



Relationships Matter

Exploring people's experience of relationships,
social isolation and loneliness

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



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.

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 and methods

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 about 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 relationships and loneliness, and explores some issues that relate to these, like happiness, choice, and support. These topics were

chosen as the focus of our first report because of the importance of relationships to people with learning disabilities, and because people with learning disabilities continue to face barriers that exclude them from experiencing these relationships on an equal basis. Further, given the unprecedented removal of support services during the Covid-19 crisis and the impact of this isolation and loneliness, addressing some of the issues raised takes on a renewed significance as we move forward.

Background

Scotland's first learning disability strategy, *The same as you?* brought deinstitutionalisation and a move towards inclusion through independent living in the community. *The keys to life* recognises that

relationships, of all different forms, are essential to the wellbeing of people with learning disabilities, and important for people's sense of belonging and social inclusion. Despite this, people with learning disabilities continue to face barriers that exclude them from full participation in society. Consequently, social isolation and loneliness remain a reality for many.

Our survey results highlight this in particular through the lack of intimate relationships for the vast majority, higher levels of loneliness, lower levels of happiness for those who did not see their loved ones as often as they liked, and higher levels of loneliness overall than seen in the general population.



Key findings

Intimate Relationships

The survey found that very few respondents were in intimate relationships:

- Only 5% of respondents lived with a partner, compared to 56% of the general population
- Only 3% of respondents were married compared to 47% of the general population
- People in older age groups were less likely to be in a relationship
- People living in mainstream accommodation were more likely to be in a relationship than people in supported accommodation, and people in medical settings and care homes least likely

Contact with loved ones

The survey found that a number of respondents did not see loved ones as often as they would like and many

were lonely:

- 21% of people did not see their family as often as they liked
- 19% of people did not see their friends as often as they liked
- 27% of people in a relationship did not see their partner as often as they liked
- Older people were less likely to see their family or partners as often as they liked
- Younger people and people with additional conditions and/or disabilities were less likely to see their friends as often as they liked
- 52% of people occasionally, sometimes, or often felt lonely
- 9% often felt lonely, compared to 5% of the general population

Support and choice

The survey found that people who got enough support and choice

were more likely to see loved ones as much as they liked and less likely to be lonely. However, getting enough support or choice were not associated with being in an intimate relationship:

- People who got enough support were much more likely to see family, friends and/or partners as much as they liked than those who did not
- People who got enough support were much less likely to be lonely
- People who had lots of choice over their free time were much more likely to see family, friends and/or partners as much as they liked than those who had little choice
- People who had lots of choice over their free time were much less likely to be lonely

Not needing support was associated with being in an intimate relationship:

- 44% of people who did not need support were in a relationship compared to 18% of people who needed support
- 23% of people who did not need support lived with a partner compared to 3% of people who needed support

Relationships matter

People told us in their own words that relationships were important to them:

- Family was the most common answer given when people were asked to tell us the most important things in their life
- Friends was the second most common answer

- A minority expressed a strong desire to find a romantic partner when asked what one thing they would change
- Seeing enough of family, friends and not feeling lonely were all associated with higher levels of happiness

Moving forward

Adequately resourced, appropriate, flexible support is necessary if people with learning disabilities are to have their rights to inclusion and the highest attainable standards of health realised. Strong relationships and social inclusion are mutually reinforcing as relationships create natural support networks. The need for this has been demonstrated acutely through the Covid-19 crisis. Support that encourages people to

have and maintain different types of relationships, including intimate relationships if people wish, is crucial.

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 having relationships 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.

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 relationships with others and loneliness, and explores some issues that relate to these, like life satisfaction, choice and support. These were chosen

as the focus of our first report because of their importance to people with learning disabilities. Further, given the unprecedented removal of support services during the Covid-19 crisis and the impact of this isolation and loneliness, addressing some of the issues raised takes on a renewed significance as we move forward.

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 also ran alongside the survey as an alternative way to

submit a person's response where this was more appropriate.

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 male
- 47% were female
- 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

A major success of Scotland's first learning disability strategy, *The same as you?* was a move away from housing people with learning disabilities in institutions, away from families and communities, towards inclusion through independent living in the community. Scotland's current learning disability strategy, *The keys to life*, aims to build on this success. It is underpinned by a commitment to the highest attainable standard of living, health and family life for people with learning disabilities, and the principles of choice, independence and active citizenship. It recognises that relationships, of all different forms, are essential to the wellbeing of people with learning disabilities, and important for people's sense of belonging and social inclusion.

The importance of relationships to individual health and well-being cannot be overstated. Studies have found that the impact of poor social relationships on risk for mortality is similar to smoking and drinking alcohol, and even greater than physical inactivity and obesity.ⁱ Research has underlined the crucial importance of maintaining social connections and good relationships with family, friends and others, in preventing loneliness and isolation.ⁱⁱ

There are a number of legislative and policy provisions in place that aim to protect people's right to have healthy social relationships.

Article 8 of the European Convention on Human Rights, which protects everyone's right to respect for private and family life, ensures the right to make and keep friendships,

find a partner and have a family.

ⁱⁱⁱ Article 23 of the United Nations Convention on Persons with Disabilities also outlines that states must take measures to ensure those with disabilities can marry and have relationships on an equal basis with others. ^{iv}

Through 'A Connected Scotland', the Scottish Government recognises the importance of the strength of people's social relationships and connections and that they play a vital role in determining the quality of someone's life.^v The same strategy highlights that people with learning disabilities might require practical support to reduce their risk of becoming isolated. *The keys to life* implementation framework 2019 – 2021 also recognises the right of people

with learning disabilities to enjoy and maintain healthy relationships, including sexual relationships.^{vi}

However, despite these provisions, we know that people with learning disabilities still face a lot of barriers when it comes to making friends, maintaining personal relationships and developing romantic and sexual relationships.^{vii} These barriers include lack of privacy in certain living situations, stigmatising attitudes from family, staff and the wider community, lack of money, poor transport options as well as lack of support and restrictions on choice.^{viii} Consequently, social isolation and loneliness are still a reality for many.

SCLD wanted to explore how people felt about their relationships, and the extent to

which they experience some of these barriers. It is hoped that the findings will inform discussions about how these barriers can be overcome.

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 globe, creating challenges across all aspects of our lives. These challenges fell disproportionately upon people with learning disabilities. Overstretched social care 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.^{ix}

However, while the Covid-19 pandemic has brought these issues into sharp focus, it is critical to remember that the pandemic did not cause these issues, but rather, exacerbated them. The findings from How's Life? outlined below highlight that social isolation and loneliness were already a reality for many. 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.

The report is broken down into the following chapters:

1. Relationship status
2. Interpersonal relationships, social contact, and loneliness
3. Support and choice and their association with intimate relationships, social contact, and loneliness
4. Relationships matter
5. Discussion
6. Questions arising from the findings



1. Relationship status

Key Points

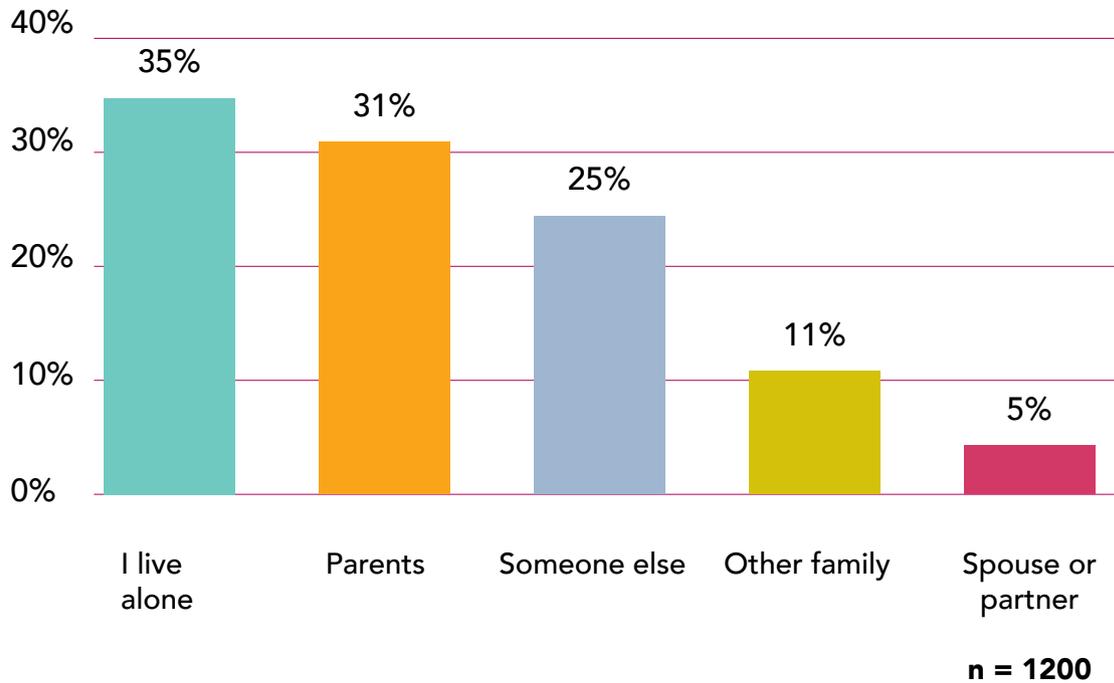
- Only 5% of respondents lived with a partner
- Only 3% of respondents were married
- People in older age groups were less likely to be in a relationship
- People living in mainstream accommodation were more likely to be in a relationship than people in supported accommodation, and people in 'other' accommodation least likely

This chapter looks at the relationship status of people with learning disabilities. It makes comparisons with the general population in Scotland. It also explores whether demographic factors; age, gender, additional conditions and/or disabilities, and the type of accommodation people lived in; are associated with being in a relationship. Only factors found to have an association are reported on.

The How's Life? survey asked people who they lived with (Figure 1). People were allowed to select more than one answer.

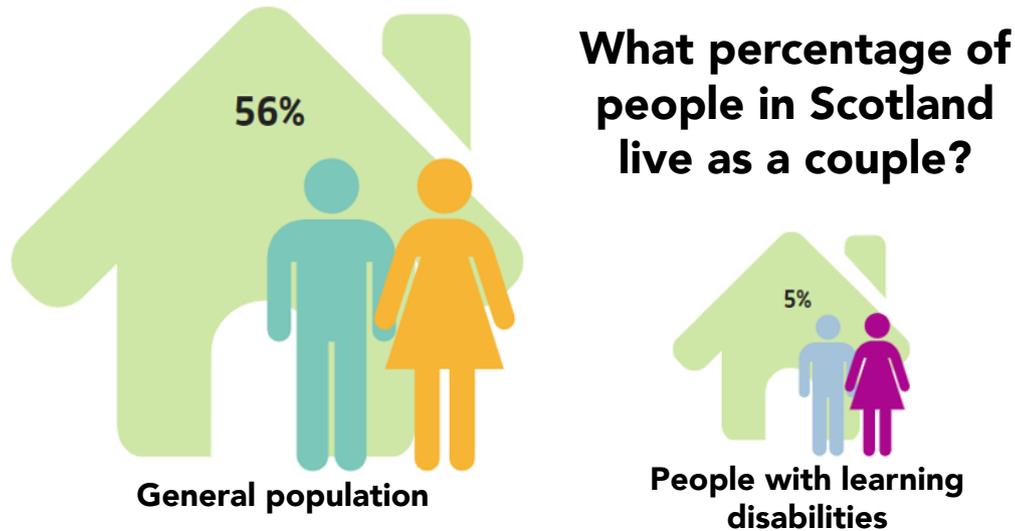
- Over a third (35%) of people who answered the survey lived alone
- Almost a third of survey respondents (31%) lived with either one or both of their parents
- A quarter of respondents (25%) lived with someone else.
- 11% lived with other family members

Figure 1: Who survey respondents live with



- 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.* (Figure 2)

Figure 2: Percentage of people living as a couple



*** General Population Source: Scotland’s Census 2011**

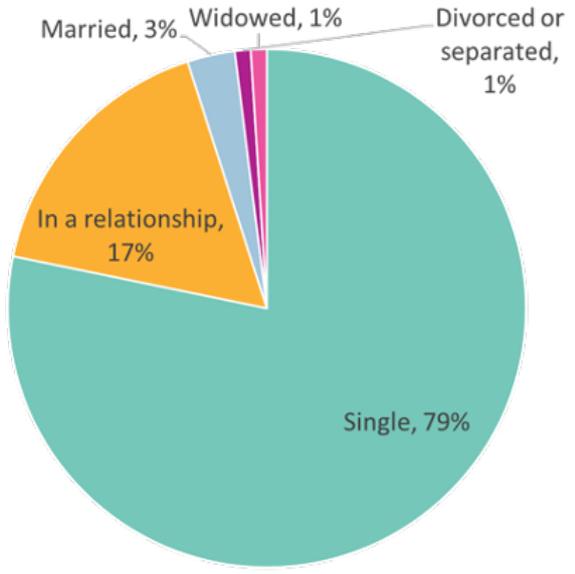
n = 1200

The expectation that intimate relationships will form part of their life is no different for people with learning disabilities than it is for the general population. However, previous research has shown that people with learning disabilities face many societal and attitudinal barriers, meaning that many do not form and maintain these intimate relationships.^{xii}

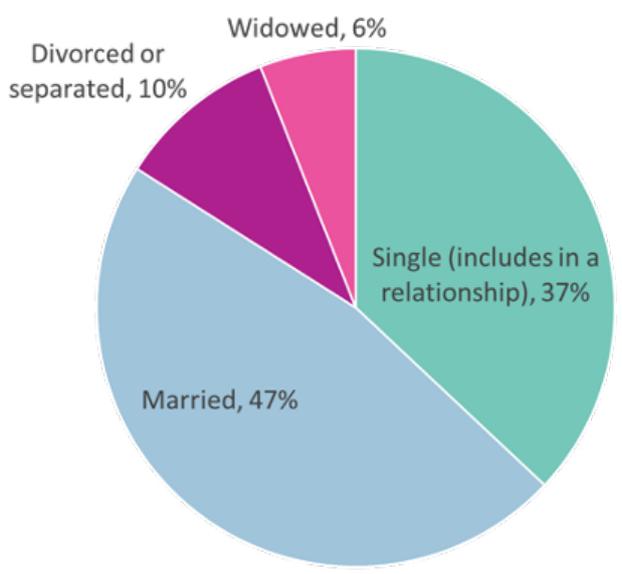
As part of the survey, we asked people their relationship status.

- The vast majority of people who responded to the survey were single (almost 4 out of 5 people) (Figure 3)
- 17 % said that they were in a relationship, but not married (Figure 3)
- Only 3 % of people were married. This compares to a figure for the general population in Scotland of 47 percent.^{xiii} (Figure 4)

Figure 3: Relationship status of survey respondents and the general population in Scotland



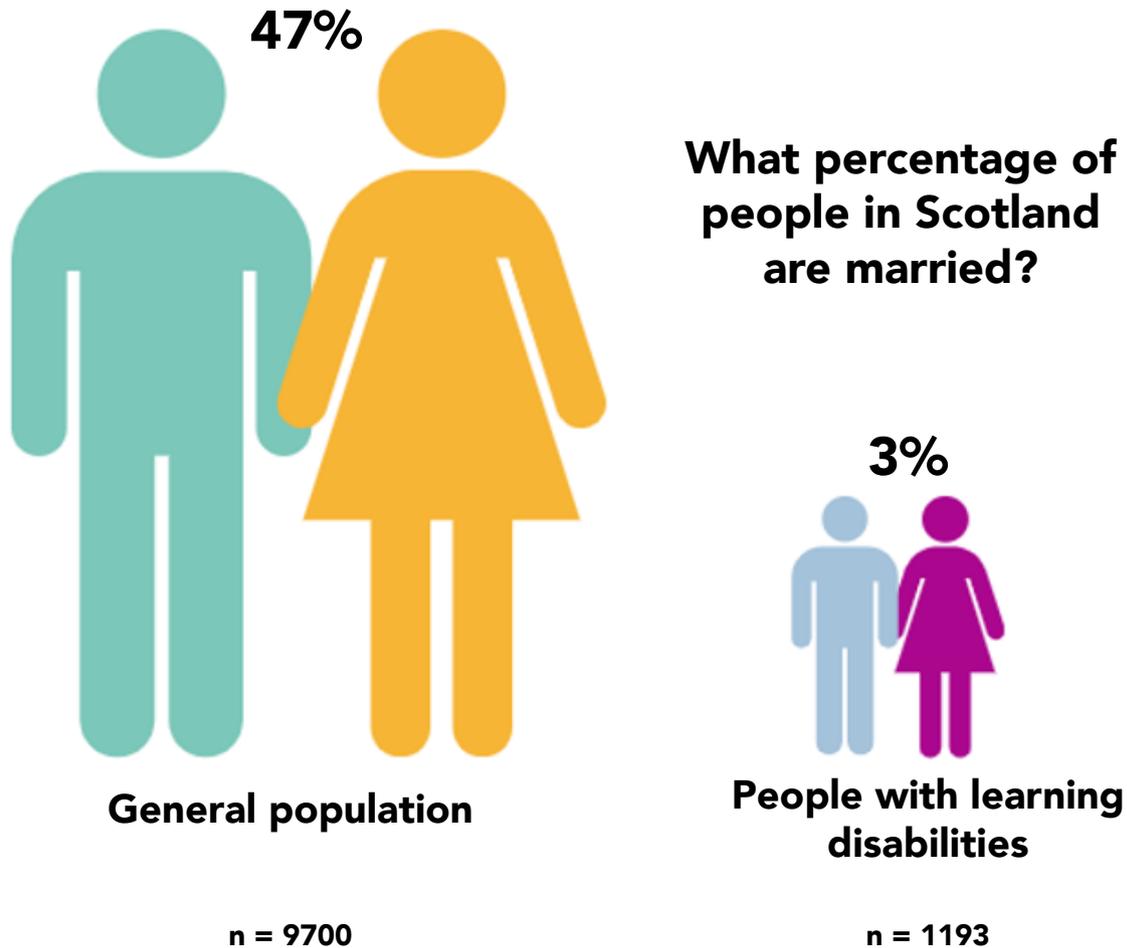
**People with learning disabilities
n=1193**



**General population*
n=9700**

***Source: Scottish Household Survey, Scotland's People Annual Report 2018**

Figure 4: Percentage of people in Scotland who are married



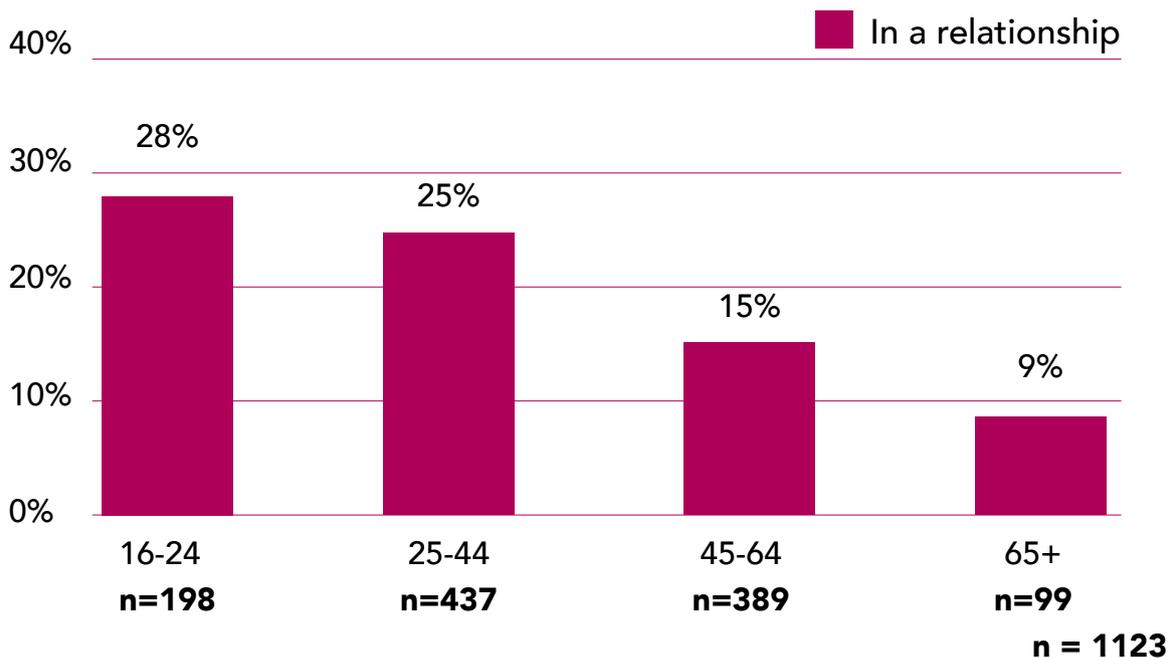
***Source: Scottish Household Survey, Scotland's People Annual Report 2018**

People in older age groups were less likely to be in a relationship (Figure 5):

- 28% of people aged 16-24 were in a relationship
- 9% of those over 65 were in a relationship

Though there is not a directly comparable figure for the general population, figures from the 2011 Census suggest that this trend is reversed. In the general population, people in older age groups were more likely to be married or in a civil partnership than those in younger age groups.^{xiv}

Figure 5: Percentage of survey respondents in a relationship, by age¹



¹For this figure, 'in a relationship' includes people who are married and those people in a relationship but not married.

The survey findings suggest also that there is a relationship between the kind of accommodation people live in, and whether or not they are in an intimate relationship.

People who lived in mainstream accommodation were more likely to be in a relationship than those who lived in supported accommodation, or other types of accommodation (Figure 6). Other accommodation includes care homes and medical settings.

Figure 6: Percentage of survey respondents in a relationship, by type of accommodation



2. Interpersonal relationships, social contact, and loneliness

Key Points

- 21% of people did not see their family as often as they liked
- 19% of people did not see their friends as often as they liked
- 27% of people in a relationship did not see their partner as often as they liked
- Older people were less likely to see their family or partners as often as they liked
- Younger people and people with additional conditions and/or disabilities were less likely to see their friends as often as they liked
- 52% of people occasionally, sometimes, or often felt lonely
- 9% often felt lonely, compared to 5% of the general population

Friendships and other interpersonal relationships are a necessary part of life, providing people with emotional support, help when needed, companionship and improving well-being and self-esteem.^{xv}

The survey asked people whether they felt they saw their family, friends, and partners as much as they liked and whether they had met up with friends in the last few weeks. It also asked people how often, if ever, they felt lonely.

This chapter outlines what people told us about their interpersonal relationships and their feelings of loneliness. It also explores answers to these questions by age, gender, additional conditions and/or disabilities, living alone and the type of accommodation people lived in. This allowed us to uncover any associations between these factors and the answers people gave to the questions on social contact and loneliness. Only factors found to have an association are reported on.

2.1. Family

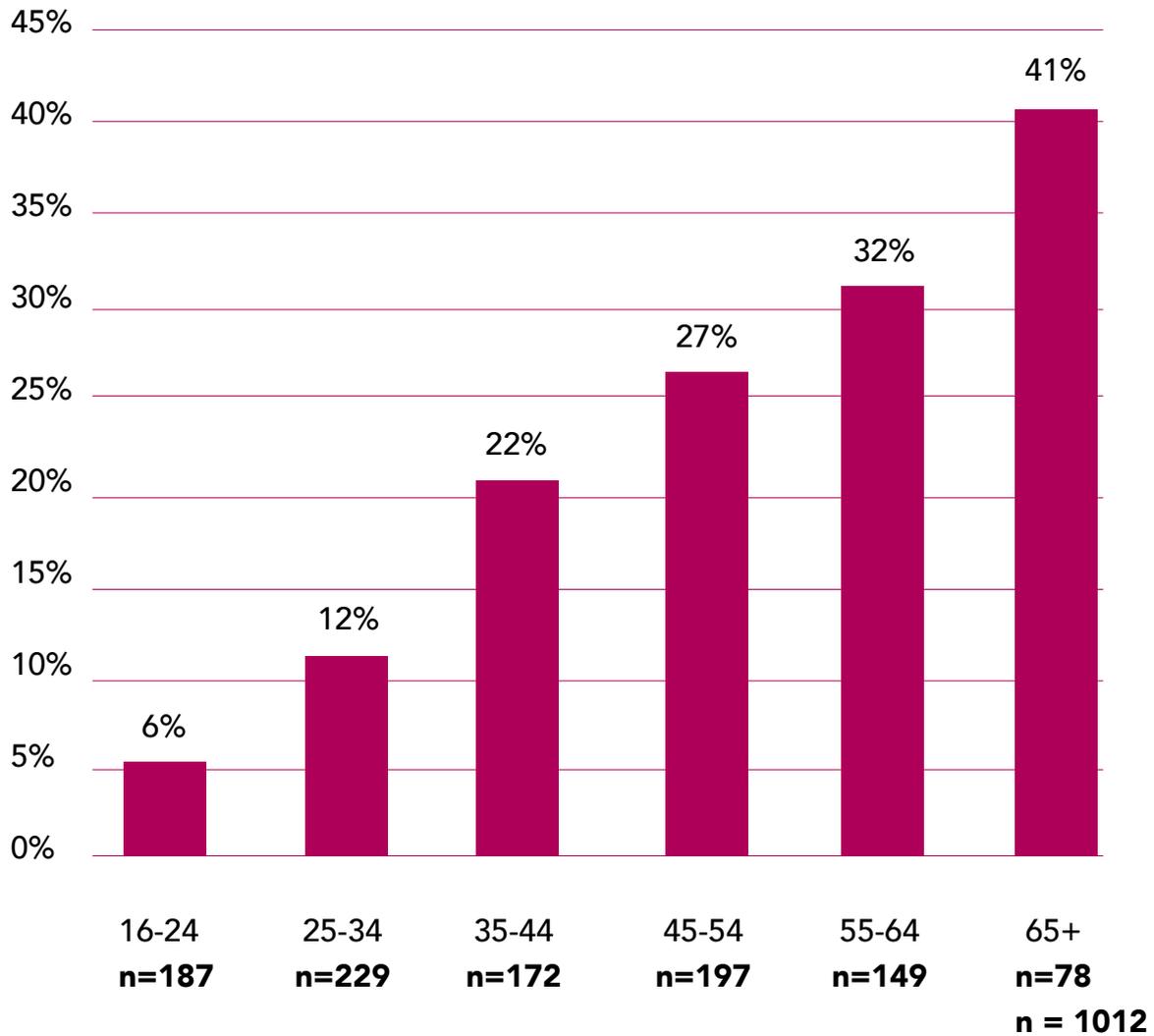
- Of the 1078 respondents with family, 230 (21%) did not see them as often as they liked

Older people were less likely to see their family as often as they liked.

- 6% of young adults aged 16-24 said that they did not see their family as much as they wanted to (Figure 7)
- This figure was 41% for older adults aged 65 and over (Figure 7)



Figure 7: Percentage of people who do not see their family as often as they like, by age



2.2. Friends

The survey found that most people (85%) had met up with friends in the last few weeks. However:

- 6% (64) of the 1030 who answered the question about friendship reported that they had no friends
- Of the 966 who did have friends, 183 (19%) said they did not see them as often as they liked

People in younger age groups were less likely to see their friends as often as they liked.

- 29% of those in the 16-24 age group said that they did not get to see as much of friends as they would like to (Figure 8)
- This figure almost halved to 15% of those aged 65 and over (Figure 8)

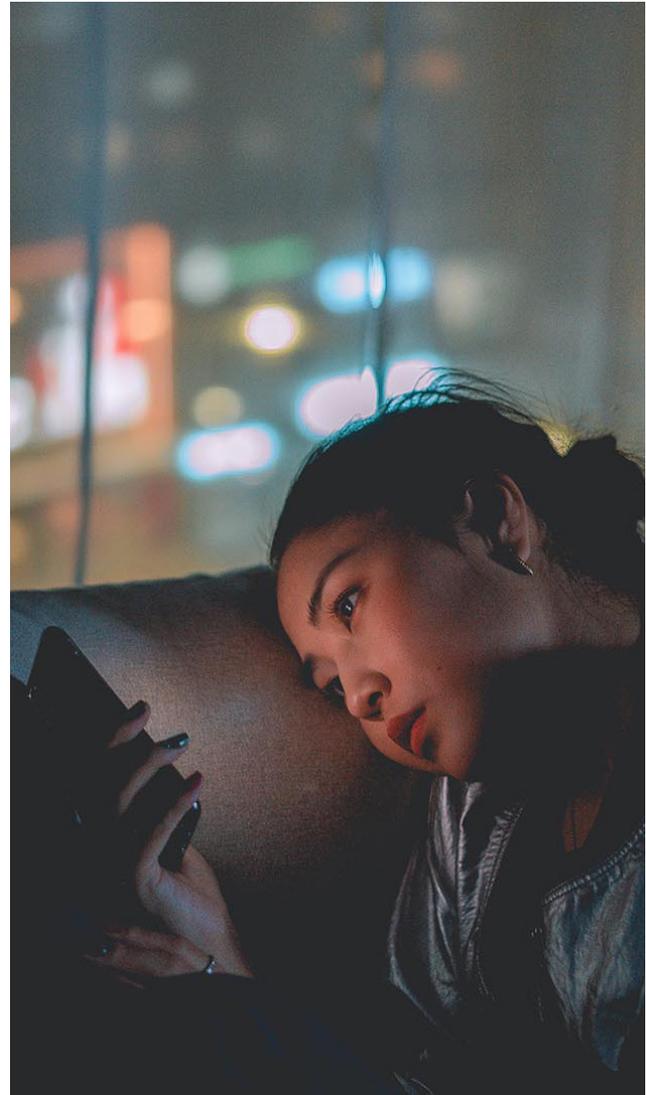
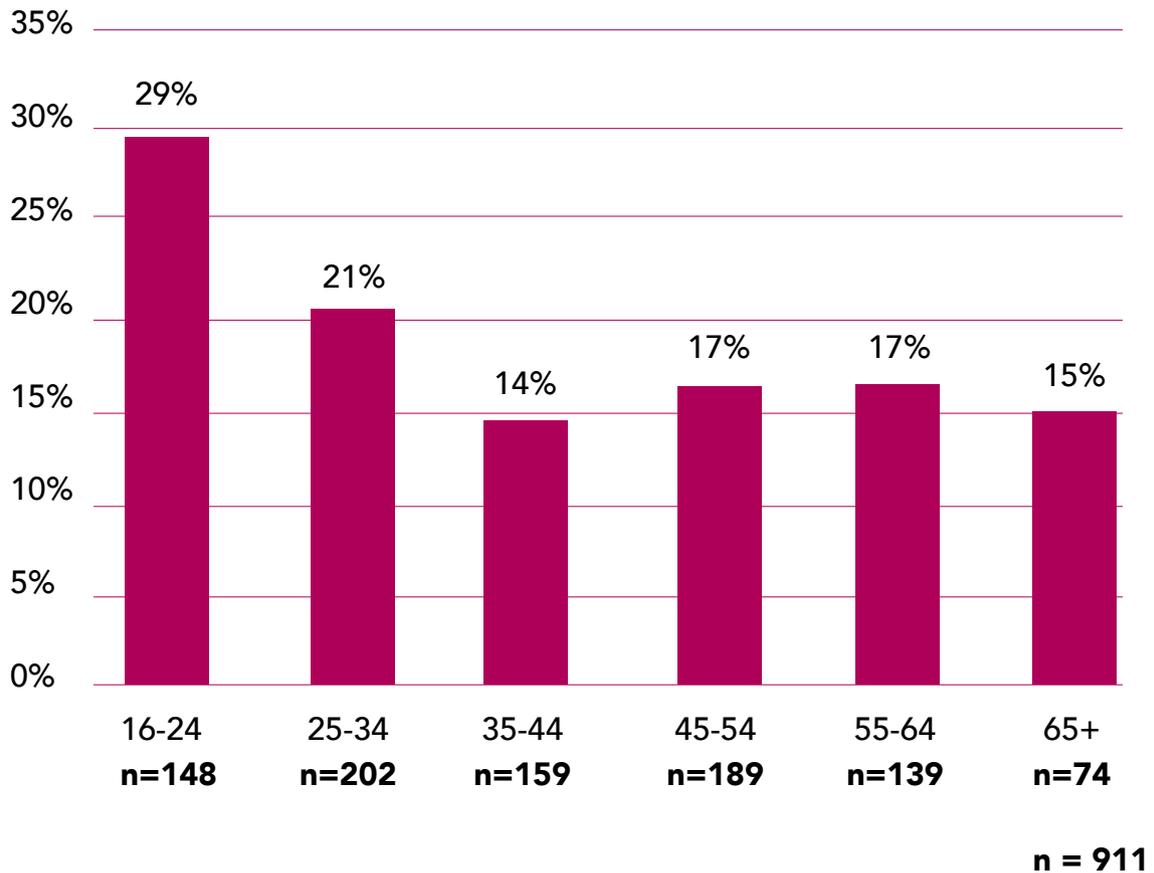


Figure 8: Percentage of people who do not see friends as often as they like, by age



Having at least one other condition or disability in addition to a learning disability was related to whether people saw their friends as often as they liked.

- 14% of people who had no additional conditions or disabilities said they did not see their friends as much as they wanted (n=241)
- This figure was 21% of people with at least one additional condition or disability (n=725)

What type of accommodation people lived in was also related to whether people had met up with friends:

- 12 % (43) of the 356 people who stayed in supported accommodation had not met friends recently
- 15% (110) of the 736 people living in mainstream accommodation had not met friends recently
- 22% (21) of the 95 who lived in other accommodation types, including hospitals, had not met friends recently



2.3. Partners

- Of the 288 respondents who had a partner, 77 (27%) said they did not see them as often as they would like to

Those aged over 35 were less likely to see their partner as often as they liked compared to their younger peers:

- 21% (27) of the 130 adults aged 16-34 who were in a relationship said they did not see their partner as often as they liked
- 32% (47) of the 147 adults aged 35 and over in a relationship said they did not see their partner as often as they liked

2.4. Loneliness

Previous studies show that people who feel lonely often suffer from a range of physical and mental health problems as a result. ^{xvi}

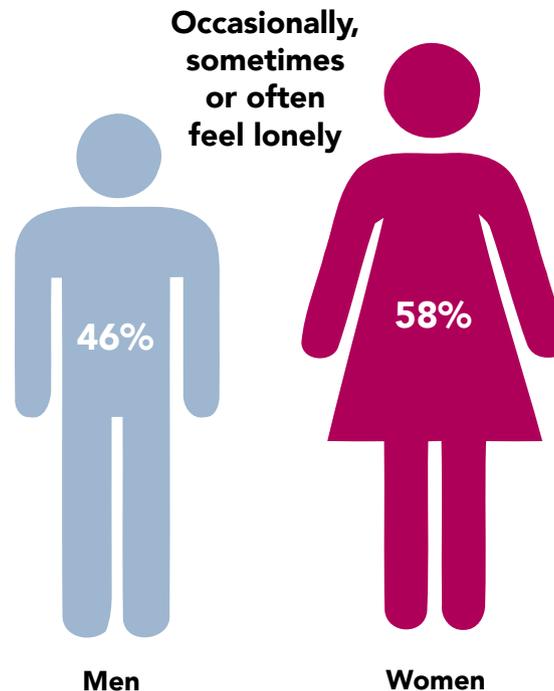
It has also been suggested that people with learning disabilities are more vulnerable to feelings of loneliness than the general population. ^{xvii} Our survey findings support this.

- 52% (618) of the 1181 respondents said that they occasionally, sometimes, or often felt lonely. This

compares to 46% of the general population

- 9% (107) of survey respondents said they often felt lonely. This compares to 5% of the general population
- A higher percentage of women (58%) said that they occasionally, sometimes, or often felt lonely compared to men (46%) (Figure 9). The equivalent figures for the general population are 52% of women and 40% of men reporting that they occasionally, sometimes, or often feel lonely

Figure 9:
Percentage of men and women who occasionally, sometimes or often feel lonely



n = 1150

People who reported having at least one additional condition or disability were also more likely to report being lonely:

- More than half (55% of 906) said they occasionally, sometimes or often felt lonely, compared to 44% of the 275 with no additional conditions or disabilities

Our findings showed that not seeing enough of family or friends were both strongly related to feeling lonely:

- 70% of the 223 people who did not see their family as much as they liked occasionally, sometimes, or often felt lonely, compared to 46% of the 830 people who did
- 77% of the 180 people who did not see their friends as

much as they liked occasionally, sometimes, or often felt lonely compared to 43% of the 767 people who did

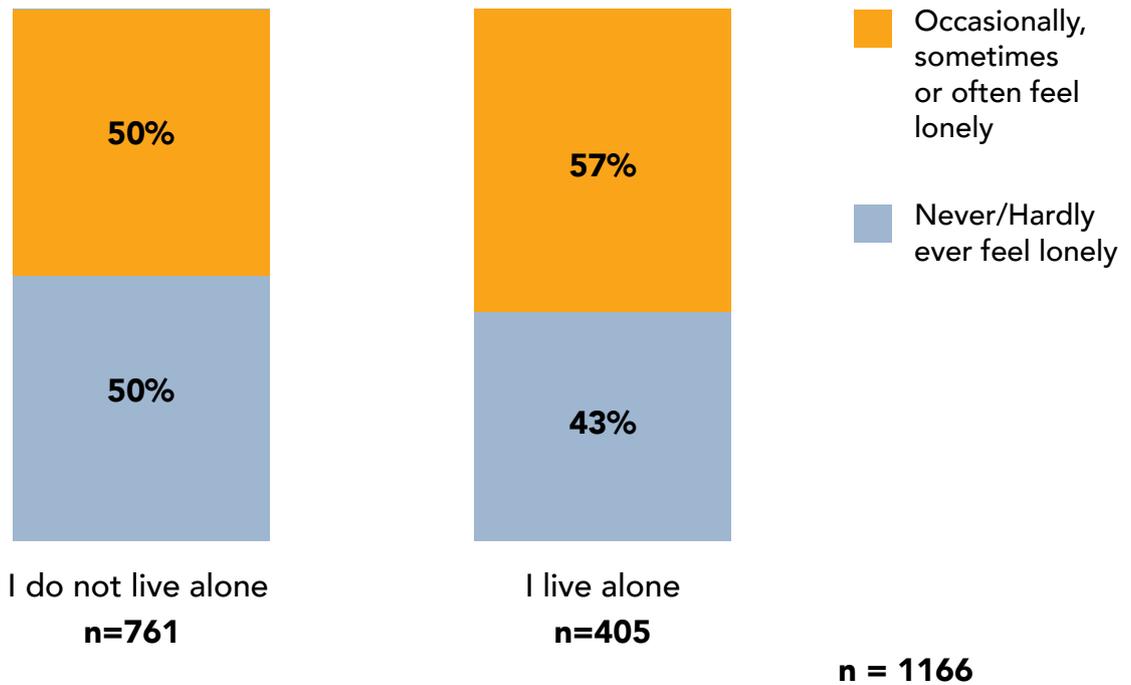
While not statistically significant, this trend is similar for seeing partners, with 61% of those who did not see their partner as much as they liked reporting feeling lonely occasionally, sometimes, or often, compared to 49% of those who did.²

Though less pronounced, our survey findings also show a relationship between living alone, and the likelihood of feeling lonely:

- 57% of people who lived alone occasionally, sometimes, or often felt lonely compared to 50% of those who did not live alone (Figure 10)

² While these results were not found to be significant, this has likely been affected by the low numbers of survey respondents who reported that they had a partner in this question (n=288).

Figure 10: Percentage of people who felt lonely by whether they live alone



3.Support and choice and their association with intimate relationships, social contact, and loneliness

Key Points

- People who got enough support were much more likely to see family, friends and/or partners as much as they liked
- People who got enough support were much less likely to be lonely
- People who had lots of choice over their free time were much more likely to see family friends and/or partners as much as they liked than those who had little choice
- People who had lots of choice over their free time were much less likely to be lonely
- 44% of people who *did not need support* were in a relationship compared to 18% of people who needed support
- 23% of people who *did not need support* lived with a partner compared to 3% of people who needed support

Ensuring that people with learning disabilities have the appropriate support to live the life they want, and choice and control over their everyday lives are fundamental principles of *The keys to life*

strategy.

The survey asked people whether they felt they got enough support to do the things that they wanted to do. This support did not

necessarily have to come from a paid service. It could be the support of family or friends. The survey also asked people how much choice they had over what they did with their time.

This chapter outlines how people felt about the support they received and the choice they had over their time. It also looks at the relationship between the answers people gave to these questions and the questions explored in the previous chapters. As with previous chapters, we have only reported where an association was found between those answers.

3.1. Support

The majority of the 1058 respondents who answered this question were happy with their support:

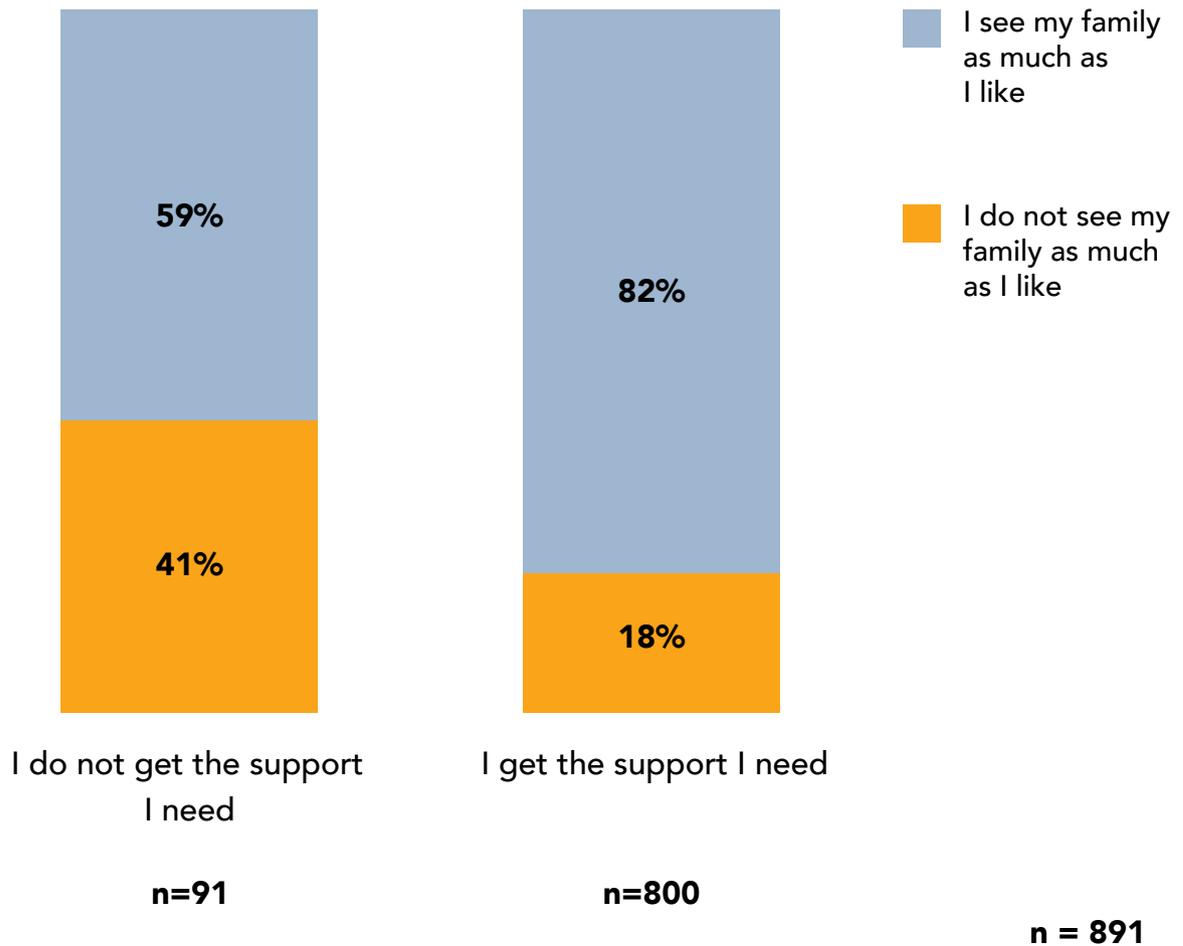
- 84% (889) said they got enough support to do the things they wanted to do

- 10% (104) said they did not get enough support to do the things they wanted to do
- 6% (65) said that they did not need support

Looking at those who needed support, the survey found that having enough support was strongly related to social contact and loneliness:

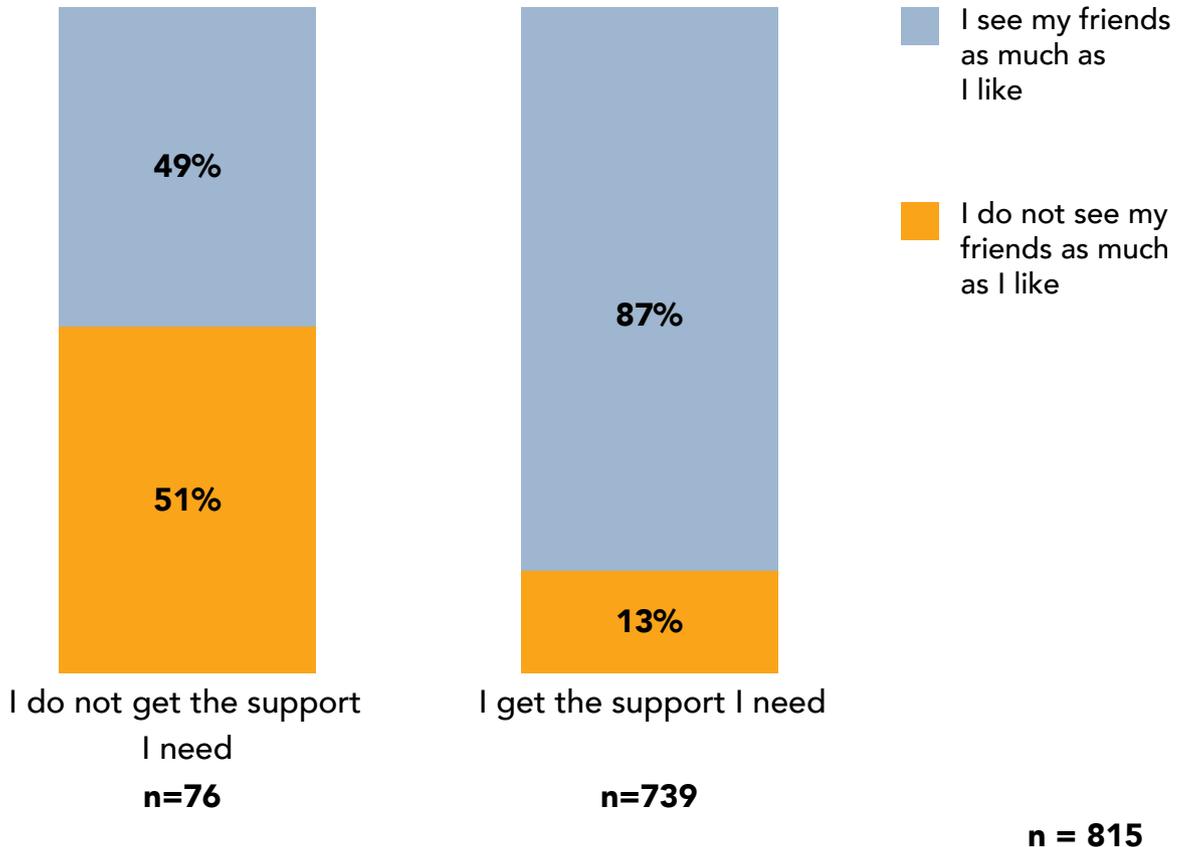
- Of those who reported not getting the support they needed, 41% did not see as much of their family as they would like (Figure 11)
- Among those who did feel they got the support they needed, this figure was much lower, though 18% still did not see their family as much as they liked (Figure 11)

Figure 11: Percentage of people who do and do not see their family as much as they like, by support



- Of those who reported not getting the support they needed 51% did not see as much of their friends as they would like (Figure 12)
- Among those who did feel they got the support they needed, this figure was again much lower, with 13% saying they did not see their friends as often as they would like (Figure 12)

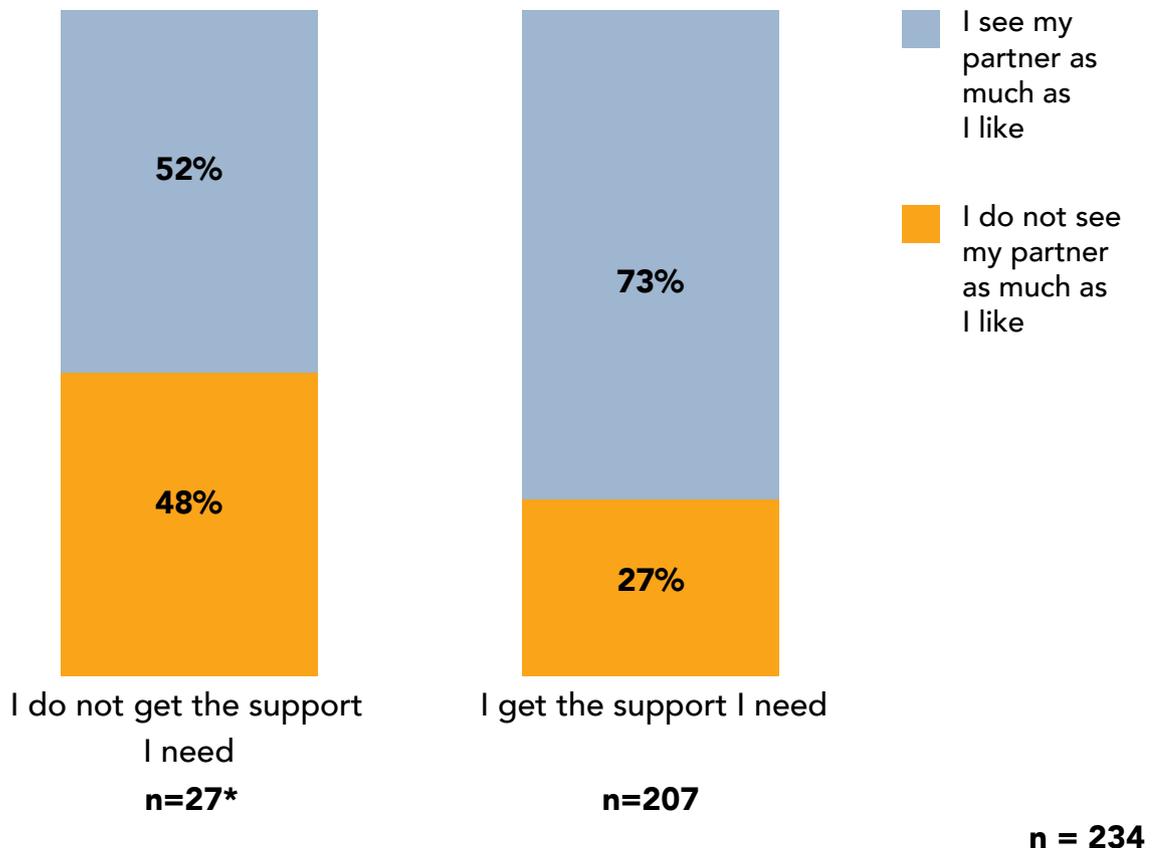
Figure 12: Percentage of people who do and do not see their friends as much as they like, by support



Having enough support was also related to whether people got to see their partners as often as they wanted.

- 48% of those who did not get enough support said they did not see their partners as often as they liked, compared to 27% of those who did (Figure 13)

Figure 13: Percentage of people who do and do not see their partner as much as they like, by support



* Due to the small sample size, these findings should be interpreted with caution.

- Almost a quarter (24%) of people who said they did not get the support they needed to do the things they wanted had not met up with friends in the past few weeks (Figure 14)
- This figure halved to 12% of people who said they had enough support (Figure 14)

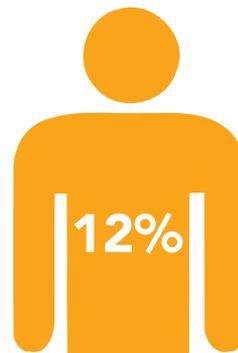
Figure 14: Percentage of people who have not met friends recently, by support

Have not met up with friends in the past few weeks



I do not get enough support to do the things I want to do

n=104



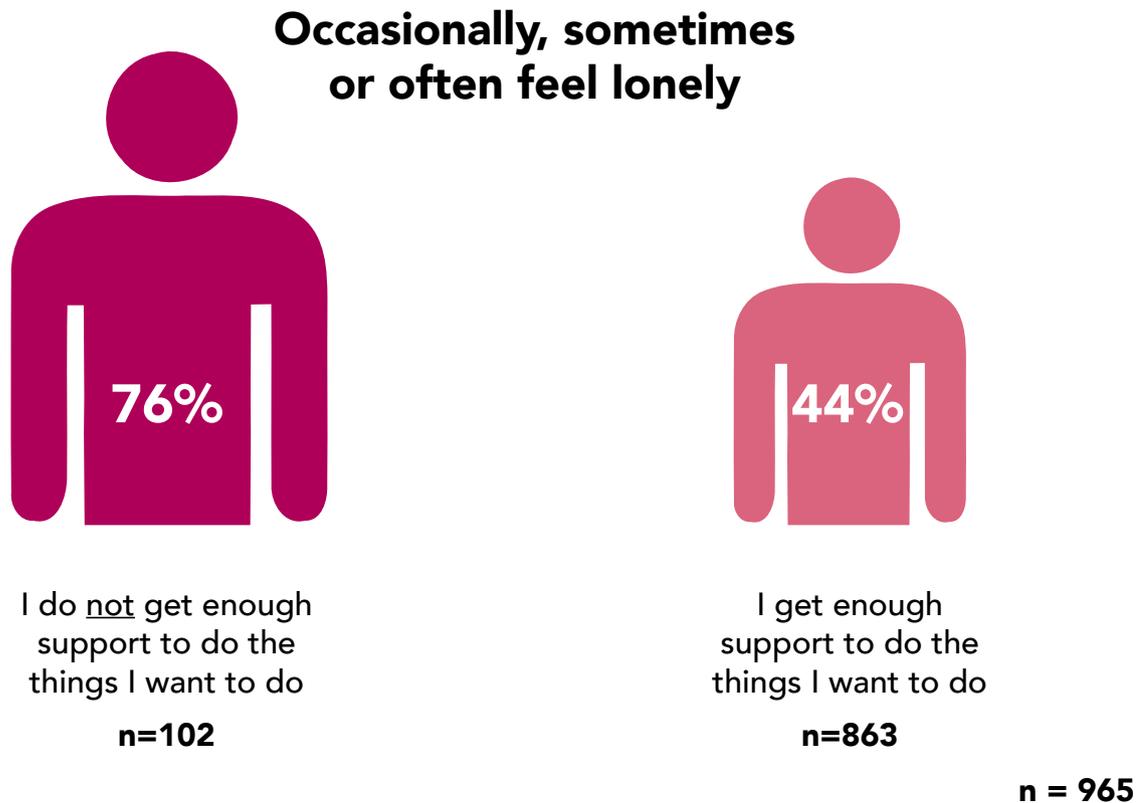
I get enough support to do the things I want to do

n=889

n = 993

- 44% of people who said they had enough support to do the things they wanted to do reported feeling lonely occasionally, sometimes, or often (Figure 15)
- This compares to 76% of those who said they did not have enough support (Figure 15)

Figure 15: Percentage of people who occasionally, sometimes, or often felt lonely, by support



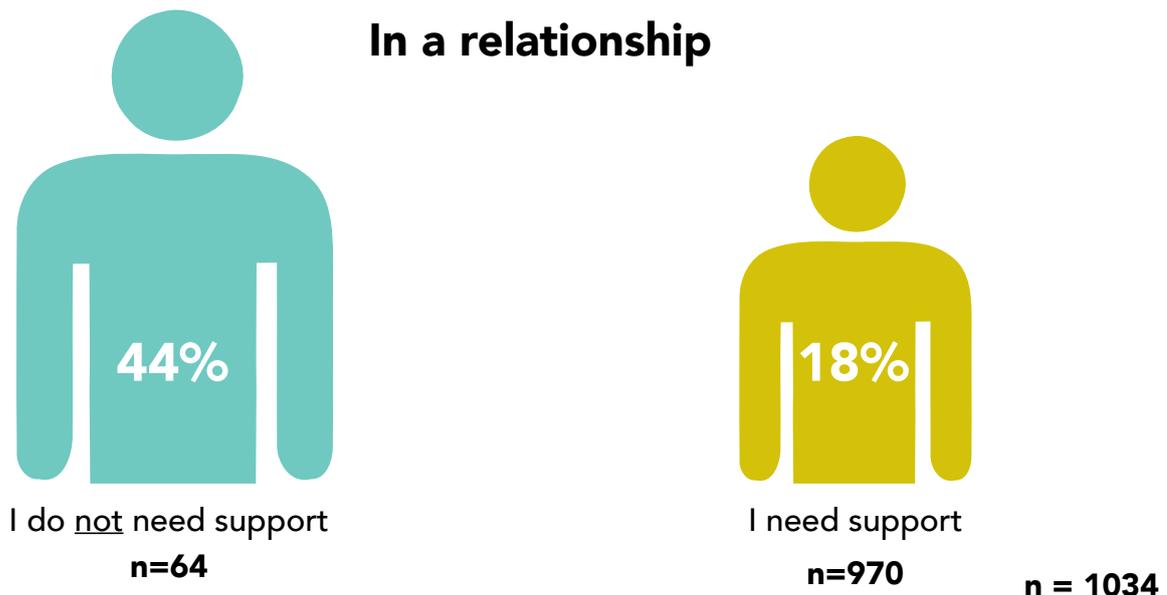
The focus of this section so far has been on those who reported on whether or not they got the support they needed.

It is important to note that not everyone with a learning disability needs support to live the life they want. 6% of respondents who answered this question said that they did not need support to do the things they wanted to do.

Interestingly, having enough support was not associated with being in a relationship, or living with partners. However, people who did not need support were much more likely to be in a relationship, and to live with their partner, than those who needed support.

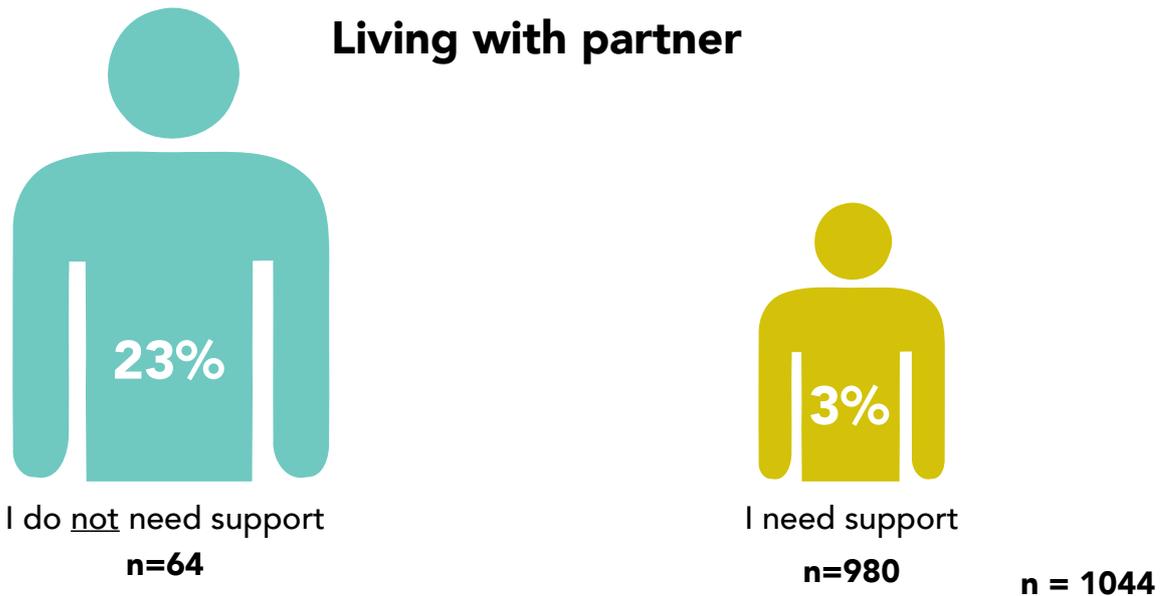
- 44% of people who did not need support were in a relationship, compared to 18% of people who did need support (Figure 16)

Figure 16: Percentage of people who were in a relationship, by whether they need support



- 23% of people who did not need support were living with a partner compared to 3% of people who did need support (Figure 17)

Figure 17: Percentage of people who were living with a partner, by whether they need support



Perhaps unexpectedly, people who did not need support were more likely to feel occasionally, sometimes, or often lonely compared to those who did need support:

- 62% (40) of the 65 people who did not need support, occasionally, sometimes, or often felt lonely
- 48% (461) of the 965 people who did need support occasionally, sometimes, or often felt lonely

3.2. Choice

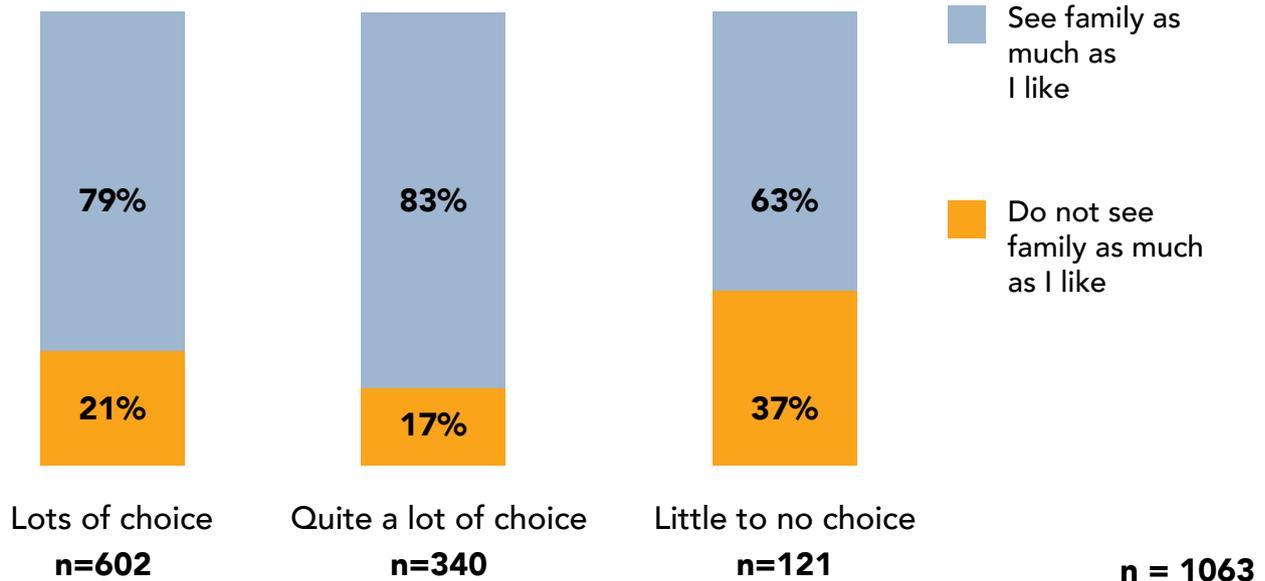
Positively, most of the 1198 respondents who answered this question felt that they had choice over how they spent time:

- 56% (673) said they had lots of choice over what they did
- 32% (387) said they had quite a lot of choice
- 9% (111) said they had a little choice
- 2% (27) said they had no choice

Notably, the survey found that choice was strongly associated with social contact and loneliness:

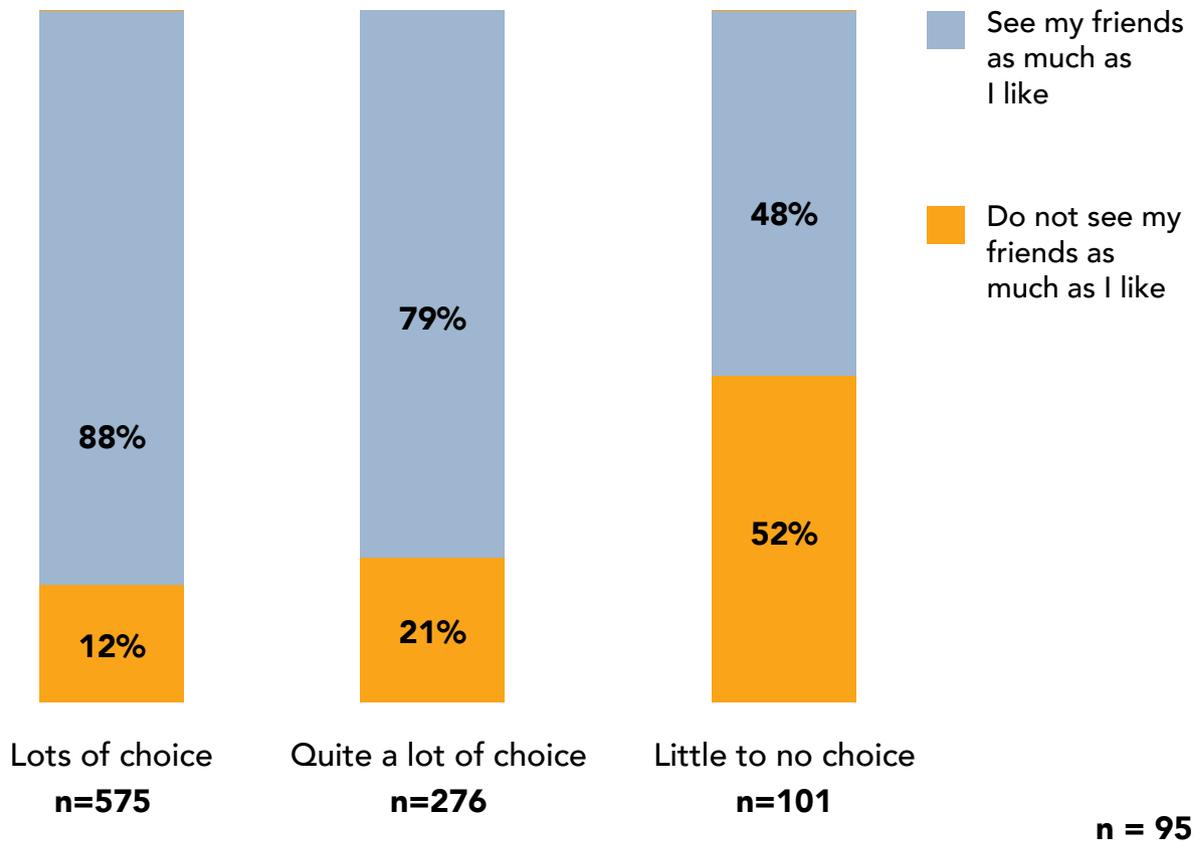
- 37% of people with little or no choice over their free time said that they did not see their family as much as they would like (Figure 18)
- This compares to 21% of those who had lots of choice: while significantly smaller, this is still one in five people (Figure 18)

Figure 18: Percentage of people who did and did not see their family as much as they liked by how much choice they had over their free time



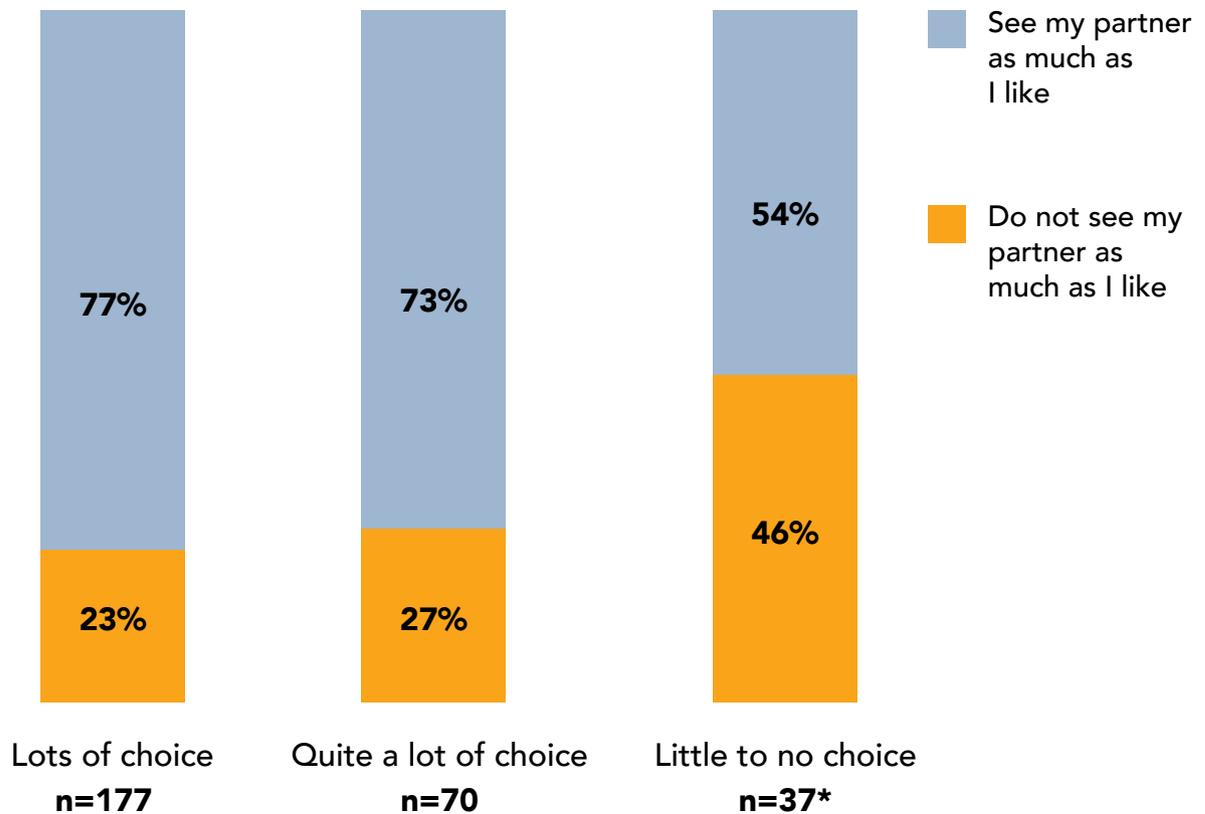
- Only 12% of those who said they had lots of choice over their free time did not see their friends as often as they liked (Figure 19)
- 52% of those who said they had little or no choice over their free time felt they did not see as much of their friends as they liked (Figure 19)

Figure 19: Percentage of people who did and did not see their friends as much as they liked by how much choice they had over their free time



- 46% of people with little to no choice over their free time said that they did not see their partner as much as they would like (Figure 20)
- This compares to 23% of those who had lots of choice: while significantly smaller, this is still almost a quarter of people (Figure 20)

Figure 20: Percentage of people who did and did not see partners as much as they liked by how much choice they had over their free time

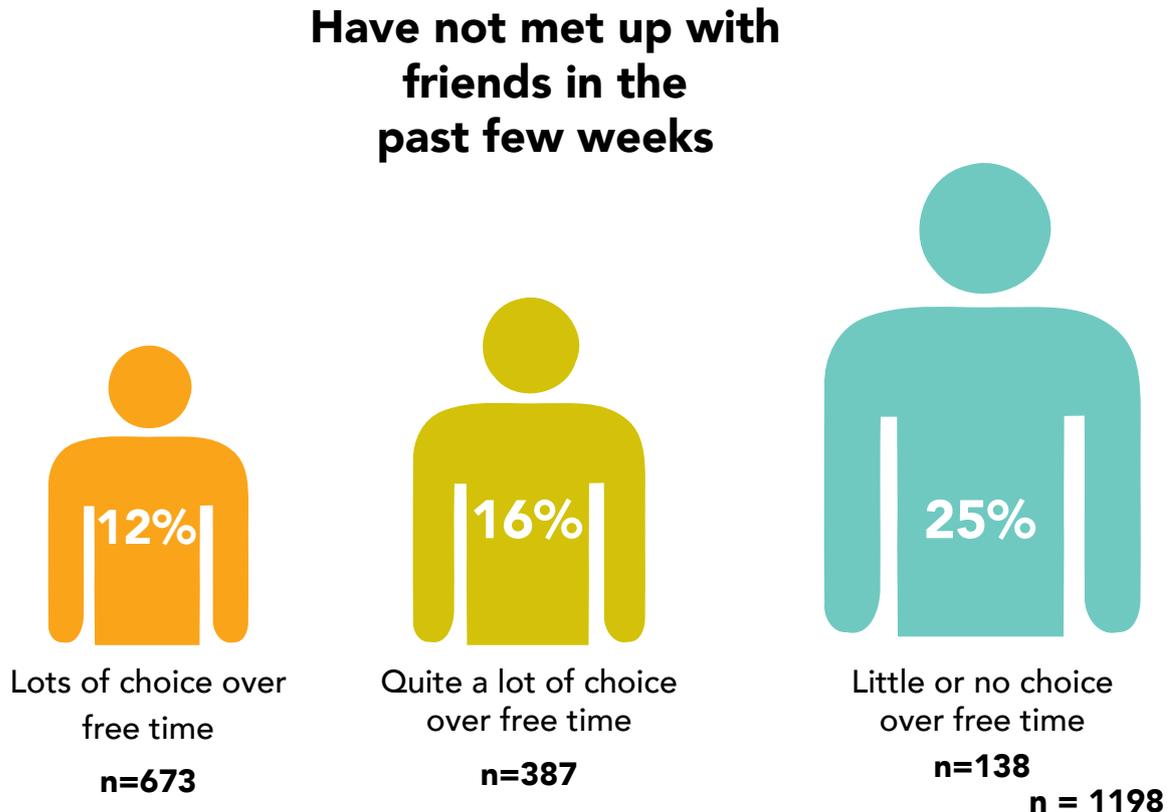


n = 284

* Due to the small sample size, these figures should be interpreted with caution.

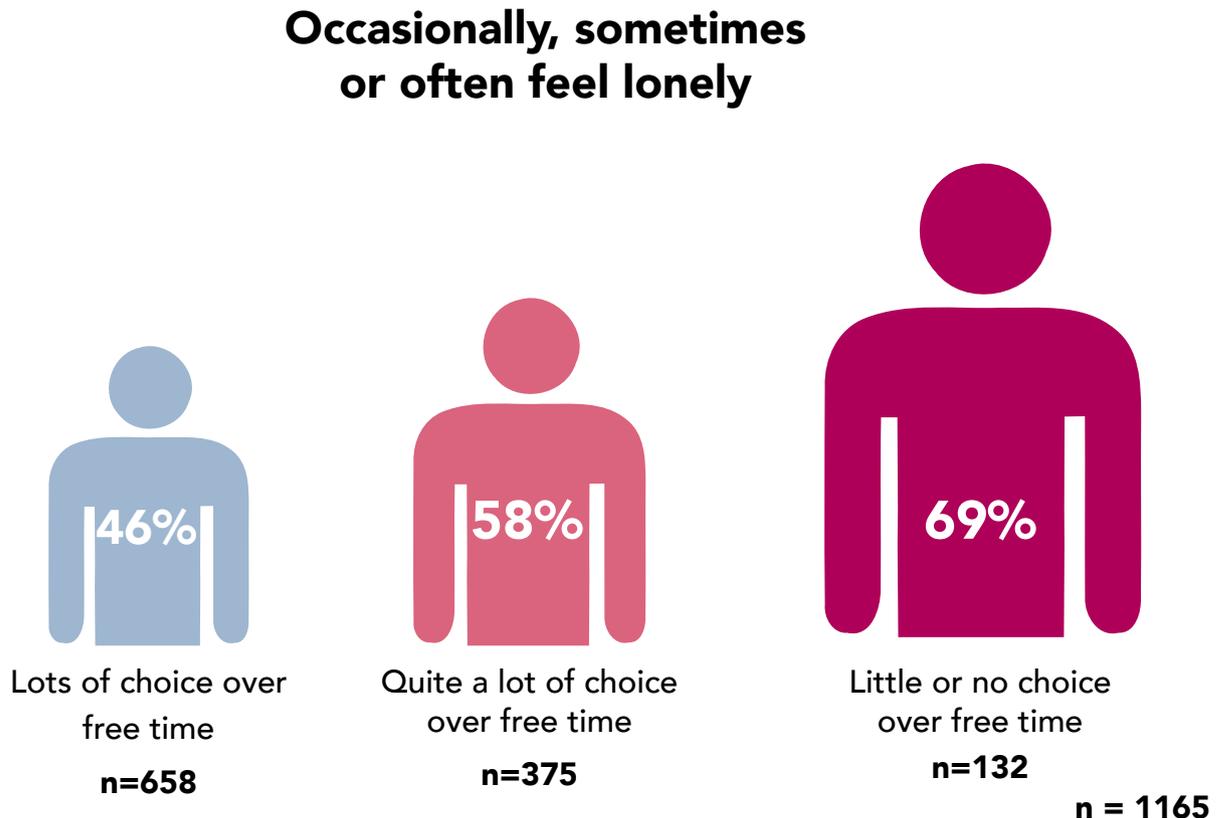
- 12% of those people who said they had lots of choice over their free time said they had not met up with friends in the past few weeks (Figure 21)
- 25% of those with little or no choice over their free time said they had not met up with friends in the past few weeks (Figure 21)

Figure 21: Percentage of people who had not met up with friends in the past few weeks, by how much choice they had over their free time



- 46% of those with lots of choice over their free time said they occasionally, sometimes or often felt lonely (Figure 22)
- 69% of those with little to no choice over their free time said they occasionally, sometimes or often felt lonely (Figure 22)

Figure 22: Percentage of people who occasionally, sometimes or often felt lonely, by how much choice they had over their free time



4. Relationships matter

Key Points

- Family was the most common answer given when people were asked to tell us the most important things in their life
- Friends was the second most common answer
- A minority expressed a strong desire to find a romantic partner when asked what one thing they would change
- Seeing enough of family, friends and not feeling lonely were all associated with higher levels of happiness

This chapter looks at how important relationships are to people with learning disabilities as told in their own words. It also explores how the answers to questions about social contact and loneliness relate to people's overall assessment of their happiness.

4.1. What are the most important things in your life?

As part of the survey, we asked people to tell us 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. But the most prevalent themes in this question were family and friends.

- Of the 1076 people who gave an answer to this question, 640 (59%) said that family was one of the most important things in their lives

- Friendships were the second most common theme in answer to this question, with 423 (39%) individuals mentioning friends as being one of the most important things in their lives
- A number of people (101; 9%) mentioned romantic relationships in answer to this question

4.2. Tell us about your relationships

The survey also allowed space for people to tell us in their own words about their relationships if they wanted to. More than 300 people provided comments.

Some people spoke of the difficulties they faced making friends or maintaining relationships:

“I feel really alone and have not been able to make friends where I live. When I see other people together in the community, it makes me feel left out. I find it hard to meet new people because I worry they will look at me differently because of my learning disability. At least I was lucky to get the opportunity to be married. OK, it didn’t work out but at least I got to do it. I know many people who never get the opportunity to even be with somebody.”

“I would like to see my family more often, but because of my client contribution, I am not left with a lot of money. I see them every two weeks. Same for seeing my friends. I feel lonely in my house. I feel when I open up, I am not listened to. I do have some housemates that I am close to and I do get on with some/most of the staff here.”

Others spoke of their desire to see more of partners, or indeed to find a partner. Some of the answers hint at paternalistic attitudes towards people with learning disabilities, from both staff and family members:

“Not living with my husband makes me feel lonely a lot. He lives in a care home he doesn’t like. I’d like to see my other family more too. I really want to see my husband more and have him living back at home.”

“I would like to have a boyfriend and live together but people say I’m not allowed. I would like to share a bedroom with my boyfriend. We would share a bed.”

“I have a boyfriend I see at discos. I can only see him if his mum arranges it with my mum.”

Some respondents spoke of their friends being people they lived with, or attended groups with. While for some this was a positive thing, some people spoke of feeling lonely when groups were not running:

“I don’t see my friends outwith the groups I go to.”

“Most of the time I have friends around me where I live. My friends are other residents in my home. If it wasn’t for a place like here, where I live, I probably would not be living anymore.”

“I feel a bit lonely when my clubs finish up for the summer and I don’t get to see my friends until they start back up. I don’t see anyone if I am not at a group.”



A sense of loss was apparent in a number of stories, through bereavement, distance, and infrequent contact:

“I was very close to my mum dad and uncle and didn’t realise how much they did for me. I miss them a lot and it has been very hard.”

“I miss my family.”

“Because of my health it means sometimes I can’t visit mum for periods of time so I miss her then. But staff assist in helping us meet up.”

“I am lonely when my son isn’t with me. I am not happy with my relationship just now and this makes me feel lonely.”

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. Parts of two of these stories, as they relate to relationships and loneliness, are reproduced below.

Case Study 1

My son does not see his family and friends as often as he would like to.

The main issue is distance. Secondly, lack of facilitators - skilled staff who know my son, who could create a meaningful, positive interaction with friends, family, visitors. The whole responsibility for this falls on to me, his mother. Thirdly, lack of suitable accommodation in which he would receive family and friends: the Learning Disability Assessment Unit does not have facilities for welcoming guests of patients. Fourthly, my own energies being stretched in many different directions - some for direct visiting, some planning future care, some

facilitating contact with friends, family, wider community without visiting, finally, the times when I do create a social event, a party, for friends/family to visit home when my son is here.

My son often feels lonely. He evidences this by crying. He does this when he is on the ward and I am not present, when staff report that he sobs. He also does it when I am with him, to communicate to me his sadness.

I also interpret much of his other behaviours as coming out of social isolation and loneliness, on the ward, when staff are not engaging with him as he would wish.

Case Study 2

My son has the benefit of family members who he has known all his life - parents, brother, grandparents, aunts, uncles, and cousins. He has no friends that he visits or sees at home. His friends are the people he sees at the day care centre he attends.

He doesn't see family as often as we think he would like. We stay in our own home for occasions such as Christmas, birthdays, etc.

We have a hydraulic changing table in our home for our son's continence care, etc. Travelling to visit family involves a huge amount of planning and packing of continence supplies, medicines, spare clothes, food/food blender,

etc. Makeshift arrangements for family visits are difficult. We get the impression when people come to visit our home however that our son enjoys seeing different people.

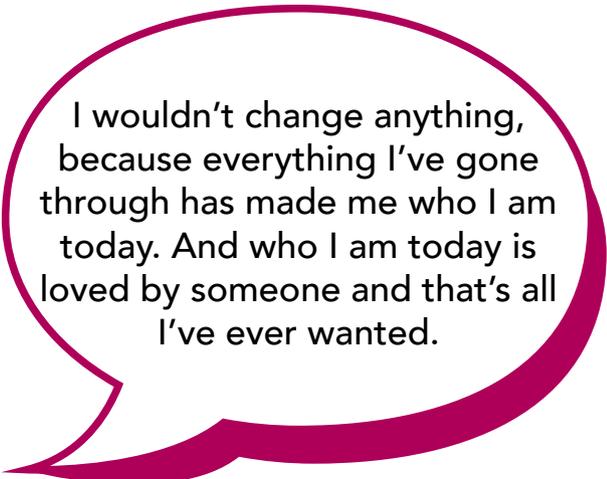
It is difficult to say if he feels lonely. He often displays behaviour that indicates boredom, but it could be loneliness too.



4.3. What one thing would you change about your life?

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. Family, friends, and partners all featured, though less prominently.

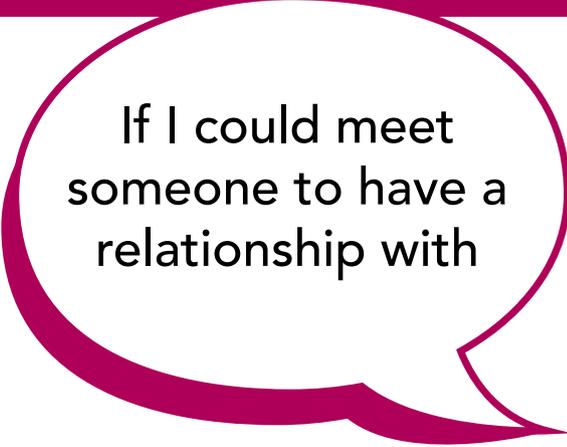
Only 149 (18%) people said that they would not change anything about their lives. Even within these answers the importance of relationships is demonstrated, as shown in the quote below from a respondent:



I wouldn't change anything, because everything I've gone through has made me who I am today. And who I am today is loved by someone and that's all I've ever wanted.

The remaining 82% mentioned a wide variety of things they would change. While mentioned by relatively small numbers, a desire for new or different relationships was clearly really important to some people.

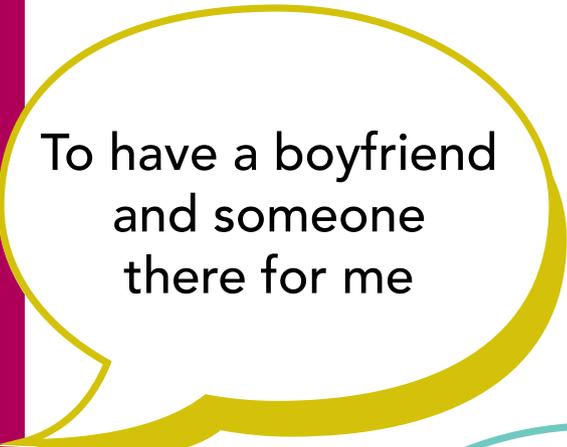
- 53 (7%) people mentioned that they would change something about a romantic relationship. The majority of those who wanted to change something about a romantic relationship expressed a desire to find a romantic partner
- 50 (6%) people mentioned that they would change something to do with their family, most that they would like to see them more often, but some mentioning that they would like to have a better relationship with their family
- 30 (4%) people mentioned seeing friends more, missing their friends or having more friends in this question



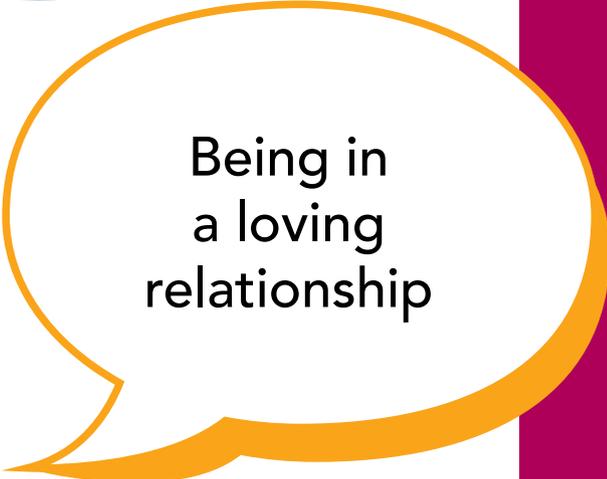
If I could meet
someone to have a
relationship with



Having a partner
to share
things with



To have a boyfriend
and someone
there for me



Being in
a loving
relationship



I would like a
partner to share
my life with

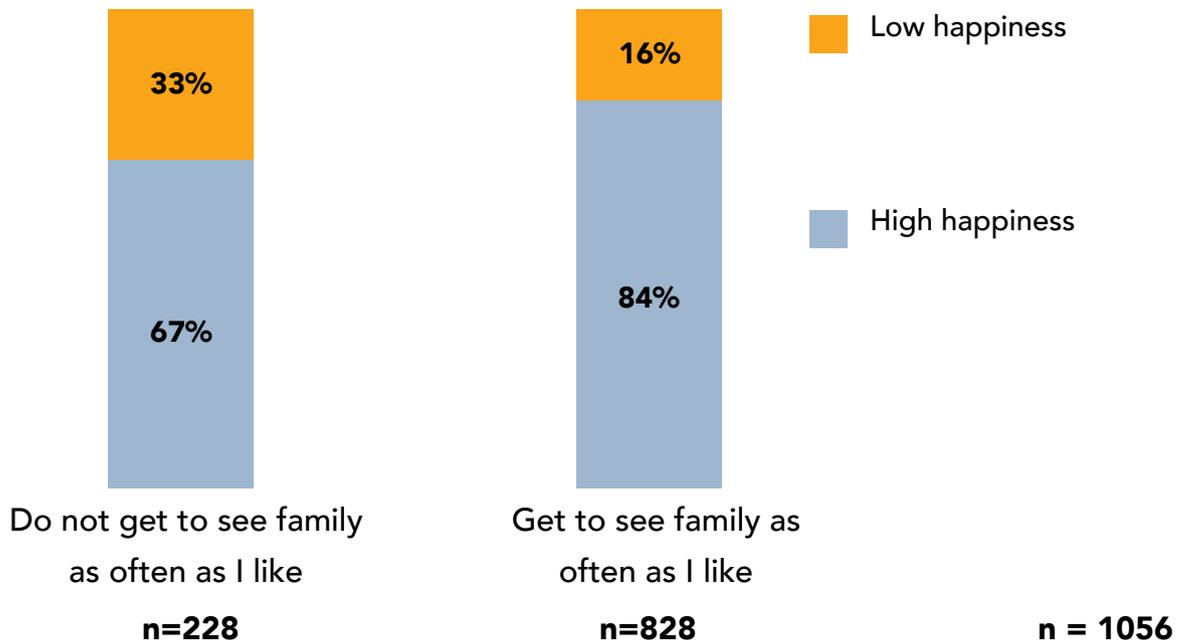
4.4. Social contact, loneliness, and happiness

SCLD was interested in people’s subjective feelings about their lives overall. We measured this by asking people how happy they felt with their lives. SCLD was keen to explore the association between social contact, loneliness, and people’s assessment of their happiness.

Being able to see family as often as people wanted was related to people’s happiness.

- 33% of people who did not get to see their family as often as they liked reported low levels of happiness (Figure 23)
- 16% of those who did see their family as much as they liked were found to have a low level of happiness (Figure 23)

Figure 23: Percentage of people reporting low and high happiness, by whether they get to see their family as much as they like



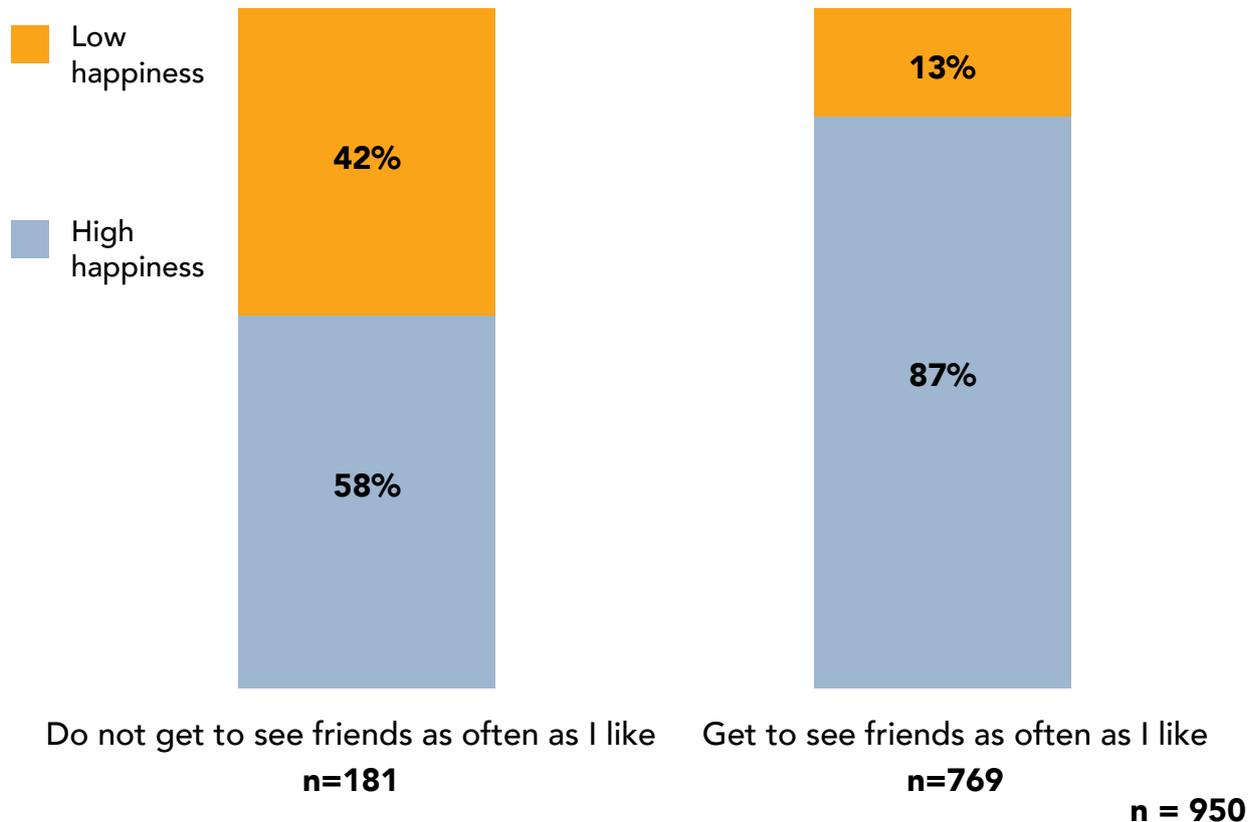
The survey also found that being able to see friends was strongly related to people's levels of happiness.

- 42% of people who said they were not able to see enough of their

friends reported low levels of happiness (Figure 24)

- 13% of people who said that they saw their friends as much as they liked reported low levels of happiness (Figure 24)

Figure 24: Percentage of people reporting low and high happiness, by whether they get to see their friends as much as they like



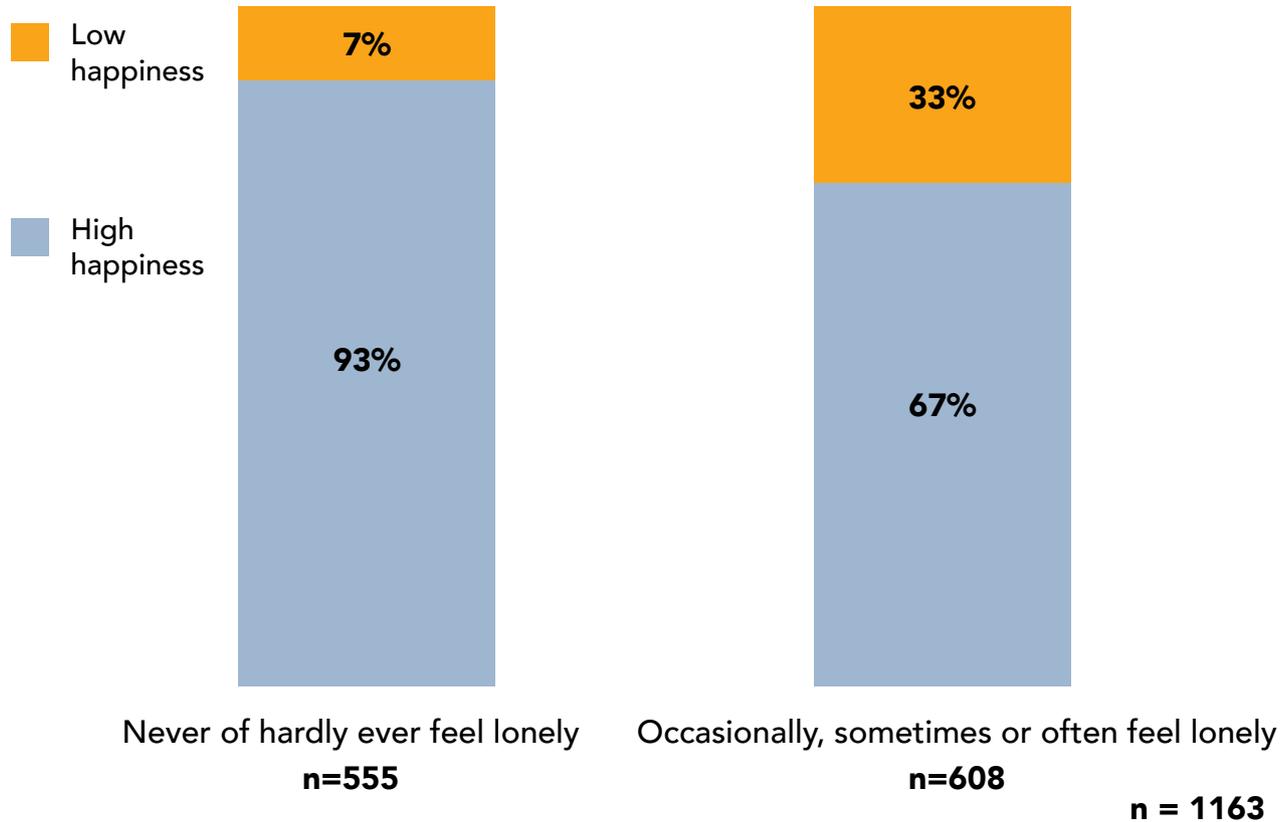
The survey also found that feelings of loneliness were related to people’s overall feelings of happiness.

- Only 7% of people who never or

hardly ever felt lonely reported low levels of happiness (Figure 25)

- This compares to 33% of people who occasionally, sometimes, or often feel lonely reporting low levels of happiness (Figure 25)

Figure 25: Percentage of people reporting low and high happiness, by loneliness



5. Discussion

We chose to focus on relationships, social contact, and loneliness in our first thematic report from the How's Life? survey, firstly, because they came through strongly as issues of great importance to people with learning disabilities. Secondly, relationships and social inclusion are areas where progress seems to have stalled since Scotland's first learning disability strategy, *The same as you?* brought a significant step forward through independent living in the community. While *The keys to life* aimed to build on this progress by recognising relationships as essential for wellbeing and inclusion, people with learning disabilities continue to face barriers that exclude them from full participation in society. Stigma, lack of resources, inadequate support and choice

coalesce to prevent people with learning disabilities from participating in the community on an equal basis.

Additionally, huge reductions in support and social care in response to the Covid-19 pandemic has increased social isolation and loneliness for many. Addressing these issues will take on a renewed significance as we move forward from the crisis, with relationships and social inclusion at the forefront of any recovery.

Our findings highlighted just how important good relationships are to people with learning disabilities. Family topped the list when people were asked what was most important to them, with friends a close second. When asked what one thing people

would change about their lives, many expressed the desire to find a partner, or to see more of friends and family.

The importance of relationships is reinforced by the fact that people who told us that they were not able to see friends as much as they would like were much more likely to be lonely. They were also less likely to be happy. The same pattern was true for those who did not see family as much as they liked. It is also worth noting that those who were living with another person were less likely to be lonely than those living alone. However, the association between living alone and being lonely was not as strong as the association between not seeing friends or not seeing family and being lonely. This points to the fact that having company will help loneliness, but the quality of social relationships is pivotal.

The findings allow us to uncover a number of factors associated with seeing enough of family, friends, and partners, as well as feeling lonely. Indeed, both appropriate support and freedom of choice were strongly associated with maintaining relationships with loved ones. Respondents who did not get enough support to do what they wanted were much less likely to see as much of loved ones as they wanted, and much more likely to be lonely. The same was true for those who had little choice over the things they did.

We must of course be careful not to see appropriate support and freedom of choice as a panacea for maintaining social connections or overcoming loneliness. Regardless of social contact, 52 percent of respondents told us that they

occasionally, sometimes, or often felt lonely. This is higher than 46 percent of the general population. Nine percent of those who felt lonely, said their loneliness was chronic. This is almost double the percentage of the general population. Our analysis also found that while the association with seeing loved ones was less clear cut, lack of money, poor transport and experiencing discrimination were all associated with feeling lonely.

Crucially, despite the importance of, and yearning for, loving relationships, it is clear that this desire is unfulfilled for a significant number of people. Around one in five people felt that they did not see their family as often as they would like. The figure was similar for seeing friends. People living in care homes and medical settings

were the least likely to have met up with friends in the last few weeks.

However, this unfulfilled desire for relationships is demonstrated most clearly by the lack of intimate relationships for the majority of survey respondents. One of the most striking findings was that only five percent of survey respondents were living as a couple, and only three percent were married. The comparison with the general population is stark. The corresponding figures are 56 percent and 47 percent, respectively. The vast majority were not in a relationship. Of the small minority who were in a relationship, more than one in four did not see their partner as much as they would like to.

While younger people were more likely to have a partner than those

in older age groups, the marked disparity with the general population is seen across the whole age range. That these numbers are universally low suggest fundamental issues are at play.

Unlike maintaining contact with loved ones and reducing loneliness, neither having enough support, nor having enough choice were associated with being in an intimate relationship. This lack of association could be due to the low sample size of respondents who had a partner. However, it could also point to a number of other issues.

For example, the fact that people living in mainstream accommodation were more likely to be in a relationship than those in supported accommodation and those in care homes or medical settings least likely,

suggests that rules and practices, as well as limited privacy in these settings may be factors.

Crucially, people who did not need support at all were much more likely than those who did to be in a relationship, and to live with a partner. The fact that simply needing support makes it less likely that someone will be in an intimate relationship could point to continuing paternalistic attitudes among those providing support.

Indeed, that so few people were in intimate relationships in spite of the majority of respondents feeling they had sufficient choice over what they did with their time raises questions about the true degree of choice afforded to people with regard to these relationships.

Previous research has pointed to all of these issues as barriers to forming intimate relationships, along with paternalistic attitudes in wider society, limited opportunities to meet potential partners and limited knowledge of sexuality and rights around intimate relationships. Additional research is required urgently to understand what is needed to make intimate relationships a reality for people; in particular those who require support to live the lives they want.

However, the fact remains that our findings show a clear, strong correlation between choice and support and maintaining social connections and reduced loneliness. This gives rise to a number of issues to consider.

Even before the Covid-19

pandemic, a prolonged period of diminishing social care budgets and reductions in community services have seen reductions to already inflexible support packages. The introduction of Self Directed Support within this context has limited the choice and control that it was hoped this would bring. Rising isolation and loneliness following the unprecedented removal of support during 'lockdown' creates concerns that things could get worse for people with learning disabilities unless a concerted effort is made to ensure this is not the case.

Adequately resourced, appropriate, flexible support is necessary if people with learning disabilities are to have their rights to inclusion and the highest attainable standards of health realised. Strong relationships

and social inclusion are mutually reinforcing, as relationships create natural support networks. The need for this has been demonstrated acutely through the Covid-19 crisis. Support that encourages people to have and maintain different types of relationships, including intimate relationships if people wish, is crucial.



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 having relationships 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.

6. Questions arising from the findings

Our findings have shown us that for people with learning disabilities, having different relationships – friendships, family relationships and intimate relationships – is an important part of their lives. They have also shown us that choice and support are strongly associated with maintaining existing relationships and reducing loneliness. But the reality remains that exercising the fundamental right to intimate relationships is not a reality for the majority of people with learning disabilities.

The research has not told us how people with learning disabilities feel about making new social connections or creating and maintaining intimate relationships. These feelings will differ from individual to individual. It is important to ensure that the individual is the driver of any decisions around making and maintaining these relationships. The following questions arise from what we have found through our survey.

Questions

What can be done to ensure that everyone with learning disabilities in Scotland is able to have, and maintain, different kinds of relationships?

What can be done to ensure service level policies and person-centred support plans recognise, incorporate, and realise people's preferences in relation to different kinds of relationships?

What can be done to ensure people with learning disabilities are aware of their rights to freedom of choice surrounding intimate relationships, as well as informed about healthy relationships and sexual health?

What can be done to ensure families and supporters of people with learning disabilities are also aware of these rights and supported to enable positive risk taking when it comes to forming intimate relationships?

What can be done to ensure that eligibility criteria for accessing support considers a person's social needs?

What can be done to make up the deficit of access to paid support, in particular for those who are deemed ineligible for paid support services?

What can be done to ensure that social relationships are maintained even when paid support is cut?

These questions are not intended to be prescriptive. Instead, it is hoped that they will be 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.

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- ^{xviii} Office for National Statistics (2018) [Loneliness - What characteristics and circumstances are associated with feeling lonely?](#) Please note this figure is for England.
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