SCLD

My home, my community

Exploring housing and communities for people with learning disabilities in Scotland

The third in a series of reports presenting the findings from the How's Life? survey

The Scottish Government

Acknowledgements

SCLD would like to acknowledge all the help we have had with this piece of work. In particular, the contribution made by our six partner organisations – ARC Scotland, Down's Syndrome Scotland, ENABLE Scotland, Key, PAMIS and People First (Scotland) – was invaluable. They have been with us every step of the way making the journey so much easier, and more enjoyable. Thanks also to individuals and groups who helped develop and test various drafts of the survey, including members of The keys to life Expert Group. Conversations with Professor Andrew Jahoda at an early stage were enormously helpful. Special thanks to People First (Scotland) for creating the easy read summary of the report and to Rachel Ormston from Ipsos MORI for her help in designing and analysing the survey.

We are very grateful to the people with learning disabilities, as well as their parents, carers, and supporters, who took the time to fill in the survey and share their stories with us.

Finally, thanks to the Scottish Government for funding this piece of work that has helped us understand a bit more about what it is like living with a learning disability in Scotland today.

Executive Summary

Aims, methods and background

During 2019, the Scottish Commission for People with Learning Disabilities (SCLD) developed the How's Life? survey with a range of partners in order to ask as many people with learning disabilities as possible how they felt about different aspects of their lives. The survey was designed to be completed by people with learning disabilities, with or without support from a family member, advocate, or paid supporter. A total of 1232 responses were received. This report is based on some of the findings from the survey. It focusses on housing and communities. This was chosen as the theme for our third report, because housing and communities are an important determinant of wellbeing for people with learning disabilities, and a key focus of *The keys to life* (2013) strategy. The Covid-19 pandemic has also highlighted the importance of housing and communities for people's wellbeing, in particular the importance of access to amenities and green space.

Key findings

- Most people (62%) lived in mainstream accommodation, followed by supported housing (30%) and residential care homes (5%). A small percentage (1%) were living in a medical setting.

- Over a third (35%) of people were living on their own.

- 52% of young adults aged 20-34 still lived with parents compared to 27% in the general population. 9% of those aged 45 and over were still living with parents.

- 35% of people had not chosen where they lived.

- 36% of people did not always feel safe in the local area.

While the majority of people were happy with their home, people were more likely to say they were happy with their home if:

- They lived in supported accommodation.

- They had chosen where they lived.

- They had enough support to live independently.

- They were treated with respect by people who supported them.

The majority of people were also happy with their local area. However, people were more likely to be happy with their local area if:

- They always felt safe.
- They were not picked on when they were out and about.
- They were happy with the transport options available locally.

Being happy with their home and the area they lived were very strongly related to high levels of life satisfaction:

- 85% of people who were happy with their home reported high levels of life satisfaction compared to 36% of people who were not.
- 85% of people who were happy with their local area reported high levels of life satisfaction compared to 37% of people who were not.

Moving forward

Based on the findings in this report, SCLD believes there are a number of measures to consider.

1. The Scottish Government and local authorities must improve local and national data collection on housing so we can better understand how many people with learning disabilities do not have access to appropriate housing, and monitor this over time.
2. Local authorities must work towards a better balance of housing, support and service options for people with learning disabilities. Local policies must take into account the particular needs of people with learning disabilities, and include working with individuals and families to plan for future support needs.
3. Local authorities must embed a 'Housing Options' approach in advice services around housing, so people can make informed decisions.
4. Health and Social Care Partnerships (HSCPs) must utilise the Community Living Change Fund to urgently design and put in place community based support for those who have been living in inappropriate medical settings and out of area placements.

5. Local authorities and public transport operators must work to make public transport fully accessible and inclusive, including learning disability awareness training for all staff.
6. Housing providers and support services must implement learning disability hate crime training and ensure that people with learning disabilities who use their services know who to report any incidents to and that they will be supported when they do.
7. Invest in making communities more inclusive. This can be supported by investing in roles like Local Area Coordinators or Community Connectors, refocusing the role of support staff towards community inclusion and promoting resources like Active, Connected, Included.

If we are to recover from the Covid-19 pandemic both inclusively and fairly, we need to overhaul the structures, processes and attitudes in the social care system, and in wider society, that create barriers for people with learning disabilities spending their time as they choose, and participating in society on an equal basis. To do this right will require not only significant investment, but strong leadership, and a commitment to the equality and human rights of people with learning disabilities.

Introduction

SCLD's vision is of a fairer Scotland where people with learning disabilities live full, safe, loving and equal lives. A Scotland where their human rights are respected, protected and fulfilled.

During 2019, SCLD developed the How's Life? survey with a range of partners in order to ask as many people with learning disabilities as possible about how they felt about different aspects of their lives.

We wanted to do this to find out which areas should be the focus for any changes in policy and/or practice in Scotland.

This report is based on some of the findings from the How's Life? survey. It focusses on where people live. While the How's Life? survey was undertaken pre-Covid-19, addressing some of the issues raised takes on a renewed significance as we move out of the crisis and beyond.

Background

SCLD worked in partnership with people with learning disabilities, ENABLE Scotland, Key, ARC Scotland, People First (Scotland), Down's Syndrome Scotland and PAMIS to design the How's Life? survey, with the help of Ipsos MORI.

The survey aimed to explore some of the key areas of life that people with learning disabilities said were important to them. The final survey was made up of six sections:

- About you
- Where you live
- Your happiness
- How you spend your time
- Family, friends and relationships
- What matters most

The survey was designed to be completed by people with learning disabilities, with or without support from a family member, advocate or paid supporter. Where a person could not fill it in themselves, instructions were provided for a supporter to fill it in with the answers the person wanted to give.

A semi-structured story telling exercise was also offered as an alternative way to submit a person's response to the survey.

A freepost service was provided for the return of the survey. If someone preferred, an online version could be completed on SCLD's website.

With help from our partner organisations, around 4000 surveys were distributed.

The survey was open from the 16th of May 2019 to the 30th of September 2019.

How many people took part in the Survey?

A total of **1232** individual responses were received. Four of these were through the story-telling exercise mentioned above.

The youngest participant was **16** and the oldest was **82**.

- 51% of those who took part were men.
- 47% were women.
- 1% were transgender or described themselves another way.

The age and gender profile of the participants was broadly in line with that of the annual Learning Disability Statistics Scotland publication.

Responses were received from **every local authority area** in Scotland.

- Most people (65%) had help to complete the survey, with most of this help coming from either a paid worker or advocate (47%).
- 21% of participants completed the survey by themselves.
- 14% were completed on behalf of a person with a learning disability.

The questions were not mandatory, and a number of respondents chose not to answer various questions. As a result, the total number of responses to each question in the survey varied. The number of responses is outlined under each chart. Where the analysis has looked at two questions together, the number under the chart denotes the number who answered both questions. Some percentages in the report may not add to 100% due to rounding.

For more information on survey respondents, methodology and analysis, please read our Methods report.

Current Policy Context

Our housing and communities play a key part in our overall wellbeing. Indeed, both are recognised as social determinants of health, and as such play a fundamental part in ensuring our right to the highest attainable standard of physical and mental health.[i]

Where people live can play a significant role in improving the lives of people with learning disabilities. The closure of long stay hospitals was a key recommendation in Scotland's first learning disability strategy *'The same as you*?' in the year 2000. As a result, housing policy for people with learning disabilities saw an accelerated move away from long stay institutions, underpinned by a focus on empowerment and human rights. By 2005, those who had resided in institutions had been moved into their own tenancies, or community-based facilities. Article 19 of the United Nations Convention on the Rights of Persons with Disabilities recognised people's right to "the opportunity to choose their place of residence and where and with whom they live on an equal basis.[ii]"

While policies in Scotland have been increasingly grounded in the values of human rights, empowerment and personalisation, a 2017 study found that there were mixed reviews on whether housing for people with learning disabilities was continuing to progress towards positive outcomes, or whether progress had stalled since the hospital closure programme.[iii]

Indeed, *The keys to life* implementation framework 2019 – 2021 recognises and seeks to address a number of issues, such as people with learning disabilities lacking meaningful choice and control about where to live; feeling they are placed in houses far away from their family and friends; and poor transport links, making it more difficult to live active and independent lives.[iv] The Coming Home report[v] also highlighted that many people with complex needs are living far from home in NHS settings because of a lack of more appropriate housing and support close to home. The issue of delayed discharge is also addressed in *Towards Transformation*, where Action 5 commits to redesigning service provision over the next three years to ensure that people are not in hospital longer than necessary, or in out of area placements inappropriately.[vi]

We wanted to explore these issues, to get a sense of what people with learning disabilities feel about where they live, the support they get to live independently, and how this relates to their wellbeing. Everyone has a right to a home within their local community, with the right support to live healthy, safe and fulfilling lives. It is hoped that the findings in this report can inform discussions about what needs to change to make this a reality for everyone.

Covid-19

Our How's Life? survey was carried out between May and September 2019, before the unprecedented events of the Covid-19 pandemic overwhelmed the world, creating challenges across all aspects of our lives. These challenges fell disproportionately upon people with learning disabilities.

Overstretched social care provision and the reduction and removal of support services for many during a period of 'lockdown' meant that people were forced to make the difficult decision either to live with or remain apart from their families. Compounded by digital exclusion, people with learning disabilities reported feeling lonelier, socially isolated, and worried about the mental health and wellbeing impacts of the pandemic in both the short and long term.[vii]

Though data is scarce, figures from England suggest that people with learning disabilities were more likely to die if they were receiving residential care.[viii] Indeed, residential care homes have a number of characteristics that put residents at additional risk in outbreaks of viruses, in particular the fact that people live in close proximity with one another, making self-isolation difficult.

Of course, not all people with learning disabilities live in supported settings. The pandemic has also brought to the fore the importance of access to local amenities, and the particular value of access to green space for improving people's wellbeing.

The experience of people with learning disabilities during the Covid-19 pandemic necessitates further reflection on the catalogue of housing options available, both what is available and where.

This report is broken down into the following chapters:

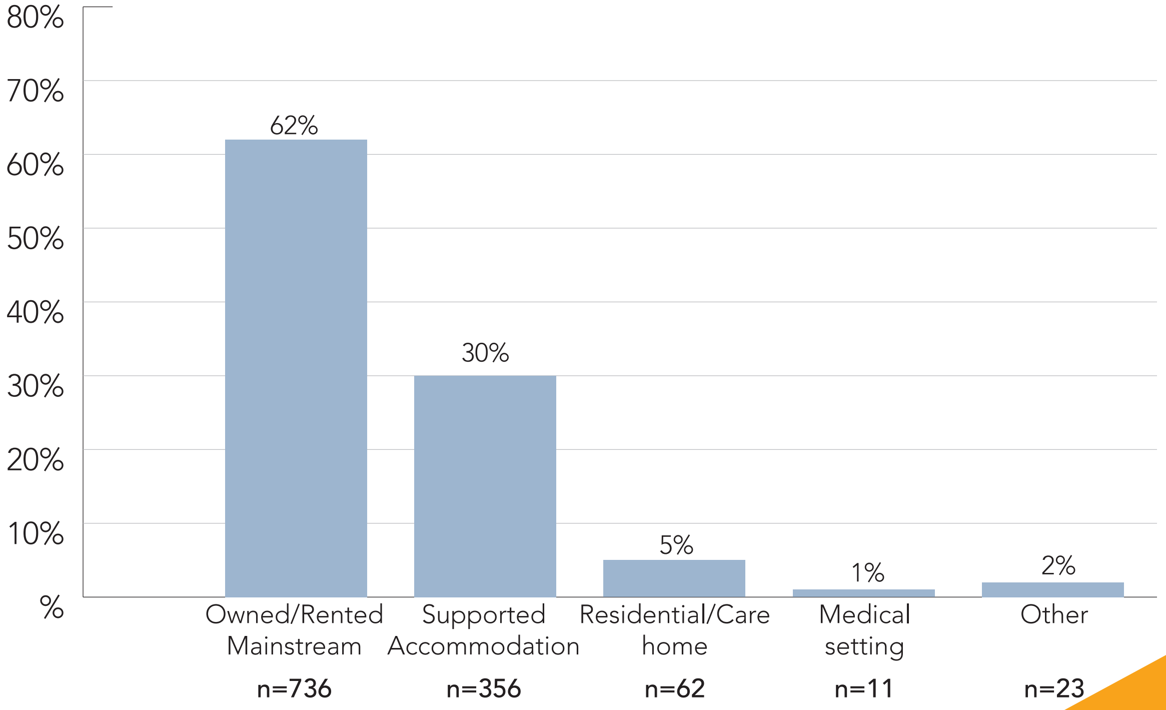
1. Where people live and how they feel about it
2. Housing in people's own words
3. Discussion
4. Moving forward

Where people live and how they feel about it

Demographics

The survey asked people what type of accommodation they were living in. The majority of respondents lived in mainstream accommodation (62%), followed by supported accommodation (30%).

Figure 1: Type of accommodation survey respondents lived in



The Coming Home report [ix] has already uncovered the fact that many people with complex needs are living far from home in NHS settings for much longer than they should be, due to a lack of appropriate housing and support close to home.

Of those survey respondents who lived in a medical setting, four provided further comments on this. The comments provided highlight the lived experience behind Coming Home, giving a sense of how difficult it can be for people who are living in medical settings, waiting for the right housing and support to become available for them.

I've been here for years and years. I'm hoping to get out soon, Social work are looking for a place for me. I've been waiting to get out for a long time.

I've been in the unit for a year. Admitted because I wasn't well. I had my own place before I came to live in the unit. I loved it. I miss it. I had lots of friends. I miss them. I just want out.

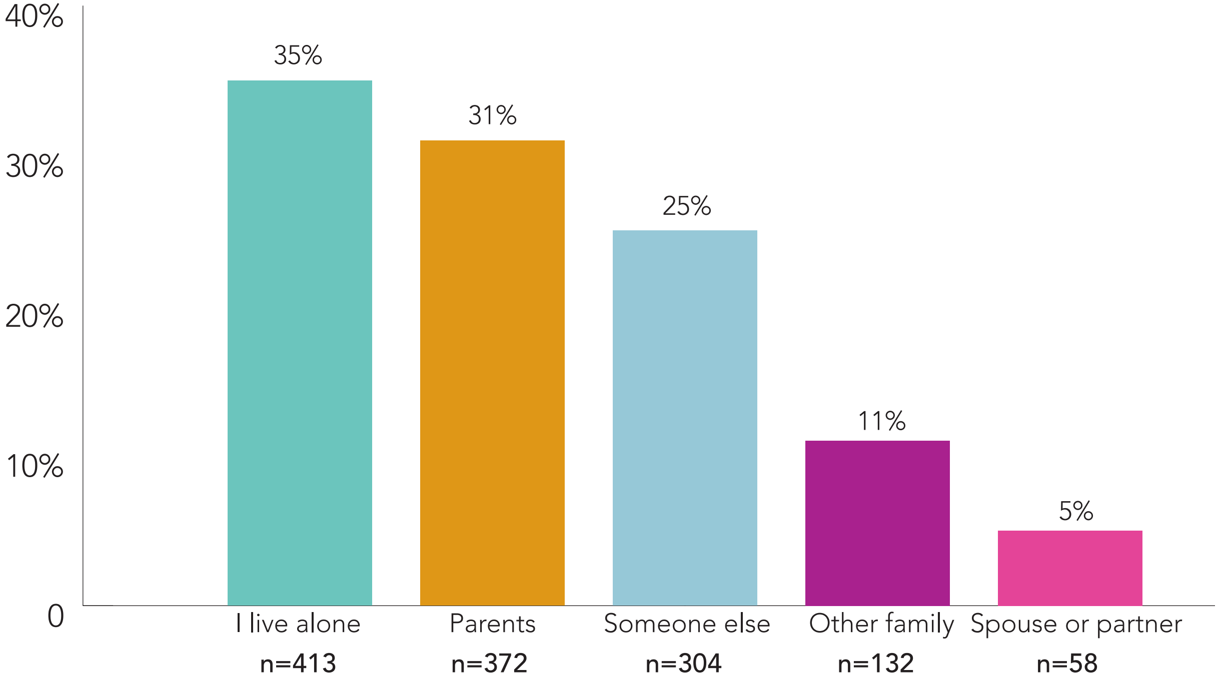
I live in a hospital unit. I smashed windows a long, long time ago so I was brought in here. I want to stay with family.

I think I've been here 3 or 4 years. I'm not happy here. There's not a lot to do. I get bored. I'm better now and am ready to move but there is nowhere for me to go. I don't know why my house isn't ready.

The survey also asked people who they lived with. People were allowed to select more than one answer.

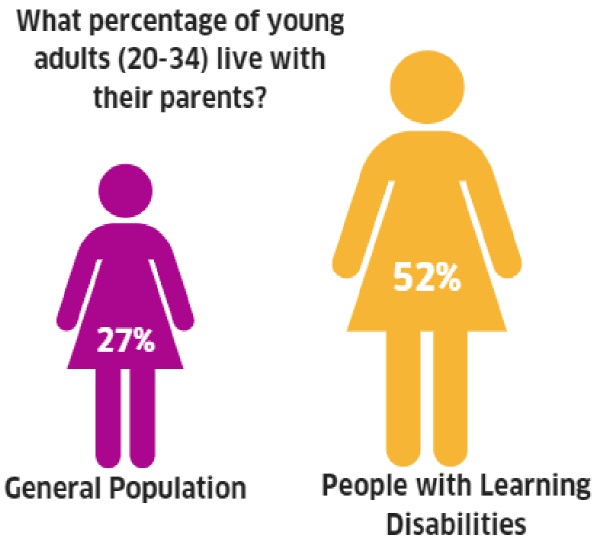
- Over a third (35%) of people who answered the survey lived alone. The same percentage of the general population in Scotland live alone.[x]
- Almost a third of survey respondents (31%) lived with either one or both of their parents.
- A quarter of respondents (25%) lived with someone else.
- 11% lived with other family members.
- Only 5% of survey respondents said that they lived with a spouse or partner. The latest available figures suggest that 56% of the general population live with a spouse or partner.[xi]

Figure 2: Who survey respondents lived with



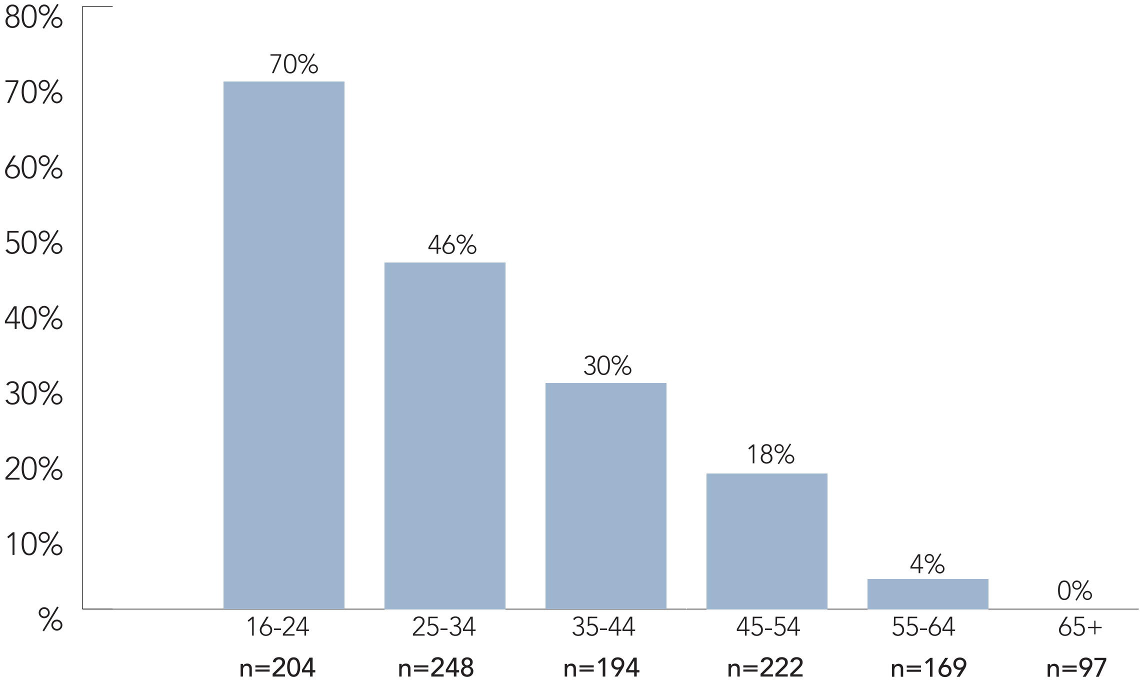
When compared to the general population, it is clear that a lot more young adults with learning disabilities live with their parents. Across the UK, 27% of 20-34 year olds lived at home with their parents.[xii] The corresponding figure from 20-34 year olds who responded to the survey was 52% (Figure 3).

Figure 3: Percentage of young people (aged 20-34) living with their parents



Though there are no corresponding figures for the general population in Scotland, Figure 4 below shows us that a considerable proportion of survey respondents were still living with their parents over the age of 35. Of those aged 45 and over, 9% were still living with their parents. This is worth highlighting, particularly for service planning, as it indicates that there are a considerable number of aging family carers, whose adult children will likely require appropriate housing to be considered in the future.

Figure 4: Percentage of people living with their parents, by age



How do people feel about where they live?

The vast majority of respondents (92%) said that they were happy with where they lived. Though most people were happy, there were variations depending on accommodation type (Figure 5):

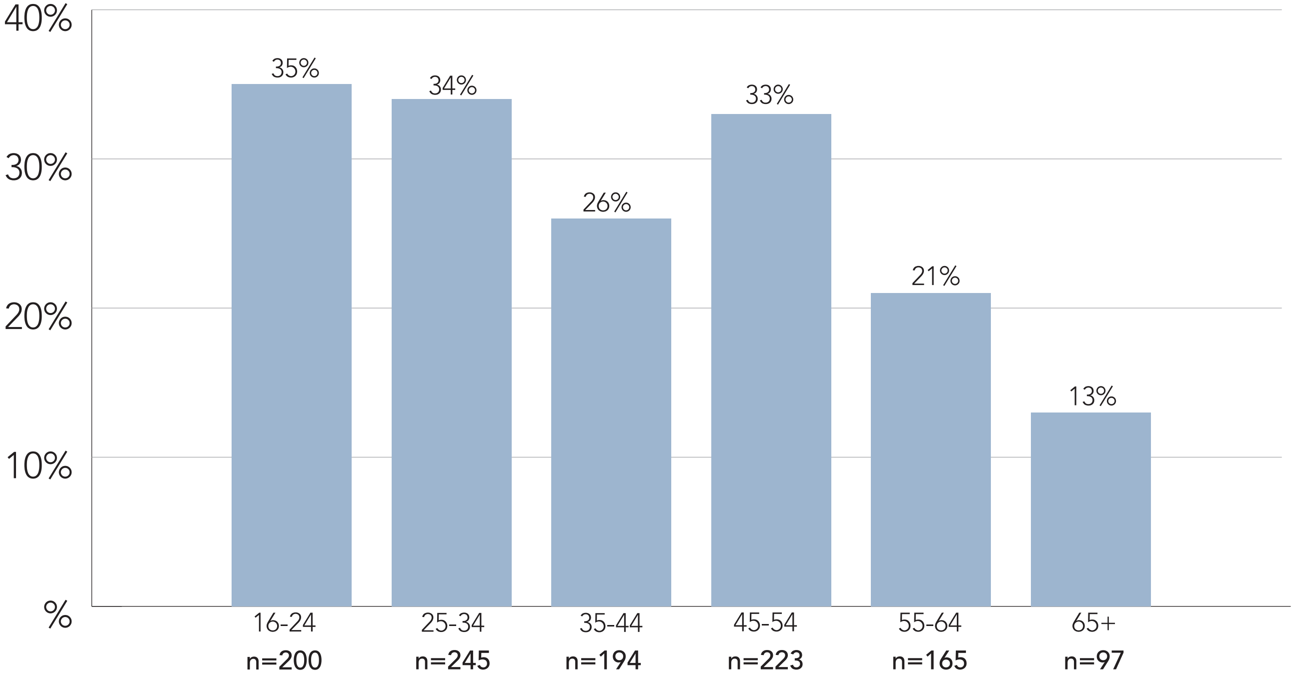
- 95% of those living in supported accommodation said they were happy with where they lived.
- 92% of people living in mainstream accommodation said they were happy with where they lived.
- 81% of people living in other accommodation types, including care homes and medical settings, were happy with where they lived.

Figure 5: Percentage of people happy with where they live, by accommodation type

An even higher majority (94%) said that they were happy with the area that they lived in.

However, over a third (36%) of respondents said that they did not always feel safe when they were out and about in the area they lived, and 29% said that they sometimes were picked on when they were out and about. People in younger age groups reported being picked on more so than those in older age groups (Figure 6).

Figure 6: Percentage of people who were picked on when out and about, by age group



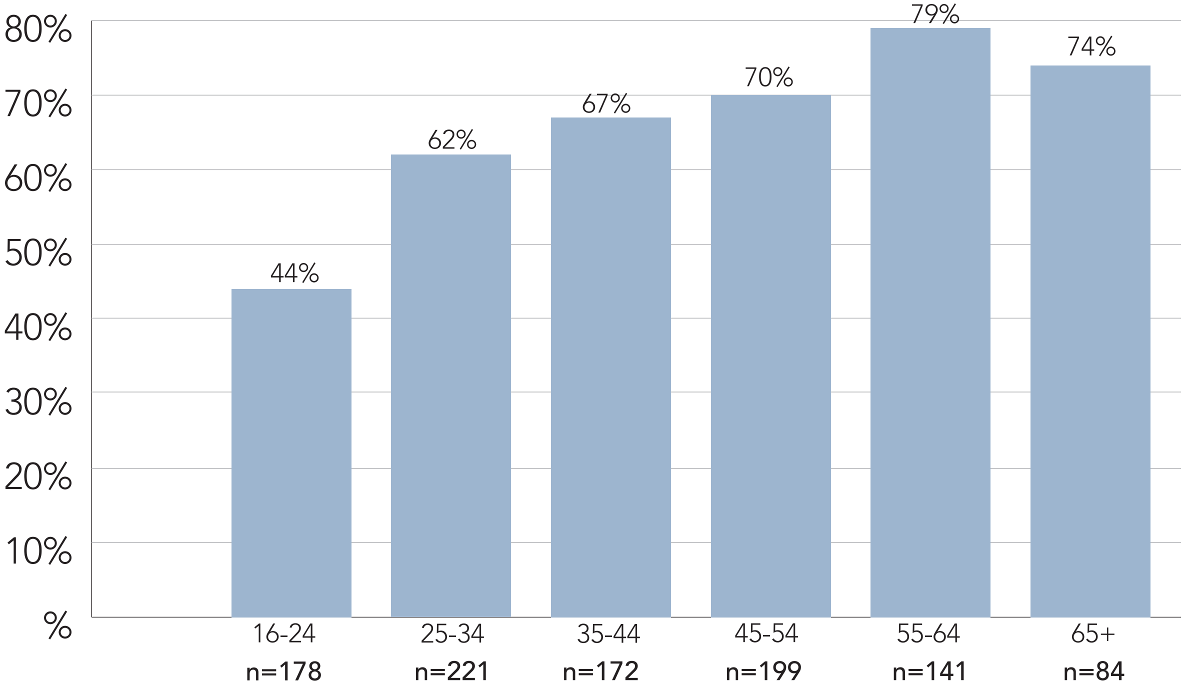
A higher percentage of people living with at least one other condition or disability in addition to a learning disability said that they did not always feel safe, and that they were sometimes picked on when they were out and about, compared to people with no additional conditions or disabilities:

- 38% of those with one or more additional conditions or disabilities reported sometimes feeling unsafe where they lived, compared to 29% of those with no additional conditions or disabilities.
- 32% of those with one or more additional conditions or disabilities reported sometimes being picked on when they were out and about compared to 22% of those with no additional conditions or disabilities.

The continued focus of *The keys to life* implementation framework on lack of meaningful choice over where to live is justified by our survey findings, with over a third (35%) of respondents saying that they did not get to choose where they lived.

Generally, as people got older, they were more likely to report having choice over where they lived (Figure 7), though this is likely related to the fact that people with learning disabilities in our survey tended to live with their families for longer than the general population.

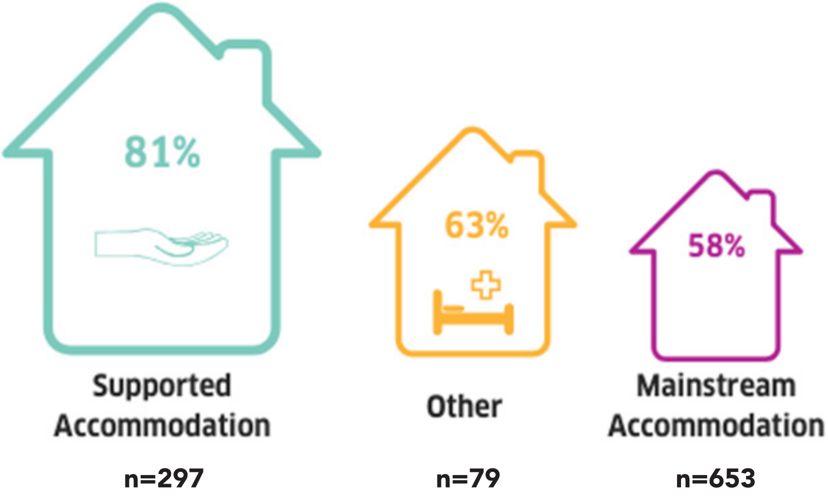
Figure 7: Percentage of people who chose where they lived, by age group



Whether people had choice over where they lived also varied by what type of accommodation they were living in (Figure 8).

- 81% of those living in supported accommodation said they had chosen their home.
- 63% of those living in 'other' accommodation, including care homes and medical settings said they had chosen their home.
- 58% of those living in mainstream accommodation said they had chosen their home.

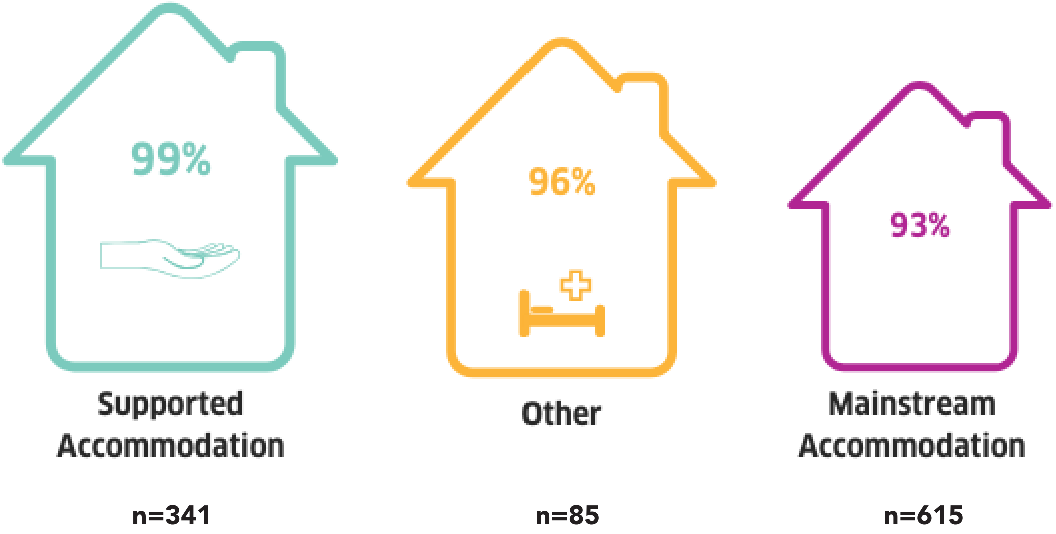
Figure 8: Percentage of people who chose where they live, by accommodation type



Of those who needed it, the majority (95%) said that they got the right support to live in their home, with 6% of those who responded to the survey saying that they did not need any support. Though most people reported getting enough support, there were small variations depending on what type of accommodation people were living in (Figure 9).

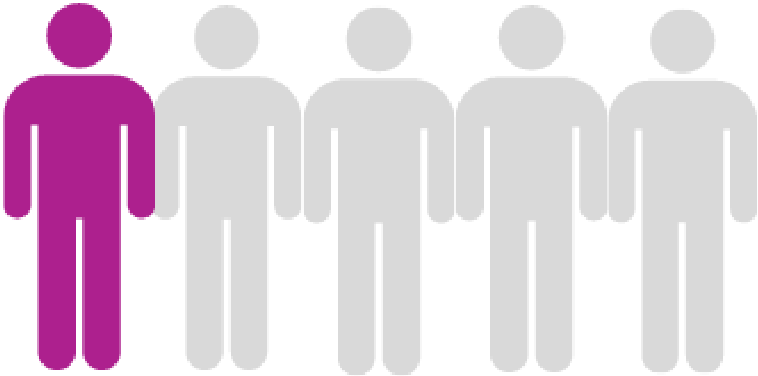
- 99% of those living in supported accommodation got the support they needed to live at home.
- 96% of those living in 'other' accommodation types, including medical settings and care homes said they got the support they needed to live at home.
- 93% of those living in mainstream accommodation said they got the support they needed to live at home.

Figure 9: Percentage of people who received enough support, by accommodation type



Of those who were supported to live at home, just over 1 in 5 (21%) said that the person who supported them did not always treat them with respect (Figure 10).

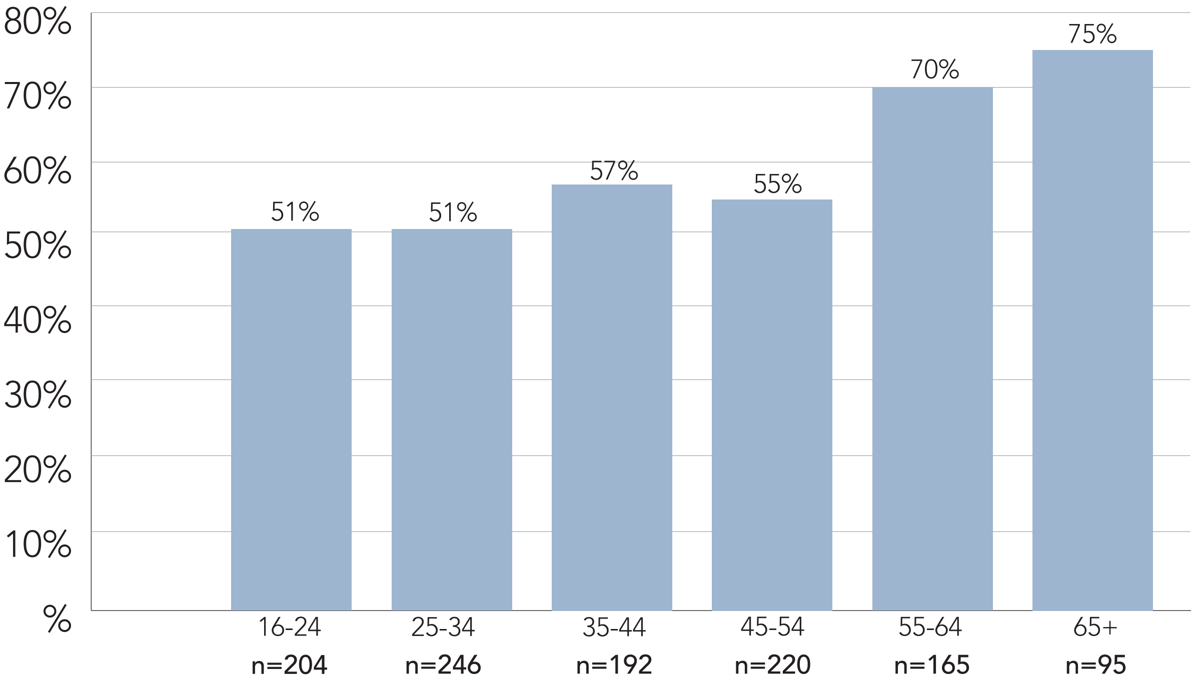
Figure 10: 1 in 5 respondents who needed support were not always treated with respect



58% of survey respondents said that they were always happy with their transport options.

A higher percentage of those in older age groups reported always being happy with their transport options than those in younger age groups (Figure 11).

Figure 11: Percentage of people always happy with transport, by age group



People living in supported accommodation were most likely to be happy with their transport options, and those living in mainstream accommodation least likely (Figure 12).

Figure 12: Percentage of people always happy with transport, by accommodation type

Other factors that relate to how people feel about housing

We know that housing for people with learning disabilities is much more than simply bricks and mortar; it includes the support provided to make a home, as well as the wider community. As we have seen above, most people who answered the survey were happy with the house that they lived in, and the area that they lived in. However, when we take a closer look at these findings, we can see that there are a number of factors that are related to this.

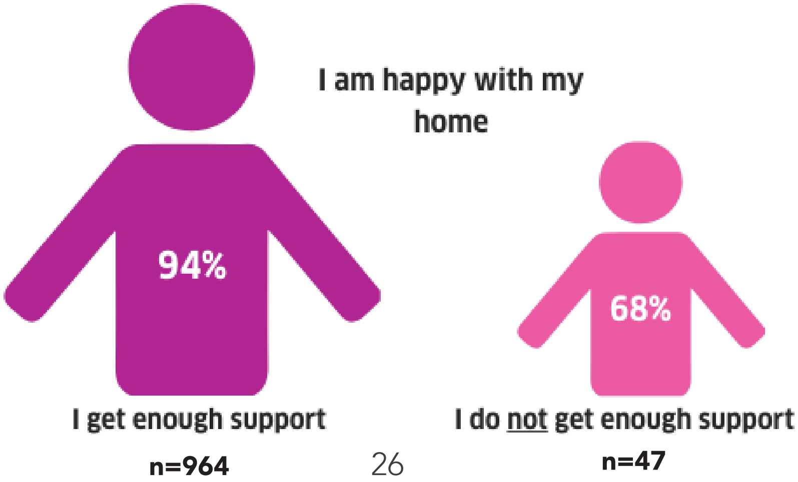
A higher percentage of people who had chosen their home said that they were happy with it than those who had not had a choice:

- 95% of those who had chosen their home were happy with their home compared to 86% of those who had NOT chosen their home.

Similar patterns were found for receiving enough support, and for being respected by those providing that support:

- 94% of those who had enough support were happy with their home compared to 68% of those who did NOT have enough support (Figure 13).
- 95% of those who said they were always treated with respect by their supporters were happy with where they lived compared to 81% of those who were NOT always treated with respect.

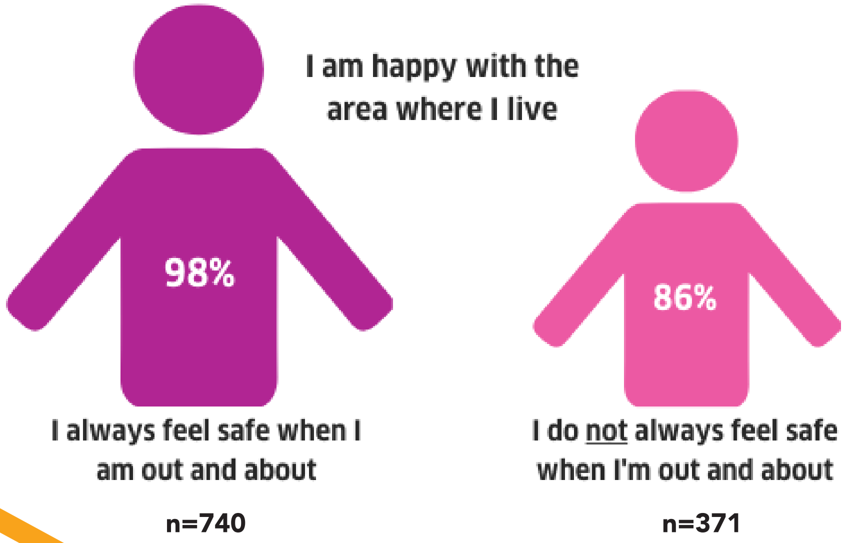
Figure 13: Percentage of people happy with their home, by whether they get enough support



As well as having chosen where they live, people's perception of their safety and their transport options were found to impact on whether people were happy with the area they lived in:

- 97% of those who had chosen their home said they were happy with the area they lived in, compared to 89% of those who had NOT chosen their home.
- 98% of people who said they always feel safe when they were out and about said they were happy with the area they lived in, compared to 86% of those who did NOT always felt safe (Figure 14).
- 96% of people who were never picked on when they were out and about said they were happy with the area they lived in, compared to 87% of those who were sometimes picked on.
- 96% of people who were always happy with their transport options said they were happy with where they lived, compared to 91% of those who said they were NOT always happy.

Figure 14: Percentage of people who are happy with the area they live, by whether they feel safe when out and about



Housing and wellbeing

Wellbeing is an important priority set out in *The keys to life* implementation framework 2019-2021. There are many different ways to define and measure wellbeing. SCLD was interested in people's subjective feelings about their lives overall, and measured this by asking people how satisfied they felt with their lives.

The survey found that the majority of people had high levels of life satisfaction. The average score for survey respondents was 8.13 out of 10, which is similar to the average life satisfaction score for the general population in Scotland of 7.69. Of the 1204 people who answered this question, 249 (21%) said that their life satisfaction was 6 or less, and 955 (79%) gave a score of 7 or higher.[1]

SCLD was keen to explore how important where people lived was to people's assessment of their life satisfaction. As discussed above, housing and communities are recognised as social determinants of health and seen as playing a key role in our overall wellbeing. Findings from the survey support this assertion, with people who were happy with their homes and the area they lived, more likely to report high levels of life satisfaction:

- 85% of those who were happy with their home said they had high life satisfaction compared to 36% of those who were not happy with their home (Figure 15).

---

[1] For ease, this report refers to life satisfaction scores of 6 or less as 'low life satisfaction' and scores of 7 and above as 'high life satisfaction' These scores were chosen due to the smaller numbers of people reporting scores below 7, to allow for statistical comparability.

- 85% of those who were happy with the area they lived in reported high life satisfaction compared to 37% of those who were not happy with the area they lived in (Figure 16).

Figure 15: Percentage of people reporting high life satisfaction, by whether they are happy with their home

Figure 16: Percentage of people reporting high life satisfaction, by whether they are happy with the area they live in

Housing in people's own words

As part of the survey, we asked people to tell us, in their own words, what the most important things in life were for them. As expected, a huge variety of answers were given to this question, reflecting the diverse lives that people with learning disabilities live. Many of the 1076 people who answered this question spoke about their housing and communities:

- 163 (15%) said that support was one of the most important things in their lives.
- 129 (12%) individuals mentioned transport and the ability to get out and about as being one of the most important things in their lives.
- Living independently (76:6%), their house (35:3%) and feeling safe (56:5%) were also mentioned by survey respondents.

The survey also asked people to tell us, in their own words, what one thing they would change about their lives. 808 people gave an answer to this question. Again, many different topics came up. However, one of the more prevalent themes was housing, with 93 (12%) people saying that they would like to change an aspect of this:

I would like to find a suitable place to live without my family

The option to choose a safe, suitable, supported living accommodation, so I could live independently

I would like to have my own home but I need support for this

Get my own house to live independently

To have my own house near my parents

I would like to live in a house with a garden and my own front door in a nice area

Case Studies

As part of the survey, a semi-structured story telling exercise was offered as an alternative way to submit a person’s response if this was more appropriate. Four responses were submitted this way, by parents on behalf of their adult children with profound and multiple learning disabilities (PMLD).

Three stories, as they relate to housing are reproduced below. Having the right support in place is a very strong theme threaded throughout all the stories, reinforcing the point that housing is about so much more than bricks and mortar.

CASE STUDY 1

My son lives in the family home with me and his dad where he has lived since birth. My son's older brother moved out of the family home five years ago. When his brother first moved out, my son would walk from room to room looking for his brother – it was heart-breaking to see.

My son is non-verbal so I gauge his feelings from his responses. His dad and I feel he is fairly happy here as he is familiar with his surroundings and appears to feel secure. As he has grown from a boy into a tall young man however, our house has become too small a space to meet his needs. He occasionally appears bored and restless. He demonstrates this from time to time by incessantly pacing from room to room, banging on windows, and sometimes peeling wallpaper off walls. We live in a modest space which we have adapted to meet our son's needs as best we can within our limited financial means. We have a garden space which we can access in good weather.

He was not directly involved in choosing where he lives. We (his parents) have legal guardianship for our son's welfare and have made the decision to keep our son living with us in the family home on the basis we think he is happy with us and that as his parents, we know his needs better than anyone else. Also, very importantly, his health care needs are continually changing at the current time. Until such time as a proper health care plan is drawn up to support his complex needs, we wouldn't feel he could be properly supported elsewhere without it. We feel we are in the best position to care for him so we have chosen that he remains living in the family home with us.

He does not get the right support. Although my son still lives in the family home, it was our hope that he would be given the opportunity to gradually adjust to sleeping somewhere other than the family home. All the advice I have heard shared by families about the person they care for moving to their own tenancy, is that planning the transition as a gradual process is key and that I should aim to avoid an abrupt move from the family home when reaching a crisis situation.

To date, there has been no suitable overnight respite offered which meets my son's needs, or as I would prefer, an offer to have a suitable place identified for overnight respite and have his name added to a waiting list for a future offer of a place. We have been advised by social care that this is not possible but have been given no explanation of how overnight respite allocation is prioritised.

However, while our son lives at home with us, we would expect him to have a reasonable social life in the evenings and/or weekends and not spend the majority of his time with just his two parents. There are few social opportunities for him and he currently spends every evening and weekend with his parents instead of having social time with a peer group.

A lack of understanding of profound intellectual and multiple disabilities (PIMD) and the complex and varied needs of people with PIMD, are among the components which prevent proper support. Also, there appears to be a lack of support through Self Directed Support (SDS) for young adults with PIMD who have left school but still live in the family home rather than in their own tenancy. My experience is that support is given to school age children with PIMD up to the age of 18, and to adults with PIMD living in their own tenancy/accommodation. However, there appears to be a lack of a structure of services and support for people with PIMD who fall into the bracket where they have left school but still live in the family home.

Many learning disability services have been autism-led for years and there's a distinct lack of acknowledgement of specific support for PIMD. The most successful support my son has had to date has been within a staff group setting where members of staff can take turns to oversee his care and supervision and to have a break when necessary. Also, having a suitable base where his intimate care needs can be met with dignity is essential. Organisations that support, or have supported my son in the past, have at times struggled to cope with his needs, mainly because he is placed into social groups where staff are trained to support autism, but not necessarily to support ambulant young adults with PIMD. If there is any specific support for PIMD, I've been unable to find it. The only support I've found has been from Pamis based in Dundee.

The majority of people involved in his support have wanted to be helpful and involve him in activities as much as possible. However, supporters are often overwhelmed by the level of care and responsibility he requires and appear to cope better when supporting him in a group setting where they can seek help or advice from more experienced colleagues when responsibility for my son's care becomes too great or challenging for one individual.

CASE STUDY 2

My son lives in a locked ward, a learning disability assessment unit (LDAU). He has a bedroom of his own, but now spends most of his day in the public areas of the ward where he does not get the quality interactions he seeks; this makes him unhappy, so he tries to get reactions from staff, or tries to influence his environment, but this is often misread as behaviour that challenges.

Due to his profound communication impairment, he cannot easily ‘chat’ to staff or patients. It takes an effort to interact with him. Consequently many staff ignore him. When I am present, some staff interact, others do not. When I am not there, it has been reported to me, he is ignored much of the time. This makes him unhappy and he makes known his unhappiness at being there by shouting. When his ‘vocalising’, as it is called by staff, becomes too great for them to bear, he is taken to his room and confined in it. Sometimes, a member of staff might make an effort to spend quality time interacting, e.g. by getting out felt pens and papers and ‘writing a letter to mum’, or paints and paper, ‘painting a picture for mum’, or simply sitting and ‘chatting’, which means repeating his words, making sense of them and feeding them back to him, treating him like a person, a human being. There is not much of that quality time available.

He does not like living there. He says ‘bye-bye hospital’ ‘enough’; when we go out for walks from hospital; when he comes home and we are driving back, he says ‘bye-bye hospital’ over and over again for fifty miles.

I have delivered training to staff, to groups (x2) and to individuals, trying to help them interact, to understand my son and his language, what he is saying, why he is saying it, how to interact with him, to improve his quality of life, and the staff's experience too; the clinical psychology service has also carried out positive behaviour assessments.

He was not involved in choosing where he stays. He was admitted in an emergency when his last care placement broke down. I supported his admission, because that placement broke down due to lack of skilled care in staff and their managers to understand my son, his language, his needs, all located in unsuitable city-centre accommodation. To me, at least the LDAU was relatively safe, and it was relatively local, it is 50 miles from my home, which meant that I could drive daily to provide him with support I knew he was needing.

By contrast, my son lived largely-happily in a care home in Glasgow, for seven years, six of which were good-quality care. When he first arrived there, he was involved in choosing his own room, his own bed. This experience that lasted so long is an indication that the problems do not lie 'in my son' - but are products of the interaction between him and his surroundings

That care home was shut by the charity that ran it, Sense Scotland. He was threatened with eviction before there was anywhere suitable for him to go - was sent in emergency out-of-country, 250 miles away - then brought back to a placement set-up to fail. It was from there he was admitted to the LDAU. There was nowhere else to go. There is no existing alternative care setting for him to go to. There wasn't provision in 2006 when he was last an inpatient. There is none now.

In the meantime, he needs to stay in this current setting, which is 'safe' but makes him unhappy, provoking in him behaviours which are responses to it, that create further unhappiness. There is no short-term solution until an alternative is created.

He does not receive the right support. As above, you can hear that he does not receive the quality care on the locked ward that he requires. He combines the age, strength and energy of a 32 year old man with developmental activity requirements of a pre-school child. I would say he needs quality understanding of his language and plentiful respectful verbal interaction, daily vigorous outdoor activity to burn off energy (at least a 3 mile walk), some meaningful indoor creative 'Early Years' activity - 'letter-writing', painting, water-play, simple cooking. He does not receive enough of that from staff. Activity on the ward mostly involves sitting in the day room with the TV on.

For the first four months of his stay, he was locked in his room, an eighteen foot by twelve foot space, with staff sitting outside the door. Sometimes I arrived to find staff outside looking at their mobile phones, or reading magazines, feet up against the door. Other times, on a positive note, I would find staff sitting at the door, with the door open, interacting through songs, repeating his language phrases back to him, offering him companionship and engagement and appropriate stimulation. The support he receives is dependent on the quality of individuals' contributions.

Staff as a stakeholder group are powerful, patients as individuals and as a stakeholder group are weak. Any patient who protests is classified as having 'challenging behaviour'; the behaviours are not sufficiently critiqued for the meaning that they hold and how care might be adapted accordingly.

In the past month, some time-to-time activity has been provided e.g. short walks, drawing, icing biscuits.

I have been surprised, however, at the lack of therapeutic assessment and input on this so called 'learning disability assessment unit'

He does not even consistently get support with physical aspects of his health, help to clean his teeth adequately, to attend to a verruca, minor bumps and scratches.

What does work for him on the ward, is the structure and consistency of an intentional community, regular mealtimes, patterns of routine around personal care, a consistent core team of staff.

There are some individual nurses who treat him with respect, but the ward lacks a systemic approach that ensures this is true from all staff. It is the whole hospital system that does not treat my son with respect.

Here is a description of how NHS Infection Control treated my son with lack of respect in regards his overall wellbeing and health. As my son has a profound communication impairment, visual prompts are very helpful tools to promote communication. In the first weeks of his stay, he and I painted pictures, we cut out photographs from magazines, he received cards from friends and family, all those we stuck on his walls - as a living 'communication wall'. He was able to take a nurse by the hand, to point to a picture and say a word, to communicate.

Four months into his stay, due to an investigation on a different subject, Infection Control 'said' that this communication wall had to be destroyed. All my son's communication tools were stripped away, they were too 'risky'. Ironically, my son had lived for four months with faeces on his ceiling, which had been a far-greater infection risk than his pictures ever were. NHS Infection Control could be understood as part of the whole system which is supposed to support my son. Clearly in this instance it did not.

CASE STUDY 3

My daughter lives in supported accommodation with a care provider. She shares the house with 3 others. She has 1-1 support in the daytime and 1- 0.5 overnight. She has lived there for 8 years.

My daughter was not involved in choosing because she wouldn't be able to make a choice, so as her mum I chose. At the time of arranging future housing the choice was limited and it was all that was offered, but thankfully it suits her needs in the main.

In the main she gets the right support, but after 8 years there is still a lot to discuss, debate, argue and negotiate to ensure she gets the support she needs. Things that we argue about have been issues around restraint and oral hygiene. Appropriate restraint is necessary sometimes to ensure her health and well-being, i.e. teeth cleaning. It proved necessary to get an amendment to my daughter's Guardianship Order before her care providers were prepared to use appropriate restraint in order to brush her teeth properly.

Another issue that is currently causing problems and debate is where the duty of care lies overnight if my daughter has to be taken to Accident & Emergency (A&E). At the moment she would have to go alone in an ambulance, be unsupported at A&E and if admitted to hospital. At present she is experiencing a high number of seizures which often lead to falls, so being taken to A&E is not an infrequent occurrence. As a result, the worry about what would happen to her in these circumstances is causing a considerable amount of anxiety as she is non-verbal, has a severe learning disability, resulting communication difficulties, limited awareness of danger, is doubly incontinent and is active and mobile.

Discussion

The findings above demonstrate the importance of housing and communities for people with learning disabilities in Scotland. Indeed, being happy with the house people lived in, and the area they lived in were both very strongly correlated with high levels of life satisfaction. Our companion report, 'Mostly a 10 but sometimes a zero'[xiii] explores this in detail, finding that being happy with their house and local area were even more strongly related to high levels of life satisfaction than other material wellbeing measures such as having enough money. This is of particular importance when we consider that for some people with learning disabilities, the choice over where they live and who they live with can be limited. At the extreme, we know that some people with learning disabilities can remain stuck living in medical settings long after there is any medical need for them to be there. While only 11 respondents to the How's Life? survey were living in medical settings, the stories that they shared with us demonstrate clearly huge delays in their discharge from hospital, and their intense desire to move out into appropriate housing in the community.

A hospital or an assessment or treatment unit is not a home. There has already been an increased focus on delayed discharge and inappropriate out of area placements since the publication of the Coming Home report[xiv] in 2018, but there is a clear need to redouble efforts to tackle this seemingly intractable issue and ensure that people are able to realise their right to a home. SCLD is very supportive of Enable Scotland's recently launched campaign 'My Own Front Door,'[xv] which seeks to highlight the issue and push for urgent change.

However, our survey showed that not having meaningful choice over where to live is not restricted to those extremes. Indeed, over a third of respondents said that they did not get to choose where they lived. Choice over where to live tended to improve for older cohorts. This likely reflects the fact that people with learning disabilities in our survey were more likely to live with their families into young adulthood and middle age in comparison with the general population. This is a point worth reflecting on, as the recent Independent Review of Adult Social Care[xvi] urges a renewed focus on prevention and early intervention. While living with family may be the first choice for many people with learning disabilities, it is imperative to put plans in place for a time when this will no longer be possible, and to include people within these conversations from the start of the planning process.

Of course, there is much more to a home than the bricks and mortar. It is important to acknowledge that while people in supported accommodation were the most likely to be happy with their home compared to those living in mainstream or other settings, the majority of people said they were happy with where they lived regardless of the setting. While there are of course discussions to be had about the appropriateness or otherwise of different housing models, in particular in light of the Covid-19 pandemic, this finding highlights that there are other considerations of equal importance.

One such consideration is having the right support in place; the importance of which is clearly demonstrated in the findings. People were more likely to say they were happy with their home if they felt that they got enough support. Through past research, and our companion reports in our How's Life? series, the right support comes up time and time again as a key enabler for people with learning disabilities in all different aspects of their lives.

In the context of housing and communities it is clear that access to the right support can make a significant difference to people's wellbeing and their ability to live independently in the community. Though it will always be difficult in the context of austerity, if we are to move towards prevention and early intervention as outlined in the Independent Review of Adult Social Care, people must be able to access the appropriate levels of support where and when they feel they need it, not simply when they hit a crisis point.

Relatedly, people were also more likely to be happy with their home if those providing support treated them with respect. It is striking that one out of five respondents did not feel that those who supported them always treated them with respect. It is important to reflect on how we recruit, train and value people with the right attitude for such important support roles.

It is also important to acknowledge that being in the right location plays a role in ensuring people are happy with their home. Exploring people's feelings about where they stay shows that they are more likely to feel happy if they feel safe, are not picked on when out and about, and are happy with their transport options. It is clear that living in the right location, with the right support provide strong foundations for people with learning disabilities to live happy lives as active citizens. And while there is a clear role in this for local authorities and service providers, there is an onus on communities themselves to become more understanding of, and ultimately inclusive for people with learning disabilities, so that everyone has the chance to live their best life.

Moving Forward

As we move beyond the Covid-19 crisis, it is pivotal that the voices of people with learning disabilities are not lost. This will require engagement with those who have lived through the crisis, as well as their carers and supporters, to ensure that their lived experience is used to shape the future. Based on the findings in this report, SCLD believes there are a number of measures to consider.

1. Collect better data to aid realisation of the right to an adequate home

The Scottish Government's Housing to 2040 vision[xvii] commits to realising the right to an adequate home for all. Progressive realisation of this right for people with learning disabilities entails a better understanding of the extent to which it is currently being met. In order to do this, local and national data collection processes must be improved in such a way that allows for the disaggregation of the experience of people with learning disabilities.

2. Ensure access to high quality, appropriate housing and future proofing through local planning

No single housing and support option will work for everyone, so it is imperative that each local authority works toward a better balance of housing, support and service options to enable people with learning disabilities to have real choices, wherever they choose to live. Strategic planning processes and housing allocation policies should consider the particular needs of people with learning disabilities. Important considerations include physical accessibility, additional space for carers, scope for adaptations as well as place and location. Housing solutions for people with learning disabilities also need to reflect their diversity through person-centred approaches focussed on choice, directed by personal preference and informed by an individual's level of need.

These processes should include working with families on planning for the future, ensuring people have plans in place for when families can no longer care for them at home, which have been informed in partnership with individuals and families.

3. Greater emphasis on choice by embedding a 'Housing Options' approach

It is crucial that people with learning disabilities have the right information to make informed choices about where they live. It is important to provide enhanced advice by embedding a 'Housing Options' approach where advice is personalised and explores all possible tenure options, and accounts for wider personal circumstances and support needs alongside accessible housing needs.

4. Utilise the Community Living Change Fund to bring people home

It is imperative that Health and Social Care Partnerships (HSCPs) utilise the Community Living Change Fund[xviii] to urgently design and put in place community-based support for those who have been living in inappropriate medical settings and out of area placements.

It will also be important to learn from the experience of individuals and families during the pandemic - how people have been impacted in different settings, the consequences of any changes to support structures and how we do thing differently to ensure their voice is central in delivering bespoke housing and care solutions for people with complex needs.

5. Make public transport fully accessible and inclusive

Scotland's Accessible Travel Framework[xix] recognises that a fully accessible public transport system is a must in enabling people with learning disabilities to lead fulfilling lives and participate fully in society. The latest delivery plan, which includes, among other things, commitments to improve signage and information and raise awareness of disability hate crime, is welcome. However, there is a need to ensure all transport customer service staff – including taxi drivers – receive learning disability awareness training to ensure they have the necessary skills to support people to use public transport.

6. Renewed focus on learning disability hate crime

Tackling learning disability hate crime must start from understanding its extent. SCLD welcomes the recent publication of a report, which disaggregated learning disability hate crime in a sample of recorded statistics. The report highlighted that in over half of disability aggravated hate crimes, the perpetrator showed prejudice towards those with a learning disability (59%).[xx]

It is incumbent upon housing providers and support services to be aware of and implement learning disability hate crime training and ensure that people with learning disabilities who use their services know who to report any incidents to and that they will be supported when they do.

7. Invest in making communities more inclusive

We must build the capacity both of communities to be more welcoming and inclusive, and of people with learning disabilities themselves to take advantage of local opportunities to meet others, forge relationships and take part in activities that are enjoyed by the rest of the population. This can be supported both by investing in roles like Local Area Coordinators or Community Connectors, and by refocusing the role of support staff towards community inclusion. Resources like Active, Connected, Included can help with this.[xxi]

If we are to recover from the Covid-19 pandemic both inclusively and fairly, we need to overhaul the structures, processes and attitudes in the social care system, and in wider society, that create barriers for people with learning disabilities spending their time as they choose, and participating in society on an equal basis. To do this right will require not only significant investment, but strong leadership, and a commitment to the equality and human rights of people with learning disabilities.

References

i United Nations, International Covenant on Economic, Social and Cultural Rights

ii United Nations Convention on the Rights of Persons with Disabilities

iii SCLD (2017) Improving outcomes for people with learning disabilities: Opportunities and challenges for housing

iv Scottish Government (2019) *The keys to life:* unlocking futures for people with learning disabilities implementation framework and priorities 2019-2021

v Scottish Government (2018) Coming home: complex care needs and out of area placements in 2018

vi Scottish Government (2021) Towards Transformation: Learning/intellectual disability and autism: transformation plan

vii SCLD (2020) The impact of Coronavirus on people with learning disabilities

viii Public Health England (2020) Deaths of people identified as having learning disabilities with Covid-19 in England in the spring of 2020

ix Scottish Government (2018) Coming home: complex care needs and out of area placements in 2018

x Office for National Statistics (2019) Families and Households in the UK: 2019

xi Registrar General for Scotland (2014) Census 2011: Detailed characteristics on Population and Households in Scotland

xii Office for National Statistics (2019) Young adults living with their parents

xiii SCLD (2021) Mostly a 10 but sometimes a zero: Exploring the wellbeing of people with learning disabilities in Scotland

xiv Scottish Government (2018) Coming home: complex care needs and out of area placements in 2018

xv Enable Scotland (2022) My Own Front Door

xvi Scottish Government (2021) Adult Social Care: Independent Review

xvii Scottish Government (2021) Housing to 2040

xviii Community Living Change Fund Guidance (2021)

xix Transport Scotland (2016) Going further: Scotland's Accessible Travel Framework

xx Scottish Government (2021) Characteristics of police recorded hate crime in Scotland: study

xxi SCLD (2021) Active, Connected, Included

Published by SCLD February 2022

The Scottish Government