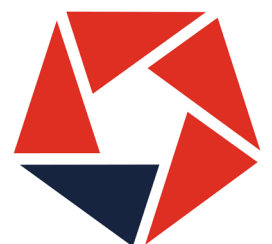




Evidence on the Financial Security of People with Learning Disabilities in Scotland

Technical Report

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INSTITUTE

Disclaimer

The analysis in this report has been conducted by the Fraser of Allander Institute (FAI) at the University of Strathclyde, and The Scottish Commission for People with Learning Disabilities (SCLD). The FAI is a leading economic research centre focused on the Scottish economy. SCLD is an organisation which supports people with learning disabilities to live full, safe, loving and equal lives.

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The analysis and writing-up of the results was undertaken independently by the FAI and SCLD. Any technical errors or omissions are those of the FAI and SCLD.

Summary

This report details the methodology used to complete the report titled *Evidence on the Financial Security of People with Learning Disabilities in Scotland*. This technical report is designed to inform those such as researchers, analysts and policymakers interested in replicating this methodology in further geographical regions or for other minority groups.

The study discussed had three objectives:

1. Gather quantitative data on the extent to which people with learning disabilities and their family/carers are supported adequately financially.
2. Gather qualitative insights on the adequacy, or otherwise, of the social security system and the impact it has on people with a learning disability and their families.
3. Provide an assessment of the impact of support provided by social care.

The researchers were also interested in piloting a microsample method for collecting data from people in minority groups – groups who are generally less well represented in national statistics covering income and poverty, such as people with learning disabilities. For Scotland in particular, where sample sizes are already small, the outcomes of minority groups can be difficult to measure and track over time. The methodology outlined below allows for a microsample of individuals within any minority group to be recruited and for data to be collected which aligns with national income/poverty statistics.

Sampling and Recruitment

The study aimed to recruit up to 30 individuals with learning disabilities in Scotland to participate in this research. The researchers aimed to collate a sample of individuals with a variety of household compositions, ages, genders, ethnicities, level/type of disability (including people with multiple disabilities or health conditions), care requirements, and geographies (including both across Scotland and urban/rural variety).

A range of recruitment methods were used to recruit those in the sample, including public advertisement of the study on social media, attending events relevant to people with learning disabilities, and approaching individuals/organisations known to the researchers who may be interested in/eligible for the study. Snowball sampling (where participants recommended someone else from their own networks to take part) was used at times. Purposive sampling was also used towards the end of the study to focus on demographics still missing from the sample. Separate social media posts were created to attract both people with learning disabilities and their unpaid carers.

Remuneration of a £20 voucher per interview was provided to each participant (£40 per person for full participation in the research). Prezzy, the online voucher provider, was used to purchase and send vouchers. If the participant was able to access email, this was sent to them digitally. Some participants requested a paper voucher to be sent to their home.

The researchers were aware that a topic such as financial security could be sensitive and potentially off-putting to some people with learning disabilities. Furthermore, it was crucial that the researchers obtained informed consent from any participants taking part in the study. Therefore, the research team included an individual who led the recruitment of, and communication with, participants with learning disabilities (henceforth referred to as the recruitment manager). This person had extensive experience working with people with learning disabilities, and as such had a wide network to which they could promote the study.

To ensure informed consent, the recruitment manager met with each potential participant before they were interviewed (in person or online). The recruitment manager talked the participant through the nature of the study, what they would have to do if they agreed to take part, and how their information would be used. An easy read version of the participant information sheet, consent form, and privacy notice were created and provided to any participants who preferred this format. If the recruitment manager had concerns that the individual did not understand the nature of the study and was therefore unable to give informed consent, their participation was not taken forward (unless it was possible to contact a family member/unpaid carer who could take part and give consent on behalf of the individual).

The final sample for this study consisted of 24 participants, 21 of whom agreed to provide financial figures. While the researchers had some success with social media recruitment, the majority of participants came from the researchers' networks and links to relevant organisations. In particular, the research manager's networks were crucial to successful recruitment. The research manager was able to access populations where they had previously been involved in community work and were a 'known face' to people accessing various organisations. This provided an initial level of trust which put participants with learning disabilities at ease.

Conversely, accessing populations where the research team did not have strong links proved much more difficult. All research team members were white, and only one participant from an ethnic minority took part in the research. Most organisations known to the researchers tended to attract mainly white people with learning disabilities – the researchers are not aware of why this is the case, and the issue has been discussed as an action point in some of the organisations. The research manager attempted to reach out to local ethnic minority communities by speaking to BAME individuals known to have wide networks. One such conversation revealed cultural differences in the understanding and treatment of those with learning disabilities, as well as different cultural opinions on talking about finances.

In terms of sample size, the researchers would recommend the use of saturation points where possible. A saturation point is reached in qualitative research when no significant new themes/findings are being collected through interviews. Different populations will have differently diverging views and experiences amongst their members, and as such saturation points will be different depending on the population of interest.

The researchers stopped at 24 participants in this study partly due to time constraints, and partly due to exhausting the number of potential participants in personal networks. Continuing to 30 participants may have provided a clearer saturation point but this would have likely taken more time

and resources to achieve. Research almost always exists within resource constraints – keeping questions focused and using purposive sampling can help to reach saturation point sooner.

Data collection

This study used qualitative, in-person interviews to collect data. Two interviews were completed with each participant. The first interview was semi-structured, and the second interview was more structured. Interview schedules can be found in Appendix A and Appendix B. Interviews were done in person rather than online wherever possible to maximise understanding and trust, and to reduce the risk of participants who found the research via social media pretending to be eligible to access vouchers (a phenomenon seen both in this research and previous projects).

Interview 1 was designed to build a rapport with the interviewee and gain an overall understanding of their financial circumstances. This interview covered the participant's housing arrangements, work experience, understanding of money and benefits, and their ability to afford a list of basic items. This interview was usually conducted one-to-one with the person with a learning disability, unless they requested to have a family member or carer present. If a family member or unpaid carer gave permission on behalf of the person with a learning disability, the family member/unpaid carer led this part of the interview with some input from the person with a learning disability.

A second schedule for the first interview was originally utilised for parents/carers. Throughout the research it was found that this schedule wasn't necessary, as the schedule for people with learning disabilities was suitable for carers who answered questions on behalf of, or with, the people with learning disabilities who they looked after. When speaking to carers, we asked for further reflections on their role and any financial pressures or difficulties faced in context.

It was recommended to us during our ethics review that paid carers should not be included in the research as they should not have control of their clients' money. At no point were paid carers officially involved in the research or given payment for participation. However, in one case a paid carer was present at interview to assist with our understanding, as the participant had a speech impediment and could not move around independently.

Interview 2 was designed to collect information which would allow the researchers to replicate income information gathered in the Family Resources Survey/Households Below Average Income Survey. This survey is the standard survey used to measure the rate of relative poverty in the UK. The questions in interview 2 were designed to collect all the figures necessary to calculate total household income for each participant and ascertain whether they were living in relative poverty.

Interview 2 also collected information on household expenditure in key areas such as food, transport, energy, care, and telecommunications. This was collected so that participants' spending on essentials could be compared with disabled participants' spending as recorded in the Living Costs and Food Survey (LCFS).

Interviewers prepared participants for the questions which would be asked in interview 2 at the end of interview 1. The researchers asked participants to bring along a bank statement or their mobile banking app, as well as any other bills or benefit letters which they felt would be useful (such as a letter stating which benefits they received if they were not sure at the time of interview). Participants were also asked to keep note of spending on food and transport for a week if possible, and take a note of their energy, care and telecommunications costs if these were not visible in their bank statement.

The method of using two interviews was highly successful in building trust and ensuring full understanding and informed consent for the participants. It also allowed the researchers to clarify any areas of misunderstanding or confusion raised in Interview 1. Several participants completed Interview 1 alone, then brought along an unpaid carer or family member to Interview 2 to support them in sharing information about their finances. This option worked well as it allowed people with learning disabilities to share their story on their own terms and have support where they needed it.

Some participants struggled with managing or understanding their money without support due to their learning disability. We encouraged those who received help with money from family or unpaid carers to bring whoever helped them with this to the second interview. On some occasions, this meant that only one interview was conducted with participants, as their family member/unpaid carer was unavailable or did not wish to take part.

Interviews were audio-recorded and later transcribed. Researchers also wrote down important information such as benefit types or monetary figures during interviews.

Analysis

Analysis of interview content was completed using NVivo software. Transcripts were added to NVivo and coded using a mix of deductive and inductive coding. The coding framework used can be found in Appendix C. Further coding was completed in Excel to understand the relationship between satisfaction with finances and satisfaction with care as discussed in the main report section titled *Does the adequacy of social care affect financial security?* (page 20).

For the quantitative analysis, income and expenditure figures were entered into a spreadsheet. The researchers calculated total income before and after housing costs for each household, and equivalised these amounts using the equivalisation factors used in the FRS/HBAI (DWP 2024).¹ The equivalised poverty line after housing costs for the latest available FRS data (financial year ending 2023) was inflated to September 2024 values and used to sort households above/below the poverty line.

A second poverty line was calculated excluding additional cost benefits such as PIP, ADP and DLA. This was completed in Stata using the latest FRS and HBAI data. This is an accepted alternative measure of poverty for those who receive benefits designed to cover the additional costs of disability (Scottish Government 2024).

The researchers also wanted to compare participants' incomes to the minimum income standard (Centre for Research in Social Policy 2025). The Minimum Income Standard is calculated for various common household compositions, such as a single adult, couple with two children, etc. However, in our sample many participants did not fit into these categories – several households, for example, included adult children living with their parents. The MIS cannot currently be calculated for households such as these.

To approximate a Minimum Income Standard for all households, the MIS for a couple with no children was used as an equivalised minimum income standard. This decision was based on the equivalisation factors used in the FRS and HBAI – Adult 1 in a household is given a value of 0.67, and

¹ Housing costs collected from participants were made up of rent/mortgage payments and council tax. FRS/HBAI housing costs contain rent/mortgage payments as well as charges such as building insurance, service charges and ground rent. These additional charges were not well understood by participants, and the decision was made to use participants' council tax costs as a proxy for additional charges. As council tax is normally deducted from BHC incomes, council tax was therefore deducted a second time to calculate AHC incomes.

any subsequent adults are given a value of 0.33, so a two-person household with no children has an equivalisation factor of 1 (DWP 2024). The researchers then used all households' equivalised incomes to check the number of participants falling above and below this new equivalised MIS².

To compare expenditure, participants' spending was equivalised using the modified OECD equivalisation factors utilised in the Living Costs and Food Survey (LCFS), which is different from those in FRS/HBAI (ONS 2023). Previous work completed by the Fraser of Allander Institute sorted respondents in the LCFS into five equally sized quintiles of income (McFadyen et al. 2024)³. The boundaries of these income groups from the latest available LCFS data were inflated to September 2024 values, and used to sort participants into one of the five income groups. This ensured that participants' spending was being compared with households of similar incomes.

Conclusions

Overall, the researchers believe that this method is a useful way of collecting income and expenditure data for marginalised groups where mainstream data is not easily available. This method could potentially be used to collect regular supplementary statistics and key priorities for minority groups, provided those undertaking the research have strong links to their community of interest. To ensure focused interviews, focus groups could perhaps be added first to assess key priorities for the marginalised group in question. Interview schedules could then be built around the key priorities raised by the focus group.

The research team are very happy to discuss any potential future uses of this method, whether these are designed to capture data on other minority groups, or more data about people with learning disabilities in other smaller geographical areas like Scotland.

² An alternative method would have been to use the standard MIS values for households where they were available, such as for single adults, and equalise only the households which do not have a calculated MIS figure. It was decided that using the same calculation for all households would make our figures more consistent, but the alternative method would be equally valid.

³ Analysis of our participants was completed before LCFS 2022-23 data was made available, so 2021-22 figures are used.

References

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Appendix A: Interview 1 schedule

Financial security (these questions were user-tested and used in a previous study by SCLD)

Do you have enough money to do the things you want to do?

Do you have your own bank account?

Check for the following:

- Own bank account (in your name only)
- Joint account with family member
- Joint account with partner
- Other (please specify)
- No
- Don't know

Does someone help you look after your money?

If yes:

Who helps you?

Check for following:

- Parent
- Partner
- Child
- Other relative
- Friend
- Paid help / PA / Support staff
- Social services
- Other
- Don't know

Sometimes, when money is tight, people have to go without things. In the last four weeks have you always had enough money for these things when you wanted it/them?

- New Clothes (yes, no, never wanted, don't know)
- New Shoes (yes, no, never wanted, don't know)
- Food (yes, no, never wanted, don't know)
- Heating (yes, no, never wanted, don't know)
- Telephoning friends or family (yes, no, never wanted, don't know)

- Paying for the internet (yes, no, never wanted, don't know)
- Going out (yes, no, never wanted, don't know)
- Visits to the pub or a club (yes, no, never wanted, don't know)
- A hobby or sport (yes, no, never wanted, don't know)
- A holiday (yes, no, never wanted, don't know)

Is there anything else you would like to be able to spend money on that you can't spend money on at the moment?

Are you able to save money regularly (£10 a month or more)?

Are you saving up to buy something or just to have savings?

Income and financial support (*this will be covered in more detail in interview 2 so don't press too hard, if participants are unsure at this point that's okay*)

1. Work

Do you have a job?

If yes, do you know how much you make?

Ask about job details

If no, would you like to have a job? Why or why not?

Have you had a job in the past? Why did you leave that job?

If participant has tried to get jobs, discuss barriers faced if present

Does anyone else in the household work?

2. Benefits

Do you get any benefits?

If yes, do you know what benefits you get?

Do you know if anyone else in the house gets benefits?

If yes, do you know which benefits?

Probe: have you heard of PIP or personal independence payment?

Probe: have you heard of the Adult Disability Payment?

(again, don't push this too hard in first interview, can explain benefits at end of interview and ask them to think about it or get support to discuss before second interview)

How do you feel about the benefits you get?

Probe if required: Do you think the benefits you get give you enough money to do the things you want to do?

Have you had any problems getting your benefits?

3. Other financial support

Does anyone else give you money to help out?

If yes, who? How often does that happen? (*don't ask how much until Interview 2 unless offered*)

How do you feel about (person) giving you money?

Social care

Do you get any help and support with everyday living?

Give examples e.g. personal care, household tasks, activities/socialising, equipment/adaptations, alarm service etc.

Who pays for that support?

Give examples e.g. government/council, me/family, unpaid care, charity

If not unpaid care: how was that support arranged?

Concluding questions

Thinking about all the stuff we've talked about, how do you feel about the support you receive and the money you have?

Do you feel secure?

Are you able to do all the things you want to do?

Do you feel independent? Would you like to be more independent?

Next interview prep

Next time we speak to you, it would be great if we could understand how much money comes into your house and how much you spend on things like food, heating, electricity and transport. For this you might need to look out some documents like your bank statement, payslips, energy bills, letters about benefits, and receipts for things like food.

Do you normally get a bank statement in the post or use a banking app?

Do you have access to information about your wages?

- e.g. payslip, bank statement that shows pay going in

Do you have access to information about your benefits?

- This includes type and amount so bank statement not enough, prompt for docs that would show type of benefits like housing as these won't show up in bank statement
- e.g. online portal, benefits letters that show how much you get, if neither of these bank statement showing payments

Do you get a letter or an email about your electricity and heating when it's time to pay?

- Again bank statement could be okay for this

Do you do your food shop in the shops or online?

- Ask if they normally keep receipt
- If they don't ask if they could for a week or two before we next meet

Do you know how much your housing costs?

- Prompt for rent/mortgage
- Prompt for housing benefit paying for this

Make list for participant of things to bring to next interview, ask if they would like it handwritten or emailed or posted to them, ask if they would like any example documents sent to them like example bank statement, payslip etc

Appendix B: Interview 2 schedule

Household makeup

Confirm household members including dependents from last interview

Income from work

Do you work?

Repeat for each person in household: does [person in the household] work?

For each person who works, ask:

How much is [person] paid for their work?

How much time does that pay cover? E.g. a week, 4 weeks, a month

Benefits

Do you receive benefits?

If yes, what kind of benefits do you receive? (*ask to see documents if they have them*)

Probe for specific benefits (*use premade list of what's available*)

For each type of benefit, ask:

How much do you receive for that benefit?

How much time does that cover? E.g. a week, 4 weeks, a month

Repeat for each person in household: does [person in household] receive benefits?

If yes, repeat above questions

Any other income

Do you or anyone else in your household receive money from other places that aren't work or benefits? This could be regular money from a family member or friend, a pension, etc.

If yes, how much is this normally?

How much time does that cover?

Housing costs

If they receive housing benefit: are your housing costs covered completely by your housing benefit?

If no or if no housing benefit, ask following questions:

How much do you pay for your home?

And how often do you pay that? E.g. monthly, weekly, every four weeks

Do you rent/have a mortgage etc

Is your electricity or any other costs like Wi-Fi included in this payment?

How much council tax do you pay?

Do you know if you get any discount or exemption on council tax?

Care costs

If person receives regular paid care and it's paid for by council (check first interview):

How many hours is your carer usually with you each day?

Is that the same every day?

If person receives care that is paid for directly by themselves or family member etc:

How much does it cost to have your carer with you?

And how much time does that cover?

Expenditure – food

Do you shop for food yourself?

If yes, do you shop in the supermarket or do you get your shopping delivered?

How much did you spend on food last week?

Is this how much you usually spend? If no, how much do you usually spend?

Expenditure – energy

Is your energy included in your housing costs?

If yes, is the cost for energy shown on your housing bill?

If no:

Do you have gas and electricity at home?

Do you pay for these together (you get one bill) or separately (you get two bills)?

If no, what type of energy does your home have?

How much was your latest payment(s) (or whichever payments they have available)?

What amount of time did that cover?

Expenditure – transport

Do you have access to a car?

If yes:

Do you own the car or does someone else own it?

Do you drive or does someone else drive you?

How much did you spend on petrol/diesel last week?

Is this how much you usually spend? If no, how much do you usually spend?

Do you have a bus pass?

If no, do you take the bus?

How much did you spend on the bus last week?

Is this how much you usually spend? If no, how much do you usually spend?

Do you take any other public transport? This could include trains, trams or ferries

How much did you spend on this last week?

Is this how much you usually spend? If no, how much do you usually spend?

Do you normally take taxis?

If yes, how much did you spend on taxis last week?

Is this how much you usually spend? If no, how much do you usually spend?

Other expenditure

Ask if participant has a mobile phone contract, Wi-Fi and how much these cost

Ask if any other expenses not covered feel essential and how much these are

Appendix C: Coding Framework

Benefits

Experiences of benefits	Any benefits experiences e.g. accessing benefits, changes to benefits. Code to appropriate positive/mixed/negative category
<ul style="list-style-type: none">• Positive• Mixed• Negative	

Feelings about benefits amount	Anything specific about whether they think benefits give them enough to do what they want to do
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Worries about benefits	Any concerns/worries about e.g. future changes to benefits
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Care

Doesn't get care	Code any interesting discussions of care here if person does not receive care (paid or unpaid)
<ul style="list-style-type: none">• Feels they want or need care	

Gets care	Experiences: what type of care, any positive or negative experiences.
<ul style="list-style-type: none">• Care finance• Experiences of care	Care finance: who pays for care, any thoughts on cost

Confusion

Benefits confusion	Where participant or carer is confused
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Other confusion	Where participant or carer is confused
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Work confusion	Where participant or carer is confused
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Debt	Any experiences of debt
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Experiences of bank accounts	e.g. how many accounts, sole or joint, whether use mobile banking
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General feelings on money	Code conclusion question here and any more general thoughts e.g. is money sufficient
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Independence

Do you feel independent	Code 'do you feel independent?' here
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Support with finances	Positive and negative examples of others having partial or full control over the participant's money
<ul style="list-style-type: none">• Increases independence• Decreases independence	

Living alone or with others

Aspirations	How they want to live ideally
Experiences	Current living situation and how they feel about it
Impact on finances	Positive or negative impact on finances due to living alone or with others
Material deprivation	
Cannot afford	Anything participants are going without
Pays for but is expensive	Anything participants note is high cost
Savings experiences	Anything on savings
Security	Code 'do you feel secure' question here
Work	
Aspirations for work	Ideal work situation or any aspirations for job/career
Barriers to work	Any barriers mentioned
Experiences of work <ul style="list-style-type: none"> • Positive • Mixed • Negative 	This can include experiences of looking for work and not getting jobs. Code to appropriate category
Feelings about having a job	Positive, mixed or negative
Feelings about not having a job	Positive, mixed or negative

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