

How's Life?

Survey Methods and Analysis

The Scottish Commission for People with Learning Disabilities October 2020



Survey and Question Development

This research was undertaken by SCLD to find out what people with learning disabilities in Scotland felt about their lives, and to see which areas might need to be the focus of policy and practice change over the coming years.

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? questionnaire, with the help of Ipsos MORI.

As well as taking account of the priorities set out in *The keys to life* framework 2019-2021, our partnership group provided invaluable support to shape the questionnaire so that the focus was on what mattered to people with learning disabilities.

Early versions of the questionnaire were discussed by the partnership group with their respective members, with a focus on the relevance of the questions, comprehension, and accessibility of the question format. Before being finalised, the survey was user tested with a wider population of people with learning disabilities who had not been involved in the questionnaire design, with the help of our partnership group and Capability Scotland.

The final questionnaire was made up of six sections:

- 1. About you
- 2. Where you live
- 3. Your happiness
- 4. How you spend your time
- 5. Family, friends, and relationships
- 6. 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. With the help of PAMIS, a semi-structured story-telling exercise also ran alongside the survey as an alternative way to submit a person's response where this was more appropriate. To be eligible to fill in the survey, a person needed to be aged 16 or over.

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

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

SCLD aims to publish a series of reports to present our findings. The planned reports will cover:

Report 1: Relationships, social isolation, and loneliness

Report 2: Well-being

Report 3: Where people live

Report 4: What people do with their time

Who took part in the survey?

It is important to understand how representative the sample of respondents are of the population of people with learning disabilities in Scotland.

With help from our partner organisations advertising the survey and distributing through their networks, as well as direct approaches from service providers and individuals to SCLD, around 4000 hard copy questionnaires were distributed. After accounting for the removal of duplicate questionnaires, a total of 1,232 individual responses were received:

- 860 hard copy questionnaires from our initial distribution of 4,000
- 137 additional hard copies downloaded and printed from the SCLD website and returned to SCLD via post
- 231 completed online
- 4 people fed in their views and experiences via the story-telling exercise.

1,232 respondents represent around 1 in 20 (5.2%) of the 23,584 adults known to local authorities in 2019 and reported to Learning Disability Statistics Scotland (LDSS).¹² It is important to note however that both LDSS, and our survey sample are likely to be biased towards those accessing services. In 2000, *The same as you?* estimated that the population of people with learning disabilities in Scotland could be around 120,000. Our survey respondents represent 1 in 100 (1%) of this estimate. People with profound and multiple learning disabilities are also underrepresented within our survey sample.

¹ <u>https://www.scld.org.uk/wp-content/uploads/2019/12/Learning-Disability-Statistics-Scotland-2019.pdf</u>

² LDSS is the main source of information about the number and profile of people with a learning disability in Scotland. It is an administrative data set published on behalf of the Scottish Government by SCLD. It comprises individual level information collected annually from local authority information management systems on people with learning disabilities and/or autism, aged 18 and over (or aged 16 and 17 but not in full-time education) who have had contact with the local authority in the past year.

Gender

The gender profile of the participants was broadly in line with that of LDSS. More men than women filled in our survey.

- 51% of those who took part were men
- 47% were women
- 1% were transgender or described themselves another way
- Less than 1% did not give their gender

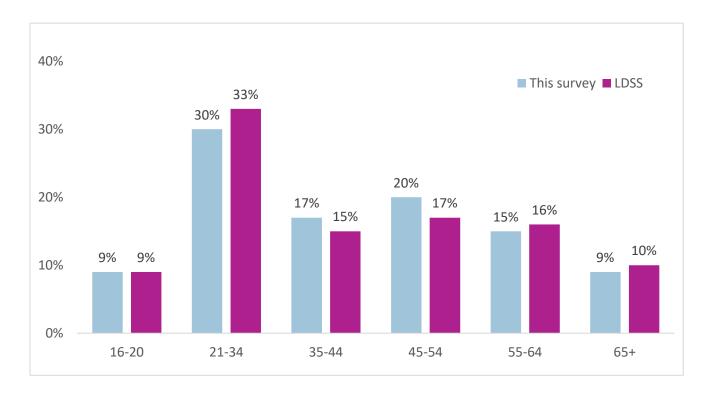
This is similar to the gender profile of adults with learning disabilities reported to LDSS in 2019:

- 59% were men
- 41% were women
- 0.01% were transgender or described themselves another way
- The gender of 0.03% was not known.

Age

The age profile of the participants was broadly in line with that of LDSS. The youngest participant was 16 and the oldest was 82.

Figure 1: Age profile of survey respondents and those known to local authorities via LDSS

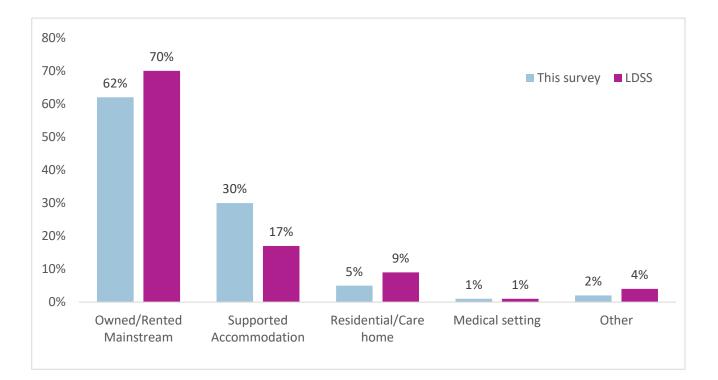


n=1153

Accommodation

More people who responded to the survey were living in supported accommodation, and less living in mainstream housing or care homes than the population of LDSS. This could potentially reflect the fact that many copies of the survey were distributed through support organisations working with, or delivering support within, supported accommodation. It could also reflect differential understandings of the term supported accommodation.

Figure 2: Type of accommodation lived in by survey respondents and those known to local authorities via LDSS



n=1188

Geography

Responses were received from every local authority area in Scotland.

955 people gave their postcode information.

Compared to figures from LDSS, some rural areas such as Dumfries and Galloway and the Scottish Borders are over-represented.

Conversely, there is underrepresentation from some large urban areas such as East Ayrshire and Lanarkshire.

Figure 3: Where respondents live compared to those known to local authorities via LDSS

Local Authority	Number	% of LDSS Population	Survey Number	% Survey Respondents
Aberdeen City	1,056	4.5	22	2.3
Aberdeenshire	1,042	4.4	29	3.0
Angus	480	2.0	29	3.0
Argyll & Bute	330	1.4	10	1.0
City of Edinburgh	2,184	9.3	109	11.4
Clackmannanshire	272	1.2	6	0.6
Dumfries & Galloway	900	3.8	89	9.3
Dundee City	1,101	4.7	67	7.0
East Ayrshire	566	2.4	6	0.6
East Dunbartonshire	476	2.0	8	0.8
East Lothian	629	2.7	18	1.9
East Renfrewshire	433	1.8	9	0.9
Falkirk	691	2.9	22	2.3
Fife	1,114	4.7	77	8.1
Glasgow City	2,171	9.2	89	9.3
Highland	1,028	4.4	46	4.8
Inverclyde	499	2.1	14	1.5
Midlothian	466	2.0	22	2.3
Moray	430	1.8	18	1.9
Na h-Eileanan Siar	152	0.6	2	0.2
North Ayrshire	605	2.6	23	2.4
North Lanarkshire	1,785	7.6	25	2.6
Orkney Islands	91	0.4	1	0.1
Perth & Kinross	433	1.8	36	3.8
Renfrewshire	826	3.5	20	2.1
Scottish Borders	555	2.4	80	8.4
Shetland Islands	164	0.7	7	0.7
South Ayrshire	470	2.0	13	1.4
South Lanarkshire	1,085	4.6	10	1.0
Stirling	396	1.7	16	1.7
West Dunbartonshire	458	1.9	6	0.6
West Lothian	696	3.0	26	2.7
Scotland	23,584	100	955	100

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

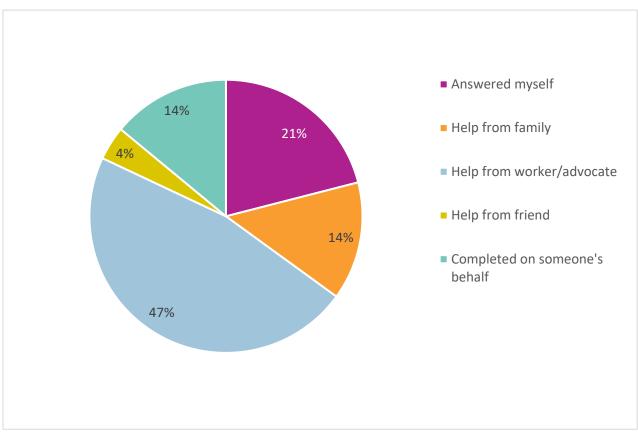


Figure 4: Support to fill in the survey

n=1183

There are obvious limitations to using a self-complete questionnaire. For example, they rely on people being able to read and understand the questions themselves, without an interviewer being able to read them out and explain any unclear terms.

However, work to make the questionnaire as accessible as possible, as well as guidance in place to aid those providing support to people with learning disabilities complete the survey, made it possible for over 1200 people to participate. Of course, those who completed the survey are much more likely to be connected to, and receiving, social work, health and third sector services.

Nevertheless, the response to the survey was not only enthusiastic, but also, overall, a good representation of the wider population of people with learning disabilities. On that basis, we believe it is a good foundation for considering people's views and experiences.

Analysis

The questionnaire comprised a total of 30 questions. These included five demographic questions and a question to capture if the person had any help to fill in the questionnaire. There were 19 tick box questions across sections 2-5, with a space at the end of each section to provide comments if the respondent chose. Section 6 comprised two open ended questions asking what mattered most to people, what they would change about their lives and a final open question for people to tell us anything they else they wanted to.

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, known as the base, is outlined under each chart. The base for each question is generally calculated on those who chose an answer other than 'not sure.' Percentages given are calculated using the stated base for each question.

Where the analysis has looked at two questions together to determine whether there was a relationship between two variables, the base number under the chart denotes the number who answered both questions. In general, we have only reported where a statistically significant relationship has been found between variables.³ To do this, we have used a statistical test called a chi-square test to determine the probability that the variables are independent of one another (i.e. any differences between the two variables are simply down to random chance). We have reported where the probability of the variables being independent of each other is less than 5% (i.e. it has a p value of less than 0.05).

The data were analysed using Microsoft Excel and a statistical software package called Stata.

Open questions were analysed manually using content analysis, whereby answers were read and the topics within each identified so that these could be counted and grouped into overarching themes. Due to the reductive nature of content analysis, the report has drawn on direct quotes from the open questions where appropriate.

³ Where this is not the case, it is stated within the report.

Contact us

Website: **www.scld.org.uk** Twitter: **@SCLDNews** Facebook: **@ScotCommission** Instagram: **@scldnews**

For information on Scotland's Learning Disability Strategy *The keys to life*, visit: **www.keystolife.info**

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