

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

Key Findings and Recommendations

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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.

Chan & Collegen

Chris Creegan, Chief Executive, SCLD



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Background and method

'The keys to life' is Scotland's learning disability strategy (Scottish Government, 2013). 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:

- 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).

This report is an extended summary of findings from a study of housing for people with learning disabilities in Scotland. The full report is available from www.scld.org.uk.

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.

Policy context

In the 20th century, housing for people with learning disabilities was underpinned by a **policy of institutionalisation** – many thousands of people were housed away from their families and communities in large-scale hospitals. Gaining independence from institutional living was a focus from the outset of the **Independent Living Movement** in the UK, a movement of disabled people who came together to advocate for their rights. A key recommendation of Scotland's first learning disability strategy, **'The same as you?'** (Scottish Executive, 2000) was that all remaining long-stay hospitals for people with learning disabilities in Scotland should close. The vast majority of remaining residents moved into community-based facilities or their own tenancies by 2005 or shortly thereafter.

The accelerated move away from long-stay institutions in the 2000s was underpinned by both the actions of the Independent Living Movement and by an increased policy focus on disabled people's **empowerment** and **human rights.** The 2006 United Nations Convention on the Human Rights of Persons with Disabilities¹ emphasised the rights of disabled people to have 'the opportunity to choose their place of residence and where and with whom they live on an equal basis'. At the same time, there has been growing recognition of the need for **personalisation, co-production, assets-based** and **preventative approaches** in public services in order to realise these human rights in practice. These core themes are apparent in many of the recent Scottish policies relevant to the current and future housing landscape for people with learning disabilities, including:

- **Self-Directed Support** (SDS), which aims to increase personalisation and empower disabled people to have more choice and control over their care and support
- the integration of health and social care, which aims to reduce barriers to personalisation and prevention by removing silos around the planning and funding of services
- the development of new National Health and Social Care Standards
- the duties on local authorities to develop housing strategies which, among other things, set out the future need for accommodation and services to help people live independently, and
- the duty on Scottish social landlords to deliver services so that, regardless of disability, every customer and tenant has their individual needs recognised, is treated with fairness and respect, and receives fair access to housing and housing services.

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. The **end of Supporting People ring-fencing**², the **financial crisis** of the late 2000s and the subsequent UK Government policies of **austerity** and **benefit reform** all have significant implications for the delivery of housing and housing support for people with learning disabilities.

¹https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html ²Supporting 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. It is within this broad historical, financial and policy context that this research has been commissioned and should be understood. Nearly 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?

Research methods

This report 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.

All names used in this report are pseudonyms, to maintain participant confidentiality.

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.

The focus of the report is on housing for people with learning disabilities. There is no **single agreed definition of 'learning disabilities'**. However, 'The keys to life' strategy 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." (Scottish Government, 2013: 6)

Scope and limitations

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 the role of housing in contributing to 'The keys to life' strategic outcomes.

Many of the topics discussed could easily be subjects of standalone reports in themselves. While our sampling approach aimed at identifying diverse perspectives and experiences, it must be acknowledged that there may be other perspectives and issues that were not captured. As this report is a shortened version of the full report, we have only included selected case studies and illustrations of key findings. Further detail is included in the full report (available from <u>www.scld.org.uk</u>).

This research 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 in Scotland is or is not contributing to meeting 'The keys for life' strategic outcomes, and to share learning about how to overcome challenges.

Findings A shifting housing landscape

Our ability to assess the current housing situations of people with learning disabilities in Scotland is impeded by some significant limitations to, and **gaps in, the available quantitative data.** In particular:

- 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. Learning Disability Statistics for Scotland is the data source that currently provides the most detail on crucial aspects of the housing circumstances of people with learning disabilities. However, it is based on data returns from local authorities and as such does not include those not known to statutory services. 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 gaps in information about the numbers of people with learning disabilities accessing formal housing support
- There is a lack of data on the balance of specific models of supported accommodation, and
- There is no quantitative data on whether or not the current housing circumstances of people with learning disabilities match their preferences.

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
- 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.

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.

Quantitative and qualitative data analysed for this study also highlight the extent to which the housing landscape for people with learning disabilities has changed in the last 15 years, and the ways in which it is continuing to evolve. This is particularly the case in relation to accommodation type.

A continuing shift away from residential care homes?

Since the early 2000s, there has been a **shift away from accommodating people with learning disabilities in residential care homes** towards greater use of supported accommodation. This was prompted partly by the financial impetus of Supporting People funding and partly by ideological concerns about the 'institutional nature' of some care homes. While residential care homes **remain a significant part of the accommodation mix** for people with learning disabilities in Scotland, our review of local authority housing documents indicates 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, **recent concerns** have been raised over:

- The number of people with learning disabilities being housed in **care homes aimed at older people** (LDAS, 2010), and
- Instances reported by professional stakeholders interviewed for this research which have suggested that people who are currently living independently may sometimes be **offered a care home place for cost reasons**.

The latter in particular highlights the **potential for financial pressures within local authorities to restrict the choices people with learning disabilities are offered,** even while the general trend appears to be away from the commissioning of new group homes for people with learning disabilities.

Recent trends in supported accommodation

'Supported accommodation' covers diverse specific models of accommodation, varying in terms of provider type, support model and location, accommodation design and size, and whether it involves individual or shared tenancies. There appears to be an appetite among Scottish local authorities to learn more about how the provision of specific models of accommodation can best meet the individual requirements and range of preferences of people with learning disabilities within their area.



Our review of local authority documents, supported by interviews with housing stakeholders, indicates a trend across a number of Scottish 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 for people with learning disabilities. However, there were 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 are housed in the same development, is there a danger that this leads to an artificial separation from the wider community?

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 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. Both these findings highlight the need to consider what models are best able to enhance independence, choice, control and community participation for tenants. Cost will also inevitably be a concern to funders and providers. In this context, a recent paper by the Centre for Welfare Reform (Squire and Richmond, 2017) presents evidence 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.

No one living in hospital without clinical need?

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. 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).³ The figures show that 17% of these patients were being accommodated in learning disability healthcare settings. There was a perception among stakeholders in the group that, while the hospital closure programme was a considerable achievement, there had

³This 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.



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". In response to this, the Scottish Government has 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.

Homelessness among people with learning disabilities

In 2016/17, 698 people who presented as homeless were recorded as having 'a learning disability'.⁴ 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' (from 10% in 2007-8 to 20% in 2016-17). Given that those assessed as having such needs may well include people with low level or undiagnosed learning disabilities, this upward trend is concerning.

Delivering on housing for people with learning disabilities: what works?

Expanded options

While there remain questions over whether the precise mix of housing options available locally or nationally in Scotland is the right one, there was agreement among stakeholders interviewed for this research that the general **expansion of housing options** in recent decades has **increased the choices available** to people with learning disabilities, and made it more likely that they can access housing that facilitates independent living.

While much of the debate about housing for people with learning disabilities has focused on the expansion of options within the social rented sector, stakeholders interviewed for this study also identified a number of examples of schemes in Scotland that aim to **open up both owner occupation and private renting** to wider groups of tenants, including people with learning disabilities.

- The **Low-Cost Initiative for First-time buyers (LIFT)** is a Scottish Government scheme which allows first time buyers on low incomes to buy homes on the open market. Buyers fund at least 60% of the property, and the Scottish Government funds the remainder, retaining an 'equity stake'
- Access Ownership is a shared-ownership scheme provided from joint investment by Horizon Housing Association and Link Group. It has helped 18 disabled people and their families, including people with learning disabilities, to either buy a more suitable home, or reduce their financial commitments in order to stay in their current home
- **Homes for Good** is a social enterprise which manages private rented properties on behalf of landlords. Their dedicated tenancy support team (funded by

⁴Based on analysis of Homelessness Statistics for Scotland, available at: http://<u>www.gov.scot/Topics/Statistics/Browse/Housing-</u> <u>Regeneration/RefTables</u>. Additional analysis by the report authors.



management fees from their property portfolio) provides an enhanced service to enable tenants who may need extra help to maintain their tenancies, access benefits and services and participate in their communities.

Enhanced advice

The move to a **Housing Options approach** and the development of advice services aimed specifically at people with disabilities has also helped to open up wider housing options to disabled people, including those with learning disabilities. Housing Options offers a more personalised approach to housing advice, which explores all possible tenure options and considers people's wider personal circumstances and support needs alongside their physical housing needs. The case study below highlights how this approach transformed the choices available for Ian and his family, opening up their choices and enabling them to access housing that maximised his quality of life, independence and community involvement in a way they had not previously thought possible.

Accessible design

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, while life expectancy remains lower, the population of people with learning disabilities in Scotland is ageing, along with the population as a whole. **Advances in accessible design** are helping people with learning disabilities and co-existing physical disabilities to have a higher standard of living and to live healthy, independent lives. 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

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 and has support 24-hours a day. Until he moved into this house, Ian lived at home with his parents. However, through advice from Housing Options Scotland, his family found out about a new shared ownership scheme (Access Ownership, described above). This option gave them control over both the type of property Ian would live in and the location (allowing them to purchase somewhere close to them). 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 personalised support package (funded through SDS) also helped him to be active in his local community. 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

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.⁵

Person-centred support and planning

Professional stakeholders believed that there had been a **shift towards person-centred and outcome-focused planning** in relation to housing and housing support for people with learning disabilities over recent decades. There was a perception that people with learning disabilities are more involved in deciding what they want from both housing and housing support, increasing the likelihood that individuals achieve positive outcomes. This was supported by the comments of people with learning disabilities interviewed for this study, who highlighted the importance of being able to decide what they do and when they do it, with support workers who know them well – effectively 'co-producing' their support plans with their workers.

"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."

Supporting community engagement

In addition to having the means to live an independent, healthy life within your own home, the wider community and your access to this is also key to everyone's health and wellbeing. **Supporting community participation** was viewed by professional stakeholders as a central element of the practice of many Housing Associations and support providers. They gave numerous examples of schemes and practices that could engage people with learning disabilities (some of which are described in the longer version of this report). Where people with learning disabilities have access to such support, it can clearly make a significant difference to their wellbeing and ability to connect with their community.

At the same time, having the right support is only one factor in enabling people with learning disabilities to be active citizens – being in the right location is also key. In fact, people with learning disabilities 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 feeling happy with their housing and their ability to be 'active' in their community. Douglas, interviewed for this study, illustrates how living in the right location, with the right support, can enable people with learning disabilities to make full use of their own skills and talents to be active members of their community.

Challenges and barriers

This research identified many examples of good practice with respect to the factors identified above. However, it is also clear that there are significant barriers to implementing these equally for all people with learning disabilities in Scotland.



Availability of suitable housing

There are **significant challenges around the current supply of housing** in general, and of accessible accommodation in particular. While several stakeholders welcomed the Scottish Government's commitment to build 50,000 affordable new homes by 2021⁶, 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. Funding pressures were seen as a factor in reducing choices available to people with learning disabilities in terms of both accommodation type and location. While living in the 'right' location is a priority for most people, issues around harassment may mean this is even more important for people with learning disabilities. Among 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. It was all on the verandas, you know what I mean, you were scared to open your door ... You couldn't leave your flat after 5 o'clock at night."

Case study: Douglas

Douglas is in his 70s. He lives on his own in a flat which he lets from a Housing Association. 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). The way in which Neighbourhood Networks worked with Douglas is an example of assetsbased 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.

Source: interview with Douglas

Difficulties accessing housing advice and guidance

Lack of information about options is a key constraint on the degree of choice people with learning disabilities are able to exercise over their housing. While there was a perception among stakeholders interviewed for this study that excellent housing advice is available in Scotland, people with learning disabilities do not always appear to be appropriately referred to such advice. 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:

"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'."

(Housing Advice provider)

People who move in a crisis – for example, following the death of a parent carer – were identified as group who may be particularly less likely to have wider housing options discussed with them. This certainly appeared to be the case for a number of people with learning disabilities interviewed for this study:

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

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

Funding of housing support

Providers of housing support interviewed for this study described major challenges around funding. Cuts to hourly rates, reductions in the size of individual funding packages, inflexibility around how support is funded, and rigidity between funding streams were all cited as having a substantial impact on providers' ability to deliver effective, personalised 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. For example:

- 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.



Welfare reform

Stakeholders identified various aspects of welfare reform that are currently having, or are expected to have, a negative impact on the housing circumstances and options of people with learning disabilities in the future, including:

- The 'bedroom tax' Although 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 - interviews for this study suggest that people with learning disabilities in Scotland and their families may still be affected. For example, a father of a man with learning disabilities and challenging behaviour 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 his son often stayed with him
- Restrictions to housing benefits for under 35s The Scottish Federation of Housing Associations has predicted that the extension of the 'shared rate' housing benefit cap to social housing will result in "A rise in rent arrears, failed tenancies, evictions and homelessness" among vulnerable tenants under 35 (2016: 2). Professional stakeholders interviewed for this study suggest 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 to Local Housing Allowance (LHA) rates for social housing – 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. However, in response to criticisms about the negative impact this change might have on the supported accommodation sector, the UK government has committed to devolve an additional amount to the Scottish Government intended to cover the extra costs of supported accommodation. Stakeholders interviewed for this study felt that these changes, and a lack of clarity about how much funding will be devolved and how this will be distributed, were creating considerable uncertainty around planning for future supported accommodation. The plan to cap Housing Benefit for social tenants to LHA rates for the private rented sector may also impact on people with complex needs who currently live in properties which are not classed as supported accommodation, but which have been adapted and consequently have higher rents.
- **Reassessments of disability benefits and the move from DLA to PIP** Where tenants have lost income through the reassessment process, this was reported to be having significant impacts on tenancy sustainability

Legal barriers

Legal barriers can get in the way of people with learning disabilities being able to access housing. In particular, a perceived need to establish capacity before people can

sign tenancies and a related increased insistence on 'guardianship orders' – was seen as undermining the ability of people with learning disabilities to access their own tenancies. It was argued that the 'all or nothing' nature of guardianship and capacity assessments is problematic and needs to be addressed.

Attitudes to people with learning disabilities

Attitudes to people with learning disabilities among some social workers, support workers and landlords were all seen as restricting the potential for housing to contribute to 'The keys to life' outcomes for people with learning disabilities. It was reported that:

- **Social workers** sometimes avoid discussing housing options before a settled support package is in place, restricting people's opportunity to exercise meaningful choice
- Landlords (including Housing Associations) may view people with learning disabilities as 'high risk' tenants and be less willing to let to them directly
- **Support workers** do not always see their role as being 'community connectors', limiting the ways in which they facilitate genuine community participation and relationships for people with learning disabilities.

People's own aspirations may also affect the degree of choice, control and independence they seek. These aspirations are in turn driven by a complex mix of familiarity, experience, awareness of alternative options, and confidence.

Who misses out?

Interviews with professional stakeholders for this report identified a number of subgroups of people with learning disabilities who were viewed as particularly likely to miss out on housing and support that meets their needs and aspirations, including:

- **People who currently live with their parents** Professionals reported an increased expectation of independent living among young people and their families, but one which local authorities are struggling to meet
- **People with a lower support requirement,** who may miss out on both benefits and housing support they would previously have qualified for as a result of an increased focus on those with critical needs
- **People with complex needs and behaviours perceived as challenging,** who may miss out on advice about different housing options and are particularly vulnerable to ending up in hospital or residential care if appropriate community support options are not available
- **People in rural areas,** who may face difficulties finding suitable housing and support close to their support networks.

Planning housing for people with learning disabilities

The review of local authority documents conducted for this report indicates **considerable variation in the level of detail in identifying and planning** for the needs of people with learning disabilities at local level. There was some evidence of good practice – for example, Argyll and Bute's Housing Contribution Statement considers 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. People with learning disabilities were consulted in drawing up the Local Housing Strategy and, while the council 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.

However, overall, where the specific needs of people with learning disabilities are discussed in local housing documents, they tend to be focused on the requirement for future supported accommodation developments – there is relatively little discussion of wider housing options that might meet their future needs.

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. There was a general perception that planning for their needs was too often reactive rather than proactive. 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** were both cited as barriers to improving planning for people with learning disabilities. However, stakeholders also identified **opportunities for improvement**, including:

- 'getting the right people in a room' to discuss individual cases
- allocating specific local leads for housing for people with learning disabilities, and
- identifying and implementing improvements to the matching process for people with more complex needs.

Progress, risks and opportunities

There were mixed views on whether housing for people with learning disabilities is continuing to progress towards more positive outcomes, or whether progress since the hospital closure programme has stalled. Overall, the **picture appears fragmented**, with variations across different areas of Scotland and divergent outcomes for different individuals with learning disabilities. Professional stakeholders expressed concern that people with learning disabilities **do not always receive sufficient priority** within

housing policy at national or local level.

"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)

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 discussed above
- **Demographic change and rising expectations** An ageing population of people with learning disabilities, higher survival rates into adulthood of people with complex health needs, and higher expectations among younger people and their families about being able to live independently earlier are all positive trends, but which 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:

- **The devolution of supported housing funding,** which presents an opportunity for Scotland to think differently
- Opportunities to extend and enhance the housing options approach, to ensure it is more accessible to and more widely used by people with learning disabilities
- Thinking creatively about housing support provision/funding, including 'banking' support hours to enable more social support. The new Independent Living Fund Scotland scheme was viewed as a valuable opportunity to test out short-term housing-related interventions that might enhance outcomes for young people with learning disabilities
- Health and Social Care Partnerships as vehicles to enhance joint working around housing for people with learning disabilities. This cannot be taken for granted and some professional stakeholders interviewed for this study felt they had yet to see any evidence of HSCPs having an influence on better planning in this area. However, others gave examples of opportunities integration has provided to plan for people with learning disabilities in a more holistic way
- Scope to further increase access to owner occupation and to enhance the sustainability of private renting. While people with learning disabilities are likely to remain disproportionately reliant on the social rented sector for the foreseeable future, good practice case studies discussed in this report nonetheless highlight scope to open up owner occupation and sustainable private renting as choices for more people with learning disabilities.



Conclusions and recommendations

This report highlights the scope for housing to make a positive contribution to 'The keys to life' strategic outcomes. When everything is working together – when people are empowered to understand their housing options and to make real choices between them, and supported to live independently and access their wider community – housing can underpin all four outcomes.

However, the report has also highlighted the challenges to getting all of this right, and the impact of failure to do so for people with learning disabilities and their families. 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.

It also indicates that there is no room for complacency about the gains that have been made to date.

The recommendations below are focused on ensuring that progress does not stall, and that everyone with learning disabilities in Scotland is able to access housing and support that enables them to live healthy, independent, active lives. Recommendations are grouped by the organisation we suggest is best placed to take an initial lead. However, each recommendation will clearly need to involve discussion between multiple parties, including 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

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

ISD (2015) Findings from the balance of care/NHS continuing care census, Census held 31 March 2015, available at: <u>http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/2015-06-23/2015-06-23-NHSCC-Report.pdf</u>

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

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: <u>https://www.sfha.co.uk/mediaLibrary/other/english/2475.pdf</u>

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

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

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





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