

“Mostly a 10 but sometimes a zero”

**Exploring the wellbeing of people
with learning disabilities in Scotland**

**The second 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 and to Rachel Ormston from Ipsos MORI for her help in designing and analysing the survey.

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

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



Executive Summary

Aims, methods and background

During 2019, the Scottish Commission for People with Learning Disabilities (SCLD) developed the How's Life? survey with a range of partners in order to ask as many people with learning disabilities as possible how they felt about different aspects of their lives. The survey was designed to be completed by people with learning disabilities, with or without support from a family member, advocate, or paid supporter. A total of 1232 responses were received.

This report is based on some of the findings from the survey. It focusses on people's self-reported wellbeing and explores the factors that relate to this. Wellbeing was chosen as the focus of our second report because improving people's wellbeing is at the heart of Scotland's learning

disability strategy, *The keys to life* (2013).

Wellbeing is also of increasing importance in social and economic policy. In particular, Scotland's National Performance Framework explicitly includes as part of its purpose 'increase the wellbeing of people living in Scotland,' placing responsibility on all parts of the public sector to work toward this outcome.

However, on almost every objective measure of wellbeing that exists, outcomes for people with learning disabilities are consistently worse than the general population. The How's Life? survey aimed to explore how different factors related to people's subjective wellbeing to find out which areas should be the focus for any changes in policy and/or practice in Scotland.

Key findings

On the whole, people with learning disabilities were happy with their lives. On a score between 0 and 10:

- The total mean life satisfaction score is **8.13**
- This is slightly higher than the general Scottish population, which is **7.69**
- However, a higher percentage of survey respondents gave a rating of 0-4 out of 10 (8%) compared to the general population (5%)
- People who had additional health conditions and/or disabilities were more likely to report low levels of life satisfaction
- People in younger age groups were more likely to report low levels of life satisfaction

A number of domains were found to relate strongly to life satisfaction. These were, relationships with others, self-determination, material

wellbeing and being treated with dignity and respect.

In particular:

- Feeling lonely was very strongly related to low levels of life satisfaction
- Not being able to see friends as much as people liked was very strongly related to low levels of life satisfaction
- Having little or no choice over free time, and not having the right support in place to facilitate those choices were both very strongly related to low levels of life satisfaction
- Not being happy with where people lived and not having enough money were both strongly related to low levels of life satisfaction
- Not being treated with respect was very strongly related to low levels of life satisfaction

Moving forward

If the Scottish Government is serious about inclusive growth and building a wellbeing economy then the wellbeing of people with learning disabilities needs to take centre stage as we move forward through the Covid-19 pandemic and beyond.

There are a number of measures SCLD believes should be considered:

1. Incorporate UNCRPD into Scots law to bridge the gap between policy intent and lived experience, through positive obligations on states to respect, protect and fulfil the human rights of people with learning disabilities.
2. Collect robust data on the experiences of people with learning disabilities, particularly in GP systems and routinely collected health data.
3. Renew the focus on reducing health inequalities by offering free annual health checks from aged 14, introducing mandatory learning disability training for all GPs and NHS staff and introducing citizen owned digital passports as standard.
4. Put appropriate support and informed choice at the heart of social care through refocussing on prevention and early intervention, allowing people to access the support they need, coupled with obligations on local authorities to discuss self-directed support options fully, with access to advocacy when appropriate.
5. All staff working with people with learning disabilities must promote their right to have and maintain different kinds of relationships, including provision of good quality Relationships, Sexual Health and Parenting education.

6. Ensure access to high quality, appropriate housing by taking the needs of people with learning disabilities into account in strategic planning processes and housing allocation policies, and embedding a 'housing options' approach to advice services.
7. Ensure material wellbeing through the social security system by ensuring eligibility criteria for the Adult Disability Payment accurately capture the impact of day to day life for people with learning disabilities, and access to paid work through specialist employability provision.
8. Everyone has a responsibility to support the increasing visibility of people with learning disabilities in all areas of society.

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 subjective wellbeing; measured by self-reported satisfaction with their lives; and explores factors that relate to this, like relationships,

choice and support, material living conditions and dignity and respect. 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

The Importance of Wellbeing

The concept of wellbeing is becoming increasingly important in Scotland, with Scottish Government priorities firmly focussed on inclusive growth and the creation of a wellbeing economy. While the link between

wellbeing and physical health has long been understood in policy circles, more recently, focus has shifted to include holistic measures of wellbeing across different aspects of social and economic life.

In 2018, the Scottish Government established the 'Wellbeing Economy Governments Group', with Iceland, New Zealand, Wales and Finland, to collaborate in pursuit of new ways to improve wellbeing, and utilise wellbeing indicators to measure economic success. Scotland's National Performance Framework explicitly includes 'increase the wellbeing of people living in Scotland' as part of its purpose, placing responsibility on all parts of the public sector to work toward this outcome.

Improved wellbeing is also explicit within Scotland's learning

disability strategy, *The keys to life* (2013), which has at its heart improving people's quality of life. The strategy outlines that when considering service delivery, statutory bodies must aim to ensure, among other things, that people with learning disabilities enjoy the best possible health and emotional wellbeing. The latest implementation framework includes a number of policy objectives aimed at improving wellbeing for people with learning disabilities, such as increasing access to primary care services and ensuring that a rights-based approach is embedded in the new social security system.

However, measuring the wellbeing of a nation, or a population, is complex, using people's subjective assessment of their own wellbeing, alongside other objective indicators which have been identified as key

components of a good life. While a lot of research has been done to understand the best ways to measure the subjective wellbeing of the general population and ascertain the other factors that add up to good quality of life, very little focusses on the wellbeing of people with learning disabilities.

Nevertheless, on almost every objective measure of wellbeing that exists, outcomes for people with learning disabilities are consistently worse than the general population. For example, a growing body of evidence shows a worrying picture in terms of premature mortalityⁱ, as well as the struggles people face in accessing educationⁱⁱ and employment.ⁱⁱⁱ SCLD's companion report, *Relationships Matter*, also evidenced that people with learning disabilities face real difficulties in establishing and sustaining a whole range of relationships, which other people

take for granted^{iv}.

SCLD was keen to find out how people with learning disabilities rated their own sense of wellbeing, and to explore how these ratings related to other aspects of their lives. The factors to explore were chosen based on key objectives set out in *The keys to life*, academic studies on quality of life for people with learning disabilities, and discussions with our Partners' Group about what factors were particularly important to people with learning disabilities. Rather than objective measures, these factors were assessed by asking people how they felt about them. It is hoped that a better understanding of what factors relate to people's self-reported wellbeing can inform discussions about what can be done to improve upon those factors, and improve wellbeing among people with learning disabilities in Scotland.

Covid-19

It is important to stress that 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. Overstretched social care, as well as attempts to protect people from contracting Covid-19, resulted in the reduction and removal of support services for many during a period of 'lockdown.' At the time of writing, 12 months have passed, and many services have yet to be reinstated. People with learning disabilities have reported feeling lonely, socially isolated and worried about the mental health and wellbeing impacts of the pandemic in both the short and long term.^v

It is critical that concerns about its long term impact are taken

seriously as we navigate our way through the crisis and beyond. Our findings indicate that there are many factors that add up to a good life for people with learning disabilities, many of which were already out of reach for some people pre-pandemic due to cuts in support services. Indeed, lack of support, loneliness and social isolation in particular were already a reality for many people with learning disabilities.

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. SCLD hopes that the findings of this report will help to inform the current conversation around how we 'build forward differently' for people with learning disabilities in Scotland.

The report is broken down into the following chapters:

1. How satisfied are people with learning disabilities in Scotland with their lives?
2. What factors are associated with being more or less satisfied?
3. Wellbeing in people's own words
4. Discussion
5. Moving forward

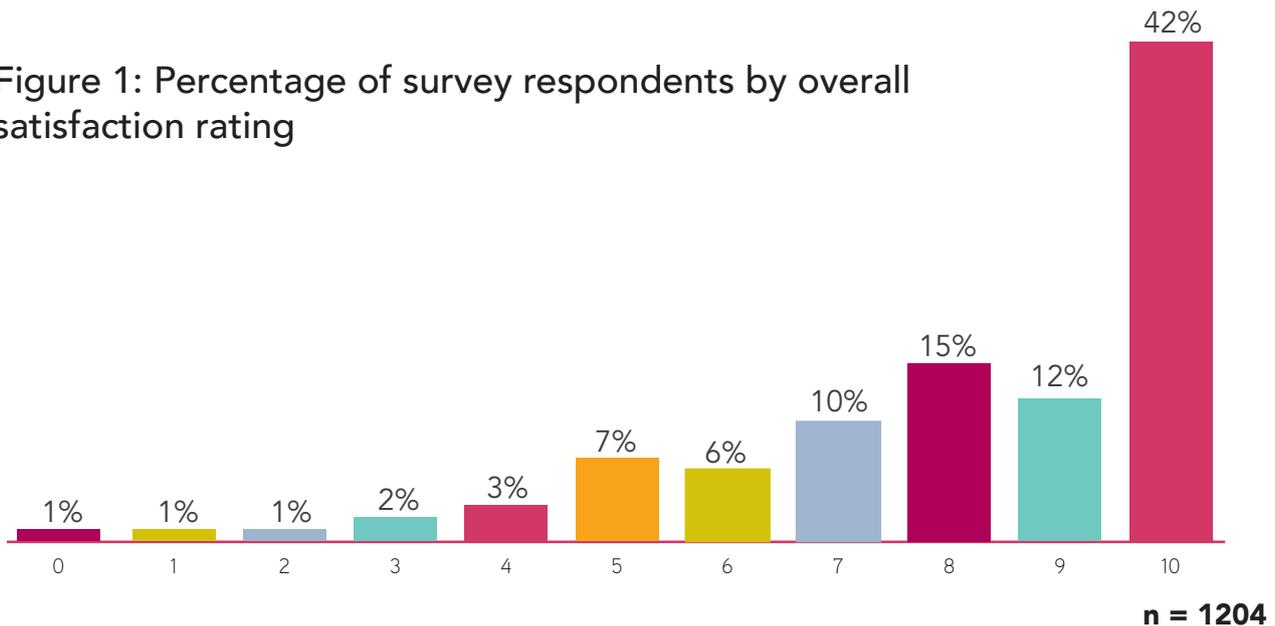
1. How satisfied are people with learning disabilities in Scotland with their lives?

To get a sense of self-reported subjective wellbeing, we adapted the 'life satisfaction' question from the Office for National Statistics to make it more accessible, and asked people to rate how happy they were with their lives overall, on a scale of '0' 'not at all happy' to '10' 'very

happy.' Figure 1 below shows the percentage of survey respondents who reported each number on the scale from lowest to highest.

As Figure 1 shows, most people who responded to the survey said that they were happy with their lives.

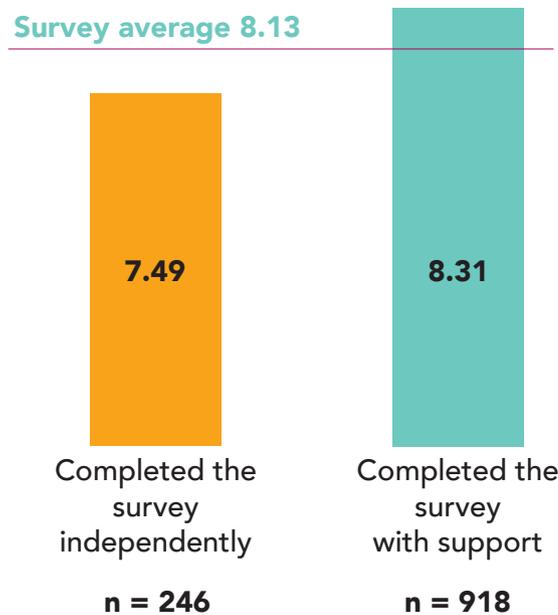
Figure 1: Percentage of survey respondents by overall satisfaction rating



- The total mean life satisfaction score is **8.13**
- This is slightly higher than the general Scottish population, which is **7.69**^{vi}

Figure 2 below shows that people who completed the survey independently had a lower mean life satisfaction score than those who were supported to complete the survey. For this comparison people who had the survey completed on their behalf are counted as having completed the survey with support.

Figure 2: Mean life satisfaction rating by how people completed the survey



- The mean life satisfaction score for people who completed the survey independently was **7.49**
- The mean life satisfaction score for people who had support to complete the survey, or who had the survey completed on their behalf was **8.31**

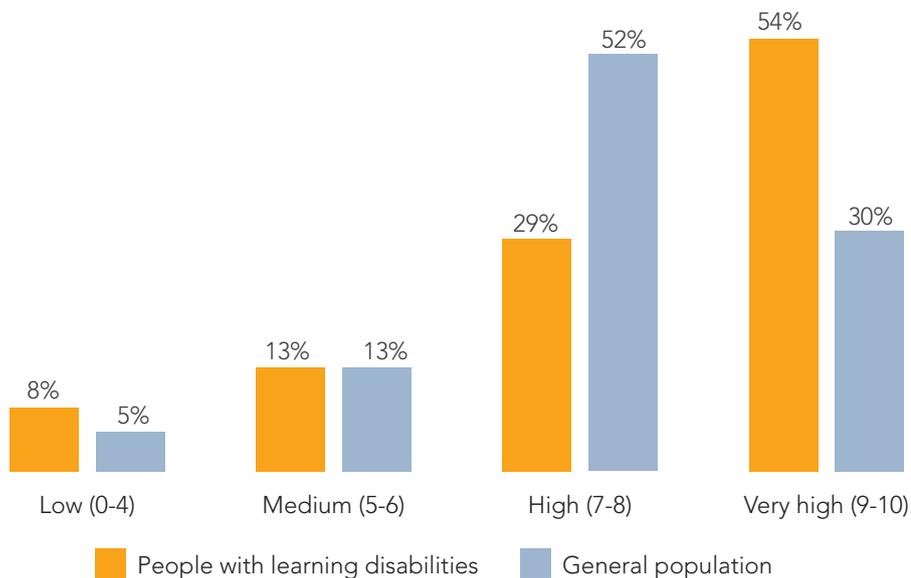
While there are many possible reasons for this difference, given the correlation between support and people's life satisfaction explored below, it is reasonable to assume that perhaps for some people having support to complete the survey is reflective of having the right support in place more generally. In any event, it is worth noting and reflecting on.

Figure 3 shows that people with learning disabilities were more likely to give a very high rating (9 or 10 out of 10) for their overall life satisfaction.

It also shows that while people with learning disabilities were in

the main very satisfied, a higher percentage gave a 'low' rating of 0-4 out of 10 compared to the general population (8% of those with learning disabilities, compared with 5% of the general population).

Figure 3: Percentage of people in Scotland reporting low, medium, high and very high life satisfaction



General Population Source: [Personal well-being in the UK: April 2018 to March 2019, Scotland data](#)

Are some groups of people more satisfied with their lives than others?

Across the general population in the UK, a number of demographic factors have been found to impact on personal wellbeing, including health, age and relationship status. In the general population, self-reported health is very strongly associated with personal wellbeing. People who are middle aged are more likely to report poor personal wellbeing than those in both younger, and older age categories. And people who are married are more likely than those who were single, co-habiting, divorced or widowed to report high personal wellbeing.

In this section, and throughout

the rest of the report, we have aggregated the life satisfaction scores into two categories, 'low' (0-6) and 'high' (7-10).

Our survey findings show that there is a relationship between having additional conditions and/or disabilities and self-reported life satisfaction.

- 22% of those with at least one additional condition and/or disability reported lower than average life satisfaction, compared to 16% of those with no additional conditions and/or disabilities (Figure 4).

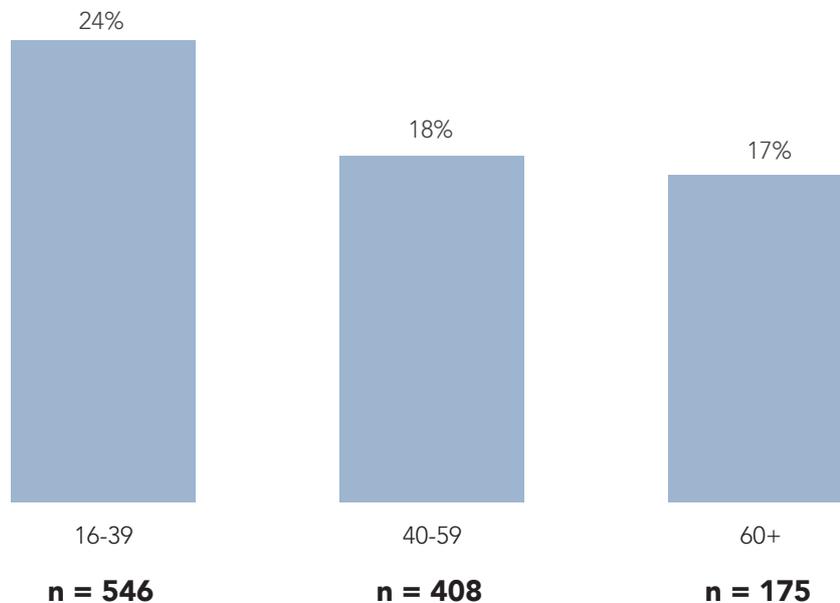


Figure 4: Percentage reporting low life satisfaction, by additional conditions or disabilities

Our survey findings also showed that there was a relationship between age and self-reported life satisfaction. However, in contrast with the general population, younger people were more likely to report lower than average life satisfaction compared to those in middle age and older age groups.

- 24% of those aged 16-39 reported lower than average life satisfaction compare to 18% of those aged 40-59 and 17% of those aged 60 and over (Figure 5).

Figure 5: Percentage reporting low life satisfaction, by age category



In contrast with the general population, relationship status was not found to make a significant difference to the likelihood of reporting lower than average life satisfaction among survey respondents. However, in the general population it is married people that rate their life satisfaction higher than single people and cohabiting couples, with single people including those in relationships but not cohabiting. Only 35 people in our survey were married, which makes comparisons with the general population difficult.

2. What factors are associated with being more or less satisfied?

SCLD was keen to explore how overall levels of life satisfaction varied by how people felt about other aspects of their lives. The domains to explore were chosen based on key objectives set out in *The keys to life*, academic studies on quality of life for people with learning disabilities, and discussions with our Partners' Group. The domains chosen included relationships with others, aspects of self-determination such as choice and support, material wellbeing such as whether people feel they have enough money and how people feel about where they live, as well as being treated with dignity and respect.

It is important to stress that in these analyses, we are looking at correlation rather than causation. This means that we can say there is a relationship between the factors explored below and

people's life satisfaction, but we cannot say that one causes the other.

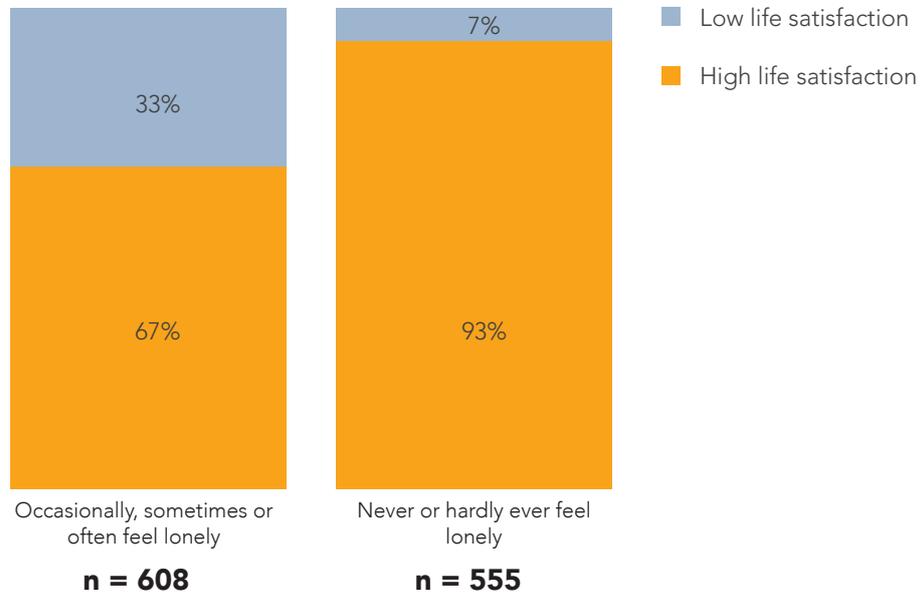
Relationships

Social relationships are recognised as an important part of individual wellbeing. Relationships in all forms are recognised in *The keys to life* as being of key importance to people with learning disabilities and essential for their wellbeing. Our findings support this, as they show that how people feel about their relationships is related to how satisfied they feel with their lives.

Indeed, while loneliness is more complicated than simply being alone, there was a very strong relationship between feeling lonely and low levels of life satisfaction.

- Only 7% of people who never or hardly ever felt lonely reported low levels of life satisfaction (Figure 6).
- This compares to 33% of people who occasionally, sometimes or often felt lonely reporting low levels of life satisfaction (Figure 6).

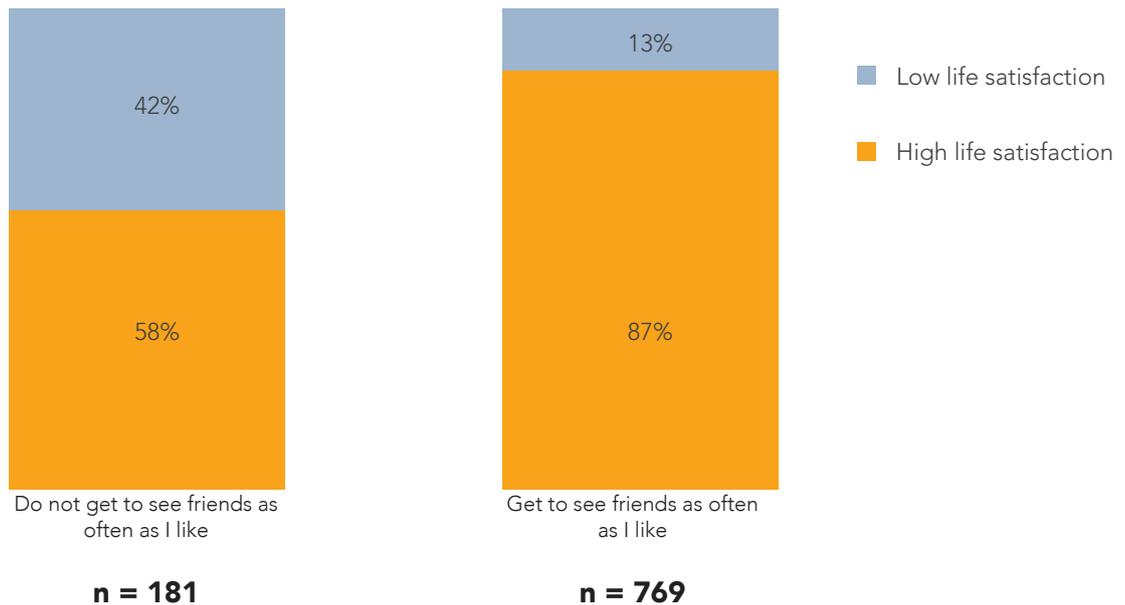
Figure 6: Percentage of people reporting low and high life satisfaction, by loneliness



The survey also found a very strong relationship between not being able to see friends as much as people liked, and low levels of life satisfaction.

- 42% of people who said they were not able to see enough of their friends reported low life satisfaction (Figure 7).
- 13% of people who said that they saw their friends as much as they liked reported low life satisfaction (Figure 7).

Figure 7: Percentage of people reporting low and high life satisfaction, by whether they get to see their friends as much as they like



Though the correlations were not as strong as feeling lonely and not being able to see friends as much as people liked, not being able to see family as much as people liked, and not having met up with friends in the last few weeks were also related to low levels of life satisfaction (See Annexe).

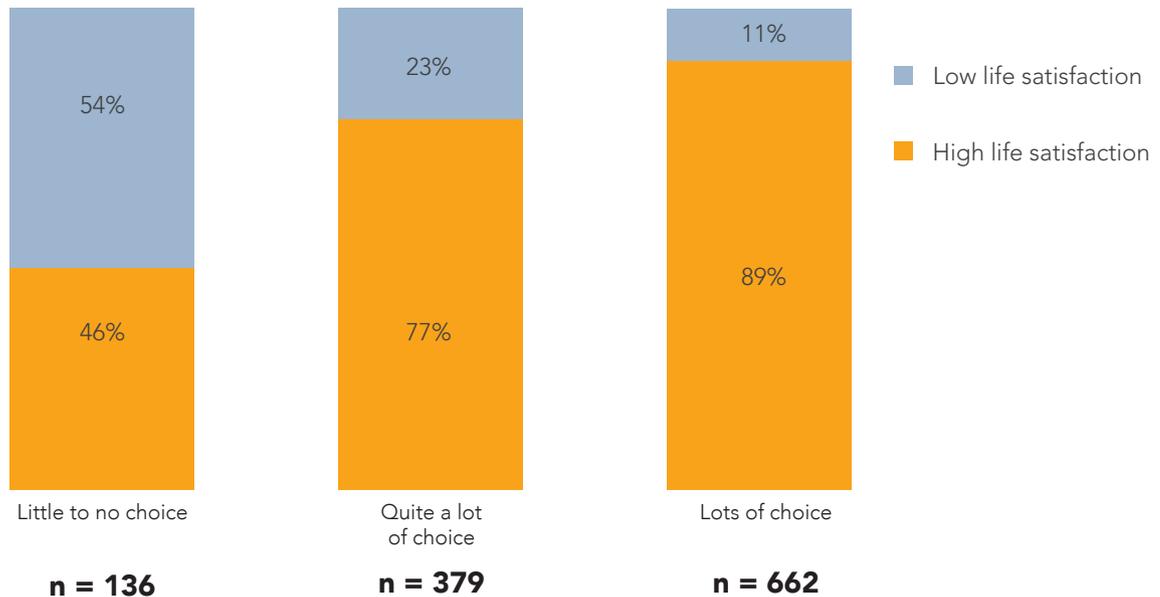
Self-determination

Academic studies have shown that self-determination is correlated with improved quality of life for people with learning disabilities.^{vii} The importance of self-determination is also reflected in *The keys to life* strategy, where choice is a fundamental pillar. Findings from our survey confirm the importance of choice as a factor in people's wellbeing.

In particular, having little to no choice over what people did with their free time was very strongly related to low levels of life satisfaction.

- 54% of people who had little to no choice over their free time reported low levels of life satisfaction (Figure 8).
- This compared to 11% of those who had lots of choice over their free time reporting a low level of life satisfaction (Figure 8).

Figure 8: Percentage of people reporting low and high life satisfaction, by choice over free time

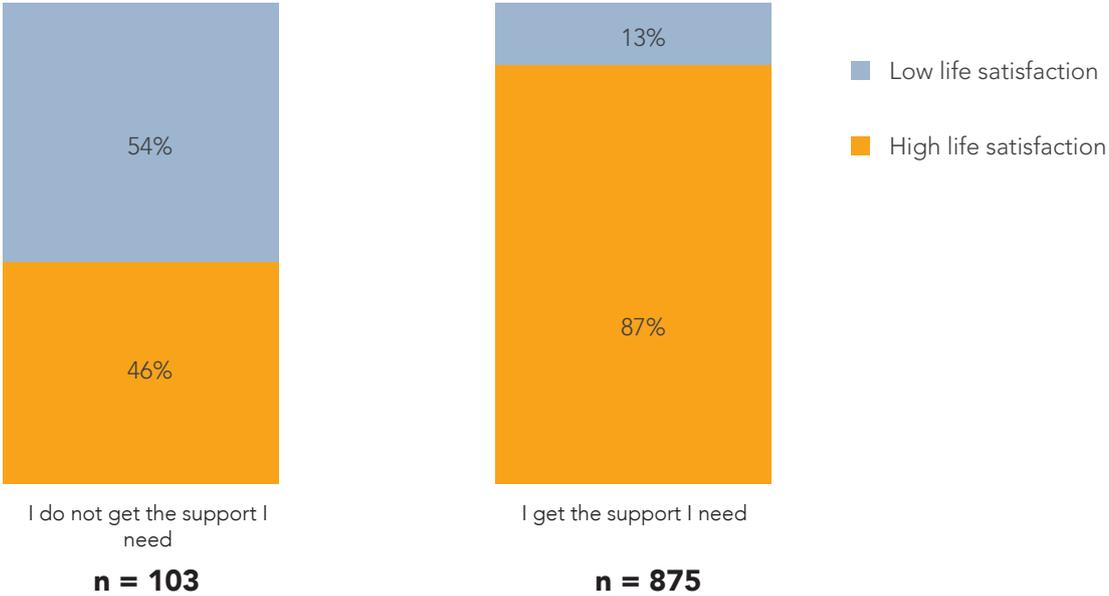


Having choice over where they lived was also related to people’s life satisfaction, though not as strongly as having choice over their free time (see Annexe).

For people with learning disabilities, a fundamental aspect of self-determination is having the right support in place to empower people to make informed choices and live the lives they want. Support is a fundamental pillar of *The keys to life*. The strategy outlines that people with learning disabilities should expect to have the right support in place to meet their everyday needs, as well as any needs that they may have because of their learning disability. Indeed, our findings show that not having the right support in place to do the things they wanted to do in their free time was very strongly related to low levels of life satisfaction.

- 54% of people who did not have the right support to do the things they wanted to do reported low levels of life satisfaction (Figure 9).
- This compared to 13% of those who had the right support to do the things they wanted to do reporting low levels of life satisfaction (Figure 9).

Figure 9: Percentage reporting high and low life satisfaction, by support to do the things they choose¹



Though the correlation was not as strong as having the right support to do the things people wanted to do, having the right support at home was also related to people’s life satisfaction (See Annexe).

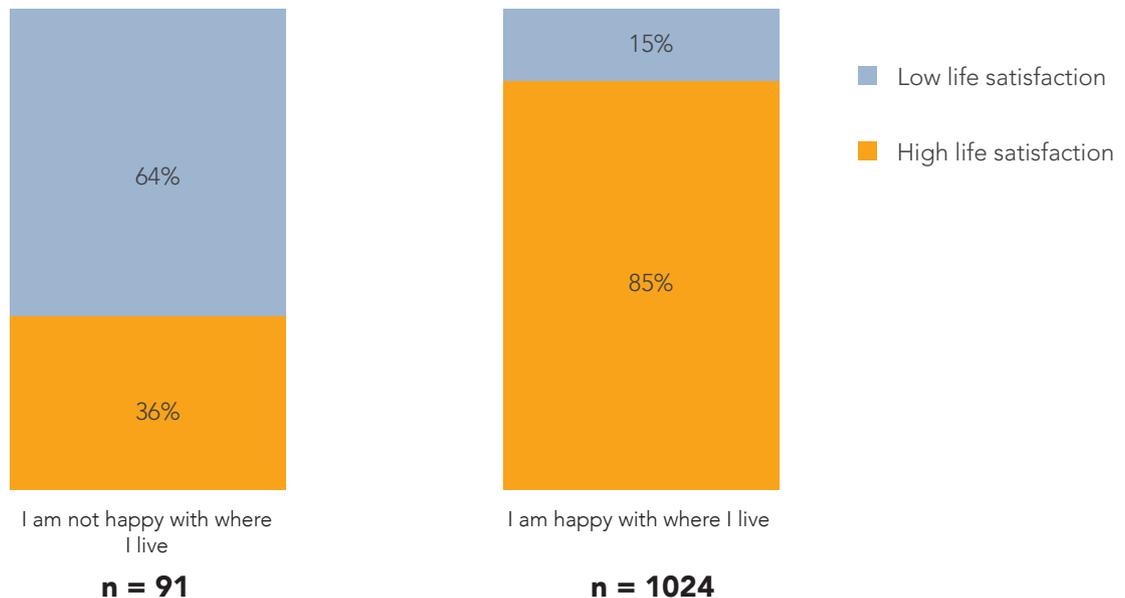
¹People who said that they did not need support have been excluded from this analysis

Material wellbeing

Material wellbeing is recognised as having a considerable role in determining an individual's self-reported life satisfaction^{viii}. Academic studies have also shown that material wellbeing is an important determinant of the wellbeing of people with learning disabilities.^{ix} While money is a key component of material wellbeing, good housing conditions are of equal importance. *The keys to life* explicitly recognises that a good quality home is at the heart of independent living and enabling people with learning disabilities to live their lives to the full. Indeed, findings from our survey show that not being happy with the house people lived in was very strongly correlated with low levels of life satisfaction.

- 64% of people who were not happy with where they lived reported low levels of life satisfaction (Figure 10).
- 15% of those who were happy with where they lived reported low levels of life satisfaction (Figure 10).

Figure 10: Percentage reporting high and low life satisfaction by whether they are happy with where they live



Being unhappy with the area they lived and not having enough money to do the things they wanted to do in their free time were also strongly related to low levels of life satisfaction (See Annexe).

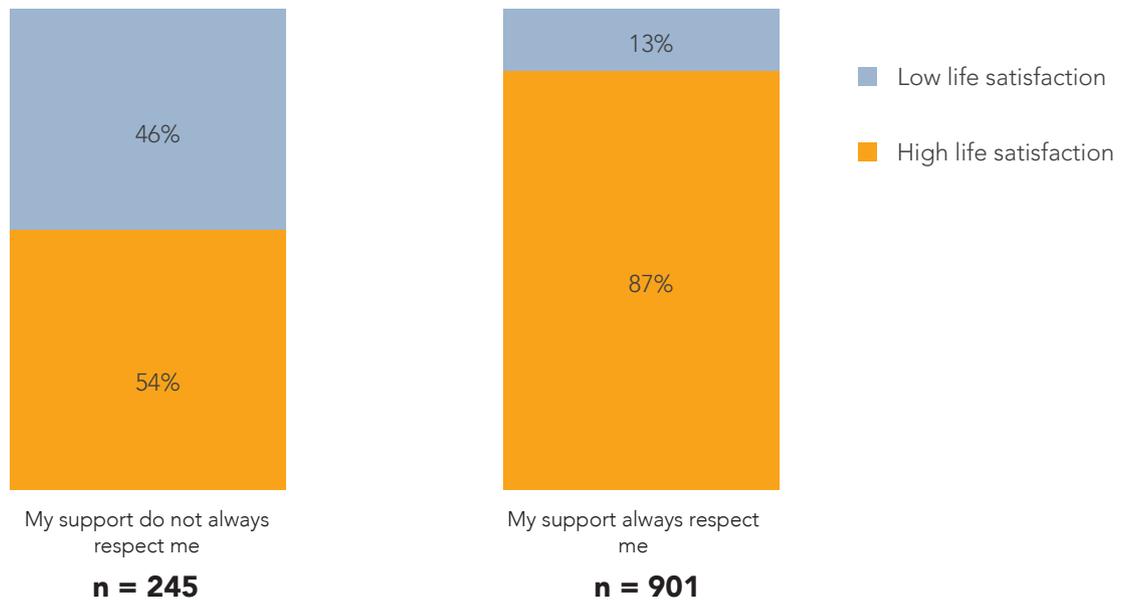
Respect and dignity

Unsurprisingly, the way that people are treated in relation to the fundamental rights of respect and dignity are important to their quality of life.^x *The keys to life* outlines as one of its strategic outcomes, that people with learning disabilities will be treated with dignity and respect, and protected from neglect, exploitation and abuse.^{xi}

Interestingly, while the survey found that both feeling unsafe when they were out in the local area, and whether they were picked on were both correlated with low levels of life satisfaction (see Annexe), there was a very strong correlation between low life satisfaction and not being treated with respect by those who were there to support them.

- 46% of people who said that those who support them did not always treat them with respect reported low levels of life satisfaction (Figure 11).
- This compared to 13% of those who were always treated with respect by those who support them reporting low levels of life satisfaction (Figure 11).

Figure 11: Percentage reporting high and low life satisfaction, by whether their support always treat them with respect²



²People who said they did not need support have been excluded from this analysis

3. Wellbeing in people's own words

How satisfied people feel about their own lives is complex and multi-faceted. No report could do justice to this complexity. However, as part of the How's Life? survey, respondents were invited to provide further comments on their self-reported life satisfaction score if they wished. 196 people chose to do so. People's additional comments elaborated on the factors that made them feel more or less satisfied with their lives.

These included reasons related to relationships and loneliness, support, housing, being treated with respect and health conditions, all of which reinforce the findings above. Some people also mentioned other factors, such as access to work, having activities to do and issues around accessibility.

A selection of the comments are provided on the next page

My support often gets cancelled and I often feel lonely living on my own. A communal area that I am able to meet others would be good and help when I feel I want someone to talk to as often our office is too busy.

Life is good. Life can be better. Living alone is a challenge.

I would like a job and to have more money.

Some days if my support gets cancelled and can't do the things I want to do I don't feel happy at all, but most of the time I feel quite happy.

I feel very isolated. All my carers are very good but my health has gone downhill and I am too far away from family!

I like it when I have friends. People call me names.

I am happy and have a varied social life, going out within the community, meeting friends and going to parties.

I would like my own home, but need a lot of support. I have been on waiting lists for over 20 years and am still waiting.

Concerned about seizures which affects daily living.

I like meeting my friends at college but I don't really go out at night as I can't go on my own and there is nothing to do at night here.

Mostly a 10 but sometimes a 0.

I like the day centre I go to. I would like more things to do though like going to more concerts. Can be harder for wheelchair users.

Lonely and stressed.

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. These stories highlight that for people with profound and multiple learning disabilities, the factors that add up to a good life are similar to the themes highlighted so far in this report.

One of these stories, as it relates to life satisfaction, is reproduced below.

It highlights in particular the importance of the having the right model of care and support in place, underpinned by respect and being listened to through accessible communications. It also demonstrates the importance of access to regular and varied activities, living close to family in an appropriate setting, familiarity and stability of routine, as well as the impact of additional health conditions.

Case Study

If I think of putting red dots on a spectrum to reflect a typical day for my son, I think that many, perhaps the majority, would be in the bottom third: 0-3, with others in 4-6 - and a sprinkling, on a good day, at 8-10: moments of intense pleasure: a bite of chocolate cake, the prospect of going home, being in the hot tub. Yet those moments of 8-10 are quickly left behind and replaced with 0-3 when he remembers unhappiness that is inside him. Even at home, when he is in the hot-tub, really enjoying himself, he is worrying about going back to hospital - the 0-3 moments return. He cries out 'bye-bye hospital'.

So my answer is 2-3.

For the last twenty eight years, my son has depended on a care model that is based in a full-time care provision, with frequent, quality periods spent at home, access to mum, step-father, sisters, granny, family friends. Over the last three years that pattern has broken down. He is now living in a locked ward, on a Learning Disability Assessment Unit (LDAU) with a very restricted life and that makes him unhappy.

To recap, he weekly boarded between age of 5 - 17 years then at the end of his school days, moved into supported tenancy, which was not suitable and broke down. He spent a period in hospital (LDAU) then moved to a new care home in

England. He then experienced the stability in Glasgow of six years in a care home, where he had familiar staff, familiar residential accommodation, familiar community activities and routines, familiar social and geographic landscape. Three years ago, that started to break down. For the last eighteen months he has had three major upheavals: Glasgow - Hartlepool; Hartlepool - Perth; Perth to the LDAU. He has lost all his familiar care team from Glasgow and his fellow residents, his familiar activities - swimming, walking, accessing cafes, Touchbase Day Centre - all that was familiar and reassuring about his life.

He was frightened in new surroundings where people spoke in different accents, did things differently. He

encountered physical and chemical restraint that had been unknown to him before. He was cared for by people he did not trust, whom he found not to be trustworthy. He lost faith in his own capacity to make himself known, he found that saying how he felt (in his own language) was not understood. So he used physical language instead - using his body to be aggressive, destroying property, shouting.

In all three changes over the last 15 months, he was frightened of unfamiliar surroundings, fearful of strangers, unable to make himself known, and angry and frustrated.

He also experiences day to day discomfort from his physical conditions and from the medications he takes.

4. Discussion

While the majority of respondents to our How's Life? survey reported that they were satisfied with their lives, it is important that this does not lead to complacency. A significant minority of respondents did not have high levels of life satisfaction. Indeed, a higher proportion of people with learning disabilities rated their life satisfaction as low (0-4 out of 10) when compared to the general population.

Crucially, the survey was undertaken before the devastation wrought by Covid-19. The pandemic has had myriad consequences for people with learning disabilities, particularly in relation to health, relationships, and self-determination, and has further entrenched already existing inequalities.^{xii} Given that our survey has shown that these factors were all strongly related

to life satisfaction, it stands to reason that life satisfaction as measured now would be lower for many people.

Importantly, by exploring the differences between those who reported lower and higher levels of life satisfaction, the findings allow us to get a better understanding of what factors relate to people's wellbeing. They help to build a picture of what a good life looks like for people with learning disabilities, and something to aim for as the country plans to 'build forward differently' in the post-pandemic world.

Demographics

In the general population self-reported poor health is the single biggest contributing factor to low levels of wellbeing. This

was reflected in our survey, where having additional health conditions or disabilities was related to lower levels of life satisfaction among respondents. This is of particular concern as we know that people with learning disabilities continue to face significant health inequalities, and die on average 20 years earlier than the general population.^{xiii}

This was felt acutely during the first wave of the pandemic. People with learning disabilities had a rate of death over three times higher than the general population, and were twice as likely to become infected.^{xiv}

Our findings also show that people in the youngest age cohort had lower levels of life satisfaction than middle aged and older cohorts, whereas in

the general population middle aged people tend to be the least satisfied.^{xv} There are a number of possible reasons for this.

Work by the Office for National Statistics has shown that the disparity in the proportion of people with disabilities who felt lonely compared to the general population was highest in younger age groups.^{xvi} Though not found to be significant, our survey results do show that people in younger age groups were more likely to report feeling lonely 'often' compared to other age groups.

It is also the case that co-morbidities, themselves linked to lower wellbeing, are prevalent at all age groups for people with learning disabilities compared to the general population, where these tend

to occur as people age.

We have seen that the impact of the pandemic has been felt more acutely by people with learning disabilities in terms of both their physical and mental health. These findings solidify the importance of improving access to healthcare and empowering people to manage their own physical and mental health when it comes to improving wellbeing.

Non-demographic factors

We have also explored the relationship between people's self-reported life satisfaction and a number of non-demographic factors. As outlined above, the factors were chosen based on key objectives set out in *The keys to life*, academic studies on quality of life for people with learning disabilities, and discussions with our Partners' Group about what factors they thought were particularly important to people

with learning disabilities. These factors can be grouped into four broad themes: relationships, self-determination, material wellbeing, and dignity and respect.

Our Relationships Matter report^{xvii} has already highlighted the importance of relationships of all kinds for people's wellbeing. Indeed, relationships with family and friends topped the list when people were asked what was the most important thing in their lives. This report has solidified these findings, showing that people who saw enough of their friends and family, met up with friends in the recent past and didn't feel lonely were all more likely to report higher levels of life satisfaction. Of these factors, loneliness and seeing enough of friends seemed to have the strongest correlation.

This is a huge cause for concern. In a short survey undertaken in

June 2020, many people with learning disabilities told us that they felt lonelier than before the pandemic. The removal of paid support left many people with little contact, cut off from families and social networks.^{xviii}

Our survey findings also highlight the importance of self-determination for people's wellbeing. Having lots of choice over how free time was spent, and the right support in place to facilitate those choices were both very strongly related to higher levels of wellbeing. Although the correlation was not as strong, those who had been involved in choosing where they lived also tended to report higher levels of wellbeing than those for whom this was not the case.

Again, the context of Covid-19 causes considerable concern in this regard. Though motivated

by concern for public health, measures taken to stem the pandemic invariably led to instances where people's self-determination was curtailed. This was demonstrated most obviously where cuts to support packages took place with no discussion or involvement with people in receipt of that support.^{xix}

Among our survey respondents, material wellbeing also was found to be a very important factor in terms of self-reported life satisfaction. As might be expected, people who felt that they had enough money to do the things they liked to do were more likely to report high levels of wellbeing. Our results showed that being happy with the house they lived in was even more strongly correlated with higher levels of life satisfaction than money.

The last theme we explored was dignity and respect, which was also found to correlate strongly with wellbeing. Survey respondents who felt safe and were not picked on when they were out in the community tended to report higher levels of wellbeing. Interestingly, our results found an even stronger correlation between high levels of wellbeing and being treated with respect by those who supported them.

The way forward from Covid-19

The findings from our How's Life? survey should not come as a surprise. What this report has highlighted is that the factors underpinning wellbeing for people with learning disabilities are, in many respects, similar to those underpinning wellbeing for the population as a whole. *The keys to life* strategy recognised this back in 2013. Indeed, it has

four strategic outcomes, which align neatly with our findings around what underpins the wellbeing of people with learning disabilities; a healthy life, choice and control, independence and active citizenship.

But even pre-Covid-19, there was already a disconnect between policy intent and the everyday experience of people with learning disabilities. Previous research, both before and during the Covid-19 pandemic, shows that people with learning disabilities face much greater challenges realising their rights to the factors that underpin their wellbeing.

As outlined above we know that people with learning disabilities continue to face significant health inequalities. We know that the vast majority of people are not in romantic relationships and many do not see their friends and loved

ones as much as they would like.^{xx}

In the context of austerity, we have seen a social security system that often fails to recognise the needs and aspirations of people with learning disabilities. A prolonged period of diminishing social care budgets have seen reductions to already inflexible support packages.

Previous reports have also shown that many people with learning disabilities are living in unsuitable homes; whether they have been housed in an out of area placement, far away from family, in group living with people they do not get on with, or simply in a house that does not suit their needs.^{xxi}

We also know that the othering of people with learning disabilities in society leads to

bullying and harassment, which is often underreported.^{xxii}

Our findings, coupled with the urgency brought by the Covid-19 pandemic, show a need to re-double efforts to tackle these seemingly intractable issues that prevent people with learning disabilities from participating in society on an equal basis. If the Scottish Government is serious about inclusive growth and building a wellbeing economy then the wellbeing of people with learning disabilities needs to take centre stage.

To move forward inclusively and fairly, we need to understand why these issues are still at play. We must reflect on what has changed over the past 10 years, and what has remained stubbornly the same.

The pandemic allows us this reflection, and to consider what

kind of recovery we want. The recently published Independent Review of Adult Social Care in Scotland^{xxiii} is right to suggest that we need to shift the paradigm of social care from helping people to get by and manage in a crisis, to enabling people to access their human rights and live fulfilling lives.

SCLD supports this vision and agrees that the social care system is not doing enough to respect, protect and fulfil people's rights. However, SCLD would echo the point made by the Fraser of Allander Institute^{xxiv} that the experience of the social care system is not the same for people

with learning disabilities as it is for other groups, and no two people with learning disabilities are the same. We must not lose sight of this. Our findings help us to identify what underpins the wellbeing of people with learning disabilities, and what we should be aiming for when we move forward from this crisis.

The paradigm shift that is needed goes beyond the health and social care systems. What is required is a wholesale culture shift across society.

5. Moving forward

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

1. Incorporate the United Nations Convention on the Rights of People with Disabilities (UNCRPD) into domestic law in Scotland

UNCRPD imposes positive obligations on states to respect, protect and fulfil the human rights of people with learning disabilities. It touches upon each of the issues that have been raised in this report. SCLD supports the recommendation

by the National Taskforce for Human Rights Leadership^{xv} that UNCRPD should be incorporated into Scots law in such a way that ensures effective protection and realisation of rights in people's everyday lives. SCLD believes that incorporation of the UNCRPD into domestic Scottish law will act as the bridge between policy intent and lived experience, ensuring that systems consistently deliver rights, as well as prevent the most serious human rights violations.

2. Collect robust data on the experience of people with learning disabilities

The collection of robust data on the experience of people with learning disabilities, in particular in GP systems and other routinely collected health data, is vital in the promotion of equality and the protection of human rights within Scotland. Without

sufficiently disaggregated and robust national data, it is difficult to plan and implement services and interventions that empower people with learning disabilities to live their best lives.

3. Renew focus on reducing health inequalities

There is no panacea to combat long entrenched health inequalities for people with learning disabilities. However, SCLD believes that a number of actions could be taken. Offering free annual health checks to all people with learning disabilities from aged 14, coupled with mandatory learning disability training for all GPs and NHS staff, would help empower people to manage any health conditions as well as reduce diagnostic overshadowing. Effective communication and

understanding between people with learning disabilities and health care workers could also be supported by the introduction of citizen owned digital passports as standard. These would hold vital health care information about the person as well as any support needs, allowing individuals to share this with health care and other staff when they chose.

4. Put appropriate support and informed choice at the heart of social care

Given the strong association between good support and wellbeing, SCLD agrees with the recommendations in the Independent Review of Adult Social Care. Specifically, people must be able to access support at the point they feel they need it, to allow a greater emphasis on prevention and early intervention.

Self-directed support (SDS) assessments should explicitly consider what people need to support their wellbeing. SCLD is supportive of the suggestion that any 'unmet need' for individuals is recorded and fed back into strategic commissioning processes. In addition, provision needs to be put in place to make sure people are supported to make informed choices. There should be an obligation on local authorities to fully discuss SDS options with people, in a way that is suitable for their communication needs, including access to independent advocacy where this is appropriate.

5. Promote the right of people with learning disabilities to have and maintain different kinds of relationships

Teachers, support workers, social workers and other staff must adopt a human rights approach to their work, which recognises the central importance of relationships to people's wellbeing. They should ensure that people with learning disabilities grow up understanding they have a right to a family life. This will include access to good quality Relationships, Sexual Health and Parenting education for young people with learning disabilities. Staff should also support people to capitalise on opportunities to maintain existing relationships and develop new ones. In doing so we need to acknowledge and move away from a culture within services that tends towards risk aversion rather than risk enablement.

6. Ensure access to high quality, appropriate housing

Strategic planning processes and housing allocation policies should consider the particular needs of people with learning disabilities. It is crucial that people with learning disabilities have the right information to make informed choices about where they live. It is important to embed a 'housing options approach' where advice is personalised and explores all possible tenure options, and accounts for wider personal circumstances and support needs alongside accessible housing needs.

7. Ensure material wellbeing through the social security system and access to work which pays

The design, rollout and future development of the Scottish social security system should be

co-produced with and consider the particular needs of people with learning disabilities. The Adult Disability Payment, which will replace Personal Independence Payment, is designed to mitigate the additional costs of living with a disability or health condition. It is critical that the eligibility criteria and descriptors for this payment can accurately capture the impact of learning disability on day-to-day life.

Alongside this, people with learning disabilities across Scotland should be able to access specialist employability support which is uniquely tailored and offers practical assistance to help them find, sustain and progress in work of their choosing.

8. Everyone has a responsibility to support the inclusion and participation of people with learning disabilities

Everyone has a responsibility to support the increasing visibility of people with learning disabilities in all areas of society – in civic life, community, political and social circles. Communities have a responsibility to welcome people with learning disabilities and support their aspirations to achieve their potential, and the learning disability community and sector has a responsibility to support communities to do that, including a move towards

accessible communication by default.

A wide range of stakeholders will be needed to put in place all the measures above. These include, but are not limited to:

- People with learning disabilities and their families
- Scottish Government
- Health and Social Care Partnerships
- Third sector organisations and staff
- Community organisations

As we start to emerge from lockdown, a national conversation about wellbeing could be very timely. However, it will only be useful if it results in committed, sustained action to improve the wellbeing of people with learning disabilities living in Scotland.

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Annexe



Annexe

Figure 12: Percentage of people reporting low and high life satisfaction, by whether they get to see their family as much as they like

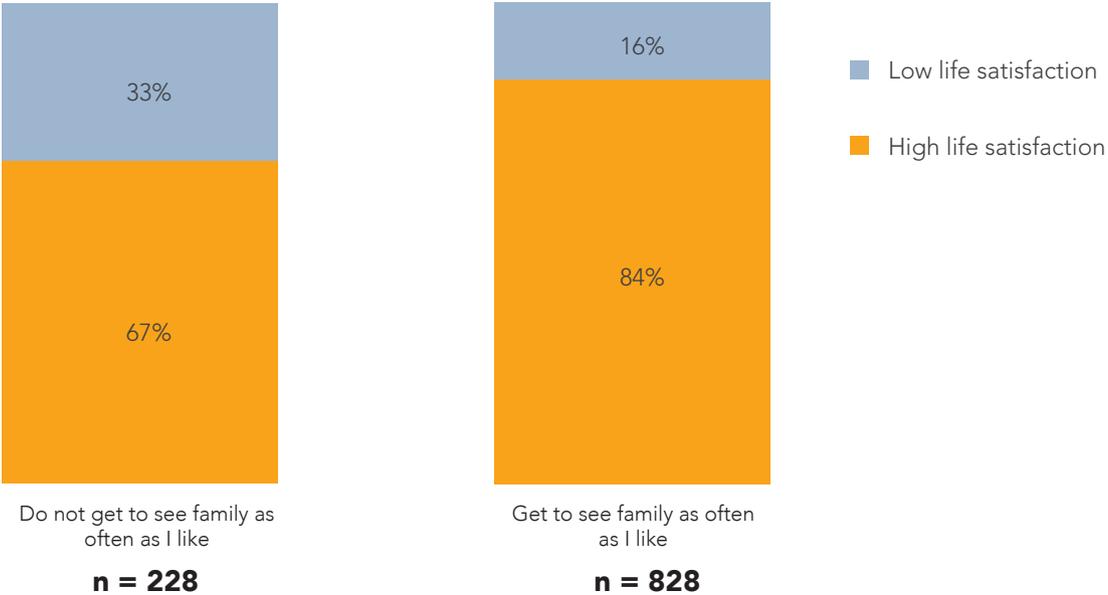


Figure 13: Percentage of people reporting low and high life satisfaction, by whether they met friends in the last few weeks

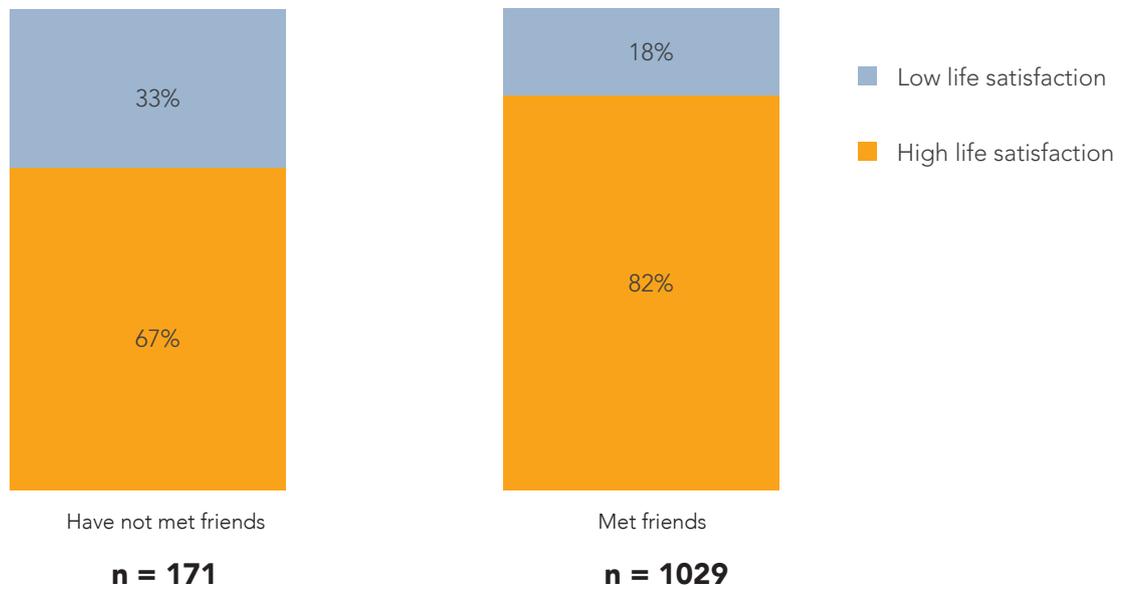


Figure 14: Percentage reporting high and low life satisfaction, by whether they chose where they live

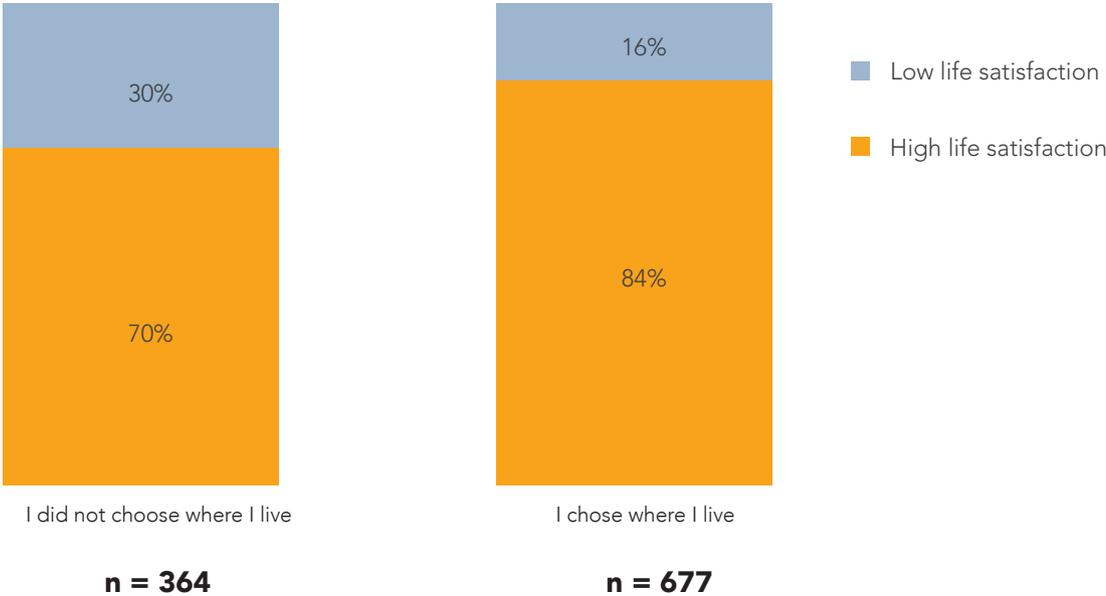
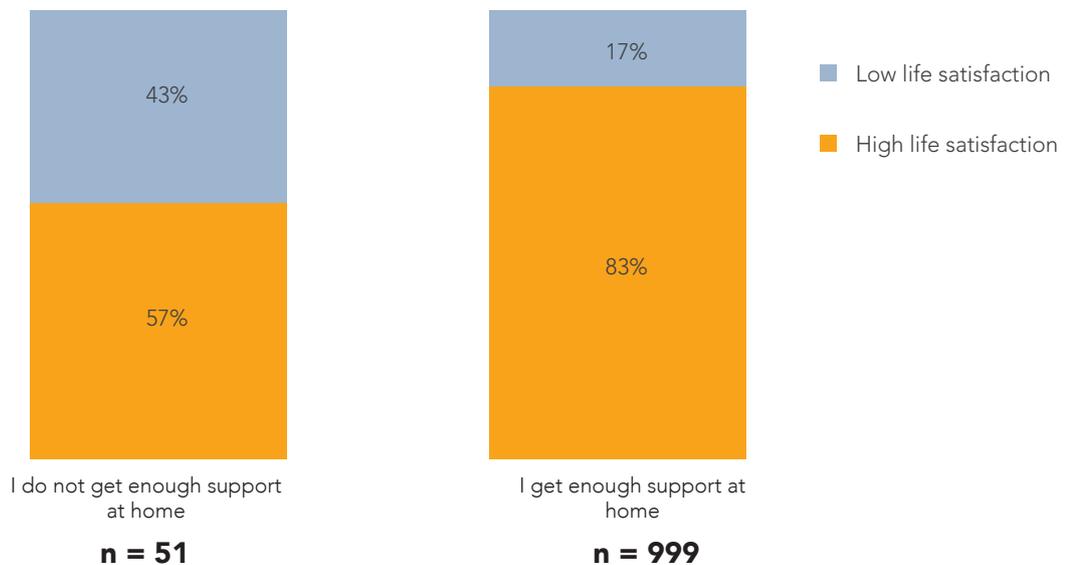


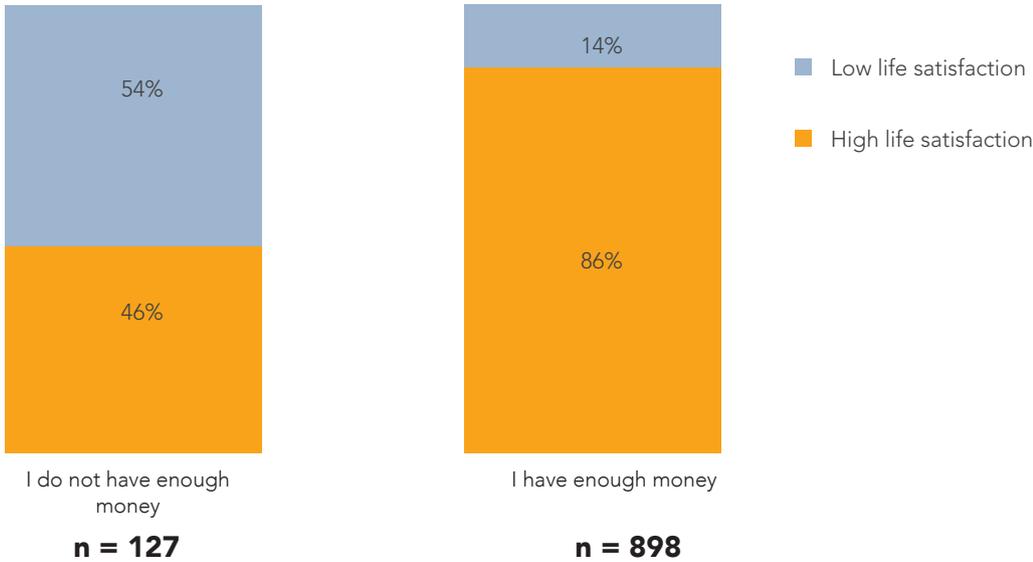
Figure 15: Percentage reporting high and low life satisfaction, by whether they get enough support at home¹



¹People who said they did not need support were excluded from this analysis



Figure 16: Percentage reporting high and low life satisfaction, by whether they have enough money



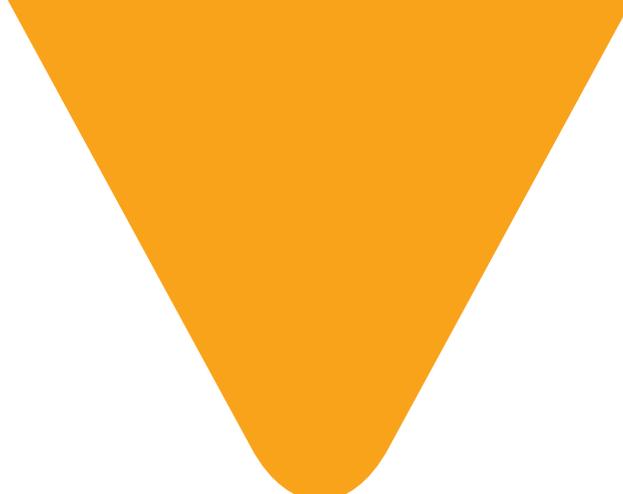


Figure 17: Percentage reporting high and low life satisfaction by whether they are happy with the area they live in

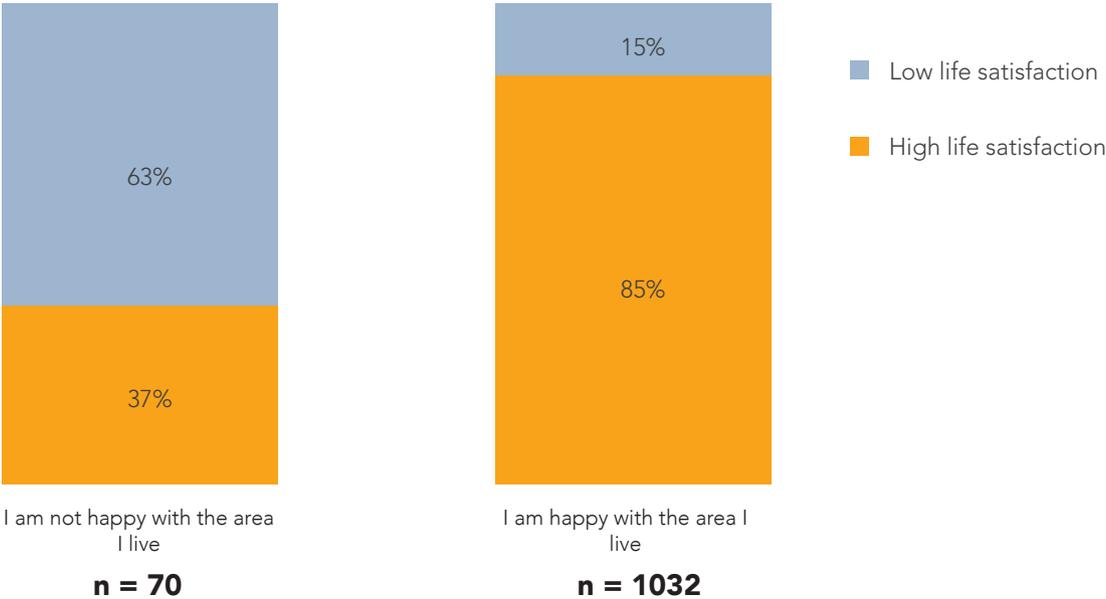




Figure 18: Percentage reporting high and low life satisfaction by whether they feel safe when they are out and about

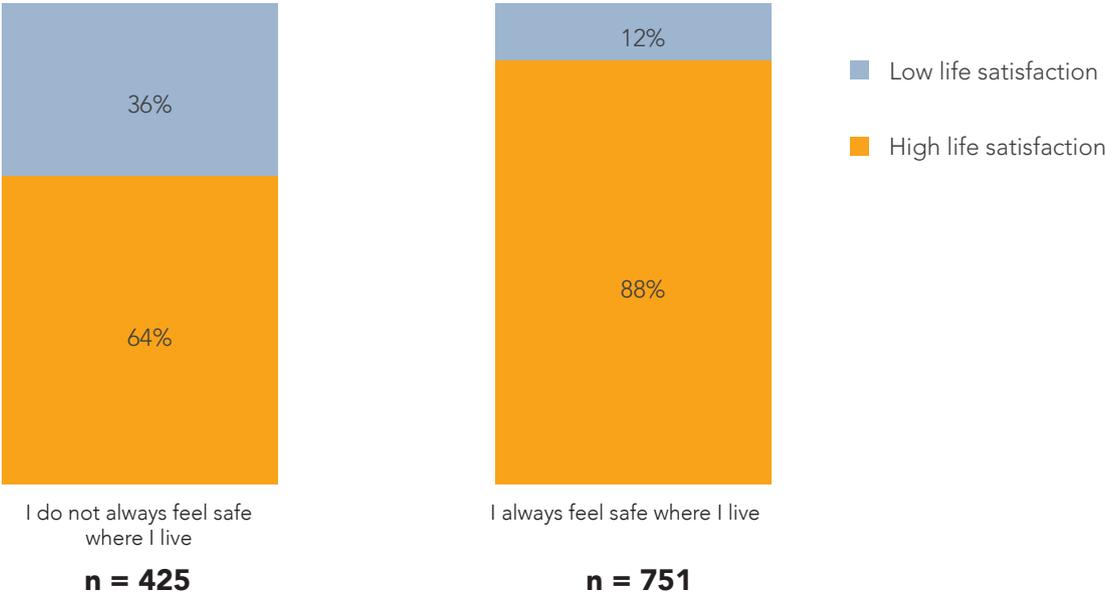
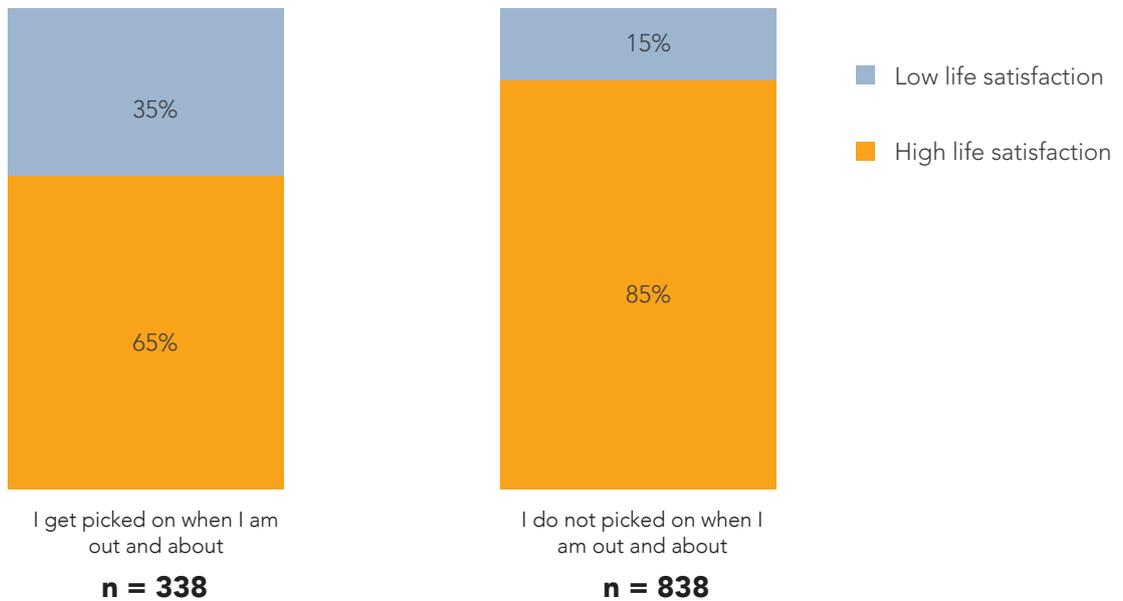


Figure 19: Percentage reporting high and low life satisfaction, by whether they get picked on when out and about



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