able to move was "all down to funding" and that he had not been a priority for social work at the time.

He was much happier in his current accommodation – he felt safe and supported by

staff who knew him well. The negative experience he had had of living on his own, in mainstream accommodation with modest support, appeared to have deterred Ben from trying this again. While he found it hard to say where he would live in the future, he said he would "probably stay here" because ""If I went, say, in my own house in the future, like on my own, I know … it will not work." This highlights the impact that negative housing experiences can have on people with learning disabilities' confidence and future aspirations about where they might live.

Source: interview with Ben

Case study: John

John has learning disabilities and behavioural problems. He was in hospital for several years as a teenager (following the breakdown of a residential school placement). He was very unhappy in hospital and stopped attending school while there. He was eventually moved to a flat on his own with a 24-hour package, but this broke down quickly after an episode which his father believed had resulted from the support workers being insufficiently skilled to manage his challenging behaviour. He then moved back to live with his parents, but they are struggling to cope. They did not have any additional support for several months, and although they now have some support his father was very unhappy with the quality and consistency of support staff – he felt they were disorganised and uncommitted, and made silly mistakes which aggravated John's behaviour.

"They are late to pick him up. They send different people, so he thinks like two staff are going to come and then different staff appear … nobody has got any … common sense, attention to detail, it's all lacking."

They do not see the current situation as sustainable for any of them and are extremely concerned that if they cannot find an alternative soon, John might end up back in hospital (which no one wants). Ideally, they want to be able to find appropriate alternative support to enable him to live in his own tenancy for some of the week, and for his parents to be able to support him the rest of the week. However, their efforts to arrange this are being hampered by difficulties finding a support provider willing to work with John because of his past challenging behaviour.

Source: interview with John's father

Welfare reform

Welfare reform was a recurrent theme in interviews with professional stakeholders. As Mencap (2012) note, while not everyone with learning disabilities relies on benefits, they are disproportionately likely to be receiving them, and so are disproportionately likely to be affected by recent changes. Specific changes that may impact on their experiences and outcomes within housing include:

- **The 'Bedroom tax'** – The removal of the 'spare room subsidy' from housing benefit in 2013 meant that unless disabled people could demonstrate that they require a spare room – for example, for regular overnight care – they were at risk of losing either part of their housing benefit or being forced to move to a smaller property. The Scottish Government has taken action to mitigate the impact of this policy – allocating £47 million in 'Discretionary Housing Payments' to affected households in 2017. However, interviews for this study suggest that people with learning disabilities in Scotland and their families may still be affected – for example, John's father (see case study above) reported that he was under some pressure from his council to move to a smaller property because he had a spare bedroom, in spite of the fact that John often stayed over with him. Without his spare room, John's father and mother would be unable to share his care between them

- **Restrictions to housing benefits for under 35s** – Tenants in the private rented sector who are under 35 are currently only able to claim this at a reduced 'shared room rate' – that is, there is an expectation that people under 35 who are in receipt of housing benefit will share with others. In 2015, the UK Government announced that this cap would also be extended to the social rented sector (from 2019-20). This has caused considerable concern among social landlords, many of whom do not tend to offer shared tenancies (SPICE, 2017). The Scottish Federation of Housing Associations has predicted that tenants under 35 will lose up to £1.3 million per annum in funding as a result of this policy, and that this will result in "A rise in rent arrears, failed tenancies, evictions and homelessness" among vulnerable tenants (2016: 2). Professional stakeholders interviewed for this study suggested this is likely to include people with mild or moderate learning disabilities, particularly where they are not currently in receipt of any formal support

- **The introduction of a cap on housing benefits for social housing to LHA rates** – In 2015 the UK Government announced plans to restrict the amount of housing benefit social tenants can claim to the equivalent 'Local Housing Allowance' (LHA) rate for housing benefits for private tenants in their area. Strong concerns were expressed about the impact of this announcement on supported accommodation in particular. The costs of supported accommodation are often higher because of factors like higher maintenance costs, up keep of communal facilities, and the provision of wardens.

  In response to these concerns, the UK Government subsequently revised its plans for supported accommodation – core rent and service charges will be

funded through Housing Benefit and Universal Credit up to the applicable LHA rate, but the UK Government has committed to devolving an amount additional to this to the Scottish Government to fund costs above this rate. These changes are scheduled for introduction in April 2019. A briefing on these changes for the Scottish Parliament (SPICE, 2017), argues that the impact on the supported accommodation sector is therefore at present unclear. Much will depend on the amount of additional funding devolved and the mechanisms for distributing this. However, council and housing association stakeholders interviewed for this study indicated that these *"moving goalposts"* are creating considerable uncertainty around planning for future supported accommodation, exacerbating difficulties around matching supply to demand (reported above).

Moreover, it was suggested that there may be particular challenges around mitigating the impact of the LHA cap on people with complex needs, including physical and learning disabilities, but who currently live in *individual* tenancies which have been built or adapted for their specific needs. One Housing Association indicated that they had a number of people living in such properties, and because of the level of adaption their rents were above LHA rates. However, they thought they were unlikely to be classed as 'supported accommodation' by local authorities as they were simply individual tenancies that had been adapted for the needs of their tenants. They were concerned that, even if the Scottish Government has funds to mitigate the impact of the LHA cap on supported accommodation, people living in individual tenancies like this might be at risk

- **Reassessments of disability benefits** – The UK Government's move to replace Disability Living Allowance (DLA) with Personal Independence Payments (PIP) has been the subject of widespread debate and criticism around both the fairness and conduct of assessments and the move to reduce the overall number of claimants. A professional stakeholder interviewed for this study reported that they were finding many of their (private) tenants were losing their benefits through this re-assessment process and that loss of benefit income was having significant impacts on the sustainability of tenancies.

Mencap (2012) argue that changes to disability benefits, particularly the move from DLA to PIP, have shifted the focus such that only those with high levels of needs are now routinely supported through the benefit system. As such, those with lower levels of need but who are still vulnerable and on very low incomes miss out

- **General complexity of changes** – An overarching comment was that the general degree and complexity of changes to the benefits system were very complex to navigate, particularly (though not only) if you have learning disabilities. Without the right support and advice, there was a perception that people could easily end up in difficulties – for example, with the transition to Universal Credit, the timing of moves between accommodation has become critical to avoid ending up in rent arrears. One stakeholder suggested that accessing the right advice was becoming more difficult in part because providers themselves are struggling to keep on top of and understand changes.

Mencap (2012) argue that many people with learning disabilities will be affected by "the cumulative impact of several of these changes" (2012: 45). The precise impact of benefits cuts for people with learning disabilities in Scotland is still unclear – in part because some of the details (for example, relating to the LHA cap and supported accommodation) are still being settled and in part because the Scottish Government is taking action to mitigate the impact of some of these changes. However, by reducing the funding available for different housing options, creating uncertainty that is impacting on the supply of new supported accommodation, and reducing people's income, the changes discussed above appear to risk jeopardising the scope for housing to contribute to 'The keys to life' outcomes.

Legal barriers

Several support and housing providers interviewed for this study **mentioned actual or perceived legal barriers that had prevented people with learning disabilities being able to access their own tenancies**. It was reported that some local authorities have received legal advice that people with learning disabilities need either to have a Guardianship Order in place or to have had their capacity established, rather than assumed, in order to be able to access their own tenancies. This was reportedly leading to delays in people being able to access housing and in some cases to people missing out on properties that had been allocated to them. There was also concern that people who previously had been allowed to sign their own lease without any issues were now being told they needed to have their capacity reassessed or get a Guardianship Order in place.

It was argued that the 'all or nothing' nature of Guardianship and capacity assessments is problematic, and that it ought to be possible to assess people as having the capacity to sign a lease if they can understand that it is their house and they are responsible for it, even if they cannot understand all the details of the lease without additional support. The Mental Welfare Commission has recently called for the law on Guardianship to be overhauled, as it is concerned that too many people with learning disabilities are having Guardianship Orders taken out and that this is compromising the human rights of people with learning disabilities. It has proposed an alternative system of 'graded guardianship', which "takes account of the UN Convention on the Rights of Disabled Persons, and seeks to ensure that human rights are taken into account in all care decisions affecting people with impaired decision-making ability".[25]

Attitudes towards and aspirations for people with learning disabilities

Finally, in addition to the various practical, legal and financial challenges discussed above, **attitudes to people with learning disabilities can also pose a substantial challenge** to accessing housing that maximises 'The keys to life' outcomes. Some of these attitudes have already been referred to – for example, several stakeholders thought that some **social workers** appeared to avoid discussing housing options with people with learning disabilities before a settled solution and support package was

[25]http://www.mwcscot.org.uk/about-us/latest-news/commission-calls-for-major-reform-of-laws-to-protect-people-with-learning-disability-or-dementia/

in place. While it was suggested that this might sometimes be motivated by a desire to 'protect' people with learning disabilities from feeling unsettled or upset, it also restricts their opportunity to exercise choice and control over their housing. It was also suggested that some social workers simply do not have high enough expectations of where and how people with learning disabilities could live, with the right support.

This view was reinforced by an interview for this study with a woman with learning disabilities who had bought her own house with support from C-Change and her family. She described having a *"very long battle"* with social work for a support package to enable this *"because they think to put me in a residential home"*, which she felt was *"typical of social workers."* That she had been able to go her own way appeared to be a result of a combination of her own determination and that of her family, and the support she had from C-Change.

Landlord attitudes were also mentioned as a barrier which restricts the housing options available to people with learning disabilities. For example, a Housing Association that particularly specialises in letting to people with disabilities reported that they had recently leased properties themselves from other social landlords in a rural area who did not want to lease to people with learning disabilities directly. They were not sure why this was, but thought the other landlords perceived people with learning disabilities as *"high risk"* tenants. In the private rented sector, it was suggested that although landlords are not legally allowed to discriminate against people with disabilities, this probably does go on 'below the radar'.

Reflecting the challenges recruiting and retaining the right support staff, discussed above, one professional stakeholder suggested that a lot of **support staff** do not necessarily see their role as being a "*community connector*", preventing them from playing the positive role described in the previous chapter in supporting people with learning disabilities to participate in their communities in a meaningful way:

> *"Staff become the barrier. Staff don't see that their role is to connect you to real people. Staff aren't your friends … So you see people visiting places, but not connecting. Day trips."*

> (Stakeholder from a charity working with people with learning disabilities)

People's own attitudes and aspirations may also affect the degree of choice, control and independence they exercise. This was highlighted by the different responses people with learning disabilities interviewed for this study gave when asked where they would like to live in the future. Some people were very clear that they wanted to stay living in their current accommodation and clear on the reasons why (primarily linked to feeling safe and having friends or family around them).

> *"I would like to live here because the people are friendly and nice. I get on with everybody."*

> *(Helen)*

> *"If my family move out (of the area), I would like to move out as well, but I'm quite happy at the moment"*

> (Douglas)

Others had ambitions to move – either into their own place (separate from family) or

even to another country. However, some were less able to say where they would like to live in the future. In these cases, their aspirations for the future appeared in part constrained by a lack of awareness of what their other options might be or whether they could apply to them (particularly in relation to home ownership, which few people had considered). People's own confidence about their ability to manage in different living situations may also impact on the aspirations for the future (as highlighted by Ben's story, discussed earlier in this chapter). Aspirations are thus driven by a complex mix of familiarity, experience, awareness of options, and confidence.

Key points

- There are **significant challenges around the current supply of housing** in general, and accessible accommodation in particular

- **Lack of information about their options** is a key constraint on the degree of choice people with learning disabilities are able to exercise in relation to their housing. Professional knowledge of wider housing options and, in some cases, professional attitudes to referring people with learning disabilities for independent housing advice were both identified as barriers

- **People who move in a crisis** – for example, following the death of a parent carer – **may be less likely to have wider housing options discussed** with them

- Providers of housing support described **major challenges around the funding of housing support**. Cuts to hourly rates, reductions in the size of individual funding packages, inflexibility around how support is funded, and rigid funding streams were all cited as having a substantial impact on providers' ability to deliver effective person-centred support for people with learning disabilities

- People with learning disabilities and their carers gave examples where funding constraints appeared to be impacting on: their ability to participate in their community in the way they would choose; their physical and mental health; and the availability of support workers with the right skill set to support them

- The housing circumstances and options of people with learning disabilities may be negatively affected by various aspects of **welfare reform**, including:
  - The 'bedroom tax'
  - Restrictions to housing benefits for under 35s
  - The introduction of a cap on housing benefits to LHA rates for social housing
  - Reassessments of disability benefits and the move from DLA to PIP

- **Legal barriers** – particularly a perceived need to establish capacity before people can sign tenancies and a related increased insistence on 'Guardianship Orders' – were seen as undermining the ability of people with learning disabilities to access their own tenancies

- **Attitudes to people with learning disabilities** among social workers, landlords and support workers were also seen as restricting the potential for housing to contribute to 'The keys to life' outcomes for people with learning disabilities. People's own aspirations and attitudes may also affect the degree of choice, control and independence they seek.

5 - Planning housing for people with learning disabilities

Introduction

The delivery of positive outcomes in housing and housing support for people with learning disabilities is underpinned by good local planning. As we acknowledged in the introduction to this report, we are not in a position to comprehensively assess planning within individual council areas. However, this chapter explores issues and challenges around local planning, as well as examples of good practice and opportunities for change that might enhance the contribution housing makes to positive outcomes for people with learning disabilities. We draw primarily on evidence from our review of local housing documents and the views of professional stakeholders.

Evidence of planning in key local housing documents

As part of this research, we reviewed four key housing documents (where publicly available) for each of Scotland's 32 local authorities: the Local Housing Strategy (LHS), Housing Contribution Statement (HCS), Strategic Housing Investment Plan (SHIP) and Local Development Plan (LDP). In each document, we searched for any mention of 'learning disabilities', 'learning disability' or 'learning difficulty' in order to examine whether and how people with learning disabilities were discussed in these key housing documents. This exercise revealed an extremely varied picture – there was **wide divergence between local authorities** in:

- the degree to which people with learning disabilities featured at all
- the level at which their housing needs were analysed
- links made with wider outcomes (such as health or community participation), and
- evidence of specific planning of how to meet their future housing needs.

The box below discusses Argyll and Bute as a case study of a local authority which includes relatively more detail on how it intends to meet the housing needs of people with learning disabilities. We are not suggesting that this is either perfect or the best example of considering the needs of people with learning disabilities in local housing planning – there were other councils who included similar levels of detail and discussion. However, it does consider the needs of people with learning disabilities explicitly, linking plans and objectives to 'The keys to life' outcomes and indicating how the council plans to increase choice and independence within housing and housing support.

In contrast, we found other examples where there was no reference to either 'The keys to life' or (for documents published before this was published in 2014) 'The same as you?', no discussion of the specific housing needs people with learning disabilities may have, and little or no discussion of how those needs might be met. In some strategies, people with learning disabilities were simply listed as one of a number of groups (including older people, people with physical disabilities and people with mental health problems) for whom specialist or supported accommodation might be required. In others, there were brief mentions of the estimated number of people with learning disabilities in the council area, but little or no additional discussion of what is known about their housing needs. In one case, we were not able to identify any mention at

all of 'learning disabilities', 'learning disability' or 'learning difficulty' in any of the four strategic documents examined.

'The keys to life' recommended that Local Housing Strategies should demonstrate explicitly the actual and anticipated contribution of all housing sectors to meeting the needs of people with learning disabilities. However, even in those documents that do include more detailed discussion of the needs of people with learning disabilities, there is little discussion of wider options for meeting those needs. Although some do reference the fact that many people with learning disabilities can and do live in mainstream accommodation, the focus overall is generally on the requirement for (additional) supported accommodation for people with complex needs. Very few strategies include any analysis of whether there are people with learning disabilities in residential care or supported accommodation who would like to live elsewhere, or discuss how they might measure the success of housing for people with learning disabilities. Aberdeenshire is an exception to this – they state that they will ask people if they feel involved in deciding on where they live and whether or not they are happy with it.

Case study: planning for people with learning disabilities in Argyll & Bute

Argyll and Bute Council's HCS explicitly refers to 'The keys to life' and the wider objectives of this, summarising Argyll and Bute's strategic priorities for people with learning disabilities under each of the four strategic outcomes, including:

- Ensuring a comprehensive range of specialist providers for community-based services such as supported living and ensuring they are trained in learning disabilities

- Integrated housing solutions to increase choice for clients with varying care needs, in order that people can access shared support and utilise SMART Technologies to increase independence and allow people to live safely in their communities

- Residential care services for those clients over 65 years old should be able to meet the additional needs of people also affected by Learning Disability

- Aiming to reduce the number of residential or specialist placements Out of Area, by developing specialist resources and working in partnership with providers within Argyll & Bute

- Self-Directed Support to be embedded into the assessment and review process to give people realistic choices and options.

The LHS discusses plans to meet future unmet needs for specialist housing via a 'core and cluster' model, enhanced levels of support within existing stock, and exploration of reconfiguring existing stock with RSLs. Meanwhile, the SHIP states that 10% of new build will be suitable for people with particular needs and that the "finer detail" of the programme will take into account the needs of "actual households on the waiting list" and consultation with local stakeholders. People with learning disabilities were consulted in drawing up the LHS and, while they acknowledge that "assessment of the level of need is ongoing", they state that they have carried out research on the needs of people with learning disabilities locally and that this will be repeated by 2020.

As discussed in chapter 2, there is clearly a debate to be had over which combination of housing options are best placed to meet the needs of people with learning disabilities, particularly in terms of promoting independence and choice. However, leaving aside any assessment of whether the plans individual local authorities have arrived at are appropriate, the level of variation in the detail of strategic planning for people with learning disabilities is striking. We recognise that these documents may not be councils' only focal points for planning for the needs of people with learning disabilities – a number of councils have specific learning disability strategies, for example. But given their importance in guiding future housing investments and planning, the fact that the housing needs of people with learning disabilities are not being consistently considered in detail in these documents is arguably cause for concern.

Proactive or reactive?

There was a perception among professional stakeholders interviewed for this study that planning for housing for people with learning disabilities at a local level was too often reactive rather than proactive. They gave examples where they believed poor planning had led to:

- The options available to people with learning disabilities being constrained – This reflects findings in previous chapters around those who were re-housed following a crisis being 'placed' in their current accommodation rather than having a range of options. Housing Associations also cited cases where a perceived lack of joint working between housing and social work led to delays organising support packages, resulting in properties earmarked for people with learning disabilities being let to 'mainstream' tenants instead to avoid lost rental income

- Long delays in finding accommodation that could effectively meet their needs - A stakeholder from a council housing team described a recent case where two young people who had reached adulthood were having to remain in their residential school because there was no suitable accommodation for their needs within the council's stock – something that was arguably predictable and could have been planned for

- People with learning disabilities being placed in inappropriate accommodation and/or out of area, because of a lack of planning for their needs.

Interviews with local authority professionals for this study again indicated that the picture in terms of quality of planning and joined up working varies substantially between local authorities (reinforcing findings from the review of local authority documents). Even within the small number of local authority interviews carried out for this study, there was evidence of very different approaches to, and perceptions of, joint working and strategic planning for people with learning disabilities, as illustrated in the case studies below.

Case studies: different approaches to planning

Local authority 1: Interviewees from housing and social care described good working relationships between them. Housing was seen by other local stakeholders as proactive about gathering information on needs of population with learning disabilities and planning for meeting individuals' needs, working together with social work colleagues to identify what kind of housing people are looking for and what kind of support they need. There was a perception that people with learning disabilities are seen as a priority locally because there is a designated lead for each strategic outcome in the LHS, including one whose focus is housing for older people, people with learning disabilities and people with physical disabilities – "it does give an emphasis and it does give that opening to explore the issues and the difficulties in accessing housing for that particular client group. I'm not for one second saying we always get it right, but it does give us that opportunity." They also have a learning disabilities strategic outcomes group, which includes health, social work, the voluntary sector, and housing who work together to identify the right model of housing for each client.

Local authority 2: Interviewees (from the local authority housing team and a Housing Association providing housing for people with learning disabilities) in this area both commented on a perceived lack of joined up working and future planning for people with learning disabilities. There was a perception there was little information sharing, either between social care and housing, or between the council and Housing Associations. This was believed to have become worse in recent years due to stretched resources – it was reported that joint meetings used to happen more often – and was leading to a lack of forward planning for individuals and an unnecessarily high level of voids. Problems with matching individuals to suitable accommodation were described as "systemic".

Barriers to better planning?

Comments from stakeholders and in local authority housing documents highlight both a **lack of resources** and a **lack of information** as challenges to more effective strategic planning for people with learning disabilities. For example, a local authority stakeholder in another area suggested that they previously had clearer protocols with social work for joint planning of housing investment for different care groups, but this was *"interrupted by the credit crunch"* (although they were looking at reviving it). A lack of detailed information about the exact numbers and needs of the local population with learning disabilities was also a recurrent theme among stakeholders and in local housing documents – in particular, people commented on the challenges of identifying all those with learning disabilities living with family carers, who may need rehousing in the near future:

There are people who, you know, have obviously lived within their family and once they have come out of the education system they're not in receipt of support from the Health and Social Care Partnership or they're not known to social services. So, actually unless they are actively seeking housing information and advice, it can be quite difficult for the local authority to actually be sure that it has got accurate information about all the people living in their particular area who have a learning disability and who might have a housing requirement.

(National stakeholder)

However, while information and resource limitations both undoubtedly present challenges to strategic planning, others highlighted ways in which planning was being or could be improved at local level, from allocating individual leads with specific responsibility for people with learning disabilities, to simply *"getting the right people in a room"* to discuss individual cases with complex housing needs. A recent study by Horizon Housing and academics at Stirling University (Anderson et al, 2017), which involved peer researchers in examining the process of matching disabled people to suitable accessible housing in one local authority, also identified simple things that could make a difference. For example, while everyone who applied for housing was offered an interview, generally this was 15 minutes with a relatively junior Housing Officer. However, by flagging the application of anyone whose housing need might be more complicated, the local authority could ensure that people with complex needs were interviewed by a more experienced member of staff who could give them advice about a wider range of housing options.

The case study below shows the potential impacts on people with learning disabilities of a failure to identify their needs within the housing system. Gavin was only identified as having learning disabilities after becoming homeless. As such, he would have been invisible to those planning to meet the housing needs of people with learning disabilities in his area. It is difficult to say which elements of the system might have needed to change to facilitate a more direct journey to accommodation and support that met his current needs – his learning disabilities had been missed by multiple people over many years. However, his story highlights the barriers that people with undiagnosed learning disabilities may face to accessing appropriate housing and support.

Case study: Gavin

Gavin is in his 30s. He currently lives in supported accommodation, in a flat of his own within a block for people with learning disabilities. He first arrived in this development after becoming homeless in his early 30s, after falling out with his father (who had been drinking heavily and threatening Gavin). He had not received any formal support before becoming homeless – he was only diagnosed as having learning disabilities after his support workers suggested that he be assessed.

His journey highlights the challenges someone with undiagnosed learning disabilities may face navigating the system, as well as the challenges for local authorities of identifying the local population with learning disabilities and their needs. Gavin's learning disabilities appeared to have been missed by school, family, and council staff when he initially presented as homeless. As a result, he was initially housed through the 'homeless' route, which was not ideal for him. He was initially referred to a hostel that his support worker felt "would never have been an option" had the council known he had learning disabilities at the time, as it was known to have problems with drink and drugs and Gavin himself was very nervous about going there. In the end, he missed the 'cut off' for 'signing in' to the hostel and the council found him a place in his current housing association development, in a block for homeless people. However, even here he reported having problems with his neighbours, who had a lot of parties meaning he did not get much sleep. It was 21 months before he moved to his current flat, after he was diagnosed with learning disabilities.

He had found the process of presenting as homeless very difficult – he felt it was "like processing meat" and thought there should be more support and advice to help people in housing crisis. In terms of 'The keys to life' outcomes, being sent through the 'wrong' route had impacted on Gavin's health and wellbeing, while his choices, at least initially, were constrained by the route he had taken into housing.

Source: interview with Gavin and additional information from his support worker

Key points

- There is **considerable variation in the level of detail around identifying and planning for the needs of people with learning disabilities** within local authority housing documents. Where needs are discussed, they tend to be focused on the requirement for future supported accommodation developments

- Professional stakeholders interviewed for this study also indicated that there is **variation between local authorities in the quality of planning and joint working** around housing for people with learning disabilities

- Poor planning can lead to:
  - o The options available to people with learning disabilities being constrained
  - o Long delays in finding accommodation that meets their needs, and
  - o People being placed in inappropriate accommodation or out of area, away from family and friends

- **Lack of resources** and **lack of information** are both barriers to improving planning for people with learning disabilities

- However, stakeholders suggested that there are **opportunities to improve planning** in spite of these challenges, including:
  - o 'getting the right people in a room' to discuss individual cases
  - o allocating specific local leads for housing for people with learning disabilities, and
  - o identifying and implementing improvements to the matching process for people with more complex needs.

6 – Moving forward: Progress, risks and opportunities

Introduction

In this penultimate chapter, we consider perceptions of how far Scotland has travelled in realising the potential of housing to contribute to 'The keys to life' outcomes for people with learning disabilities. We summarise risks to future progress, and possible avenues and opportunities for delivering better outcomes, drawing on both suggestions from interviewees and the implications of findings discussed in earlier chapters.

How far have we travelled?

The answer to the question of how far we have travelled in realising the potential of housing for people with learning disabilities depends in part on when you take as your starting point. On the one hand, there was consensus among the professional stakeholders interviewed for this study that the lives of many people with learning disabilities are far better now than they were 20 years ago, when there was an expectation that many people with learning disabilities would live in hospital or large-scale residential care. On the other hand, when asked to consider whether the housing options available to people with learning disabilities had improved or deteriorated over

the last 10 years, the views of professional stakeholders were more mixed. Some felt that progress had and was continuing:

> "I would definitely say improved, definitely still a work in progress, and definitely still an evolving process."

(Local Authority Housing team)

However, others felt that progress had stalled or was even going backwards in some respects:

> *"If you look at every hospital closure, there has actually been no future planning for housing thereafter. So, what about the next generation of people who eventually, you know, may have the potential to end up in hospital? Well, sadly what we have discovered is many of them have ended up in hospital … or in settings like old people's homes."*

(Housing Association)

Concerns about stalled progress were accompanied by a perception that people with learning disabilities are not as high a priority within housing as they should be – there was a recurrent view that housing policy locally and nationally is often more focused on older people:

> *"I certainly think it's way down the list … You hear a lot of discussion about 'we need to adapt the accommodation', you hear a lot of discussion about 'we need more accommodation for elderly' … but you very very seldom hear about Learning Disability as a group, getting referred to as a group in terms of housing."*

(Housing Association)

Other stakeholders felt the picture across Scotland was so "fragmented" it was very difficult to say whether or not progress was being made. This picture of fragmentation is borne out by both the differences in housing circumstances of people with learning disabilities in different areas of Scotland discussed in Chapter 2 and the variation in approaches to planning discussed in Chapter 5.

The perception that we have travelled a long way, but that we are still some distance from maximising the potential contribution of housing, was echoed in the experiences of a number of people with learning disabilities interviewed for this study. For example, Rose's account of the lack of control she had over her environment in Lennox Castle and the treatment she received from some staff there contrasted with her more positive experience in her current supported accommodation:

> Of Lennox Castle: *"You couldnae have your own stuff and that … and I didnae like some of the nurses that were there … strict and cheeky. … I didnae like it, you know."*

> Of her current accommodation: *"I like that I've got my own room, I've got my table to sit at … and I've got my own furniture … community support workers take me out where I want to go … Me, I decide."*

At the same time, there were aspects of Rose's housing journey that perhaps had not contributed as fully as they might have to her quality of life, choice and control – in particular, the limited degree of choice she recalled being offered over where she moved to after her mother died, and the level of control she had over when she was able to go out, which she thought was constrained by funding for support staff.

Risks

Regardless of whether or not people felt that progress had been made in the last 10 years, interviews with professional stakeholders highlighted a number of risks that, if not addressed, create the possibility that progress for people with learning disabilities within housing will stall or go into reverse in the next 10 years. There are significant risks associated with:

1. **The UK policy context** – As discussed in Chapter 4, the impact of benefit reform is already creating pressures for individuals and providers. And the full impact of all the changes instigated by the UK Government since 2010 is not yet known. In particular, there are ongoing uncertainties about the implications of the decision to restrict Housing Benefit for social tenants to LHA rates for people with learning disabilities, whether living in supported accommodation or mainstream social rented accommodation

2. **Demographic change (and rising expectations)** - The population of people with learning disabilities is ageing, as medical advances lead to increases in their life expectancies. At the same time, professional stakeholders reported that younger people with learning disabilities and their families have higher expectations about their rights to be able to live independently at a younger age. While both of these trends are to be welcomed, they will also create additional pressures on housing and support that need to be planned for to ensure these needs and aspirations can be met

3. **Availability of suitable housing stock** – The challenge of providing housing stock that meets the needs and aspirations of a diverse population is clearly one that affects many people across Scotland, not only those with learning disabilities. However, as a group who are often on lower incomes and who often require additional adaptations relating to co-occurring physical disabilities, the options available to people with learning disabilities may be particularly constrained by wider shortages of affordable and accessible housing

4. **Challenging climate for housing support funding and staffing** – as discussed in previous chapters, housing support providers report facing an extremely challenging funding climate. Without action to address the challenges the sector is facing, their ability to recruit and retain the right staff will continue to have a knock-on impact on the scope for providing flexible, person-centred support to people with learning disabilities to enable them to live independent, active lives in their community.

It is essential not to underestimate the significance of the risks and challenges discussed above. Indeed, one view among stakeholders was that the issues in housing for people with learning disabilities are simply "all down to funding" and that fundamentally these risks and challenges cannot be overcome without more money. All of these risks individually and collectively have the potential to limit the scope for housing to contribute effectively to positive outcomes for people with learning disabilities if they are not addressed. They also increase the importance of quality and consistency of planning for people with learning disabilities at a local level – without effective planning, at a strategic level and for particular individuals, the scope for preventing these risks from impacting on outcomes will be compromised.

Opportunities

While this report has identified significant risks to progressing 'The keys to life' outcomes within housing, it also highlights the scope to get things right when partners can be brought together to think creatively about solutions. And there is clearly an appetite to get things right for people with learning disabilities. As one professional from a local authority housing team put it: "who knows if we'll ever get it right? But there is absolutely a will to do that." There was also a perception that solutions do not always need to be "over complicated", and that rather than thinking every support package is going to be there "for life", solutions should focus on thinking creatively about what would best enhance independence, control and participation for each individual at this specific point in their life.

Interviews for this report suggest a number of possible opportunities and avenues for influencing change:

1. **Devolution of supported housing funding** – There are clearly risks attendant to changes to the benefits system, and much will depend on the size of the pot that is eventually devolved to Scotland. However, devolution of some of the funding for supported accommodation also presents an opportunity for Scotland to think differently

2. **Extending and enhancing the Housing Options approach** – While stakeholders welcomed the Housing Options approach as having the potential to enhance genuine choice within housing generally, interviews with both professionals and people with learning disabilities for this study suggest that it is not yet being fully utilised for people with learning disabilities. But again, there was an appetite and a belief that advice could be made more accessible. Suggestions about further opening up advice included: more widely available easy read materials on housing and housing options; more advocacy and rights training for people with learning disabilities, so that they are more aware of their own rights as tenants or within housing generally; and disseminating information on housing options and where to go for further information to a wider range of professionals who may come into contact with people with learning disabilities, so that the advice people are accessing is less dependent on which professionals or organisations you happen to be working with.

3. **Thinking creatively about housing support (and what/how it is funded)**
   – Although there was a strong view among housing support providers that providing effective, person-centred support to people with learning disabilities was becoming more challenging – and that there are limits to how creative you can be if the money is simply not there – interviewees also highlighted examples where providers were thinking creatively about how to use budgets to enhance outcomes, including:

   - Looking at ways of enabling people to 'bank' hours of support, so that they can use them more flexibly – for example, saving them up to use to support more social activities
   - Allocating funding to short-term housing support with scope to enhance longer-term outcomes. Examples included:

     o a Housing Association that was looking at using its own funds to provide Housing Officers with small 'tenancy sustainability' budgets to use flexibly to support tenants' short-term needs to avoid tenancy breakdown

     o an "upskilling" model adopted by the council in one area, where people with learning disabilities moved into a transitional house where they could be supported intensively to prepare for independent living, before moving out to live on their own and/or with lower levels of support

     o a small project run by Values Into Action Scotland and the Glasgow Centre for Independent Living involving 'systematic instruction' to train young people to travel independently (using their Direct Payment budgets) – a model they believe could be applied to other areas like housing

   The new Independent Living Fund Scotland scheme, which will initially focus on providing young disabled people aged 16-21 with support at this key transitional phase in their lives,[26] was viewed as a valuable opportunity to test out short-term housing-related interventions that might enhance 'The keys to life' outcomes for young people with learning disabilities

4. **Health and Social Care Partnerships (HSCPs) as vehicles to enhance joint working** – A fundamental purpose of HSCPs was to break down funding and professional silos to enable more effective joint working between health and social care and their partners, including housing. This cannot be taken for granted – some professional stakeholders interviewed for this study felt they had yet to see any evidence of HSCPs having any influence on better planning for housing and support for people with learning disabilities. However, others gave examples of the opportunities they present to get the right people in a room together and to plan for people with learning disabilities in a holistic way. For example, a local authority housing professional reported that in their area there was a new group with a focus on housing for people with learning disabilities which had resulted directly from health and social care integration and been instigated by social work rather than housing

[26]http://ilf.scot/news-and-events/new-scheme/

5. **Scope to further increase access to owner occupation and to enhance the sustainability of private renting** – As discussed in Chapter 2, people with learning disabilities are currently disproportionately reliant on the social rented sector. This is unlikely to change in the near future – and indeed one stakeholder view was that it is unhelpful for policy to focus too much on owner-occupation when this is only likely to be a genuine option for a minority of people with learning disabilities. However, the case studies discussed in Chapter 3 of this report nonetheless highlight the scope to open up both owner-occupation and sustainable private renting as choices for more people with learning disabilities. While Access Ownership and the LIFT scheme have already made a small but positive contribution in opening up ownership to people with learning disabilities, it was suggested that both could do more. Additional funding could enable Access Ownership's partners to offer the scheme to more people, while considering a more flexible approach to the level of equity available through the LIFT scheme would open it up to more people and facilitate greater choice over area (which is particularly essential to people with learning disabilities in terms of feeling safe and having access to support networks). At the same time, Homes for Good are keen to share their model, which offers scope to help potentially vulnerable tenants, including those with mild or undiagnosed learning disabilities, thrive in private rented tenancies.

Key points

- There are **mixed views** on whether housing for people with learning disabilities is continuing to progress towards more positive outcomes, or whether progress since the closure of large-scale hospitals has stalled
- Professional stakeholders expressed concern that people with learning disabilities **do not always receive sufficient priority** within housing policy nationally and locally
- Overall, the picture appears **fragmented**, with variations across different areas of Scotland and in the outcomes achieved for different individuals with learning disabilities
- **Key risks** to the scope for housing to contribute effectively in the future to realising 'The keys to life' include:
  - **The UK policy context** and the negative and uncertain impacts of welfare reform
  - **Demographic change and rising expectations** – An ageing population of people with learning disabilities, in combination with higher expectations among younger people and their families about being able to live independently earlier (positive trends, but which both create pressures within housing)
  - **Availability of suitable housing stock**, and
  - **A challenging climate for housing support funding and staffing.**

- **Potential opportunities** for positive change include:
  - o **The devolution of supported housing funding**
  - o Opportunities to extend and enhance the **housing options approach**
  - o **Thinking creatively about housing support provision/funding**, including 'banking' support hours to enable more social support and allocating funding to short-term support with the scope to enhance longer-term outcomes
  - o Using **Health and Social Care Partnerships** as vehicles to enhance joint working around housing for people with learning disabilities, and
  - o Scope to further **increase access to owner occupation** and to **enhance the sustainability of private renting**.

Conclusions and recommendations

This report has highlighted the scope for housing to make a positive contribution to 'The keys to life' strategic outcomes. When everything is working together – when people access the right advice, are empowered to understand their options and to make real choices between them, are able to access housing in the right area for them, and have the right support to enable them to live independently and access wider community – housing can underpin all four outcomes.

However, the report has also highlighted the challenges of getting all of this right, and the impact of failure to do so for people with learning disabilities and their families. While the housing circumstances of many people with learning disabilities are a long way from those experienced 20 years ago – and that is clearly to be celebrated – interviews with both stakeholders and people with learning disabilities indicate that there is still some way to go to maximise the contribution of housing to achieving the aspirations of 'The keys to life' for everyone with learning disabilities in Scotland.

Moreover, it also indicates that there is no room for complacency about the gains that have been made to date. It has highlighted concerns that the numbers of people in hospital may increase again without planning for the next generation of people with complex needs. It identifies a worrying increase in the proportion of people presenting as homeless with basic housing management needs – a group which is likely to include people with mild or undiagnosed learning disabilities. And it has described concerns about whether aspects of current commissioning patterns both for housing (such as local trends back to shared living) and housing support risk undermining independence and choice, both for those already living independently and for those who may wish to do so in the future.

In the previous chapter, we outlined some of the key risks to and potential opportunities for ensuring that housing and support contribute effectively to positive outcomes for people with learning disabilities. In this final chapter, we outline recommendations for addressing those risks and maximising opportunities. Recommendations are grouped according to the organisation we suggest is best placed to take an initial lead on taking these forward. However, each recommendation will clearly need to involve discussion between multiple parties, including in each case people with learning disabilities themselves.

Recommendations for SCLD

RECOMMENDATION 1: Initiate a national conversation on how to achieve better housing related outcomes for people with learning disabilities

At the start of this report, we set out the aim of opening up a conversation, rather than providing a definitive assessment of everything that does or does not work within housing for people with learning disabilities. As such, our first recommendation is that there should be an ongoing national conversation on the future of housing for people with learning disabilities.

A key aim of this conversation would be ensuring that specific housing-related challenges raised in this report are discussed and debated in the context of the wider learning disability agenda. The challenging financial climate, the changing demographic context, and increased expectations as a new generation of young people with learning disabilities assert their right to independent living make this discussion essential. The conversation will need to engage multiple key stakeholders, including people with learning disabilities, carers, organisations representing and working for people with learning disabilities, Housing Associations, private sector landlords, advice bodies, national and local policy makers, and practitioners in housing, social care and health.

SCLD is well placed to initiate this conversation and to identify fora to take it forward. This could include establishing a working group tasked with supporting and guiding the additional recommendations below.

Recommendations for the Scottish Government

RECOMMENDATION 2: Identify a local authority test site to review data collection, information sharing and evaluation to improve strategic planning and delivery

This report has identified significant challenges posed by the lack of accurate information on the profile and housing circumstances of those who have a learning disability. Improving local data collection and making more effective use of the existing data offers huge scope to improve strategic planning processes and delivery. There is also a need to develop better evaluation of 'success' in housing delivery and greater monitoring of progress against 'The keys to life' outcomes in local planning processes. The Scottish Government can take a lead by identifying a local authority willing to work with key stakeholders to trial new ways of working to generate learning and act as a catalyst for wider improvement. For example:

- Collecting data on housing tenure to provide a clearer picture of the precise housing circumstances of people with learning disabilities known to local authorities, enabling mapping of the relationships between accommodation type, tenure, and who people live with

- Disaggregating data by type of disability to enable tracking of the numbers of people with learning disabilities in receipt of housing support, and the size of their support packages

- Enabling Housing and Integrated Joint Boards to access and use data held by education authorities on the population of people with learning disabilities who will be leaving school and may need housing and/or support within the next 5-10 years

- Reviewing the housing preferences of people with learning disabilities at regular intervals to ensure that they are not being accommodated in unsuitable housing.

RECOMMENDATION 3: Develop an implementation framework to prevent people with learning disabilities being accommodated in health care settings unnecessarily

This report has identified concerns about people with learning disabilities and complex needs being accommodated in health care settings for long periods because of a lack of appropriate support for them to live in the community. This suggests a need to consider how best to ensure continued strategic focus to prevent this. An implementation framework which takes forward the findings from the complex needs work which will be published in 2018 and other on-going work in this area is one way of achieving this.

Recommendations for the Scottish Government and local planners

RECOMMENDATION 4: Develop more specific guidance to ensure Local Housing Strategies (LHS) more effectively address the needs of people with learning disabilities

The Scottish Government's current guidance on Local Housing Strategies identifies people with learning disabilities as one of the groups whose needs should be addressed within the section on specialist provision and mentions 'The keys to life' as a useful reference for developing strategy (Scottish Government, 2014). However, there is a lack of specific guidance on planning for people with learning disabilities and, as we have seen, inconsistencies in approaches to assessing and planning for the needs of people with learning disabilities at a local level. More specific guidance could include:

- A requirement for LHS to include a specific section on the housing-related needs of local people with learning disabilities
- A requirement for LHS to evidence consultation with people with learning disabilities and how their views have helped inform planning
- A requirement for LHS to take account of the contribution of all housing sectors in how peoples' needs are or could be met, including mainstream accommodation and the private rented sector as well as specialist accommodation and social renting
- A more prescriptive approach to assessing need which includes looking at:
  - Those who will shortly be reaching adulthood and may need support to access independent living
  - Those who may be living with parents when they do not want to
  - Those who currently live in hospitals without clinical need.

Recommendations for local planners

RECOMMENDATION 5: Greater consideration of 'The keys to life' outcomes within strategic planning and commissioning processes

There is an opportunity to review the extent to which the housing needs of people with learning disabilities are currently prioritised, and to ensure that the outcomes of 'The keys to life' feature more strongly within Housing Contribution Statements (HCS). In the context of the integration of health and social care, HCS are an integral part of Strategic Commissioning Plans and should identify the role and contribution of the local housing sector in meeting the outcomes and priorities identified within these.

Key areas to be addressed include:

- Establishing clear local priorities and effective leadership around housing for people with learning disabilities

- Ensuring effective planning is taking place around:
  - Transitions
  - Homelessness among people with learning disabilities
  - Families with elderly carers
  - People with learning disabilities in healthcare settings

- Ensuring funding, planning and allocation processes for housing and support improve the lives of people with learning disabilities.

Recommendations for housing providers and professionals

RECOMMENDATION 6: Develop joint protocols between local authorities and other Registered Social Landlords (RSL) around the provision of housing and achieving positive outcomes for people with learning disabilities

The development of joint protocols between local authorities and RSLs would provide a focus and enhance shared understanding of the specific housing needs of people with learning disabilities. There is an opportunity to build on existing partnership and collaboration between different organisations and professionals working at a local level to maximise positive housing outcomes for people with learning disabilities.

RECOMMENDATION 7: Develop a 'hub' for sharing good practice in housing planning and practice for people with learning disabilities

There appears to be a strong appetite for more information, particularly about different models of housing that can achieve positive outcomes for people with learning disabilities. This report has identified various examples of good practice around housing and housing support for people with learning disabilities including, for example, the invaluable role professionals (including support workers and housing officers) can play in empowering people with learning disabilities to live independent, active lives in their communities. The development of a hub linking housing stakeholders with each other would allow these examples to be shared and disseminated more easily. It would also provide a platform for additional conversations about how existing good practice could be improved further.

RECOMMENDATION 8: Provide greater transparency in housing allocation decisions and ensure people with learning disabilities receive appropriate advice and support to make an informed choice on their housing options

Interviews with both people with learning disabilities and professionals for this report indicate that people do not always fully understand the full range of options they have or the basis on which housing allocation decisions are made. They also suggest that housing advice offered to people with learning disabilities can vary dependent on the knowledge and attitudes of the particular professionals they interact with. There is a need to ensure that all individuals receive appropriate and accessible advice and information to make informed choices. Both person-centred planning and independent advocacy have a role to play in this regard.

References

Anderson, I, Theakstone, D, Baird, C and Jago, L (2017) Matching up: A pilot study of effectiveness in letting adapted social housing, Horizon Housing

Anna Evans Consultants (2016) Evaluation of Access Ownership (available from Horizon Housing)

Care Inspectorate (2017) The keys to life: Report of the Care Inspectorate's Inspection focus area 2014-2016, available at: http://www.careinspectorate.com/images/documents/3741/Keys%20to%20life%20report.pdf

Care Services and Improvement Partnership (2006) Extra Care Housing toolkit, available at: https://www.housinglin.org.uk/Topics/type/Extra-Care-Housing-Toolkit/

CCPS (2016) Business Resilience Survey 2016, available at: http://www.ccpscotland.org/hseu/resources/business-resilience-survey-2016/

Christie Commission (2011) Commission on the Future Delivery of Public Services, available at: http://www.gov.scot/resource/doc/352649/0118638.pdf

Craigforth (2015) Research into the impact of charging for housing support services, Housing Support Enabling Unit, available at: http://www.ccpscotland.org/hseu/news/impact-charging-housing-support/

Department of Health (2012) Transforming care: A national response to Winterbourne View Hospital Department of Health Review: Final Report, available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf

Edinburgh Council (2011) Edinburgh City Housing Strategy 2012-2017, available at: http://www.edinburgh.gov.uk/info/20245/services_for_communities/1003/housing_strategy

Emerson, E and Hatton, C (2008) Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England, CeDR Research Report

GCIL and Capability Scotland (2013) Housing options for disabled people in Scotland, available at: http://www.capability-scotland.org.uk/media/417401/housing_options_guide.pdf

Housing Options Scotland (2014) Benefits Based Borrowing A guide for disabled people using their benefits to buy property suited to their needs, available at: https://www.housingoptionsscotland.org.uk/wp-content/uploads/Benefits-based-borrowing-2014.pdf

Housing Support Enabling Unit (2012) Local authority funding of housing support, available at: http://www.ccpscotland.org/hseu/wp-content/uploads/sites/2/2014/01/HSEU_LAfundingreport2.pdf

Ipsos MORI, Imogen Blood & Associates and Housing and Support Partnership (2016) Supported Accommodation Review: The scale, scope and cost of the supported housing sector, DWP and DCLG, available at: https://www.gov.uk/government/publications/supported-accommodation-review

ISD (2015) Findings from the balance of care/NHS continuing care census, Census held

31 March 2015, available at: http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/2015-06-23/2015-06-23-NHSCC-Report.pdf

ISD (2016) Care home census for adults in Scotland: Figures for 31 March 2006-2016, available at: http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/2016-10-25/2016-10-25-CHCensus-Report.pdf

LDAS (2010) Stuck! People with learning disabilities resident in care homes for older people in Scotland, available at: http://www.ldascotland.org/docs/stuck.pdf

Mencap (2012) Housing for people with a learning disability, available at: https://www.mencap.org.uk/sites/default/files/2016-08/2012.108-Housing-report_V7.pdf

Mental Welfare Commission for Scotland (2016) No through road: People with learning disabilities in hospital, available at: http://www.mwcscot.org.uk/media/296413/no_through_road.pdf

Midlothian Council (2017) Strategic Housing Investment Plan 2017/18-2021/22, available at: https://www.midlothian.gov.uk/downloads/file/1792/midlothian_council_strategic_housing_investment_plan_2017

NDTi (2010) Supported living – making the move, available at: https://www.ndti.org.uk/uploads/files/Supported_Living_-_Making_the_Move,_May_2010.pdf

NRS (2015) Household composition for specific groups of people in Scotland, available at: http://www.scotlandscensus.gov.uk/documents/analytical_reports/HH%20report.pdf

ONS (2017) Families and households in the UK: 2016, available at: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/families/bulletins/familiesandhouseholds/2016

People First/Capability Scotland (2010) Housing Discussion involvement event report, available at: http://www.capability-scotland.org.uk/media/63607/people_first_housing_event_report_4_10_10_21773_26598.pdf

Scottish Executive (2000) The same as you? A review of services for people with learning disabilities, available at: http://www.gov.scot/Resource/Doc/1095/0001661.pdf

Scottish Executive (2003) Care homes, Scotland – March 2003, available at: http://www.gov.scot/Resource/Doc/47171/0029209.pdf

Scottish Federation of Housing Associations (2016) A second SFHA report on the capping of social rents to the rate of local housing allowance, available at: https://www.sfha.co.uk/mediaLibrary/other/english/2475.pdf

Scottish Government Communities Analytical Services (2010) A select review of literature on the relationship between housing and health,

Scottish Government (2013) The keys to life: improving quality of life for people with learning disabilities, available at: https://keystolife.info/wp-content/uploads/2014/05/

the-keys-to-life-full-version.pdf

Scottish Government (2014) Local Housing Strategy Guidance, available at: http://www.gov.scot/Resource/0045/00458185.pdf

Scottish Government (2015) The keys to life: improving quality of life for people with learning disabilities – implementation framework and priorities 2015-2017, available at: https://keystolife.info/

Scottish Government (2015) Joint Housing Delivery Plan for Scotland, available at: http://www.gov.scot/Publications/2015/05/3392

Scottish Government (2016) A fairer Scotland for disabled people – our delivery plan to 2021 for the United Nations Convention on the Rights of Persons with Disabilities, available at: http://www.gov.scot/Publications/2016/12/3778

Scottish Government (2017) Social Care Services Scotland available at: http://www.gov.scot/Resource/0051/00510699.pdf

Scott, J, MacMillan, K and Reid, S (2011) The Evaluation of Low Cost Initiative for First Time Buyers (LIFT), Scottish Government, available at: http://www.gov.scot/Resource/Doc/338455/0111369.pdf

SCLD/ENABLE (2014) The National Confidential Forum: estimating the number of people with learning disabilities placed in institutional care as children, 1930-2005, available at: https://www.scld.org.uk/publications/the-national-confidential-forum-estimating-the-number-of-people-with-learning-disabilities-places-in-institutional-care-as-children-1930-2005/

SCLD (2016) Learning Disability Statistics Scotland, 2015, available at: https://www.scld.org.uk/evidence-and-research/statistics/

SCLD (2010) Learning Disability Statistics Scotland, 2009, available at: https://www.scld.org.uk/evidence-and-research/statistics/

South Ayrshire HSCP (25th June 2015) IJB paper: Supported accommodation for people with learning disabilities – available at: http://www.south-ayrshire.gov.uk/health-social-care-partnership/documents/item%2010%20-%20supported%20accommodation%20for%20adults%20with%20learning%20disabilities.pdf

SPICE (2017) Briefing for the public petitions committee: Local Housing Allowance ('Bedroom tax 2'), available at: http://www.parliament.scot/ResearchBriefingsAndFactsheets/Petitions%20briefings%20S5/PB17-1638.pdf

Squire, A and Richmond, P (2017) The Economics of independent living: a discussion paper for the centre for welfare reform, available at: http://www.centreforwelfarereform.org/uploads/attachment/578/no-place-like-home.pdf

Watson, L, Joseph, G, Fitzpatrick, J, Britain, A (2012) Mind the step: an estimation of housing need among wheelchair users in Scotland, available at: http://horizonhousing.org/static-content-wysiwyg-downloads/Horizon-Housing-Mind-the-step-report.pdf

Appendix A – Sample of people with learning disabilities and carers

Table A1 – Sample structure for people with learning disabilities and carers

Age group	Gender	Accommodation type	Accommodation tenure	Who we interviewed
16-34	Male	Mainstream with support	Socially rented	Parent
16-34	Male	Residential care	Socially rented	Parent
16-34	Male	Mainstream without support	Owner occupied	Individual
16-34	Male	Mainstream with support	Socially rented	Individual
35-54	Female	Mainstream with support	Socially rented	Individual
35-54	Female	Mainstream with support	Socially rented	Support worker
35-54	Female	Mainstream with support	Owner occupied	Individual
35-54	Male	Mainstream with support	Socially rented	Individual
35-54	Male	Mainstream with support	Owner occupied	Parent
35-54	Male	Supported accommodation	Socially rented	Individual
35-54	Male	Supported accommodation	Socially rented	Individual
55+	Female	Mainstream without support	Private rented	Individual
55+	Female	Supported accommodation	Socially rented	Individual
55+	Female	Supported accommodation	Socially rented	Individual
55+	Female	Supported accommodation	Socially rented	Individual
55+	Female	Supported accommodation	Socially rented	Individual
55+	Female	Supported accommodation	Socially rented	Individual
55+	Male	Mainstream without support	Private rented	Individual
55+	Male	Mainstream with support	Socially rented	Individual
55+	Male	Supported accommodation	Socially rented	Individual
55+	Male	Registered group home	Socially rented	Individual

List of organisations who helped recruit people with learning disabilities and carers

The following organisations acted as 'gate keepers' to introduce the research to people with learning disabilities they worked with and ask if they would be willing to take part in an interview:

- Places for People
- C-Change
- Housing Options Scotland
- Loretto Housing
- ENABLE Scotland
- Kindred
- Homes for Good
- Neighbourhood Networks
- Cornerstone

Appendix B – Size and cost of the supported accommodation sector in Scotland

Secondary analysis of data collected for the Supported Accommodation Review conducted by Ipsos MORI in 2015 for the DWP and the Department for Communities and Local Government (DCLG) provides further information about the size and cost of the supported accommodation sector in Scotland. As the report notes (Ipsos MORI et al, 2016), there are limitations to this data – figures are estimates based on grossing up responses from local authorities and assuming non-responding local authorities are similar. However, the data is nonetheless the most accurate picture of key characteristics of the sector available since 2009, when Supporting People data returns stopped being collected. Key findings include:

- **10% of supported housing provision in Scotland – an estimated 6,000 units – is for people with learning disabilities.** This figure is somewhat higher than the 4,622 adults with learning disabilities estimated to be living in supported accommodation based on local authority returns for the Scottish Learning Disability Statistics, probably reflecting the different methodologies used. Supported housing for people with learning disabilities accounts for a slightly larger proportion of the overall supported accommodation sector in Scotland than in Britain as a whole (10% vs. 7%)

- **Most supported housing for people with learning disabilities in Scotland is provided by registered charities (40%) or Housing Associations (38%). However, local authorities play a bigger role in the sector in Scotland than they do across Britain as a whole** – they directly provide 22% of all supported housing for people with learning disabilities in Scotland, compared with 7% across Britain as a whole. Charities also play a bigger role in Scotland, providing 40% of supported housing for people with learning disabilities compared with 17% across Britain as a whole

- **Spending on care and support for people with learning disabilities in supported housing accounts for a substantial share of the overall budget.** The total additional spend, on top of Housing Benefit - that is, spending on the care and support components of supported housing – for people with learning disabilities in Scotland is estimated to be £176 million a year. This represents 45% of the total additional spend on supported housing in Scotland. The additional spend per unit on people with learning disabilities is estimated to be substantially higher in Scotland, at £29,500 per unit per year, compared with £17,850 across Britain as a whole

- Combining average Housing Benefit spend on supported housing for people of working age with estimated additional spend for housing for people with learning disabilities suggests the **estimated total spend in Scotland is at least £39,500 per unit per year in Scotland, compared with an estimated £26,925 across Britain** as a whole. Evidence from qualitative interviews conducted for the review indicates that geography is one contributor to this – greater economies of scale are possible in more densely populated areas in England than are possible in Scotland. Remote rural areas were identified as creating significant challenges around the costs of delivering supported housing in Scotland

- **The main reasons Scottish Housing Benefit teams and Commissioners gave for the higher costs of supported housing relative to mainstream housing related to the higher cost of maintenance, up keep of communal facilities, and the provision of wardens, security and concierge services.** Other factors include needing to cover the costs of potentially long void periods (where the property cannot be let to a suitable tenant, or is waiting on a care package being put in place for a tenant to move in), the need to adapt housing, and the fact that units tend to be larger and therefore to command a higher rent. Interestingly, Scottish local authorities were less likely than authorities across Britain as a whole to attribute the higher costs of supported housing to some providers redefining elements of support as housing-related in order to lever in additional income.[27]

---

27 Housing-related costs are eligible to be paid for via Housing Benefit whereas support costs are not.