



# **BIG LEARNING DISABILITY SURVEY 2022**

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# FOREWORD

Thank you to everyone who took part in our Big Learning Disability Survey. Nearly 2,000 of you took part which means that we have a really good picture of what is important to you.

We were particularly interested in how COVID-19 is still affecting you, and also about your everyday lives and experiences. We were also keen to get your views on key issues like access to healthcare, discrimination, and money and support.

We will use the information you have given us to work with government and public bodies to make change. We will also use it to guide our own work. Our Big Plan says that we should be led by people with a learning disability and should respond to what you want and need – and you telling us what you think will help us do that.

There are some key areas we will need to work on:

## Healthcare

- Over 40% of you have not had an annual health check in the last year.
- Nearly 60% of you who did have an annual health check in the last year said you did not receive a health action plan from your GP or nurse. We will work with health organisations like the NHS to improve this.

## Discrimination

- Over 40% of you said there were times you did not go out because you were worried about something which happened in the past month. The most common reason was: 'People calling me names or bullying me' (14.7%).



- We need to increase visibility of people with a learning disability in society so that this sort of bullying does not happen anymore.

We also asked you what one thing would make your life better.

You said getting a paid job, getting more personal support, having friends and socialising, tackling discrimination, sorting out the cost-of-living crisis, and having greater independence.

So, there's lot of work to be done – particularly to help more people get jobs and to support people through the cost-of-living crisis. We also need to create opportunities for greater visibility of people with a learning disability in the media, in public life and in communities. The result of this survey gives everyone the evidence to show that we all need to act.

Thank you for completing it – we will act on what you have told us!

## Edel Harris

Chief Executive Officer

# EXECUTIVE SUMMARY



*“We would like to say thank you to everyone who took part in the 2022 Big Learning Disability Survey! I am a Research & Impact Assistant at Mencap. I also have a learning disability. I feel that it is very important to listen to the voices of people with a learning disability in research. It is for this reason that I joined the survey working group. I am proud to have contributed to this report because it will be used by Mencap and other organisations to improve the lives of people with a learning disability across the UK.”*

**Dan Newton**

## 1. Context

It is estimated that 1.5 million people in the UK have a learning disability<sup>1</sup>. People with a learning disability are a very diverse population, with individual needs (Department of Health, 2001). Research has shown that people experience longstanding and wide-reaching inequalities compared to the general population from access to health care to social isolation (Department of Health, 2011). In the aftermath of the COVID-19 pandemic, pre-existing inequalities worsened and negatively impacted the mental health and wellbeing of people with learning disabilities (Lunsky et al., 2022). It is imperative that all services, from healthcare to personal support effectively

engage with the needs of people with learning disabilities by providing the necessary support during these challenging times.

## 2. Key learnings and recommendations

### Accessing healthcare services

The findings demonstrate that access to healthcare services was a significant issue for people with a learning disability. We found that over 4 in 10 (40.7%) respondents said they have not had an annual health check in the last year. Of those who did have an annual health check in the last year, almost 6 in 10 (58.9%) said they did not receive a Health

<sup>1</sup> — This estimate has been calculated using learning disability prevalence rates from Public Health England (2016) and population data from the Office for National Statistics (2021).

Action Plan. Steps must be taken to improve the number of people with a learning disability receiving accessible communications from general practitioners (GPs). These findings underscore the importance of ensuring that all people with a learning disability are added to the learning disability register. Steps must also be taken to improve the number of people with a learning disability receiving accessible communications from GPs.

More positively, almost half (47.4%) of respondents reported that their most recent GP or hospital appointment was good. However, over 1 in 10 (12.9%) respondents felt that their most recent appointment was poor. When asked what one thing would have made their appointment better, a number of ideas were given. A majority of respondents stated that better reasonable adjustments such as Easy Reads (e.g., Easy Read versions of cervical cancer screening invitations) would have improved their experience. Others expressed a wish for shorter waiting times before appointments. Some felt that longer appointments would have enabled them to communicate more effectively with their GP or hospital doctor.

A concerning finding was that some respondents felt that their GP did not have a

good understanding of learning disability. It is vital GPs are equipped with the necessary training to provide a high standard of care to people with a learning disability. Mencap encourages GPs to consult people with a learning disability on how best to address their needs, and proactively offer support to ensure that each and every patient receives the care that they are entitled to.

### **Paid work**

Over a quarter (26.7%) of respondents to the Big Learning Disability Survey said that they have a paid job. This is a small increase in the proportion of people in paid employment compared to the 2019 Big Learning Disability Survey (22.9%). Of those in paid employment, almost 4 in 10 (39.7%) said they work 16 hours or less in a week. With over a third (36.7%) of working age respondents saying they would like to be in paid employment, these findings demonstrate a need for increased support for people with learning disabilities to find paid work and more full-time employment opportunities. Our 2019 Big Learning Disability Survey showed that people with learning disabilities face multiple barriers to accessing employment, such as the attitudes of employers and a lack of good quality support in getting and maintaining employment.



Mencap calls on the government to address the barriers that prevent people with learning disabilities from accessing paid employment.

## **Mental health**

Mencap's recent research showed the COVID-19 pandemic lockdown had a detrimental impact on the mental health of people with a learning disability (Mencap, 2022). This report builds on this research and provides valuable insight into the mental health of people with a learning disability in the months following the end of COVID-19 restrictions. As respondents expressed a wide range of thoughts and feelings, our findings show a mixed response. Over two-thirds (66.4%) of respondents reported they had felt happy in the past week, whereas almost 1 in 3 (31.7%) reported that they had felt lonely. Over 4 in 10 (43.5%) respondents said they had felt sad, and over a quarter (25.2%) said that they had felt confident. Over 1 in 3 (30.9%) respondents said that they had felt angry. The most common thoughts and feelings reported by respondents (in order) were "anxious", "frustrated", "confused", and "worried". People who reported that they felt lonely were also more likely to have worries and concerns about living costs and money and financial support. This illustrates the importance of adequate care and social support during the ongoing cost of living crisis. These results mirror our recent 'Listen To Us' campaign which showed that nearly a third (32%) of families and carers were struggling with mental health issues. This report further highlights the need for greater local support services and resources to support people with learning disabilities and their families and carers with their mental health.

## **Discrimination**

Over 4 in 10 (41.1%) respondents reported that they did not go out in the past month because they were worried. The most common reason why people with a learning

disability did not go out was because people were calling them names or bullying them. It is our belief that the general public's understanding and perception of the condition must improve if we are to eliminate discrimination against people with learning disabilities in the UK. Almost 7 out of every 10 (69.6%) respondents reported that they would go to their family or friends for help and support when being treated unfairly. Over 1 in 10 (12.3%) respondents said that they did not know where to go for help and support, and over 1 in 10 (13.8%) said they would go to charities. Mencap currently offers online resources, in addition to a Learning Disability Helpline, providing guidance and support on a range of different topics, including discrimination. These findings also demonstrate a need for greater awareness of the different types of support available for people with a learning disability experiencing psychological or emotional abuse, such as bullying.

## **Money and support**

Responses show that there are worries about money and financial support among people with learning disabilities. Almost a quarter (24.3%) of respondents reported that they do not have enough money. Over 1 in 5 (22.4%) respondents said that they do not have enough support and over 1 in 10 (12.3%) respondents said that they did not know where to go for support. However, over half (53.6%) of people with a learning disability said that they are not worried about any of these things, indicating that they do not have any monetary worries. Our findings suggest that people with learning disabilities are not as concerned about the cost-of-living crisis as we might have expected. This might be explained, in part, as most respondents shared that their parent/carer or financial deputy is largely or wholly responsible for their finances and so they do not manage their own money. However, for others it may indicate that they are not looking ahead or taking pre-emptive

action to ensure they will be able to stay warm, fed, and well. The ongoing work of Mencap's 'Policy Shapers' group will provide us with an in-depth understanding of this issue. Some respondents shared that they are aware of their parent or carers concerns about increased living costs and the financial implications on their households. Results also show that people who live independently were more likely to worry about money and support compared to people who live with others. Mencap encourages councils to provide proactive, accessible, and targeted information on how people with learning disabilities and their families and carers can receive support during the ongoing cost of living crisis.

### **Making life better**

People with a learning disability aspire to live in a society that is welcoming and inclusive, where they are treated as equals, and afforded the same opportunity to lead a happy and healthy life. Our results show that people with a learning disability have a strong desire to improve their lives across a broad range of areas. Respondents shared that a range of things would make their life better, including getting a paid job, getting more personal support, tackling discrimination, a lower cost of living, and greater independence. Others discussed that they would like to have better health and healthcare, to be in a relationship, and to be able to go on holiday. Many respondents emphasised that their care support hours are insufficient or not flexible enough to allow them to pursue a lifestyle of their choice. Notably, a few respondents shared that they would like to gain paid employment in specific industries of interest, such as working on a train. These responses illustrate that there is a need for improved support for people with learning disabilities across different areas such as employment and care and support.



### **Information**

To get support you can contact Mencap's **Learning Disability Helpline**. It offers free advice and support for people with a learning disability, their families and carers.

Phone: 0808 808 1111

Email: [helpline@mencap.org.uk](mailto:helpline@mencap.org.uk)

### **Northern Ireland**

Phone: 0808 808 1111 (Option 2)

Email: [helpline.ni@mencap.org.uk](mailto:helpline.ni@mencap.org.uk)

### **Wales**

Phone: 0808 8000 300

Email: [helpline.wales@mencap.org.uk](mailto:helpline.wales@mencap.org.uk)



# INTRODUCTION

Mencap's 2022 Big Learning Disability Survey was completed by almost 2,000 people with a learning disability across the UK. The survey was designed to explore the everyday lives and experiences of people with a learning disability in the country. The survey focused on topics that people with a learning disability told us were important to them, including employment, healthcare, discrimination, and money and support.

Mencap is committed to ensuring that people with a learning disability are able to lead happy and healthy lives. We understand that our ability to effectively advocate for and support people with a learning disability requires an in-depth understanding of their everyday lives and experiences, particularly in these challenging times.

It is for this reason that we adopted a wholly inclusive approach. The survey was co-designed and co-produced with colleagues with a learning disability from the planning phases onwards. In our core research group, 50% of colleagues had a learning disability. We are proud to share that every question included in the survey was a collaborative effort between colleagues with and without a learning disability.

The survey provides a snapshot of the learning disability community that goes beyond the people we support. It gives us a picture of the lives of people with a learning disability across England, Northern Ireland, Scotland, and Wales. It is our hope that this information will be used by other charities, organisations, and the government to inform their campaigning, policy work, and planning of future initiatives for and with people with a learning disability.

We would like to thank all 1,972 people who shared their thoughts and experiences with us by taking the survey. This is an increase of almost 400 responses compared to our 2019 survey! Mencap opened the Big Learning Disability Survey on 6 May until 29 July 2022. As a result, our findings provide a record of the everyday lives and experiences of people with a learning disability in the months following the end of COVID-19 restrictions.

## Methods

### Survey design

The design of the Big Learning Disability Survey was informed by a working group of people with and without a learning disability. This ensured meaningful involvement of people with a learning disability in decisions around the content and format of the survey. This group helped to improve the accessibility of the survey. A mixed methods approach was used, with some open text questions. This allowed respondents to share their thoughts, feelings, and experiences of a learning disability.

Question topics included in the survey aligned with Mencap's strategic priority areas and the findings will be used to inform our: 1) strategic direction, 2) influencing and campaigning, and 3) programme and service delivery.

There were a total of 24 questions. Following feedback, this was reduced from 43 questions in 2019.

The survey took an estimated 10–15 minutes to complete.

### Survey dissemination

The Big Learning Disability Survey was delivered online through the Alchemer platform. The survey was made available in English and Welsh in an Easy Read format. Other languages were available upon request. The online English version featured audio clips of questions for improved accessibility. Paper copies and freepost envelopes were available upon request. Face-to-face support was also available for those completing the survey, upon request.

The survey was promoted using a mixed communication approach with various channels such as social media (including Facebook, Twitter and LinkedIn) and promotion via emails and newsletters. We would like to express our thanks to Mencap's Network Partners, learning disability organisations and groups, and stakeholder network across the UK for their promotion of the survey.



# DATA ANALYSIS

## Quantitative data analysis (numbers)

For this analysis, we addressed a number of outcome questions:

- Does this person have a paid job?
- Is this person in a relationship?
- Is this person worried about money and support?
- Is this person worried about living costs?
- Does this person experience loneliness?
- Is this person accessing healthcare services?

Other things we measured were: age, gender, region, relationship status, living arrangements, independent living, future outlook, loneliness, money and support, help and support, living costs, and connection to Mencap<sup>2</sup>.

More detailed statistical analysis is available on request. Please contact [research@mencap.org.uk](mailto:research@mencap.org.uk).

## Qualitative analysis (words)

The Big Learning Disability Survey included 2 open text questions. A few questions also presented an open text box for those selecting 'other'. A colleague with a learning disability co-led on the coding of responses. We used thematic analysis to analyse people's comments. This means we coded and categorised the comments according to the topic they were referring to<sup>3</sup>.

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<sup>2</sup> — We examined the distribution of all covariates (variables of interest) in the survey sample. Frequencies were used for categorical variables. Crude odds ratios for the association between predictor variables and response variables were calculated. P-values were estimated using the Wald test. Variables with p-values <0.05 were retained in the logistic regression model. People aged 65 and over were excluded from analyses wherein paid job was identified as a significant variable, as we wanted to focus on working-age adults. Logistic regression was used to estimate adjusted odds ratios with 95% confidence intervals to explore the association between variables of interest. All analyses were performed with SPSS v27.0.

<sup>3</sup> — These responses were manually coded for all respondents. All personally identifying information was removed to maintain anonymity of the data. A total of 3,180 responses were provided to all free text questions. No word limit was given. Single responses were up to 175 words in length. A manual coding approach was used to analyse responses. An inductive coding process was used for the thematic analysis of participant responses. Qualitative data analysis software (NVivo) was used to support data analysis.

# WHO TOOK PART IN MENCAP'S BIG LEARNING DISABILITY SURVEY?

1,972 adults (aged 18+) with a learning disability, living in the UK took part in Mencap's Big Learning Disability Survey.

## Age

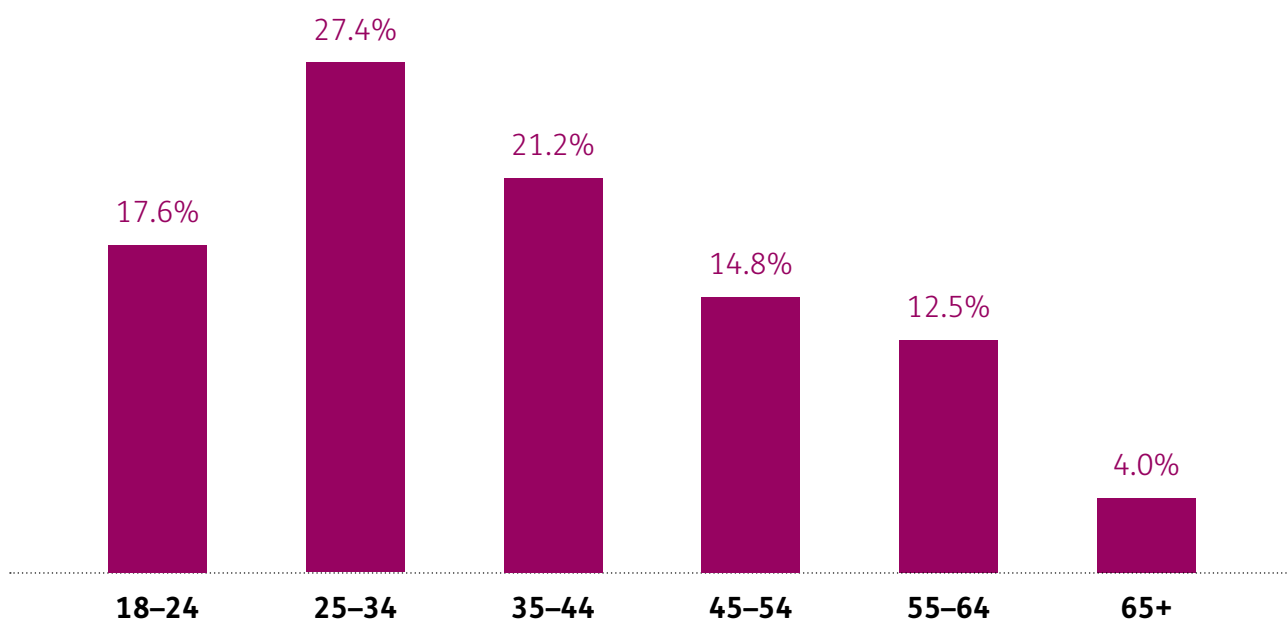
The majority of people who took part (93.4%) were aged 18-64 years old, while only 4.0% were 65 and over.

## Gender

51.8% of respondents were female and 44.1% were male. 0.9% were transgender, 1.1% selected 'other', and nearly 3% said they didn't know or would prefer not to say.

## Ethnicity

88.8% of respondents identified as White, 3.0% identified as Black or Black British, 2.7%



Age (years)

Figure 1: Age of respondents

identified as Asian or Asian British, 2.3% identified as Mixed or multiple ethnic groups, 0.1% identified as 'Other ethnic group', and 3.1% said they didn't know or would prefer not to say.

### Geography

84.4% of respondents were from England (3.8% North East, 11.0% North West, 8.3% Yorkshire & the Humber, 10.3% East Midlands, 7.6% West Midlands, 6.9% East, 13.2% London, 14.7% South East, 8.6% South West). 5.7% were from Wales, 2.8% Scotland, 4.6% Northern Ireland, and 2.6% said 'don't know'.

### Living arrangements

76.1% of respondents live in a house or flat, 14.1% live in supported housing, 3.8% live in residential care or a care home, 0.5% live in a caravan or mobile home, 0.2% live in a long stay hospital, and 5.3% live somewhere else.

42.1% of respondents live with their parents, 18.7% live on their own, 13.4% live with a partner, 13.1% live with friends or housemates, 10.4% live with other family members, 7.1%

live with a paid support worker, 6.3% live with their children, and 5.3% selected 'other'.

### Connection to Mencap

Respondents were asked whether they have a connection with Mencap. This was a multiple response question.

1. I do not have a connection to Mencap (39.2%)
2. I have heard of Mencap (37.9%)
3. I am supported by a Mencap service (17.1%)
4. I go to a Mencap local group (13.0%)
5. I work or volunteer for Mencap (7.6%)
6. I campaign for Mencap (3.2%)
7. Other (8.5%)

Most respondents who selected 'other' said that they are currently (or have previously been) members of a Mencap group. Some people mentioned that their family or friends have previously worked for Mencap. Others shared that they currently (or have previously) received support from Mencap services or engaged with Mencap Trust Company.





# RESULTS

## Paid work

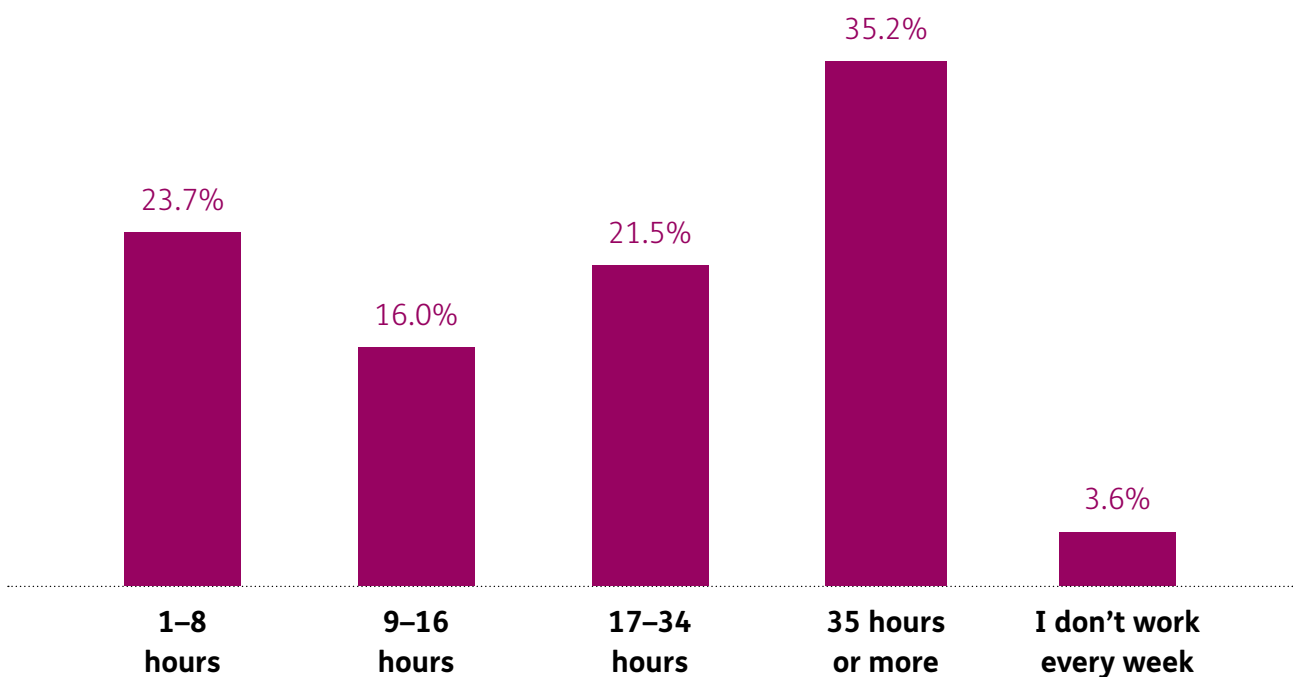


Over a quarter (26.7%) of working age adults ( $\geq 18$  to  $< 65$  years) who took part in the survey said they have a paid job. This is an increase from 2019, whereby 23% of working age adults said they have a paid job.

Of these respondents, 23.7% said they work for 1 to 8 hours each week, 16.0% work for 9

to 16 hours a week, 21.5% work for 17 to 34 hours a week, 35.2% work for 35 hours or more, and 3.6% said 'I don't work every week'.

73.3% of respondents said they do not have a paid job. Of these respondents, 36.7% said they would like a paid job.



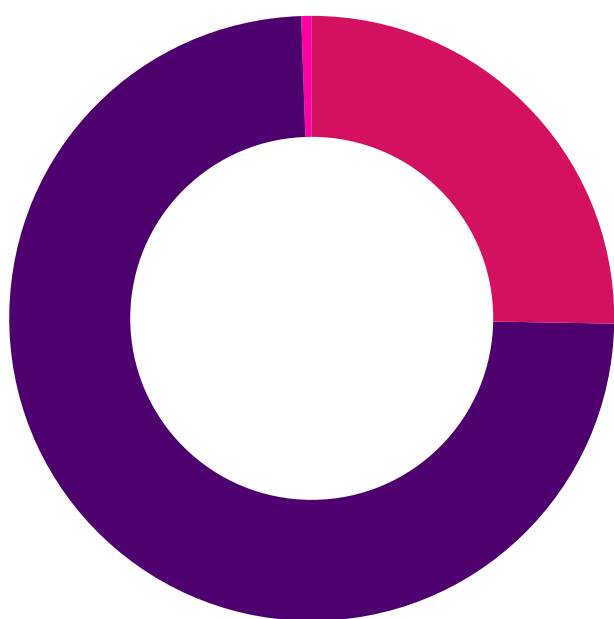
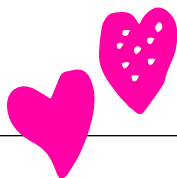
How many hours of paid work do you do in a week?

Figure 3: Number of hours of paid work per week

### We also found that:

- People aged 35–44 years were significantly more likely to have a paid job compared to the youngest group (18–24 years).
- People who are in a relationship were more likely to be employed compared to people who are single or divorced or widowed.
- People who live in London were more likely to have a paid job compared to people who live in the rest of the UK.
- People who live in supported housing were less likely to have a paid job compared to people who live in a private home.
- People who live on their own were more likely to have a paid job compared to people who do not live on their own.
- People who selected ‘agree’ or ‘neither agree nor disagree’ for the statement “I am feeling good about the future” were more likely to have a paid job compared to people who said ‘disagree’.
- People who said they are worried about living costs were more likely to have a paid job compared to people who said they are not worried about living costs.

## Relationship status



- 'I am married' or 'I am in a relationship': 25.4%
- 'I am single' or 'I am divorced or widowed': 74.3%
- Prefer not to say: 0.3%

Are you single or in a relationship?

Figure 4: Relationship status of respondents

25.4% of people with a learning disability reported that they are in a relationship ('I am married' or 'I am in a relationship'). 74.3% said

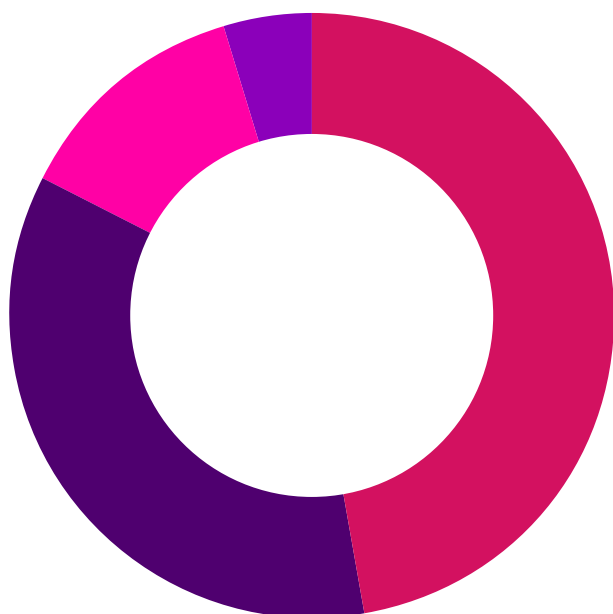
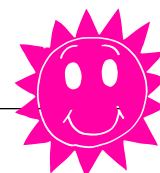
that they are not in a relationship ('I am single' or 'I am divorced or widowed'). 0.3% said 'prefer not to say'.



### We also found that:

- People aged 25–64 years were significantly more likely to be in a relationship or married compared to the youngest group (18–24 years).
- People who identified as Mixed were less likely to be in a relationship or married as those who identified as White.
- People who have a paid job were more likely to be in a relationship or married compared to people who are unemployed.
- People who live on their own were less likely to be in a relationship or married compared to people who said they live with other people.
- People who said they are worried about living costs were more likely to be in a relationship or married compared to those who are not worried about living costs.

## Healthcare



- Good: 47.4%
- Okay: 35.2%
- Poor: 12.9%
- Don't know: 4.5%

*Think about your most recent appointment with a GP or hospital. How was your appointment?*

**Figure 5:** Respondents' rating of their most recent GP or hospital appointment

When asked about their most recent GP or hospital appointment, 47.4% of respondents said it was 'good' and 35.2% said it was 'OK'.

Worryingly, over 1 in 10 (12.9%) said their most recent appointment was 'poor', meanwhile 4.5% said 'don't know'.

We asked people what is the most important thing that could have been better at their appointment.

The vast majority of respondents said that better reasonable adjustments in healthcare settings to address their personal needs, would have made their appointment better:

***“I had my smear [test]. I think it would be good that when you receive your letter in the post about needing it, that if you are on the learning disability register, [they] should send [an] Easy Read guide to help. It wasn’t easy to find a simple version online.”***

(Female, 25–34 years)

A number of people said that they would prefer face to face appointments and expressed an aversion to online and/or telephone appointments. For example, one man said:

***“[An] actual face to face [appointment]. A phone appointment is not helpful for me as I find phone calls difficult to cope with.”***

(Male, 45–54 years)

Others with a learning disability may require or prefer online or telephone appointments. It is important to provide alternative forms of communication to facilitate access to healthcare services for people with specific needs.

Others mentioned lengthy waiting times before appointments:

***“They made me wait [a long] time in the waiting room. This made me distressed. And I became agitated at my appointment.”***

(Male, 35–44 years)

Some people expressed a wish for longer appointments. One man said:

***“More time to express [my] concerns and feelings better.”***

(Male, 45–54 years)

Many people also expressed a desire for healthcare professionals to improve their knowledge and understanding of people with learning disabilities:

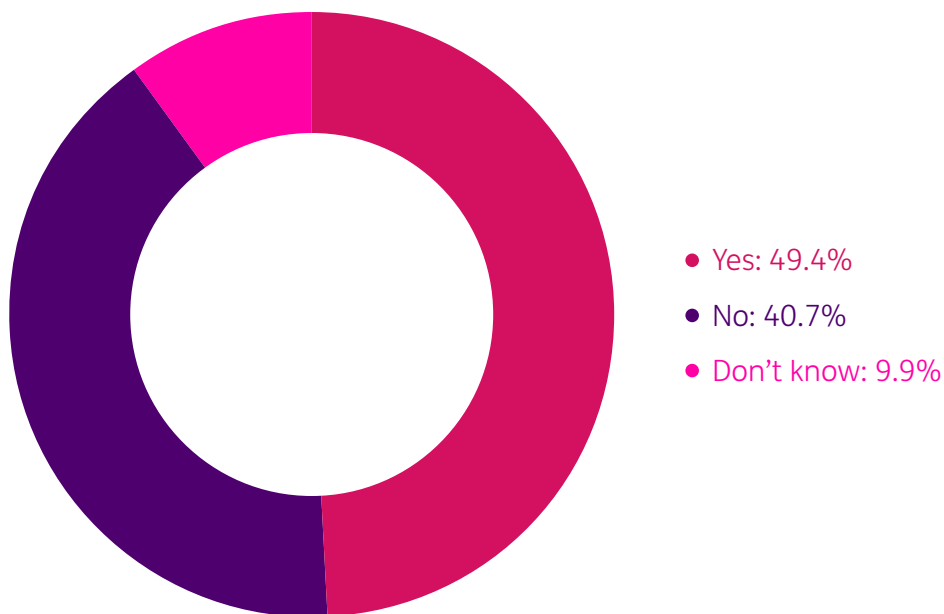
***“Understanding that because I have learning difficulties does not make me stupid or [that] they need to speak to my partner and not me.”***

(Female, 25–34 years)

***“The doctor had no real idea of how to talk to me. I use [Picture Exchange Communication System] PECS and [they] did not really understand my learning disability or autism...”***

(Male, 18–24 years)

## Annual health checks



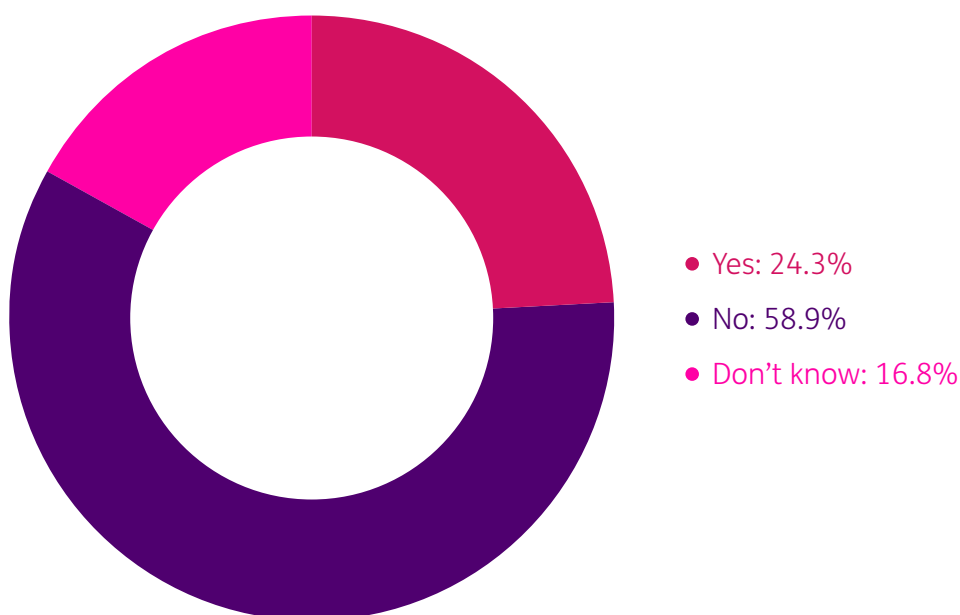
- Yes: 49.4%
- No: 40.7%
- Don't know: 9.9%

*Have you had an annual health check in the last year?*

**Figure 6:** Respondents' annual health check attendance in the last year

When asked if they have had an annual health check in the last year, 49.4% of respondents said 'yes', 40.7% said 'no' and 9.9% said 'don't know'.

When asked about their most recent health check, 58.0% of respondents said it was 'good', 32.9% said it was 'OK', 6.5% said it was 'poor', 2.6% said 'don't know'.



- Yes: 24.3%
- No: 58.9%
- Don't know: 16.8%

*Did you get a Health Action Plan at your most recent annual health check?*

**Figure 7:** Percentage of health action plans received at most recent annual health check

## We also found that:

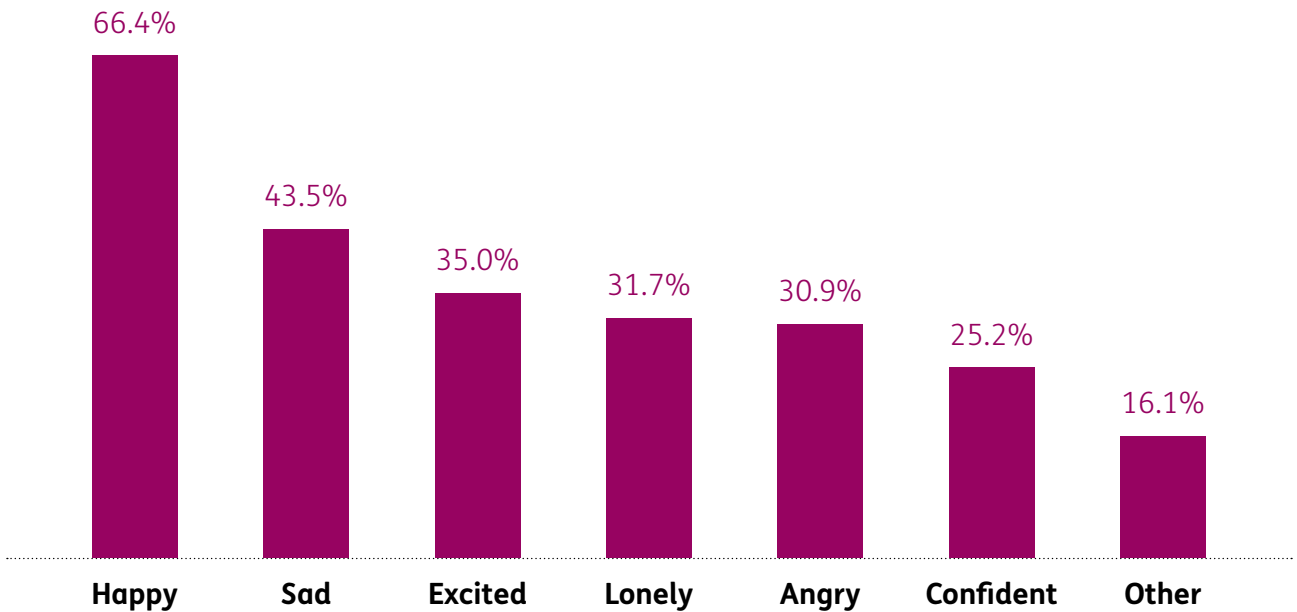
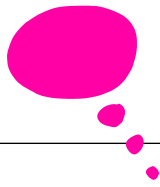
- People aged 55–64 were significantly more likely to have had an annual health check in the last year compared to 18–24-year-olds.
- People who said they are in a relationship or married were less likely to have had an annual health check in the last year compared to those who are single or divorced/widowed.
- People who live in supported housing were more likely to have had an annual health check in the last year compared to people who live in private homes.
- People who said they ‘agree’ or ‘neither agree nor disagree’ with the statement “I am feeling positive about the future” were more likely to have had an annual health check in the last year compared to people who ‘disagreed’.
- People who said they have been worried about going out in the last month were less likely to have had an annual health check in the last year compared to those who did not feel worried about going out.
- People who said they are worried about money and support were less likely to have had an annual health check in the last year compared to those who said they are not worried about money and support.

Previous research has established that people with a learning disability are at an increased risk of avoidable death and reduced life expectancy when compared to the general population (Ramsey et al., 2022). Annual health checks provide a crucial opportunity for healthcare professionals to monitor the health and wellbeing of people with learning disabilities. Our results show that over 4 in 10 (40.7%) respondents did not have an annual health check in the last year. This finding



illustrates a significant need for additional support and resources to facilitate access to primary care services. Mencap’s recent GP surgery survey provided close insights into the mixed experiences of people with a learning disability, wherein one respondent said that they “insisted” on an annual health check, whilst another respondent described their GP as “proactive”. Our research emphasises that GPs must improve engagement of people with a learning disability to ensure their continuity of care.

Accessible communications enable people with a learning disability to effectively engage with healthcare services. Our results show that almost 6 in every 10 (58.9%) people with a learning disability did not receive a Health Action Plan at their most recent annual health check. Furthermore, over 1 in 10 (16.8%) did not know whether or not they had received a Health Action Plan. These findings emphasise an urgent need for improvement in the quality of annual health checks. In light of these findings, we encourage GPs to ensure that people with a learning disability receive the support they require in accordance with the Accessible Information Standard.



Think about the past week.  
Which feelings and thoughts have you had?

Figure 8: Respondents' feelings and thoughts in the past week

Respondents were asked to think about their feelings and thoughts in the past week. This was a multiple response question.

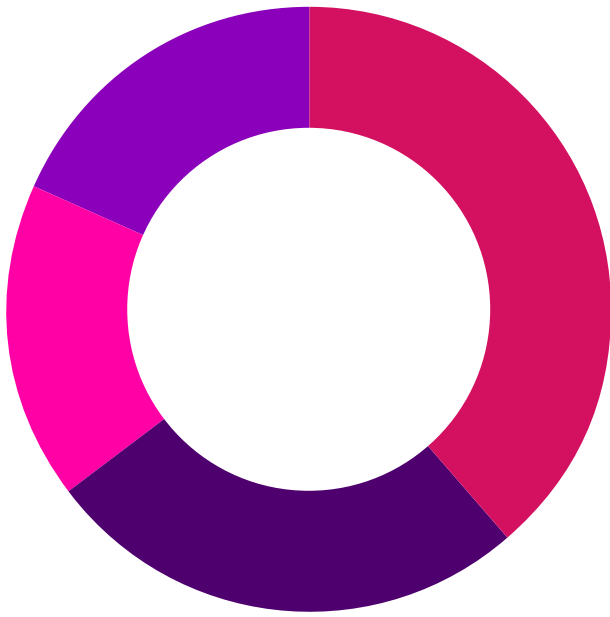
A few people expressed that they have been experiencing mixed emotions. One woman said:

1. Happy (66.4%)
2. Sad (43.5%)
3. Excited (35.0%)
4. Lonely (31.7%)
5. Angry (30.9%)
6. Confident (25.2%)
7. Other (16.1%)

**“Up and down as my feelings can change.”**

(Female, 45–54 years)

The most common ‘other’ responses were “anxious”, followed by “frustrated”, “confused”, and “worried”.



- Agree: 38.8%
- Neither agree nor disagree: 26.0%
- Disagree: 17.1%
- Don't know: 18.1%

How much do you agree or disagree with the following statement?  
 “I am feeling positive about the future”

Figure 9: Respondents' future outlook

Respondents were asked how much they agree or disagree with the following statement “I am feeling positive about the

future” and in response, 38.8% said ‘agree’, 26.0% said ‘neither agree nor disagree’, 17.1% said ‘disagree’, and 18.1% said ‘don’t know’.

## Discrimination



Respondents were also asked if, in the last month, there were any times that they didn’t go out because they were worried about something. Results showed, 41.1% said ‘yes’, 46.6% said ‘no’, and 12.3% said ‘don’t know’. When asked what stopped them from going out, the most common worries people identified were:

1. People calling me names or bullying me (14.7%)
2. Using public transport (10.8%)
3. Getting lost (10.6%)
4. Asking a member of the public for help (10.5%)
5. People ignoring me (9.6%)
6. People laughing at me (3.5%)

Almost a third of people (33.2%) selected ‘other’ and shared a range of reasons why they were worried about going out. Some people commented that COVID-19 remains an issue of concern, including the impact of the pandemic on their mental health and wellbeing. One woman said:

**“I have lost my confidence due to the Covid restrictions and it has left me anxious about going out into the community to access activities.”**

(Female, 25–34 years)

Others expressed worries relating to being around the general public. One man said:

***“Getting overwhelmed in a busy city centre and having to [face] anxiety interacting with people in shops.”***

(Male, 35–44 years)

A few people commented that their main worry was the mistreatment they had received from the general public, due to a lack of understanding about learning disabilities. For example, one woman said:

***“A lot of people like me who have a learning disability and possibly other non-visible disabilities [receive] abuse from the public who are uneducated...”***

(Female, 18–24 years)

Respondents were asked where they would go for help and support if they were being treated unfairly. This was a multiple-response question.

1. Family or friends (69.6%)
2. Support workers (37.0%)
3. Police (17.4%)
4. Charities (13.8%)
5. Day centres (12.7%)
6. I do not know where to go for help and support (12.3%)
7. Other (8.8%)

Most respondents who selected ‘other’ emphasised that they are unable to independently ask for help or support. One man said:

***“I am not capable of getting help, my family would have to do it for me.”***

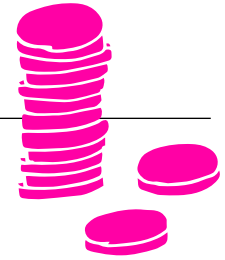
(Male, 25–34 years)

Additional responses we received under ‘other’ included going to their Mencap day centre, or support workers. Others said that they would go to staff at their college or university and a few people said that they would go to their healthcare workers such as their GP.

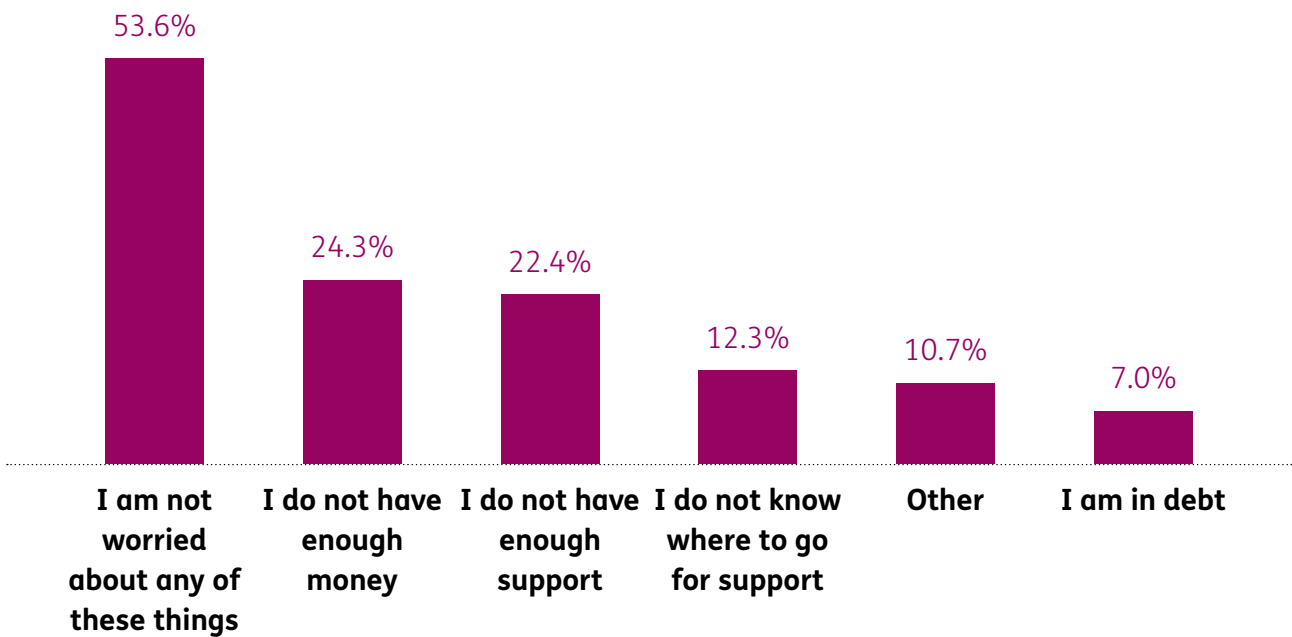
#### **We also found that:**

- People who said they ‘agree’ or ‘neither agree nor disagree’ with the statement “I am feeling positive about the future” were significantly less likely to have felt lonely in the past week compared to people who ‘disagree’ with the statement.
- People who said they were worried about going out in the past month were more likely to have felt lonely compared to people who said they were not worried about going out in the past month.
- People who said they were worried about money and support were more likely to have felt lonely compared to people who said they were not worried about money and support.

## Money and support



As part of a multiple-response question, respondents were asked to think about money and financial support worries that they have had in the past week.



Think about the past week. Which of the following things have you been worried about?

1. I am not worried about any of these things (53.6%)
2. I do not have enough money (24.3%)
3. I do not have enough support (22.4%)
4. I do not know where to go for support (12.3%)
5. Other (10.7%)
6. I am in debt (7.0%)

Respondents who selected 'other' raised a range of topics. Some people said that they were concerned about money, from an increase in living costs to having enough to maintain their current lifestyle. One woman said:

**“Cost of price raises means cutting back on things such as outings... hobbies and specific dietary requirements.”**

(Female, 45–54 years)

Some respondents said that they were worried about COVID-19. One man said:

**“COVID getting worse again.”**

(Male, 18–24 years)



Others mentioned they would like to gain paid employment. A number of people expressed a desire to make a change in their living arrangements. One man said:

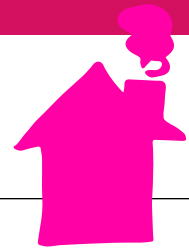
*“I’d like to have enough money to live in my own home.”*

(Male, 18–24 years)

### **We also found that:**

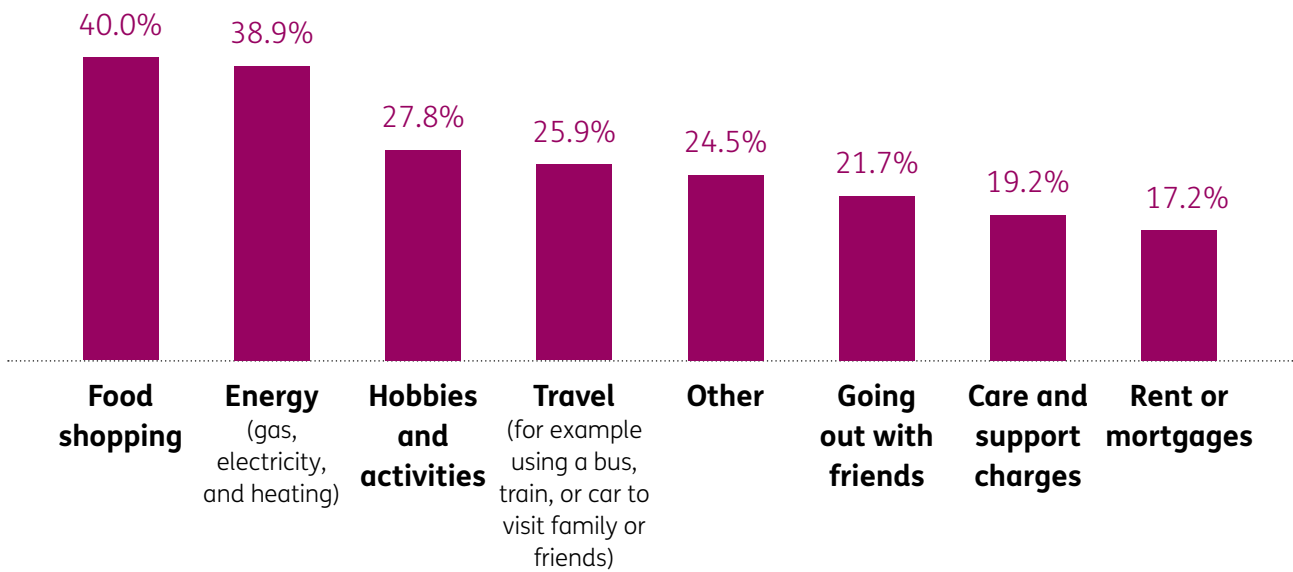
- People who said they felt lonely in the past week were significantly more likely to have worried about money and support compared to people who had not felt lonely in the past week.
- People who said they felt worried about going out in the past month were more likely to have worried about money and support compared to people who had not felt worried about money and support.
- People who said they felt worried about living costs were more likely to have worried about money and support compared to people who had not worried about living costs.
- People who said they had an annual health check in the last year were less likely to have worried about money and support compared to people who had not had an annual health check in the last year.





## Living costs

Respondents were asked to think about which living costs they have been worried about in the past week. This was a multiple response question.



*Think about the past week. Which of the following living costs have you been worried about?*

**Figure 11:** Respondents' worries about living costs

1. Food shopping (40.0%)
2. Energy (38.9%)
3. Hobbies and activities (27.8%)
4. Travel (25.9%)
5. Other (24.5%)
6. Going out with friends (21.7%)
7. Care and support charges (19.2%)
8. Rent or mortgage (17.2%)

Most respondents who selected 'other' said that their parent/carer, advocate, or financial deputy are wholly responsible for their living costs. One man said:

***"My parents take care of these things."***

(Male, 45–54 years)

Others expressed that they do not understand the concept of living costs or money. One man said:

***"I do not understand money so don't worry."***

(Male, 25–34 years)

Some people mentioned that their parent/carers are worried about living costs. One woman said:

***"My mum is my carer and I know she is worried about all of these things as she gets no financial support."***

(Female, 45–54 years)

A few people showed an understanding of the impact that the cost-of-living crisis will have on their households. One woman said:

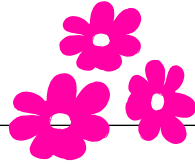
***"...the cost of living will [affect] us all and we will have to watch our spending."***

(Female, 25–34 years)

### **We also found that:**

- People who are in a relationship were significantly more likely to have worried about living costs compared to people who are single or divorced/widowed.
- People who have a paid job were more likely to have worried about living costs compared to people who are unemployed.
- People who live in supported housing were less likely to have worried about living costs compared to people who live in private homes.
- People who live on their own were more likely to have worried about living costs compared to people who do not live on their own.
- People who said they have felt lonely in the past week were more likely to have worried about living costs compared to people who had not felt lonely.
- People who said they are worried about money and support were more likely to have worried about living costs compared to people who said they are not worried about money and support.

## Making life better



At the end of the survey, we asked people what is the most important thing that would make their lives better. We also asked if there was anything else they would like to tell us.

The most common responses were related to getting a paid job, getting more personal support, friendships and socialising, tackling discrimination, a lower cost of living, and having greater independence. Other things that people said would make their life better included better health and healthcare, being in a relationship, and being able to go on holiday.

### **Paid work**

Many people said that having a paid job would make their life better. One person expressed a desire to participate more effectively in society:

***“To have a job [and] to feel [like a] valued member of society.”***

(Female, 25–34 years)

Others also attributed their current unemployment to the COVID-19 pandemic, with one man saying:

***“A job. I lost mine after 20 years due to the Covid restrictions.”***

(Male, 45–54 years)

A few respondents said that as well as getting a paid job, they would like to find opportunities in specific industries of interest. For example, one man said:

***“[Working] on the train. This is my dream job.”***

(Male, 18–24 years)

### **Personal support**

Many people expressed that an increase in personal support hours would improve their life, including on weekends and during the evening. For example, one woman said:

***“I would like to go out in the evenings, but I don’t have a [one-to-one] carer after 3:30pm every day.”***

(Female, 25–34 years)

Some commented that improved training for support staff to better address their (inter) personal needs would improve their life:

***“Support staff should be better trained in person centred approaches and how to handle mobility aids.”***

(Female, 55–64 years)



Some people said their life would be better if they had more things to do, especially in their local area:

***“More local activity groups for my age group.”***

(Transgender, 18–24 years)

***“More activities for people like me in my local area.”***

(Female, 25–34 years)

Others raised concerns relating to a lack of continued care provision by support workers in addition to limited availability:

### **Friendships and socialising**

***“My [support workers] keep changing. No one stays in the job long enough to get to know me. The agency can't find workers.”***

(Female, 35–44 years)

A number of people who took part in the survey said that more opportunities to socialise and take part in activities would make their life better. A few activities and interests were mentioned, including: knitting, trips to the cinema, going swimming, watching football, and joining a dance group. For example, one person said they wanted:

***“More arts and craft groups during the day.”***

(Female, 45–54 years)

Many people said that the opportunity to socialise during activities appealed most to them. For example, one woman said that the main thing that would make their life better would be:

***“To have a sport to enjoy and to have friends. I have never had any friends only support workers and that is not the same.”***

(Female, 55–64 years)

### **Cost of living**

Many respondents expressed that increased living costs have caused them to feel worried, stressed, and unable to cope. Several people emphasised that a reduction in living costs would make their life better:

***“Being able to afford life, paying my bills keeps me awake and anxious. Food shopping unaffordable, bills, rent, unaffordable.”***

(Female, 25–34 years)

***“Feeling financially safe. Anxiety ruling not being able to afford cost of living scandal. No help whatsoever.”***

(Female, 25–34 years)

***“That the cost of everything wasn't going up so much. Electric, food, oil, diesel.”***

(Female, 65 years and over)

***“Not having to watch prices going up when my money doesn't.”***

(Male, 35–44 years)

***“Lowering prices so my money goes further and I can feed my family.”***

(Female, 25–34 years)

***“Getting the cost of living down, although I have accepted that will never happen. Once prices go up they never come down again.”***

(Male, 55–64 years)

One participant shared more insight into their financial circumstances:

***“I hardly have any money to live on after my care top up has gone out. I have to pay for activities for myself and 2 carers to keep me safe due to my high needs. Haircuts, toiletries, clothes, shoes, petrol for journeys to see my family every week all has to come out of the £25 I have left.”***

(Male, 18–24 years)

Some people remarked that their life would be better with additional support from the government:

***“More money from the government.”***

(Male, 35–44 years)

***“The government to talk about cost of living and how things can improve.”***

(Male, 25–34 years)

## **Discrimination**

Some people expressed that less discrimination towards people with learning disabilities from the general public would make their life better. For example, one person said:

***“People to listen and not look down on [us]. [We] have a learning disability, not stupidity”.***

(Female, 55–64 years)

Another respondent said:

***“Not living in a society that treats people like me as less than.”***

(Queer, 35–44 years)

Other respondents discussed improving the general public's understanding of people with learning disabilities, including preconceived assumptions about their abilities and needs:

***“Stop, listen, and learn. Don't wrap us up in cotton wool. Everyone should be given an opportunity & choice to achieve the things they want in life. Stamp-out: attitudes and making assumptions must stop.”***

(Female, 35–44 years)

One participant highlighted a need for improved representation for people with learning disabilities within the LGBT community:

***“Representation. There are about 5 groups for LGBT at work but none for learning difficulties. [No one] seems to know what support is available, and the government help I did sign up for was awful and degrading.”***

(Female, 25–34 years)

## Independence

Many respondents said that they would like to be more independent in many areas of their life, from getting a job to being able to go out more without a parent/carer or support worker. Some people said that living in a place of their choice (such as a private household or supported accommodation) would provide independence whilst meeting their needs. One man said:

***“I would like to live in my own home, or maybe shared with people my own age, with the support I need.”***

(Male, 25–34 years)

Others expressed they would like to have more independence in the place they are currently living:

***“Having more freedom. I can't do what I want to do without having my parents take me there. I want to have more independence and that is hard [as I] am nearly 20.”***

(Female, 18–24 years)

A few people said that they would like to have more places suitable for their needs available in their area.

***“More independent living places became available in my area to enable me to move out of home.”***

(Male, 25–34 years)



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