SCLD

My time, my choice?

Exploring what people with learning disabilities do with their time.

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 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 what people do with their time. This was chosen as the theme for our fourth report, because the different ways in which people spend their time are important determinants of wellbeing for people with learning disabilities, with choice and control and employability in particular a key focus of *The keys to life* (2013) strategy. The Covid-19 pandemic has also highlighted the importance of how people spend their time for their wellbeing, and the potential far reaching impact of restrictions on people's choice and control over their own lives.

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Key findings

Most of our survey respondents told us that they were happy with the resources available to them that enabled them to do the things they liked: support, choice, money and transport. Despite this, across economic, civic and social activities that people took part in, there were clear disparities between the participation rates of our survey respondents and the general population:

- 38% of survey respondents volunteered, compared to 48% of the general population.
- 14% of survey respondents undertook paid work compared to 75% of the general population.
- 51% of survey respondents had voted in the last few years compared to 71% of the general population who had voted in the General Election.
- 52% of survey respondents had taken part in exercise over the last few weeks compared to 80% of the general population.
- 33% of respondents had used social media in the last few weeks compared to 61.5% of the general population.

There were some areas of note where the participation rates of our survey respondents and the general population were similar:

- 17% of both our respondents and the general public had written to their MSP.
- 21% of respondents

compared to 16% of the general public had attended a public meeting.

- Meeting friends, going to the cinema, attending live music and going to the library all had participation rates broadly in line with the general population.

It is also worth noting some activities that are specific to people with learning disabilities:

- 28% of our survey respondents said that they had undertaken self-advocacy in the previous year.

- 34% of survey respondents attended a day centre.

People who said that they did not need support to do the things they wanted to do, were much more likely to be in paid work or to have used social media in the last few weeks than those who needed support and felt they got enough, and those who did not get enough support.

Those people who said they did get the right support were the least likely to vote, or to have undertaken self advocacy. However, they were also the most likely to have exercised in the last few weeks.

For people with profound and multiple disabilities (PMLD), the things they do with their time are severely limited by a society that does not cater for their needs, such as a lack of fully accessible, Changing Places toilets and the current lack of access to day and respite services.

Moving forward

Additional research is needed to understand the role of support in enabling, or otherwise, people to do the things they want to do. However, we believe that the findings from the survey give rise to the following questions, aimed at people with learning disabilities themselves, their families, carers and supporters and those working in policy and practice:

- *What can be done to ensure that everyone with learning disabilities in Scotland is able to do more of the things they want to do, including seeing more of their friends and families?*

- *What can be done to ensure service level policies and person-centred support plans recognise, incorporate, and realise people's preferences in relation to how they spend their time?*

- *What can be done to ensure families, supporters and paid staff do not let their own values restrict people's choice over what they want to do?*

- *What can be done to build on the unprecedented expansion of digital inclusion for people with learning disabilities brought about by the pandemic, and ensure no one is left behind as services move to digital first?*

- *What can be done to ensure that everyone who wants to can get a job?*

- *What can be done to ensure that the basic needs of people with PMLD are met when they are away from home, such as through the provision of Changing Places toilets?*

These questions are not exhaustive. Neither are they intended to be prescriptive. Instead, it is hoped that they will provide a lens for interested parties; whether that is people with learning disabilities themselves, their families, carers and supporters, or those working in policy and practice; through which to consider and discuss what might need to change. With Scotland's new National Care Service currently in its design phase, we believe now is the right time to be having these discussions.

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. Critically, this includes people spending their time as they choose, and participating in society on an equal basis. We expect that the design of the new National Care Service will take account of these findings and the questions raised by them, to ensure that the voices of people with learning disabilities and their parents and carers are listened to. To do this well 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

How people spend their time is important for their overall wellbeing. Across the population, work, education, leisure and active citizenship are all recognised as pivotal dimensions of a person's quality of life.[i] Importantly, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) affirms the right of people with disabilities to access work (Article 27), education (Article 24) political life (Article 29) and leisure (Article 30) on an equal basis with others.[ii]

In the decades leading up to the publication of *The same as you?* (2000),[iii] people with learning disabilities in Scotland spent much of their time in large institutional settings including hospitals that provided little in the way of promoting interests or developing skillsets. *The same as you?* shifted this paradigm, encouraging support services to become more community focused, helping people access further education and development, meaningful work and to be more active and involved in their communities.

Undoubtedly, much progress has been made in the years since. The policy landscape in relation to people with learning disabilities has been increasingly grounded in the values of human rights, empowerment and personalisation. *The keys to life*[iv] and its subsequent implementation frameworks have focussed in particular on choice and control and supporting people into mainstream employment. There has been a sharp rise in supported employment opportunities, with organisations such as DFN Project SEARCH leading the way. Many third sector organisations focus on supporting the involvement of people with learning disabilities in community life, and numerous self-advocacy groups encourage people to speak up for what they want.

Despite this progress, it is clear that there is still some way to go before the ambitions of UNCRPD and the aspirations of national learning disability policy are realised, enabling people with learning disabilities to participate in society on an equal basis. A particularly striking example is that employment rates for people with learning disabilities remain stubbornly low, with the latest official figures suggesting only 4.1% of people with learning disabilities were in paid work.[v]

Unfortunately, we already know that it is not only in employment where people face barriers that exclude them from exercising choice and control over how they spend their time. Many people with learning disabilities regularly experience stigma and prejudice, and are excluded from society and the communities that they live in.

With our How's Life? survey, SCLD wanted to explore how people felt about the ways that they spent their time, and the extent to which they experienced some of these barriers. It is hoped that the findings will inform discussions about how these barriers can be overcome.

Covid-19

The How's Life? survey was carried out between May and September 2019, before the unprecedented events of the Covid-19 pandemic overwhelmed the globe, creating challenges across all aspects of our lives. These challenges fell disproportionately upon people with learning disabilities. Overstretched social care services and the reduction and/or removal of support services for many during '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 impacts of the pandemic in both the short and long term. Lack of day service provision left parents and carers at breaking point.[vi]

The Scottish Government's

recently published *Towards Transformation*[vii] plan recognises the impact that the pandemic has had on people with learning disabilities. It contains a number of actions that relate to the ways people with learning disabilities spend their time. Regarding employment, it commits to continuing to work toward halving the disability employment gap by 2038. It also recognises the importance of having the right support to ensure people with learning disabilities can live independent lives in their communities; the necessity of improvements in education; and, importantly, plans to tackle digital exclusion.

However, while the Covid-19 pandemic has brought these issues into sharp focus, it is critical to remember that the pandemic did not cause them. People with learning disabilities have experienced significant and prolonged discrimination for many years.

The findings from How's Life? outlined below highlight that, when it comes to how people spend their time, disparities already existed across economic, civic and social activities. The Covid-19 pandemic will have far reaching impact, and makes long-term, meaningful change all the more urgent. It is more important than ever that we address these issues if we are to create the fairer, more inclusive Scotland we all aspire to.

This report is broken down into the following chapters:

- How do people with learning disabilities spend their time?
- Do people with learning disabilities have the resources they need to live fulfilling lives?
- What differences are there in how different groups spend their time?
- What people do with their time, in their own words
- Discussion
- Moving forward

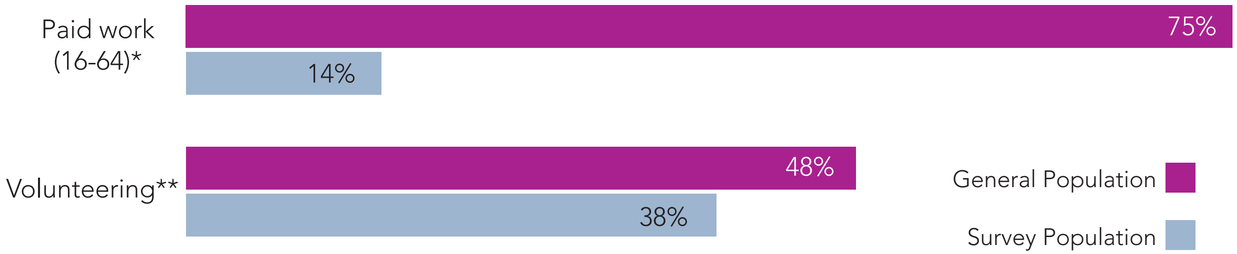
How do people with learning disabilities spend their time?

The How's Life? survey asked people whether they had spent any of their time over the last few weeks doing economic or leisure activities. It also asked people whether they had participated in civic activities anytime in the last few years. The results are discussed below, with a particular focus on disparities with the general population.

Economic Activities

As part of the survey, respondents were asked if they spent any of their time doing paid work or volunteering. Figure 1 shows the percentage of survey respondents who engaged in these activities, compared with the general population.

Figure 1: Percentage of respondents who spent time doing economic activities

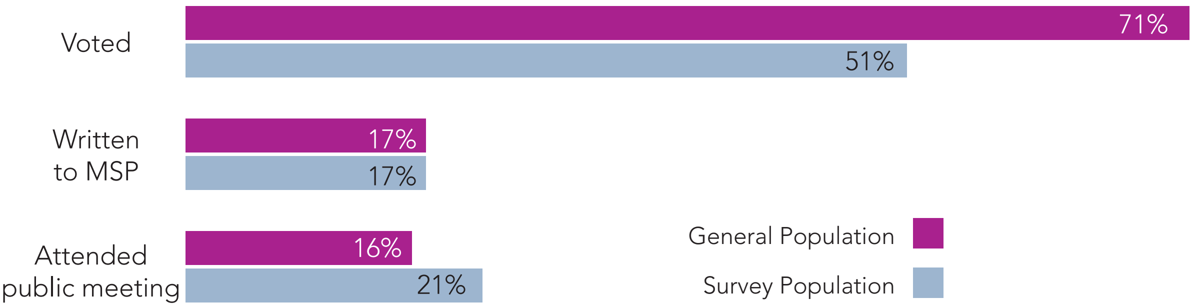


*General Population Source: Annual Population Survey 2019
** General Population Source: Scottish Household Survey 2018

Civic Participation

As a way to measure civic participation, the survey asked whether respondents had taken part in a number of activities in the last few years, including voting in an election, writing to their elected representatives or attending public meetings. Findings suggest that people with learning disabilities in Scotland had relatively high levels of engagement in the political process.

Figure 2: Percentage of respondents who spent time doing civic activities



* General population source for election turnout: House of Commons Library, General Election 2019

** General population source for other info: Scottish Household Survey 2018

As shown in Figure 2, 51% of people had voted in an election in the last few years. The comparison figure of 71% for the turnout for the 2019 General Election in Scotland is likely the higher end of the estimate for general voter turnout, as turnout tends to be higher for General Elections compared to Scottish parliamentary or local elections.

Interestingly, 17% of survey respondents had been in touch with an elected representative in the last few years; the same percentage of the general population.

A higher percentage of survey respondents had attended a public meeting; 21% compared to 16% of the general population.

The self-advocacy movement was born out of the recognition that people with learning disabilities should take control of their own lives, by speaking up about what they want. Self-advocacy is an important tool for people with learning disabilities to have their voices heard and communicate their needs. As such, there is no comparator with the general population, though it is clear that self-advocacy is an important indicator of civic participation for people with learning disabilities.

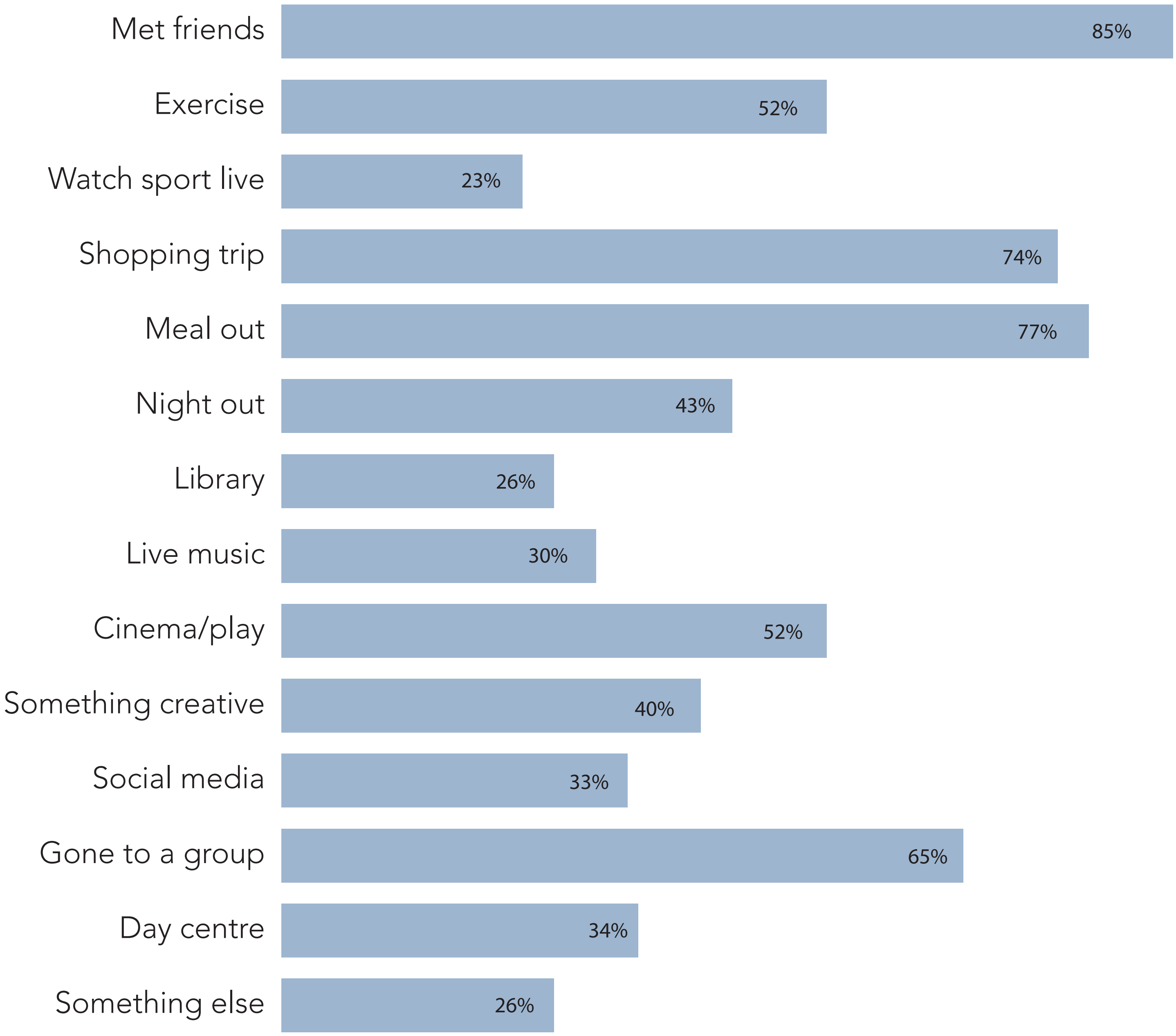
Figure 3: Self advocacy among survey respondents

28%, or around 1 in 3 people who responded to our survey said that they had attended a self-advocacy group in the last few years.

Leisure time

The survey also asked people what activities they had done for fun over the past few weeks. Figure 4 shows that survey respondents had undertaken a lot of different activities.

Figure 4: Percentage of survey respondents who spent time doing fun activities



It is not possible to compare the participation levels of survey respondents in each of these activities with the general population, however, the Scottish Household Survey (2019) does allow us to do some comparisons.

The most common activity for survey respondents was meeting friends, with 85% of people having done so in the last few weeks. While not the focus of this report, our Relationships Matter report[viii] highlighted the importance of meeting friends for reducing loneliness and increasing people's sense of wellbeing. Though not directly comparable due to the different time period, and inclusion of people other than friends, the Scottish Household study suggests that in 2018, around three quarters of adults in Scotland (73%) met socially with friends, relatives, neighbours or work colleagues at least once a week.

The 2019 survey also provides some statistics on participation in some cultural activities; library use, going to the cinema and going to see live music. It is important to note that the time frames are different. The Scottish Household Survey asked whether people participated in activities 'in the past year' whereas How's Life? asked whether people participated in activities 'in the past few weeks.' However, it is interesting to note that levels of participation were broadly similar:

- 26% of survey respondents had used the library compared to 27% of the general population.

- 30% of survey respondents had been to see live music compared to 37% of the general population.

- 52% of respondents had been to the cinema or seen a play compared to 58% of the general population (though it is important to note the general population figure does not include seeing a play).

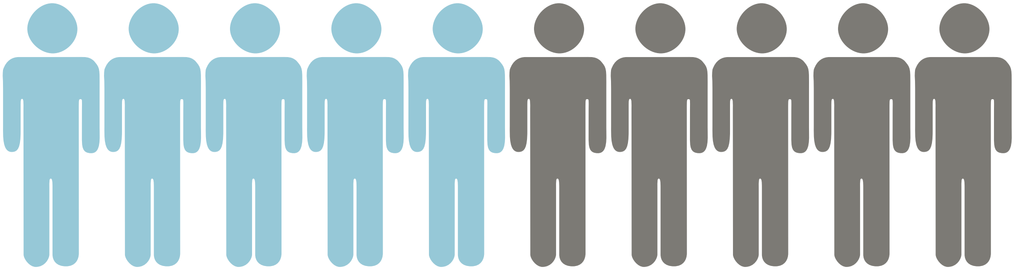
The Scottish Household Survey (2019) also allows for comparisons of participation in exercise and social media use with the general population, where differences are more pronounced.

Exercise

As shown in Figure 4, only 52% of survey respondents had undertaken exercise in the last few weeks. This is around 5 out of every 10 people with learning disabilities (Figure 5). The Scottish Household Survey (2019) suggests that 80% of adults in the general population had participated in physical activities over the previous four weeks. This is 8 out of every 10 people (Figure 5)

Figure 5: Participation rates in exercise of survey respondents compared to the general population

People with learning disabilities



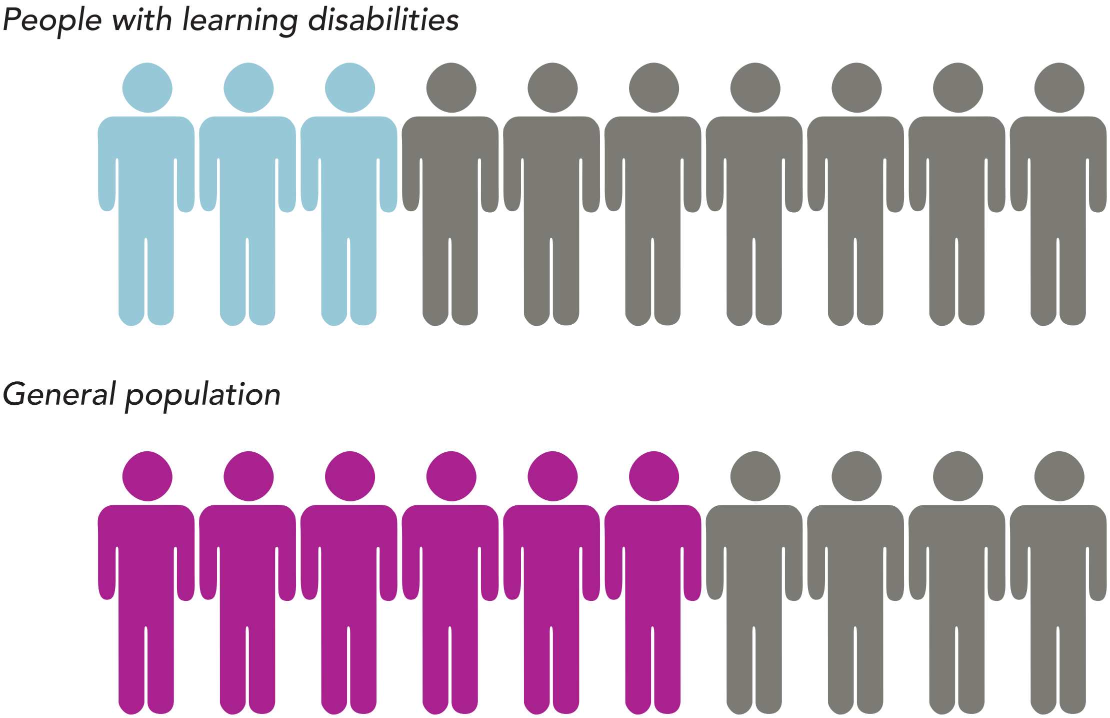
General population

The survey provided space for people to tell us more about how they spend their free time if they wished to. Of those who talked about exercise, walking was the most common form of exercise people enjoyed, closely followed by swimming. People also enjoyed Boccia and horse-riding. A few people mentioned that they liked to go to the gym, as well as other sports, such as bowls, rugby and golf.

Social Media Use

Figure 4 shows that 33% of people had used social media in the last few weeks. This is around 3 in 10 people who responded to the survey (Figure 6). Figures for the general population suggest that 61.5% of people used the internet to access social media.[1] This is around double the rate of people with learning disabilities, at 6 in 10 people (Figure 6).

Figure 6: Participation in social media by survey respondents compared to the general population



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[1] Figure provided through bespoke analysis of the Scottish Household Survey (2019) by Ipsos MORI.

Within the section that allowed for people to tell us more about their free time, very few people mentioned the use of social media specifically. It is important to note however that How's life? was undertaken before the Covid-19 pandemic, where social media has become an important tool for keeping in touch with loved ones.

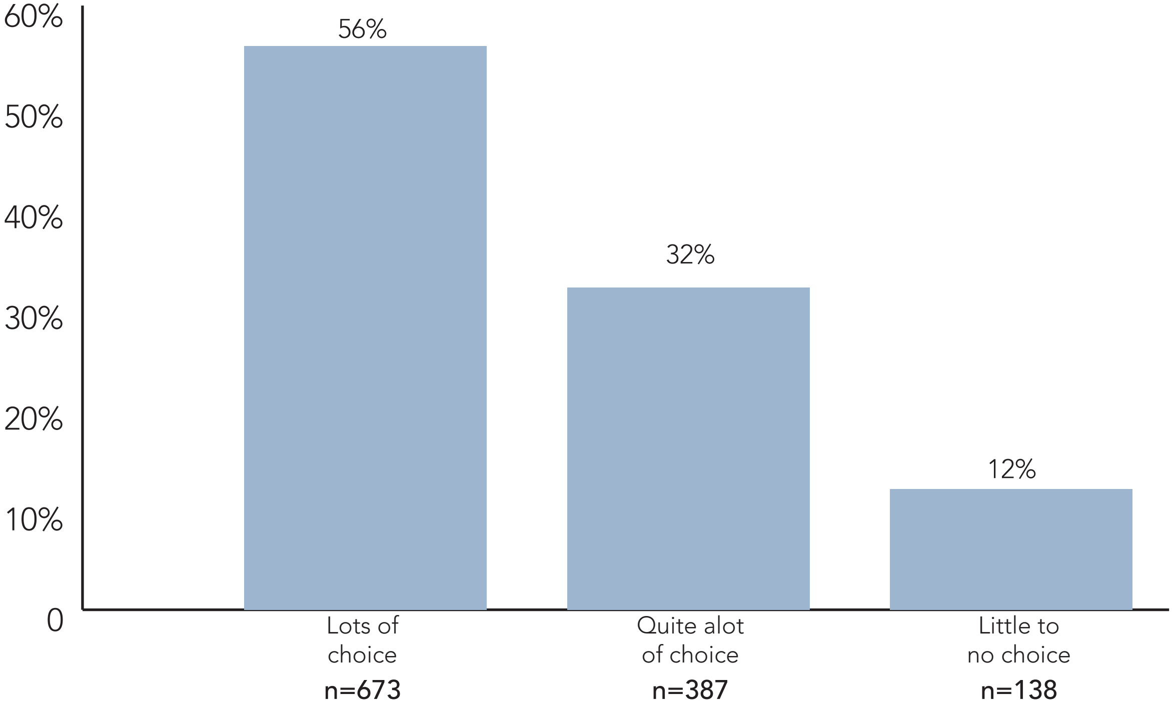
While there is no comparator for the general population, it is worth noting that Figure 4 also shows us that 34% of people attended a day centre, which is around 1 in 3 survey respondents. This is a higher percentage than in the most recent Learning Disability Statistics Scotland publication (2019), where 18.2% of adults known to local authorities attended a day centre.

Do people with learning disabilities have the resources they need to live fulfilling lives?

The things that we do are limited by the resources we have to put toward doing what we want. Within the How's Life? survey, people were asked how they felt about four specific resources that enable them to live the lives they choose; choice, support, money and transport.

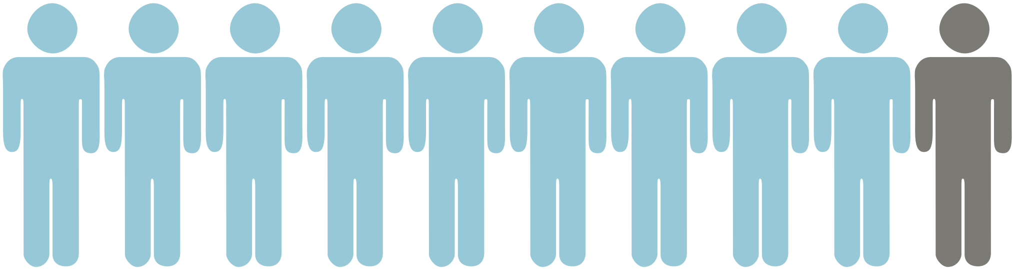
As shown in Figure 7, 88% of survey respondents felt that they had lots, or quite a lot of choice over their free time.

Figure 7: Percentage of people by how much choice they have over their free time



Happily, 9 out of 10 (90%:889) of those respondents who needed support said that they got the support they needed to do the things they wanted to do (Figure 8).

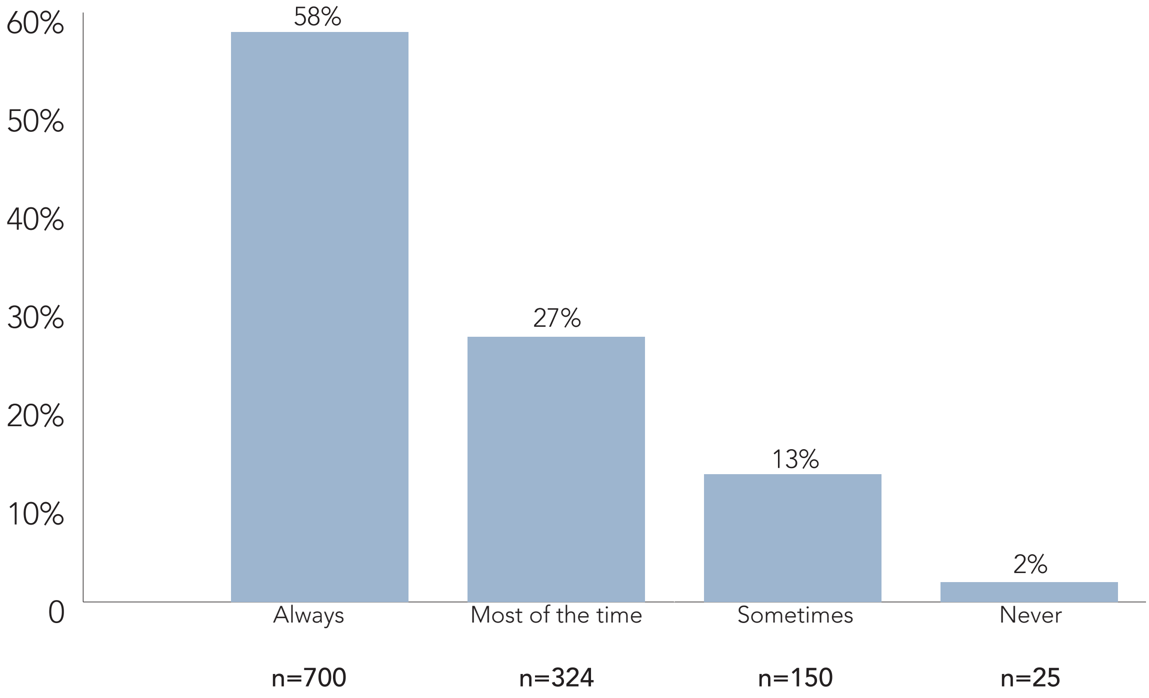
Figure 8: Survey respondents (who needed support) who got the right support



The majority of survey respondents (88%:911) also said that they had enough money to do the things that they wanted.

As shown in Figure 9, the vast majority of people (85%) were happy with their transport options all or most of the time.

Figure 9: Percentage of people by whether they are happy with the transport available for them to do the things they want to do



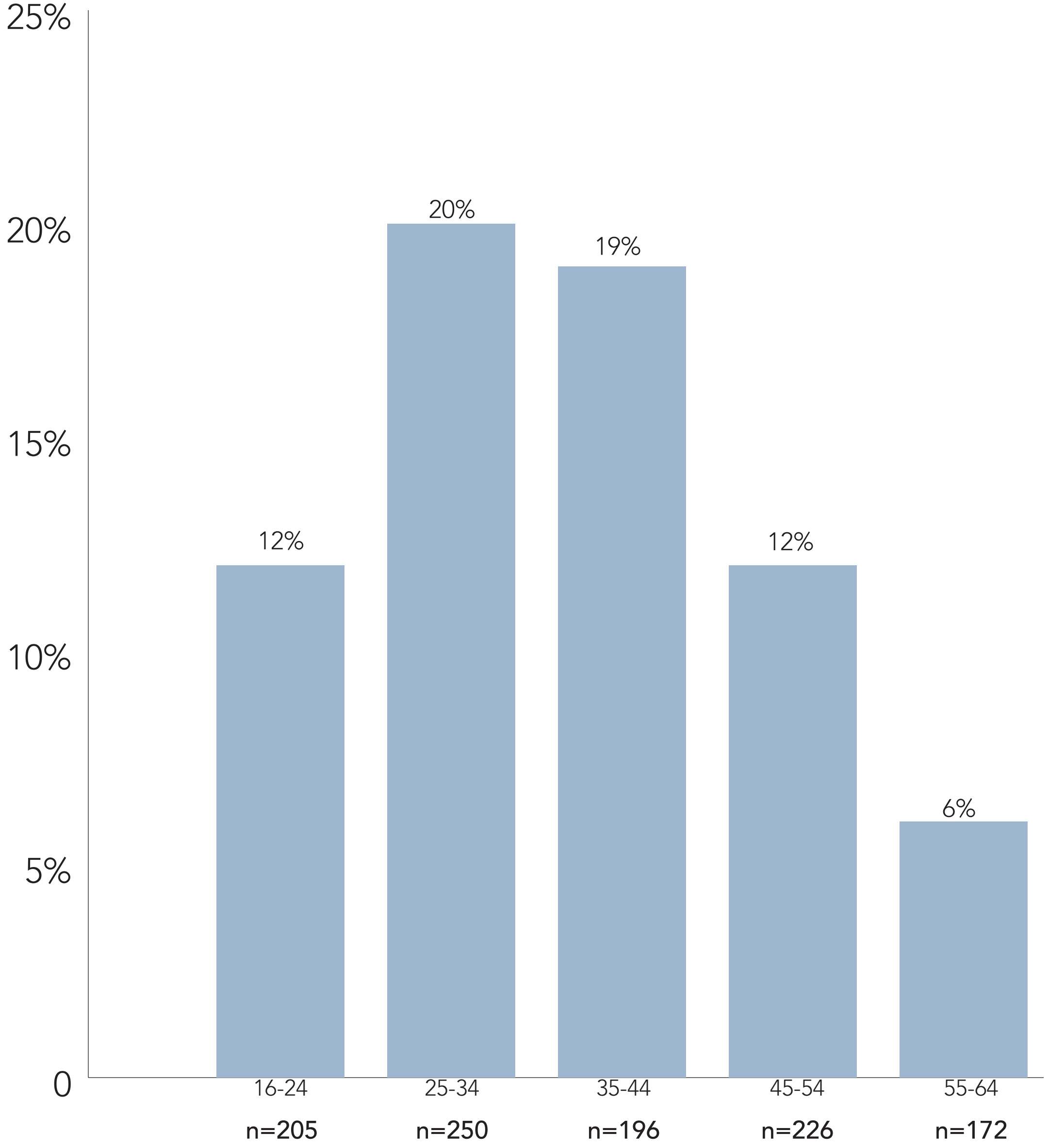
What differences are there in how different groups spend their time?

Work and volunteering

In the general population in 2019, men aged 16-64 were more likely to be in employment than women aged 16- 64 (74 and 68 per cent respectively) (Scottish Household Survey 2019). While the same pattern was seen in our How's Life? survey, where the corresponding figures were 15 and 13 percent, this was not found to be a significant difference.

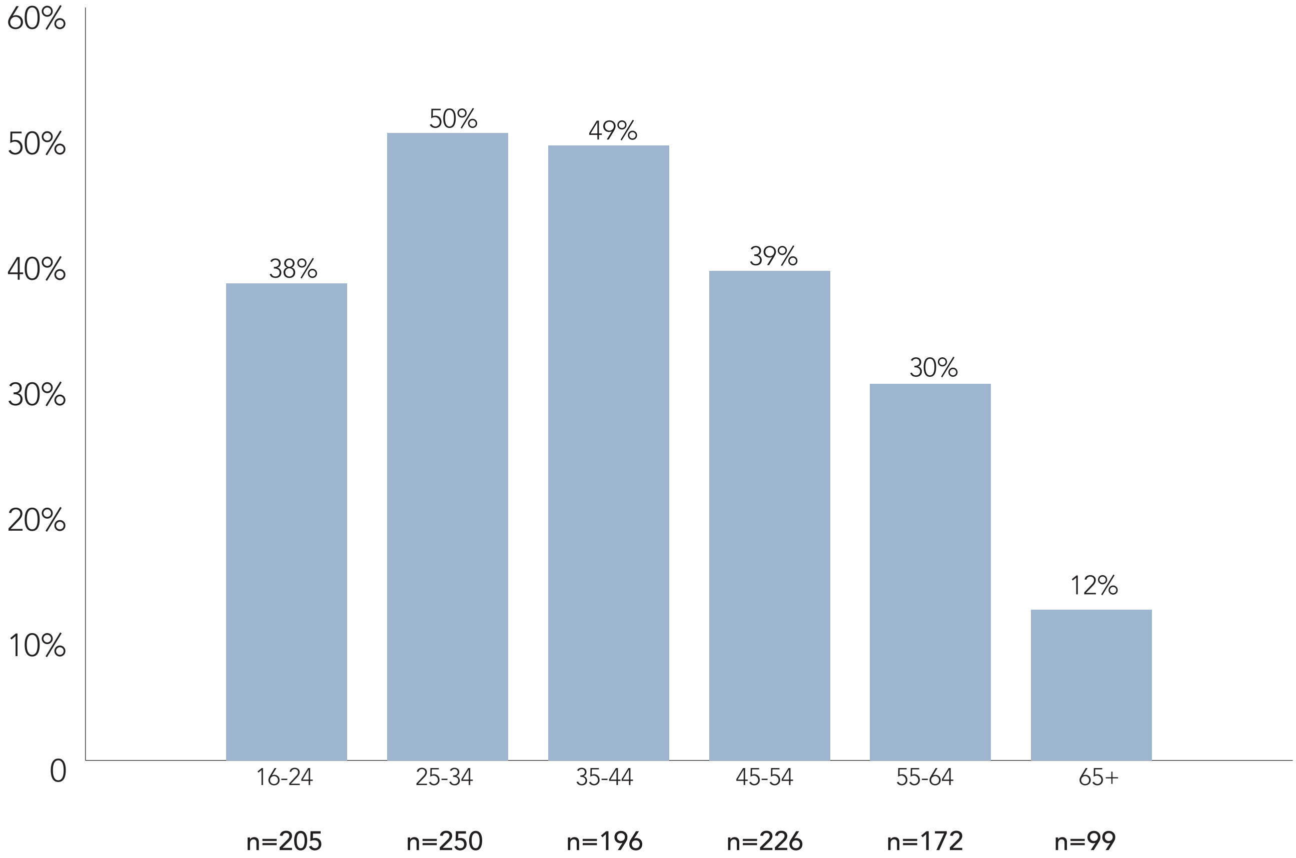
Figure 10 below shows that those in the 25-34 and 35-44 age groups were significantly more likely to say they spent some of the last few weeks doing paid work than those in other age groups.

Figure 10: Percentage of survey respondents (16-64) in paid work, by age



A similar pattern was found with volunteering. Those aged 25-34 and 35-44 were significantly more likely than those in other age groups to have spent time volunteering over the last few weeks (Figure 11).

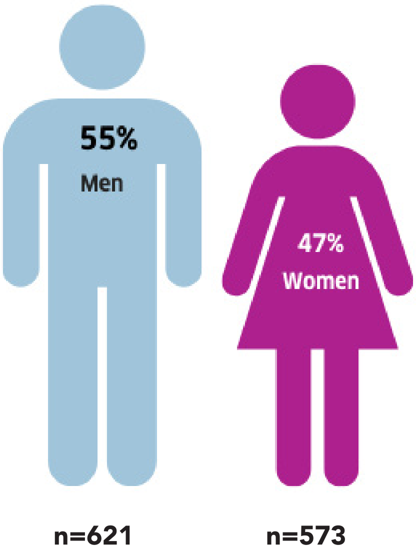
Figure 11: Percentage of survey respondents who volunteered, by age



People living in mainstream accommodation were more likely than those in supported accommodation or other accommodation to take part in volunteering (Figure 12).

Figure 12: Percentage of people who volunteered, by type of accommodation

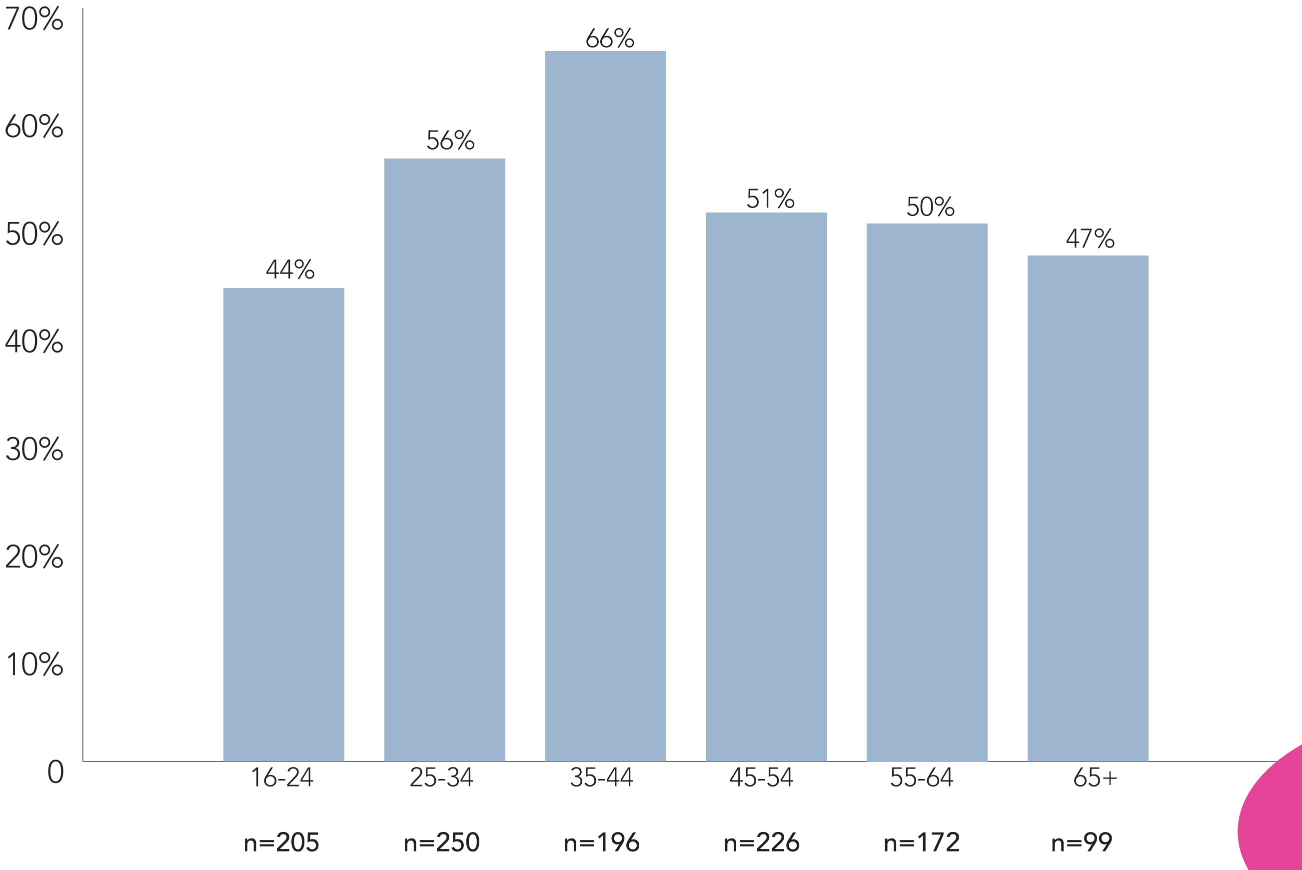
Figure 13: Percentage of people who voted, by gender



Men who responded to the survey were more likely to have voted than women. 55% of men had voted in the last few years compared to only 47% of women.

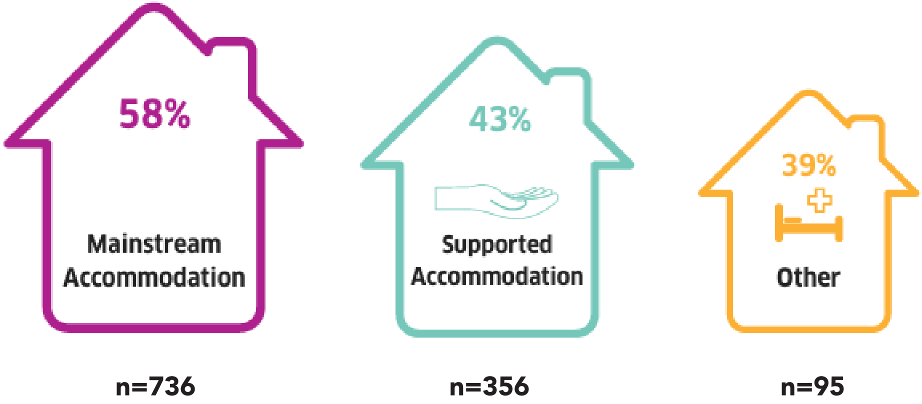
People aged 35-44 were the most likely age group to have voted in the last few years, with 66% of that age group having done so. This is an interesting contrast to voting behaviour in the general population, where younger people are less likely to vote than older people, and turnout rises in older age groups.[ix]

Figure 14: Percentage of people who voted, by age



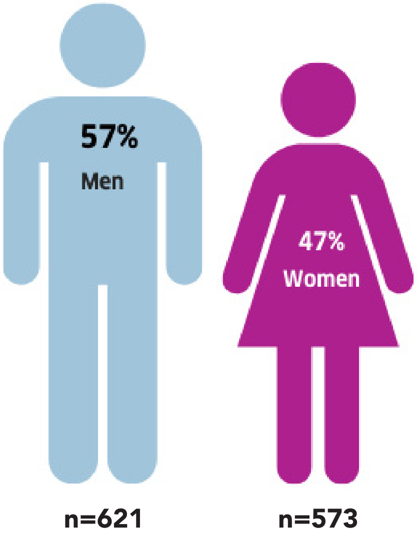
People living in mainstream accommodation were more likely than those living in supported, or other accommodation, to have voted in the last few years (Figure 15).

Figure 15: Percentage of people who voted, by accommodation type



Exercise

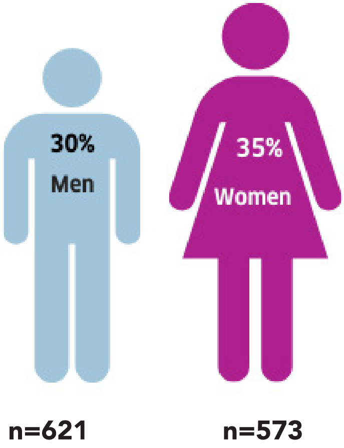
Figure 16: Percentage of people who participated in exercise in the last few weeks, by gender



As in the general population, men who responded to the survey were more likely to have participated in exercise in the last few weeks than women.

Social media

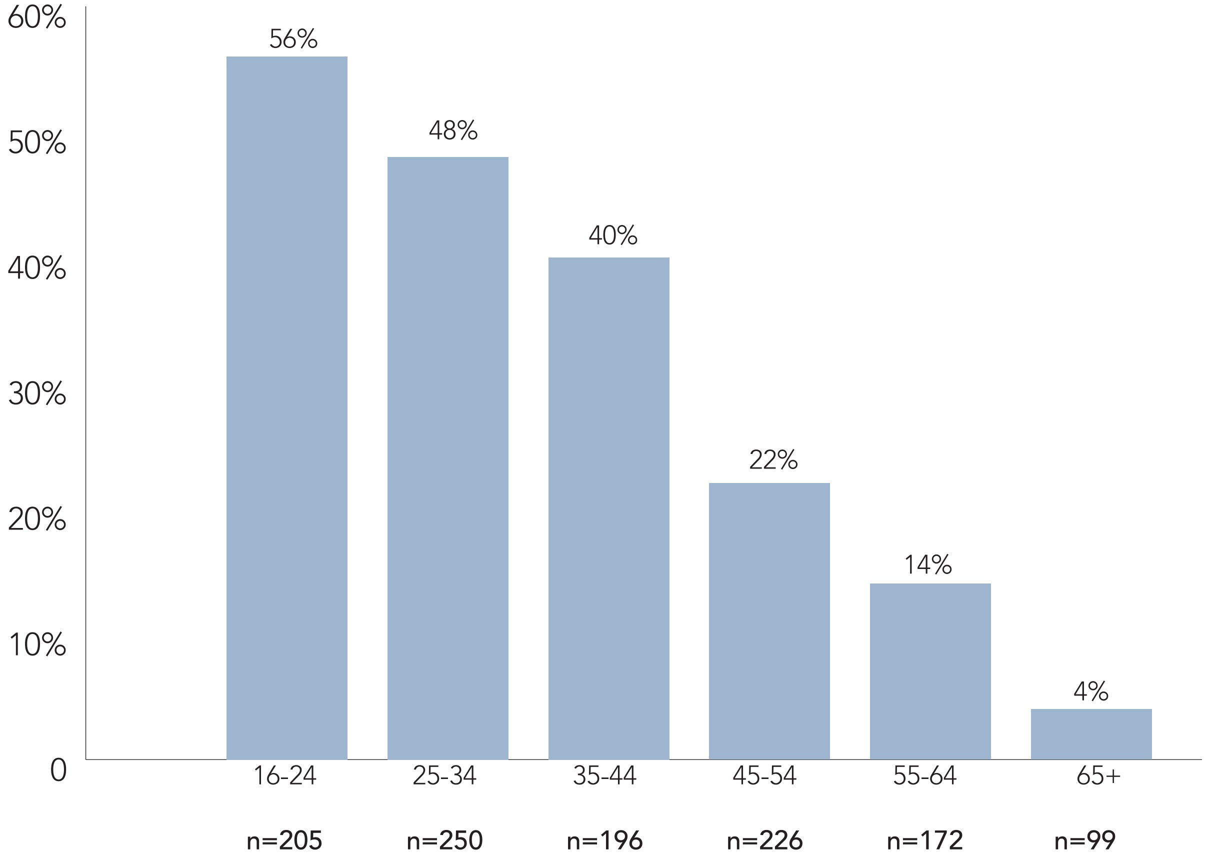
Figure 17: Percentage of people who used social media in the last few weeks, by gender



Women were more likely than men to have used social media in the last few weeks.

Unsurprisingly, people in younger age groups were much more likely than those in older age groups to have used social media in the last few weeks. 56% of those aged 16-24 had used social media compared to just 4% of those over 65 (Figure 18).

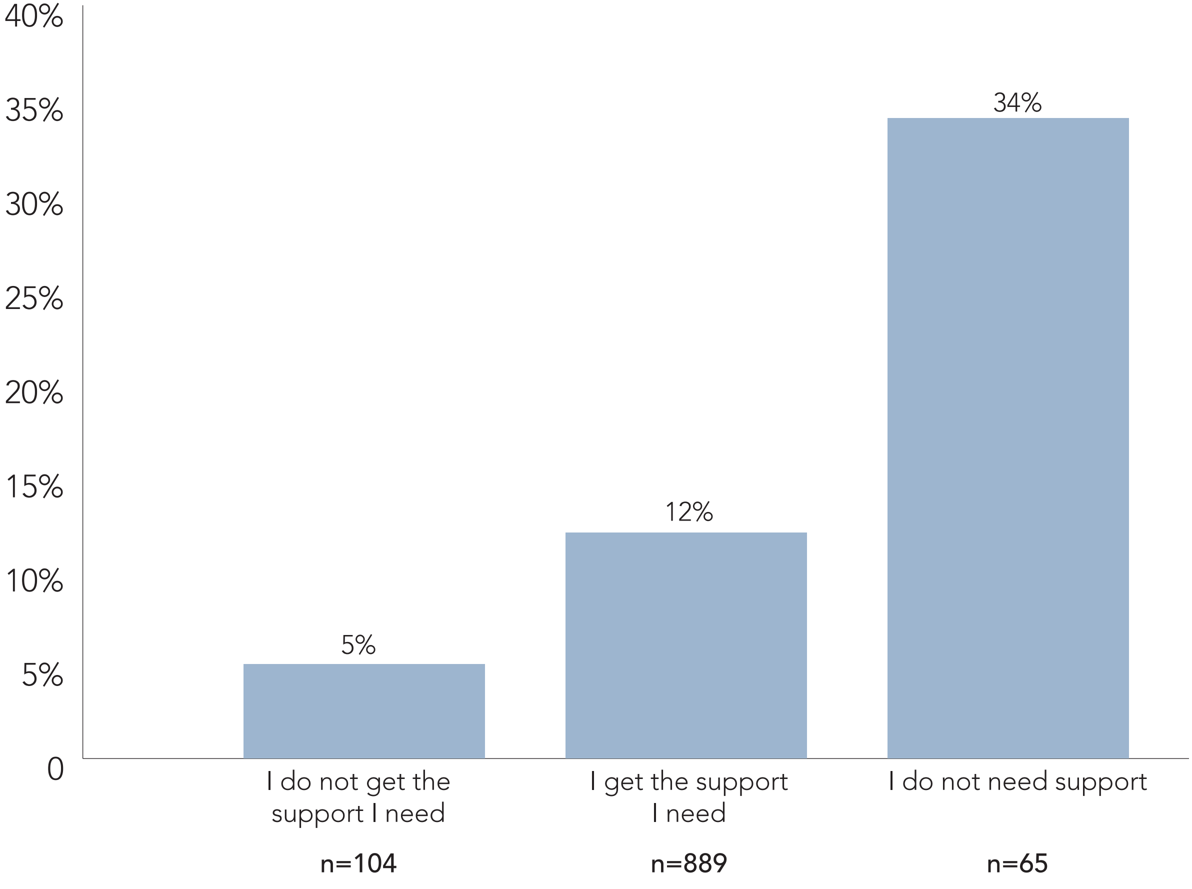
Figure 18: Percentage of people who used social media in the last few weeks, by age



As well as exploring the demographic factors above, we investigated whether there were any significant differences in participation in activities against the resources people feel they have to take part. Perhaps unsurprisingly, support was found to have a significant correlation with almost all of the activities, though not always in ways that we might have expected.

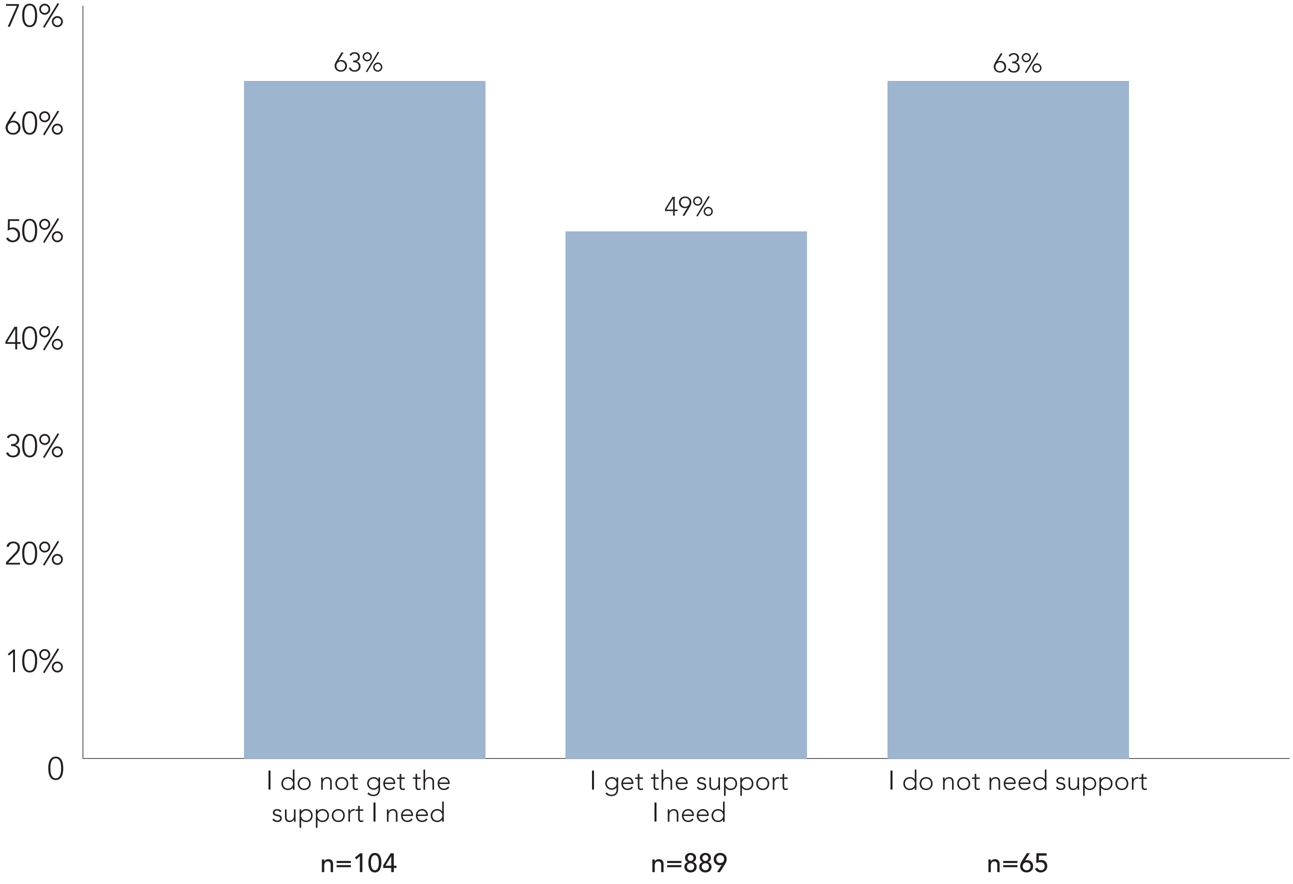
There was a correlation between support and whether people were in work. As shown in Figure 19 below, only 5% of people who did not get the support they needed were in work, compared to 12% of people who did get the support they needed, and 34% of people who did not need support to do the things they wanted.

Figure 19: Percentage of people who were in paid work, by support



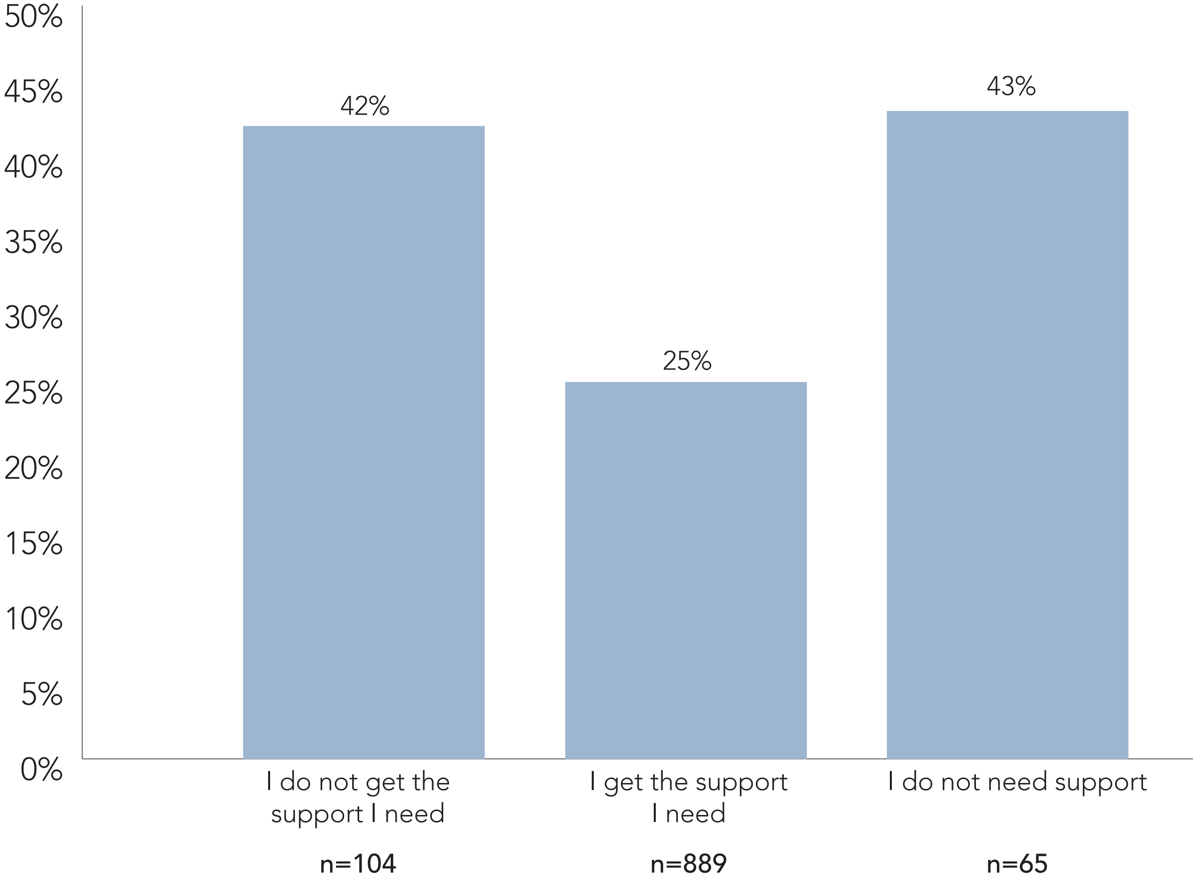
There was also a correlation between support and whether people had voted in a recent election. Interestingly, as shown in Figure 20, the same percentage of people who did *not* get the support they need and people who did not *need* support (63%) had voted, compared to 49% of people who did get the support they needed.

Figure 20: Percentage of people who had voted, by support



There was a very similar pattern to the correlation between support and whether people undertook self-advocacy. As shown in Figure 21 below, 42% of people who did *not* get the support they needed undertook self-advocacy. A similar percentage (43%) of those who did not need support undertook self-advocacy. This compared to only 25% of people who got the support they need.

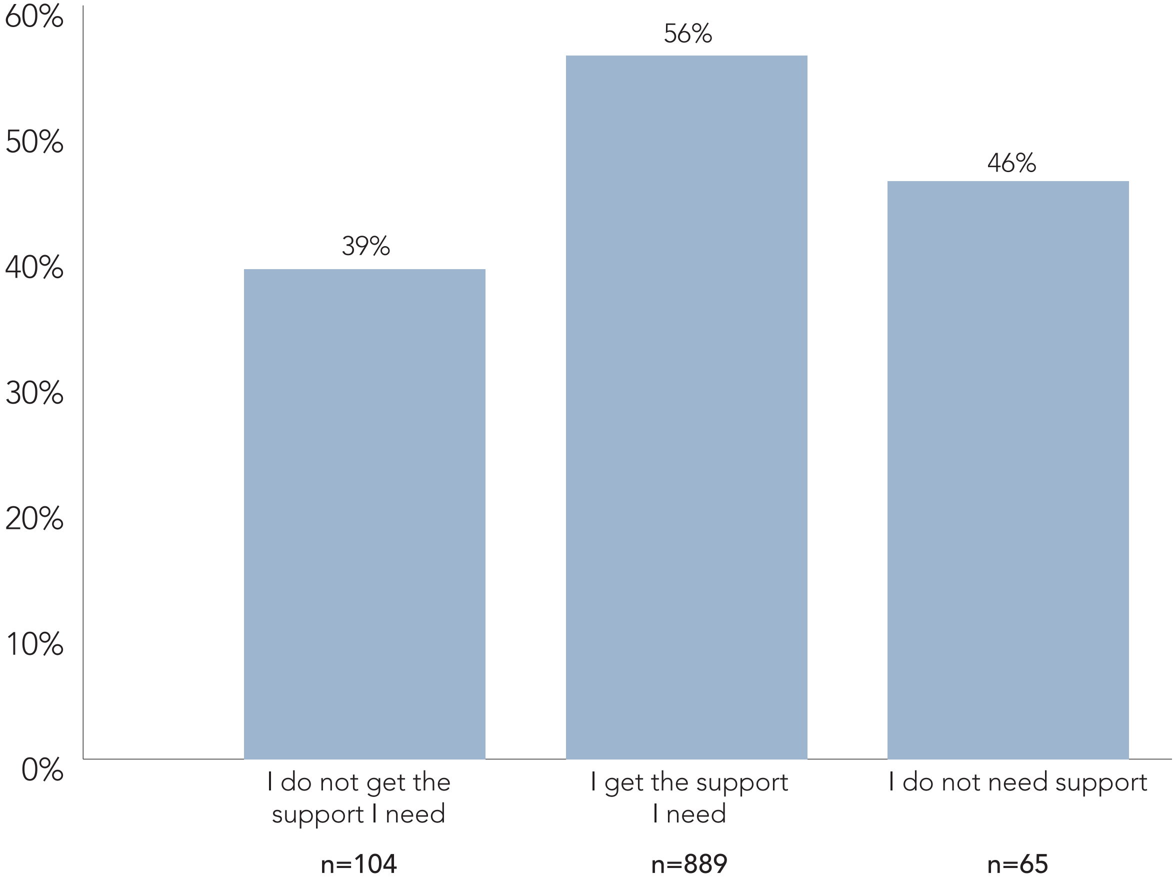
Figure 21: Percentage of people who undertook self-advocacy, by support



It is not possible to know the reason for this pattern. One possible reason could be that people with learning disabilities feel more inclined to participate in civic activities, such as voting or self-advocacy, when they feel that they do not have the right support, in order to change this, either for themselves or others.

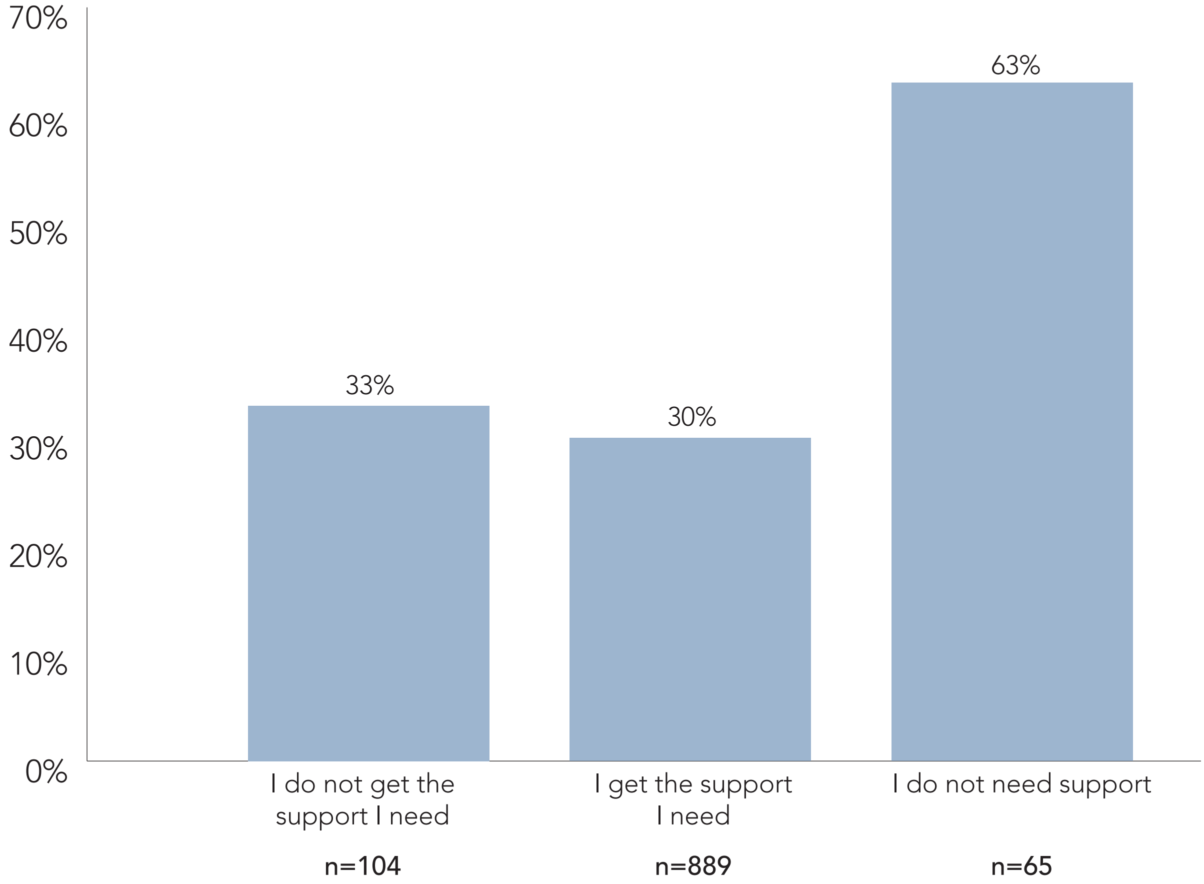
Interestingly, people who got the right support were the most likely to participate in exercise, with 56% of those respondents having done so in the last few weeks. This was followed by those who didn't need support (46%) then those who did not get the right support (39%) (Figure 22).

Figure 22: Percentage of people who had exercised, by support



As shown in Figure 23, there was very little difference in the percentage of people who did and did not get the right support in relation to whether they had used social media in the past few weeks (30% and 33% respectively). However, around double the percentage of people who did not need support had used social media in the last few weeks (63%).

Figure 23: Percentage of people who used social media, by support



What people do with their time, in their 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.

Of the 1076 people who answered this question, 316 (29%) spoke about the activities that they took part in.

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 the range of activities people undertook, with 102 (13%) of people saying that they would change an aspect of this.

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 of these stories, as they relate to what people do with their time, are reproduced in full below.

These stories highlight that for people with profound and multiple learning disabilities, what they spend their time doing is severely limited by a society that does not meet their needs. And it is important to remember that this was the case even before the Covid-19 pandemic.

Case Studies

CASE STUDY 1

My son attends a day care centre for 25 hours per week. It's a lifeline for us to function as a family. Feedback we receive from the centre is that he enjoys mixing with others in a safe environment that meets his needs. Within the centre he can listen to music and enjoy the garden area. He also has access to transport along with others that allows him to be involved in certain activities such as (assisted) ten pin bowling.

We are pleased that he is encouraged to go for walks as much as possible as it's essential for him to maintain a form of weight bearing exercise to stave off other health issues. He receives cooked food in the centre which is prepared to his individual needs to avoid him choking. In addition, he attends approximately 17 sessions per year of a social group which lasts for six hours each session. Days out are often planned for these sessions, however my son is severely limited in where he can go because of continence care, safety and feeding issues. His involvement in trips out is usually determined following a risk assessment process between parents and support staff taking account of safety, dignity and practical support issues.

My son has a swing in his garden which was ordered from a specialist supplier. He has hypermobile joints and sits inside his swing. He enjoys strolling in the garden. He has occasional half-hour rebound therapy sessions at a trampoline centre. He listens to music at home and enjoys a long bath time each evening which provides therapy and a degree of relief from the effects of Crohn's disease. He has a number of toys, books and DVDs and an iPad that he sometimes likes to have on while lying in bed to watch programmes or to listen to music.

My son is very limited in his choice of things to do. He can take part in limited activities supported by parents and staff at the day care centre he attends. His choice is dictated by availability and assessment of the things he seems to enjoy best.

My son has little choice in where he can go and what he can join in because of barriers such as:

- a lack of Changing Places toilets[2] which prevents him from visiting places;
- a lack of understanding and appropriate support for people with Profound Intellectual and Multiple Disabilities (PIMD) from third party organisations not specifically trained to support PIMD;
- unavailability of social opportunities because of a lack of identified activities and venues suitable to meet the care needs of people with PIMD;
- in the absence of any suitable alternatives, families being forced to accept social support offered where people with PIMD are placed in support groups set up for people with a wide range of learning disabilities, but mostly for people able to take part in a range of activities that are not easily accessible or suitable for people with PIMD, and;
- staff needing to be better supported to cope with the complex needs of people with PIMD.

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[2] More information about Changing Places toilets can be found here: Changing Places Toilets (changing-places.org

CASE STUDY 2

My daughter has fun. She attends Motor Activity Training Programme (MATP) classes, goes to Touch Trust, carriage riding at Riding for the Disability Association (RDA), loves her hot tub, goes to discos and social clubs and the pub.

She is offered choice over things they do but it's limited by how much she can make a choice or how she can communicate her choice.

Her physical disability and her health, wheelchair access and lack of Changing Places toilets in the community stop her doing the things she wants to do.

CASE STUDY 3

My daughter attends her day service 5 days per week. At her day service she goes swimming, bowling, Sporting Opportunities Motor Activities Programme (SOMA), musical events, goes out for walks, trips to the park and attending special events. Other things my daughter does are rebound therapy, music therapy, outings, spends time on her swing. She enjoys storytelling, picture books, attending book festivals.

She has a lot of choice within the things that are identified for her and many of these have been initiated by PAMIS.

There are many things that stop my daughter doing what she wants to do. Difficulty in communicating her likes and dislikes, her health and her epilepsy. Her physical limitations prevent her doing things she might like because of the limitation of her fine and gross motor skills. Pain also limits what my daughter can do. She suffers a lack of confidence because of her physical limitations and she has no awareness of danger. Limited understanding of situations and continence issues and lack of Changing Places toilets all play their part in limiting her choices.

Discussion

The decision to focus the last in our series of thematic reports from the How's Life? survey on how people spent their time predated the Covid-19 pandemic. It stemmed not only from the focus of *The keys to life* on empowering people to have choice and control over their lives, but also from the recognition that the way we spend our time has a significant impact on our wellbeing.

It is clear that significant progress has been made since people with learning disabilities would spend large portions of their time in institutionalised settings. However, there is still progress to be made to ensure that people with learning disabilities enjoy equal access to opportunities to spend their time the way they want. Importantly, this focus takes on renewed significance in the face of the Covid -19 pandemic. Covid-19, and the restrictions that have been used to manage the pandemic, continue to have widespread impacts on how people spend their days and the resources available to them.

At the time the How's Life? survey was undertaken, most of our respondents told us that they were happy with the resources available to them that enabled them to do the things they liked: support, choice, money and transport. Despite this, across economic, civic and social activities that people took part in, there were clear disparities between the participation rates of our survey respondents and the general population.

What people do with their time, and disparities with the general population

Looking at economic activities,

38% of survey respondents volunteered, compared to 48% of the general population. However, these figures are overshadowed by the huge chasm between the rates of employment for the general population (75%), and our survey respondents, with only 14% of people having undertaken paid work in the last few weeks. Perhaps unsurprisingly, people aged 25-44 were more likely to work or volunteer compared to their peers in other age groups.

Our findings show that a lower percentage of our survey respondents had voted in the last few years than the general population: 51% and 71% respectively, with men more likely to have voted than women. Perhaps more surprisingly, people aged 35-44 were more likely to have voted than those in other age groups. This is a departure from the trend in the general population where voting rates tend to increase with age. Interestingly, our survey respondents had taken part in other civic activities at similar rates to the general population. 17% of both our respondents and the general public had written to their MSP and 21% of respondents had attended a public meeting, compared to 16% of the general public. 1 in 3 of our survey respondents said that they had undertaken self-advocacy in the previous year.

The survey also demonstrated that people had undertaken a wide range of social activities over the previous few weeks. The most common activity listed was seeing friends. Yet, as reported in a previous How's Life? report Relationships Matter, we know that many people did not get to see their friends and families as often as they would have liked, and that the consequences of this were increased loneliness and isolation and a lower sense of wellbeing.

Going to the cinema, attending live music events and going to the library all had participation rates broadly in line with the general population. However, two areas in particular were notable for the disparity between respondents and the general population.

Only 52% of survey respondents had taken part in exercise over the last few weeks compared to 80% of the general population, with women less likely to have exercised than men. This is particularly worrying given the role that exercise plays in maintaining good physical and mental health.[x]Our findings also showed that 33% of respondents had used social media in the last few weeks compared to 61.5% of the general population. Women were slightly more likely than men to have used social media, and younger people a lot more likely. Whilst arguments can be made about the desirability or otherwise of social media, these low rates of use do point to the wider issue of digital exclusion, which will only become more pressing as more services move to digital first. Further, there is no doubt that social media has played a pivotal role in keeping people connected throughout the Covid-19 pandemic, and will likely play an increasing role in future.

While not possible to compare with the general population, it is worth noting that 34% of survey respondents attended a day centre; a higher percentage than is generally seen in the annual Learning Disability Statistics

Scotland publication.

Though our survey respondents told us that they had undertaken a wide range of activities, the stories demonstrated that for people with PMLD in particular, the things they do with their time are severely limited by a society that does not cater for their needs. Lack of fully accessible Changing Places toilets means that even basic needs are not being met when people are outside of their homes. It should be noted that it is not just people with more complex needs and their families that find value in day centres. And while it is correct that policy is focussed on areas such as increasing employment rates and promoting independent living, we must take note of critical importance that day services can provide for families.

Exploring the role of support

SCLD investigated whether people's views about the resources they had to do the things they wanted to do related to the activities that they took part in. We noted earlier that most people felt they had enough support, choice, money and good transport options to do what they wanted to do. However, we found that there were significant differences in almost all of the activities when taking into account the levels of support that people had, though not necessarily in ways that would be expected.

People who said that they did not need support do the things they wanted to do, were much more likely to be in paid work or to have used social media in the last few weeks than those who needed support and felt they got enough, and those who did not get enough support.

Interestingly, those people who said they did get the right support were the least likely to vote, or to have undertaken self-advocacy. However, they were also the most likely to have done exercise in the last few weeks.

It is easy to assume that people who are receiving the support they need would participate in activities at a similar rate to those who don't need support, but this was clearly not the case for our survey respondents. The nature of the survey does not allow us to know why this is so, but it does remind us that support is a complex issue.

And it gives pause to reflect. Are people who don't get the right support more likely to self-advocate precisely because they don't get the right support and want to make this known? Or is it that those who self-advocate are more inclined to voice their dissatisfaction with their support? Are people who do get the right support more likely to have exercised because their support staff or family stress its importance and encourage people to take part? And are they least likely to have used social media for similar reasons – that support staff or family disapprove? Does the low percentage of people who get the right support in paid work reflect the fact that people do not want paid work or low aspirations of their supporters, or that most jobs remain inaccessible to people who need any level of support? Or all of these?

Additional research is needed to explore these questions. However, we believe that on the back of this report there are other pertinent questions to be asked of the Scottish Government, of support providers and others, which will help to shape policy and practice moving forward. These are outlined in detail below.

Moving Forward

6. Moving forward

Covid-19 has brought the issue of what people do with their time into sharp focus. Reductions in, and for some a total loss of, support drastically changed what people were able to do. Many are still not receiving support at pre-pandemic levels. At the time of writing, day services remain closed across many areas, with families struggling to cope.[xi]

Social media has become a lifeline for many who would otherwise have lost social contact with friends. It is imperative that we learn lessons from the pandemic – both what went wrong and what went right. To do that it is helpful to be able to remind ourselves how people spent their time pre-Covid, and how the support they got helped or hindered them in doing the things they wanted to do.

We believe that the findings from the survey give rise to the following questions, aimed at people with learning disabilities themselves, their families, carers and supporters and those working in policy and practice:

- What can be done to ensure that everyone with learning disabilities in Scotland is able to do more of the things they want to do, including seeing more of their friends and families?
- What can be done to ensure service level policies and person-centred support plans recognise, incorporate, and realise people's preferences in relation to how they spend their time?
- What can be done to ensure families, supporters and paid staff do not let their own values restrict people's choice over what they want to do?
- What can be done to build on the unprecedented expansion of digital inclusion for people with learning disabilities brought about by the pandemic, and ensure no-one is left behind as services move to digital first?

- What can be done to ensure that everyone who wants to is able to get a job?
- What can be done to ensure that the basic needs of people with PMLD are met when they are away from home, such as through the provision of fully accessible Changing Places toilets?

These questions are neither exhaustive nor prescriptive. Instead, they provide a lens for interested parties; whether that is people with learning disabilities themselves, their families, carers and supporters, or those working in policy and practice; through which to consider and discuss what might need to change. With Scotland's new National Care Service currently in its design phase, we believe now is the right time to be having these discussions.

If we are to recover from the pandemic both inclusively and fairly, SCLD believes 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. We must ensure we listen to the voices of people with learning disabilities and their parents and carers. To do this will require not only significant investment, but strong leadership, and a commitment to the equality and human rights of people with learning disabilities.

Refrences

i European Commission (Eurostat) Quality of Life

ii United Nations Convention on the Rights of Persons with Disabilities

iii Scottish Executive (2000) The same as you?: a review of services for people with learning disabilities

iv Scottish Government (2013) The keys to life: Improving quality of life for people with learning disabilities

v SCLD (2019) Leaning Disability Statistics Scotland

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

vii Scottish Government (2020) Learning/Intellectual Disability and Autism: Towards Transformation

viii SCLD (2020) Relationships Matter: Exploring people’s experience of relationships, social isolation and loneliness

ix British Election Study (2019) Age and voting behaviour at the 2019 General Election

x NHS Inform (2020) Keeping Active: Health Benefits

xi UKRI (2021) Coronavirus and people with learning disabilities study

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