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University of Strathclyde Glasgow

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

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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 investigated the financial situations of working-age people with learning disabilities in Scotland.

The research highlighted significant financial insecurity, with a large proportion of participants living below the Minimum Income Standard and experiencing material deprivation. Over half of participants were in relative poverty (below 60% of median income after housing costs) when additional cost benefits such as Personal Independence Payment (PIP) and Adult Disability Payment (ADP) were excluded from their incomes.

The research showed that both the social security system and the social care system can be confusing and difficult to navigate for people with learning disabilities. There were challenges with benefit and care adequacy, and participants did not tend to access independent advocacy. The report also found a correlation between the adequacy of social care and financial security.

The following options for improvement were identified:

1. Better promotion and implementation of independent advocacy.
2. More accessible information on Universal Credit rollout and upcoming health-related benefit changes.
3. Exploration of ways to provide clarity on Universal Credit and employment with a disability.
4. Support for existing recommendations for Self-Directed Support implementation.
5. Wider, joined-up consideration given to improving financial security for people with learning disabilities and their families.

Introduction

Improving the quality of the lives of people with learning disabilities in Scotland was guided between 2013 and 2021 by Scotland's Keys to Life Strategy. The strategic outcomes of the Keys to Life Strategy included health outcomes, choice and control, independence, and active citizenship. In 2021, COSLA and the Scottish Government introduced the Towards Transformation Plan to further support people with learning/intellectual disabilities and autism. The Towards Transformation Plan looks at the actions needed to shape support, services and attitudes to ensure that the human rights of autistic people and people with learning/intellectual disabilities are respected and protected and that they are empowered to live their lives, the same as everyone else.

The Keys to Life definition of a learning disability states that:

> *"People with learning disabilities have a significant, lifelong, condition that started before adulthood, which affected their development and which means they need help to:*
>
> - *understand information;*
> - *learn skills; and*
> - *cope independently."*
>
> *Scottish Government, 2019*

People with learning disabilities' experiences are not well understood on a national scale in Scotland because available data in this area is poor. Counting the number of people with learning disabilities in Scotland is a difficult task, and national statistics used to track labour market trends and poverty rates are not disaggregated to the level of learning disability. People with learning disabilities may struggle to engage with national surveys due to inaccessible data collection methods, which reduces the chance of any available data being representative.

This report aimed to fill a gap in the available evidence on the financial situation of working age people with a learning disability in Scotland and assess whether the support they, and their families/carers are able to access, adequately addresses their financial security needs and allows them to live a fulfilling life free from poverty, realising their human rights.

The objectives of this report were as follows:

- Gather quantitative data on the extent to which people with learning disabilities and their family/carers are supported adequately financially.
- 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.
- Provide an assessment of the impact of support provided by social care.

To achieve these objectives, a sample of 24 participants with learning disabilities were interviewed. Researchers collected both quantitative and qualitative data from the participants and their household members with measures put in place to ensure that the process was adjusted to ensure people could participate as fully as possible in the research (for more information on methodology, please see the accompanying technical report).

The following sections discuss the research findings and options for improvement which could be taken forward by policymakers and other relevant parties to provide better financial security for people with learning disabilities in Scotland, allowing them to live free from poverty and to realise their human rights.

Findings

Our findings are split into thematic sections. The first section provides an overview of participants' financial situations, including their income levels, spending levels, and evidence on material deprivation. The second section highlights participants' experiences of benefits, including their experiences interacting with the social security system. The third section covers participants' experiences of work. The fourth section discusses social care, unpaid care, and support from third sector organisations.

Overview of financial situations of participants

Income

We gathered information on household incomes from 21 of 24 participants. Three participants either refused to provide this information or did not know the information for their household. The information we collected included all household income from work, pensions, benefits, and investments. For a detailed explanation of data collected and calculations used, please refer to the technical report.

Table 1 shows the number of households that fell below various measures of poverty and low income. 70% of households interviewed did not meet the minimum income standard (MIS). The MIS is a level of income calculated annually based on what is agreed to be a decent standard of living in the UK (JRF 2024). When additional cost benefits were excluded, 86% of households did not meet the minimum income standard.

14% of households in the sample were in relative poverty if all benefits were included in income calculations. When additional cost benefits were excluded from income, over half of households (57%) were in relative poverty. This is a method used by the Scottish Government to measure poverty for disabled people on a like-for-like basis with the rest of the population by discounting benefits to compensate for the additional costs of disability (Scottish Government, 2024).

Table 1: Number of households below minimum income standard and poverty line

Measure of poverty/income	Frequency
Total number of households who provided financial information	21
Number of households not meeting equivalised minimum income standard (excluding additional cost benefits)	18 (86%)
Number of households not meeting equivalised minimum income standard (including additional cost benefits)	15 (71%)
Number of households in relative poverty (excluding additional cost benefits)	12 (57%)
Number of households in relative poverty (including additional cost benefits)	3 (14%)

These figures match the general sentiment of the participants when asked their feelings on money. More than half of those we spoke to felt they did not have enough money or could do with more: these participants mentioned difficulties paying for heating, clothing, food, and transport (see Table 2 for more detail). Some participants felt they were financially secure but were missing out on key activities or experiences such as socialising or going on holiday (this is discussed further in the section on material deprivation and cost of living). The overall sentiment from these participants was that they could live day to day, but were having to go without things that they felt others in society were able to enjoy. Only five participants reported feeling happy with the amount of money they received.

Despite the low incomes of many participants, only a few received financial support from their families and friends. For those who did receive financial support, they tended to receive small amounts (£10 or £20). This support was irregular and only used when participants felt it was absolutely necessary. The participants who borrowed or received gifts of money from family and friends did not like feeling that they were reliant on others' financial support.

A lack of savings was common for participants: only three participants reported savings of £1000 or more. Several participants were not sure how much they had in savings or did not mention a figure during their interview. However, 14 of 24 participants reported being able to regularly save £10 or more per month. Some participants mentioned being worried about saving too much in case they lost some of their benefits. In the quote below, one participant reflects on their savings causing them to lose out on financial aid while moving from a care home to their own home:

> *"I've just moved, and I did have savings, from my work, because I knew I was eventually going to move. So I thought, right, just in case, I'm going to save up. But everybody was saying, "Oh, you'll get help, you'll get financial help, don't worry about it," but as it turned out, it was to my detriment, because I had savings, not much savings, by any standard, but I was not given any financial help because I had these savings. So pretty much I was cleaned out with my savings, because I had to pay for this floor, I had to pay for the furniture. The floor was about nearly £2,000, if not more. So, yes, at the moment my savings pot is a bit low." - participant*

Low monthly incomes and low levels of savings combined to cause significant financial insecurity for many participants.

Spending on essentials

We collected information on spending in the categories of food, energy, transport, telecommunications, and care. These were categories of spending deemed essential by the participants. In Charts 1-4, we compare food, energy and transport spending from our sample with spending by disabled households in the Living Costs and Food Survey. This analysis was completed to understand how our sample of participants' spending compared with disabled people's spending at a national level. We wanted to understand if there were any specific extra costs for people with learning disabilities highlighted by our sample, which may not be picked up in national data since people with learning disabilities are less likely to be able to take part in surveys due to accessibility issues. However, it should be noted that our sample size is small, and these spending differences may not reflect Scotland's population of people with learning disabilities as a whole.

Participants have been grouped into five income brackets. This allows us to compare spending from households with similar income levels. More details on the data and methods used can be found in the accompanying technical report.

Chart 1: Number of participants in each income quintile using inflated LCFS 2021-22 figures

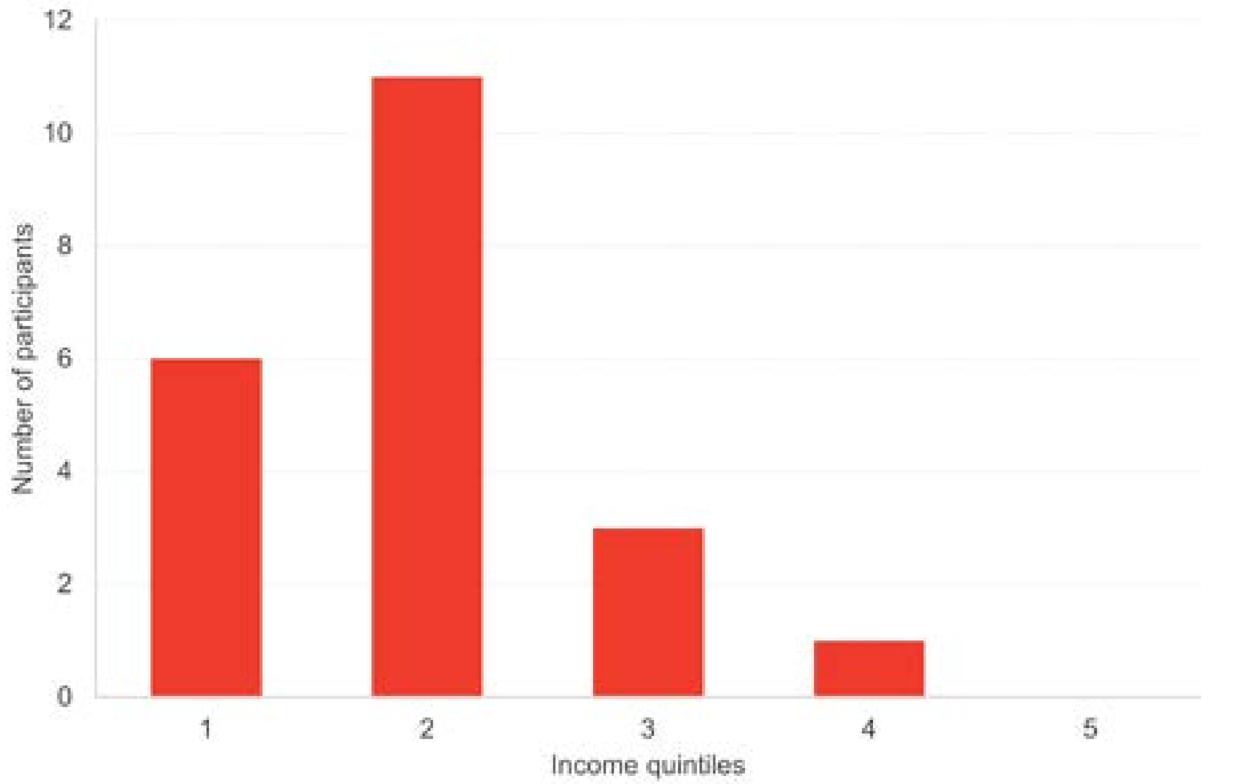


Chart 1 shows that most of our participants were grouped into the lowest three income quintiles. We therefore omitted quintiles 4 and 5 from the following chart due to small sample sizes. Charts 2, 3 and 4 compare the average spending of our participants with average UK household spending by households including and not including disabled people.

Chart 2: Comparison of average monthly food spending (UK data from LCFS 2021-22, figures inflated)

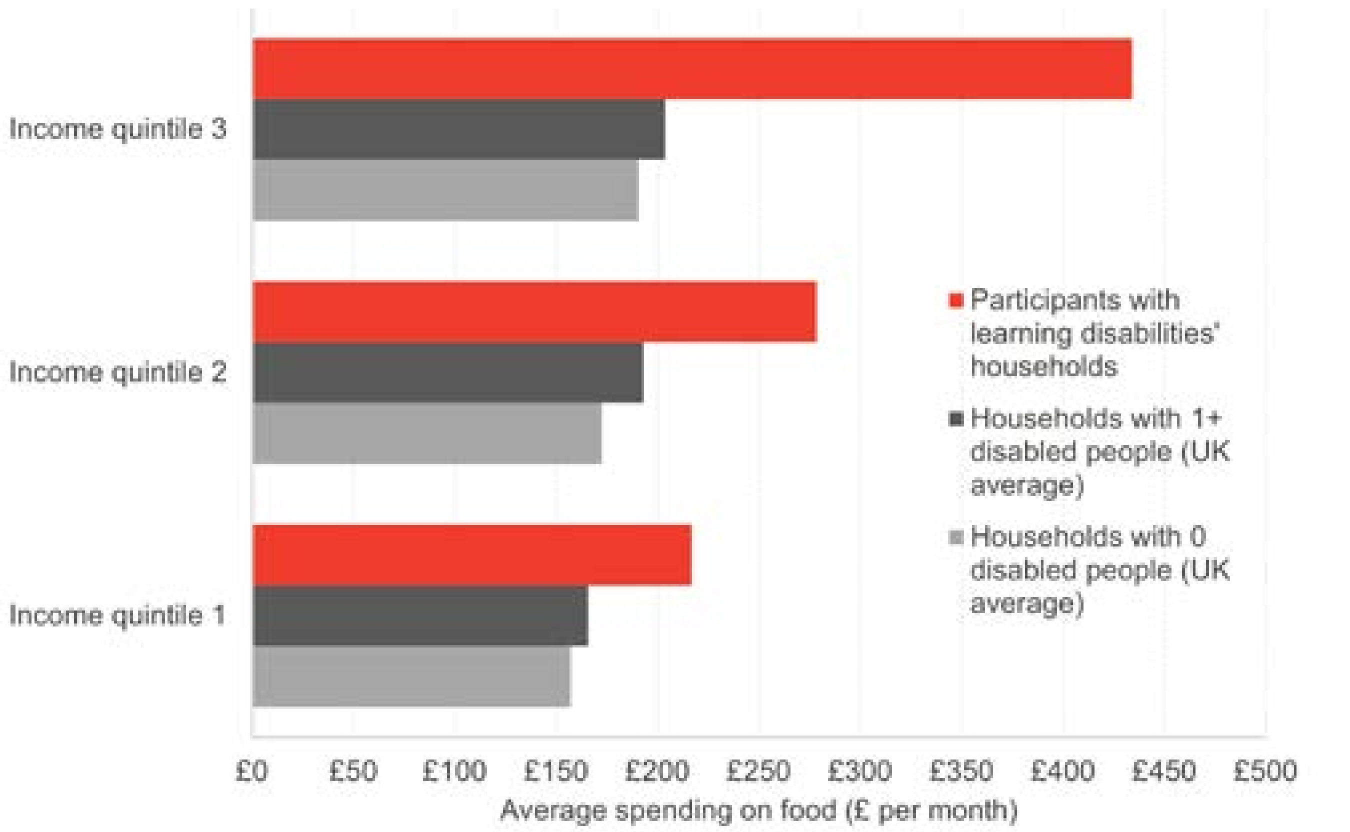


Chart 3: Comparison of average monthly energy spending (UK data from LCFS 2021-22, figures inflated)

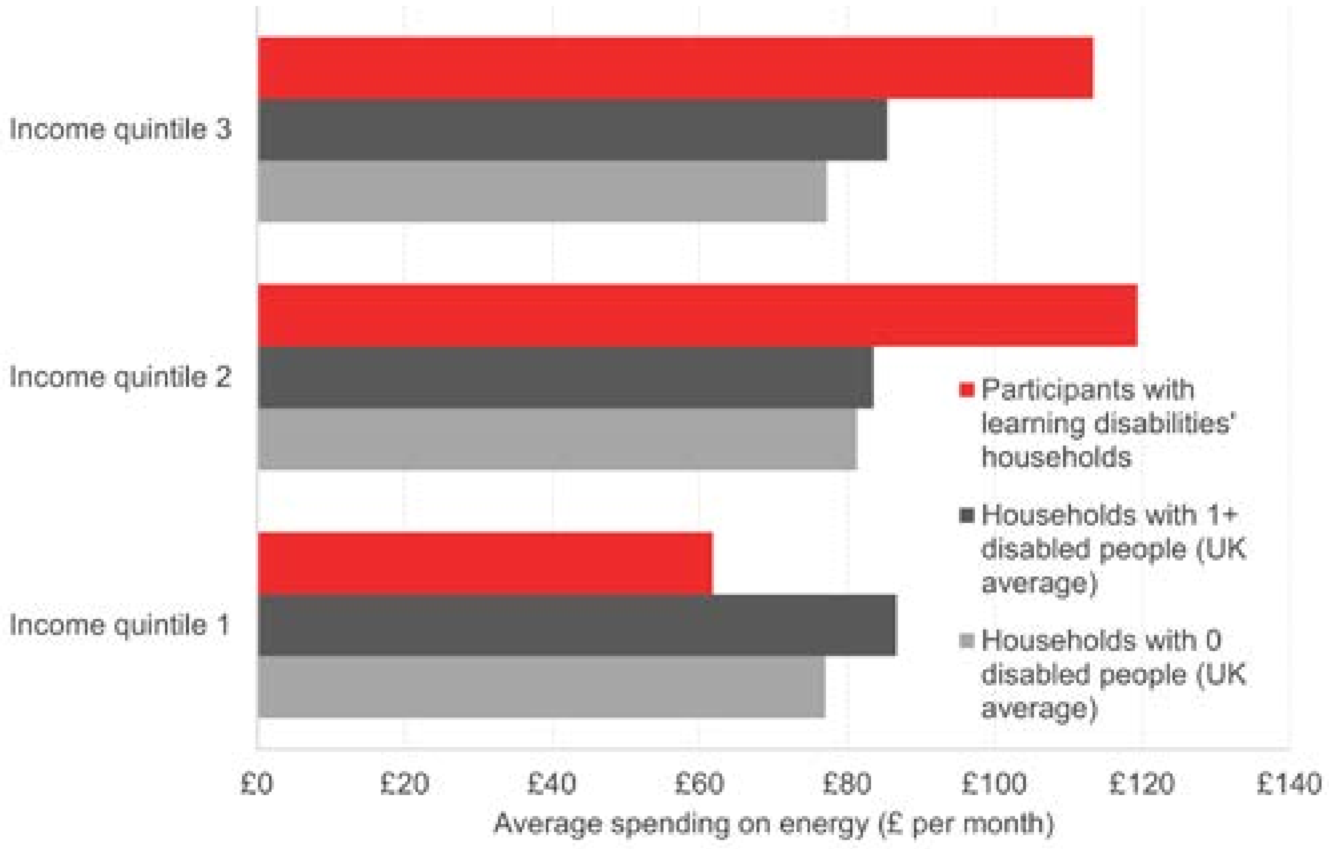
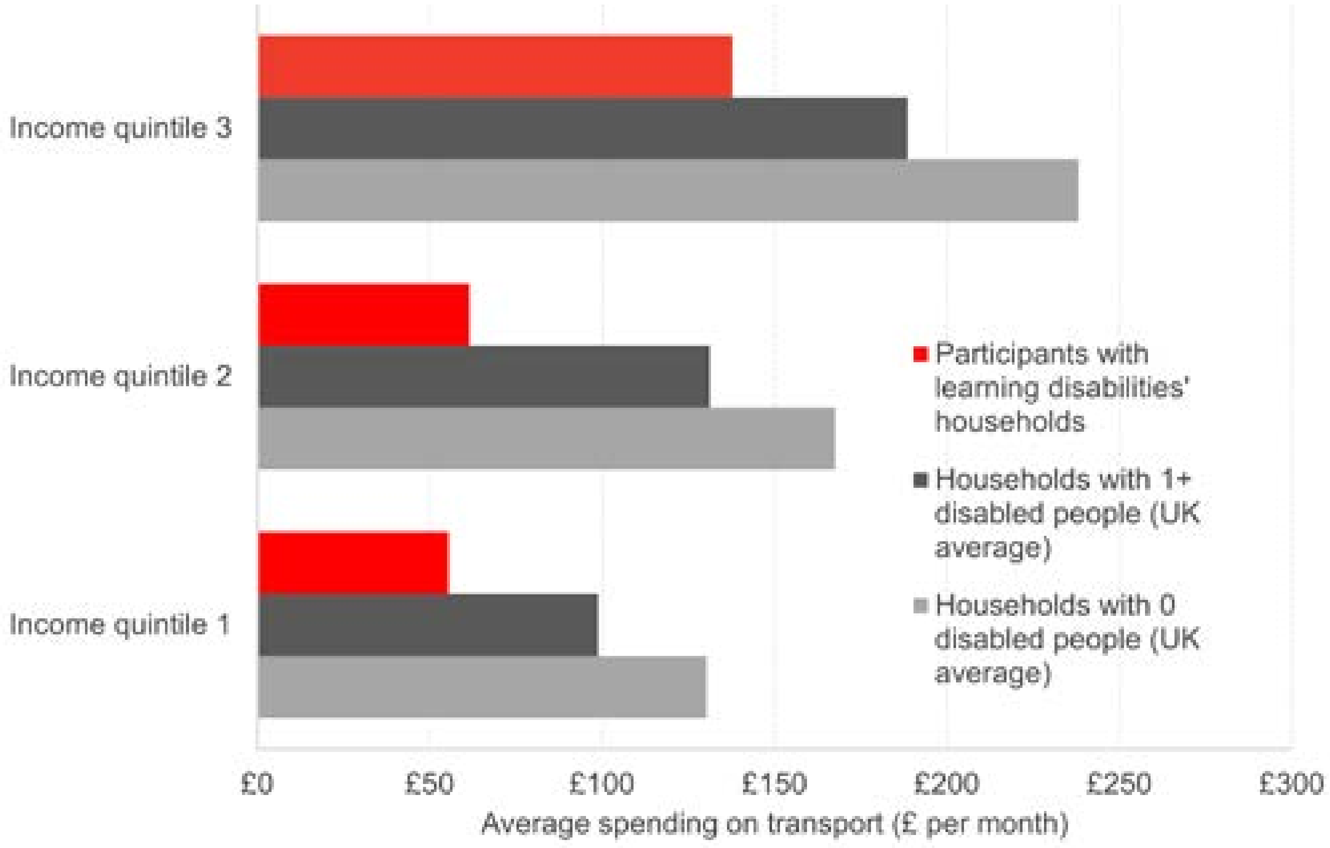


Chart 4: Comparison of average monthly transport spending (UK data from 2021-22, figures inflated)



Previous research by the Fraser of Allander Institute and the Poverty Alliance showed that disabled households spend more on food and energy compared to non-disabled households, and less on transport (McFadyen et al. 2024). The spending of participants with learning disabilities in this research followed these trends. In chart 3, energy spending by income quintile 1 is less for our sample as some participants in this group could not afford enough energy to meet their needs.

For our participants with learning disabilities, Chart 2 shows that additional spending on food may be more extreme for people with learning disabilities based on our sample. However, a key difference here is that spending on takeaway and convenience food was included in participants' spending, whereas this was not included in the LCFS food expenditure figures. We included spending on takeaways in our food spending figures since many participants relied on these for accessibility reasons. Several participants were not confident cooking from scratch or shopping for ingredients and therefore felt they had no choice but to pay a premium for ready meals and takeaways. Some participants also had extra food costs in the form of specific dietary requirements.

There are several key points to take from Chart 2. Firstly, spending on food is higher for participants with learning disabilities even in the lowest income quintile. This could suggest a need to spend more on food due to increased dependence on convenience items or takeaway options as noted above. Secondly, spending on food goes up as income goes up for those with learning disabilities. This trend is not reflected in the LCFS data for disabled households. What this suggests is that spending on food for those on the lowest incomes is constrained by their level of income.

Reduced spending on transport is also more extreme for our sample compared to the average UK households. It was theorised in FAI's previous work that this is due to a combination of free transport provision for disabled people, and disabled people traveling less due to inaccessible transport options (McFadyen et al. 2024). Participants with learning disabilities spent less on transport due to both of these factors. Those on lower incomes who had access to a bus pass tended to prioritise bus travel – they said this was to save money. However, some participants, particularly with additional disabilities or health conditions such as physical disabilities or autism, found buses inaccessible. These participants therefore spent less on transport since they found taxis unaffordable and would instead opt to not travel. Participants in this situation wanted to travel more often but could not do so on their current incomes.

Due to small sample sizes, these figures should be used with caution. However, we feel these findings warrant further investigation of people with learning disabilities' spending needs. Our findings on transport spending are supported by Transport Scotland's Disability and Transport report (2023), which shows that disabled people have become more dissatisfied with public transport since COVID.

Material deprivation

We asked participants whether they were able to afford each of the items in Table 2 over the last four weeks. Participants were able to answer "yes", "no," "yes but it was expensive", or they "did not want the item in the last four weeks". These questions are similar, but not identical to, the material deprivation questions used for adults in the Family Resources Survey (DWP 2024a). Material deprivation is a way of measuring poverty based on a lack of access to essentials. Table 2 shows that participants had several common areas where items were unaffordable or expensive. The most common items which were unaffordable or expensive were heating, going out, holidays, food, and phone contracts.

Table 2: questions related to material deprivation over the 4 weeks prior to interview

	Could afford	Could not afford	Paid for but was expensive	Did not want (or did not answer)
Food	14	0	8	2
Heating	14	2	8	0
New clothes	16	2	1	5
New shoes	14	3	0	7
Going out	12	2	7	3
Pub/club	8	2	1	13
Hobbies/sports	16	2	2	4
Wifi	15	0	3	6
Phone	15	0	7	2
Holiday	8	4	4	8

Half of participants shopped at budget retailers in order to afford food and/or clothing (e.g. LIDL/Aldi, Primark, Temu/Shein, or charity shops). Two participants used community food banks or pantries to make their food more affordable. Many participants were very careful with their money in order to afford their essentials. Coping strategies included: looking for the cheapest deals before going out or avoiding going out entirely; using cash only and giving themselves a weekly allowance (or other forms of budget setting); using cheap websites; avoiding putting the heating on or keeping it at a low temperature; and bulk buying or batch cooking. For those who could afford a holiday, several participants said they looked for last-minute deals, went away for less than a week, or only went on holiday within the UK to make a holiday affordable.

Participants with more than one disability or health condition, such as a physical disability, mental health issue or autism were more likely to avoid going out or going on holiday. This was due to a combination of significant extra costs related to accessibility (such as needing taxis or accessible accommodation), and participants' health limiting their activity levels. Some participants were facing a significant negative impact on their wellbeing due to being unable to regularly leave the house.

Some participants who said they 'did not want' certain items discussed that they would want such items (e.g. a holiday) if they felt more financially feasible. Participants reflected that they felt disabled people were not supposed to want luxuries or that they felt they had to limit their wants due to disability making certain things unaffordable. In these cases, participants were able to afford food and other basic necessities, but they had such high additional costs due to their disability in terms of going out or going on holiday that these activities were not considered practical.

Due to a lack of support for budgeting and understanding information such as bills and legal rights, some participants had particularly difficult financial experiences. Two participants had experienced homelessness in the past, and three participants reported energy debt, with one person having no gas on multiple occasions due to running out of money. The quote on the following page shows a participant discussing how they 'cut back' on spending to afford their upcoming holiday.

> *"Participant: I do without food or… so that I can go on holiday, or new clothes or…*
>
> *Interviewer: Yeah, okay. So, how much did you feel you had to cut back to, sort of, afford to pay for the holiday?*
>
> *Participant: Quite a lot actually. Well, not that much, but the holiday's £288. But I've had to cut back on food, or going out or…*
>
> *Interviewer: Yeah. Okay. What kind of ways would you cut back on food?*
>
> *Participant: Not eat.*
>
> *Interviewer: Yeah. Okay.*
>
> *Participant: We don't get enough to live on."*

In some cases, unpaid carers and social care such as support workers were able to help with budgeting and understanding letters and bills. Five participants got help from their unpaid carers with budgeting and bills and letters. Two participants were currently receiving this type of care from their support workers, with a further two having previously received this type of care – in both cases, their care was cancelled by their providers due to staff shortages. Both participants felt they still needed support with their budgeting and bills.

Finances and independence

Most participants said they felt independent, although we recognise that we were much more likely to reach participants who felt independent than those who did not. For example, we were not able to recruit participants who lived in care homes or in hospital, and our participants generally had a positive relationship with their unpaid carers.

There were many participants who had support which helped them to feel more independent, whether that was from support workers or from unpaid carers. Some participants had escaped situations where they felt less independent, such as living in a care home or with parents who tightly controlled their money or misused their funds. These participants highlighted that being treated like an adult when it came to their finances was important to them.

A few participants said they would like to be more independent. Things which they thought would help them to feel more independent including having more money, having more care, and being able to drive. Overall, participants who had as much freedom as possible with their money, and adequate support to help them understand anything difficult or challenging, felt the most independent.

Benefits experiences

Types of benefits claimed

Participants in the research claimed two main types of benefits: income-related benefits, and additional cost benefits. Income-related benefits are means-tested and are designed to replace or supplement income from work and are often referred to as incapacity benefits. Additional costs benefits are not means-tested and are designed to cover some of the additional costs which disabled people face day to day and are often referred to as disability benefits. A summary of the number of participants and their household members claiming each benefit is shown in Table 3.

Table 3: Types of benefits claimed by participants and their household members

Benefit type	Number of participants claiming
Employment and Support Allowance (ESA)	12
Universal Credit (UC)	8
Disability Living Allowance (DLA)	6
Personal Independence Payment (PIP)	9
Adult Disability Payment (ADP)	4

Income-related benefits included Universal Credit (UC) and Employment and Support Allowance (ESA)[1]. Everyone in GB[2] is eligible for UC (or previously ESA) if they earn under a certain amount of income from work. However, people with a disability or health condition can be assessed as having a limited capability for work, which means they are not required to prove that they have been looking for a job while on these benefits. In some cases, this also comes with a top-up to the income-related benefit.

ESA is a legacy benefit being replaced by UC. The deadline on which the UK Government are planning to close legacy benefits is currently the end of March 2026 (Mackley et al. 2024). Those claiming ESA only or ESA plus housing benefit are the last cohort being sent migration notices – DWP began sending these out in September 2024 and aim to have them all sent by December 2025 (ibid). It is therefore not surprising that a high number of participants in our sample were still receiving ESA.

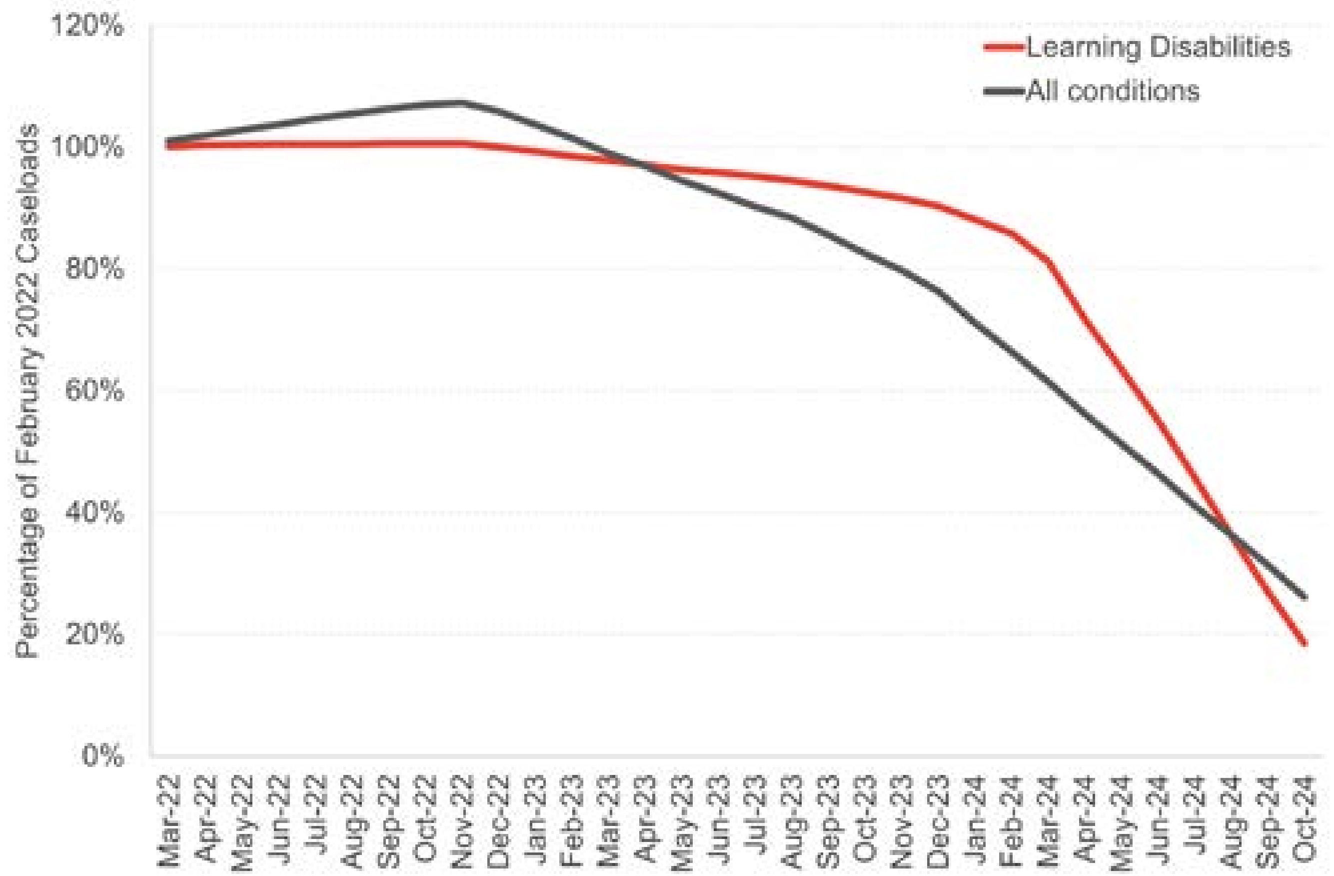
As of August 2024, there were 1.5 million people claiming ESA in Great Britain, 1.3 million of which were in the support group (this group includes those who have a limited capability to work due to disability or other health conditions) (DWP 2024b). We cannot say whether people with learning disabilities are more or less likely to still be claiming UC at this stage compared to those with other disabilities, as ESA statistics are not disaggregated in a way that shows learning disabilities as their own category of medical condition.

Most of our participants with a learning disability claiming income-related benefits (UC or ESA) had a 'limited capability to work' attached to their income-related benefit. This meant they could work less than 16 hours per week paid at the minimum wage (or equivalent) without their benefits being impacted.

Additional cost benefits included Disability Living Allowance (DLA), Personal Independence Payment (PIP), and Adult Disability Payment (ADP). PIP and ADP are UK and Scottish versions of the same benefit, while DLA is a legacy version of PIP. DLA, PIP and ADP are non-means tested benefits designed to meet the additional costs associated with having a disability. This means individuals can claim additional cost benefits regardless of their total income. Each of these benefits include a care component and a mobility component, and individuals are assessed at different rates in each component depending on how much they can do by themselves without help from others (such as cooking a meal, getting dressed, or going for a walk).

Those in Scotland claiming PIP are due to be transferred to ADP by the end of 2025 (Social Security Scotland 2024). The latest figures show that as of October 2024, there were 80,000 PIP claims in Scotland still to be transferred to ADP (DWP 2024c). Chart 5 shows the Scottish PIP caseload per month, as a percentage of its February 2022 value (ADP was introduced in March 2022). The chart shows that PIP caseload numbers with the main condition noted as a learning disability did not start falling significantly until early 2024. As of February 2024, the learning disability caseload was still 86% of February 2022 figures. Our interviews were completed between May and October 2024, where the caseload was between 64% and 19% of February 2022 figures. If we include one participant who was told they were ineligible for ADP, 64% of those who should be eligible for ADP in our sample were still receiving PIP. Therefore, our sample aligns with the available DWP statistics.

Chart 5: Scottish PIP cases as a percentage of February 2022 caseloads



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[1] It is believed that participants claiming ESA were on the legacy benefit ESA, which is being replaced by UC (as opposed to 'new-style' ESA which can be claimed alongside UC). This is because many discussed not wanting to move onto UC, and were not claiming UC alongside ESA.

[2] Northern Ireland operates a completely devolved social security system

As of August 2024, there were still 71,000 claimants of DLA in Scotland (DWP 2024b). This figure has fallen steadily over the past few years as individuals were transferred to PIP. Those who still have not transferred to PIP will now be transferred to ADP (unless they were born before 8 April 1948). We cannot say whether individuals with learning disabilities are more likely to still be on DLA compared to those with other disabilities or health conditions, as DLA statistics do not have a separate category for learning disabilities.

Feelings on benefits amounts

Participants had mixed feelings about the benefits they received. While some were happy with the amount of money they were provided, many felt they 'could do with more'. There was a common theme of surviving but not living a full life which came up in a number of interviews, as shown by the quote below:

> *"I feel lucky to have it, and I can survive, but I'm not living on it. It's very much I'm living a certain way, so that, I'm not being irresponsible, but, I'm making a lot of choices that I wake up in the morning – and it's not because I feel good about them, it's like, "Well, I can afford this so I'll get this." It's always restrictive. It's always in the back of your mind. It makes you feel so stuck" - participant*

Some participants expressed frustration at benefits not increasing in line with the level of impact they felt from the cost-of-living crisis. Others were resigned to the amount they received, with one participant explaining to the interviewers that 'you just tend to cope'.

Some participants noted that they felt they were punished for building savings by the benefits system. Universal Credit allows claimants to save up to £6000 without affecting their claim, but any amount above this reduces a claimant's UC payments. In some cases, this encouraged financial irresponsibility or overspending on items which were not necessarily required. While the amount of UC available does not reduce significantly based on having extra savings (£4.35 per month for every £250 saved over £6000), participants were fearful of any change in benefits which disincentivised saving. In some cases, a family member with an understanding of the benefits system would hold a savings account for a participant so that they could save more without affecting their benefits.

Worries and confusion about benefits

Many participants faced some kind of confusion or worry regarding their benefits. The most common worry was about any changes to benefits, particularly changes to payment amounts and migrating to Universal Credit. Fearmongering stories about UC were prevalent in the minds of participants (particularly around the five week wait for UC), and many on legacy benefits were worried about triggering a UC migration. This is a legitimate fear for those working above the UC work allowance as they would likely lose money on UC, due to UC reducing by 55p for every £1 over the work allowance. Rules surrounding benefit entitlement (such as maximum work hours or savings allowed) also caused worry or confusion for many participants. Participants who were struggling to afford everything they needed were particularly fearful of any potential policy changes which could impact their level of entitlement to benefits. Our research was completed before the government announced plans to change benefits for disabled people in the spring 2025 statement.

Another area of confusion was related to any kind of transition in benefits. Moving from PIP to ADP or from child disability payments to adult payments, for example, was confusing and sometimes stressful for people with learning disabilities and their family/carers. The prevalence of people with disabilities and health conditions still on legacy benefits ESA and DLA mean that many people with learning disabilities are likely to experience benefits migration throughout 2025. Our research suggests that this could cause significant stress for people with learning disabilities and their families/carers.

One person reported that they previously received PIP but have been denied ADP. We have no more detail on how this happened, but it should be noted that there has been evidence of this occurring in other research (Scottish Government 2024b).

Despite these worries, very few participants sought support from advocacy or third sector organisations. People with learning disabilities have a right to independent advocacy when issues could affect their health and wellbeing (Scottish Executive 2005). Social Security Scotland directs people who require independent advocacy to the charity VoiceAbility who can provide support in claiming Social Security Scotland benefits (Social Security Scotland 2022). Unfortunately, VoiceAbility cannot provide advocacy for UK-wide benefits such as Universal Credit.

We did not delve into this issue with participants unless it was explicitly brought up by them. However, we believe it is highly likely that many of the participants in this research were not aware of their right to independent advocacy. Consideration should be given to how advocacy information may be better communicated to people with learning disabilities – especially those who may not be accessing care or benefits due to a lack of understanding of their entitlements.

Work experiences

10 of 24 participants in the sample had some form of employment. Participants' roles included casual work in their community and irregular work for various organisations (such as experts by experience roles), as well as contracted roles with regular hours. Hours ranged from 1-2 hours per month to 25 hours per week (including overtime).

No participants worked full-time. Disabled workers are more likely to work part-time than other workers (DWP 2024d), and due to the low percentage of workers with learning disabilities, we expect there are very few full-time employees with learning disabilities in Scotland.

Participants who had worked had more positive experiences of work than mixed or negative experiences. Positive examples included work being fulfilling and increasing confidence, independence, purpose, and responsibility, as well as providing a routine. Those who worked for charities were particularly positive about their work experiences, describing their workplaces as accessible, flexible and supportive. A few negative experiences of work were mentioned, including some participants having to step back from work because it was impacting their health.

Barriers to work

Some people with learning disabilities are unable to work, and this should not prevent them from leading a full life. However, evidence has shown that many people with learning disabilities want to work but do not currently have a job. Work can act as a much-needed source of additional income as well as being a fulfilling part of a person's life. The employment rate of people with learning disabilities in Scotland is estimated to be just 4-7% (Fraser of Allander Institute 2021). As mentioned previously, none of the sample worked full-time, and some working participants would have preferred to work more hours or work in a higher-paying role. The following sections summarise the barriers to working full-time, or working at all, for participants.

Barriers to full-time employment

Participants gave many reasons for part-time work, the most common of which was because of benefit rules. The vast majority of participants were claiming Employment and Support Allowance (ESA), which required them to work no more than 16 hours per week at minimum wage (or a maximum of £183.50 per week as of January 2025 (Welfare Benefits Unit 2024). These participants were classed as having a limited capability for work or work-related activity, which comes with a maximum number of working hours/pay when claiming ESA.

The cap on working hours/pay in ESA suited participants who had a limited capability to work due to their physical health or due to specific conditions such as autism. However, several participants did not like the hard cap on hours/pay as it did not leave them any room for progression or growth in their roles. Participants were also prevented from pursuing higher-paying roles, since they would only be able to work a small number of hours before their benefits were at risk. A few participants chose instead to do voluntary work, some of which required a high level of expertise and skills.

Box 1: Universal Credit, Employment and limited capability for work/work-related activity

Universal Credit (UC) is an income-related benefit which all individuals/couples are eligible for if they earn under a certain amount. All UC recipients receive a 'standard allowance':

"The 'standard allowance' is always included in your award. It is the basic amount to cover essential living costs for you, and for your partner if you are claiming jointly." Disability Rights UK 2024, p. 103)

The base amount for a single person over 25 is £393.45 per month, and for a couple over 25 it is £617.60 per month (Disability Rights 2024). Top-ups, called amounts, are available for a variety of circumstances. A 'maximum amount' can be calculated for each claimant which may include a child amount, a housing cost amount, a work capability amount, a carer amount, and a childcare costs amount (Disability Rights 2024).

Once a 'maximum amount' is calculated, any earnings must then be taken into account. The 'maximum amount' of UC is reduced by 55p for every £1 earned by working, unless the claimant has a 'work allowance' due to having 'limited capability for work or work-related activity':

"When you are calculating your earnings, you may be able to disregard some of them by applying a 'work allowance'. This will only apply if you or your partner:

- *Are responsible for one or more children or qualifying young people; or*
- *Have a limited capability for work.*

There are two different rates:

- *A 'lower work allowance' of £404 a month; and*
- *A 'higher work allowance' of £673 a month.*

The lower work allowance will apply if a housing costs amount is included in your award or, if you are in temporary accommodation, you receive housing benefit. If a housing costs amount is not included in your award (and you do not receive housing benefit for temporary accommodation), the higher work allowance will apply instead. In each case, the same rate will apply whether you are a single claimant or claiming jointly with your partner." Disability Rights UK 2024, p. 107)

The limited capability for work or work-related activity mentioned in the above section entitles you not just to a work allowance, but also a 'work capability amount' (see the Disability Rights Handbook for more detail on the work capability assessment):

"If you have a 'limited capability for work-related activity', a 'work capability amount' of £416.19 a month (the higher rate) is included in your award. This is tested under the 'work capability assessment'. Before 3.4.17, if you were only found to have a limited capability for work at this assessment (and not work-related activity) a lower rate of the work capability amount could be included in your award. The lower rate, currently set at £156.11 a month, does not normally apply to new claims for universal credit."

If you are claiming universal credit jointly, and both you and your partner meet the condition for the work capability amount, only one such amount is included." (Disability Rights UK 2024, p. 105)

There are some work-related conditions which claimants must agree to when claiming universal credit. Not meeting work-related conditions can lead to sanctions. Whether someone is classed as 'fit to work', have a 'limited capability for work', or a 'limited capability for work-related activity' affects which work-related conditions apply to them.

Box 1 continued:

"There are four types of work-related condition that apply in the universal credit system:

- *Work-focused interview condition;*
- *Work preparation condition;*
- *Work search condition; and*
- *Work availability condition." (Disability Rights UK 2024 p. 116)*

If a person has a limited capability for work-related activity, none of the work-related conditions apply (ibid). If they have a limited capability for work, only the work-focused interview and work preparation conditions apply (ibid). As mentioned previously, having a limited capability for work and not work-related activity is usually not an option for new UC claims, but may apply to those migrating over from legacy benefits (ibid). For more detail on these conditions, please refer to the 2024 Disability Rights Handbook in the references.

Table 4 summarises some of the above information for clarity.

Table 4: Work allowance and work capability amounts under UC for different households where individuals have a limited capability for work/work related activity

Limited capability for work/work-related activity example households	Work allowance	Work capability amount
Individual with LCW with housing costs not included in UC	£673 per month	£416.19 per month for LCWRA (or £156.11 for LCW)
Individual with LCW, housing costs included in UC	£404 per month	£416.19 per month for LCWRA (or £156.11 for LCW)
Couple, both with LCW, housing costs not included in UC	£673 per month total	£416.19 per month for LCWRA (or £156.11 for LCW) but only one payment
Couple, both with LCW, housing costs included in UC	£404 per month total	£416.19 per month for LCWRA (or £156.11 for LCW) but only one payment

If a person is applying to UC for the first time and they are earning over £793.17 per month (which is a similar level to the hard cap in ESA) and are not claiming additional cost benefits, they will automatically be classed as 'fit to work' (Welfare Benefits Unit 2024). This would mean they would not receive a work capability amount, and they would not receive a work allowance (unless they are responsible for qualifying children or young people as noted in the quote above).

If a person is already claiming UC and their earnings increase, they would not automatically lose their additional disability amount (CPAG 2024). However, there is a possibility that the DWP could reassess their work capability level if they feel their condition has improved or their circumstances have changed. Higher earnings or increased hours count as a change of circumstances, and a change of circumstances can mean that the work capability assessment outcome could change at reassessment. If one person in a couple is reassessed as 'fit to work' and the other remains with a limited capability for work or work-related activity, the couple will still receive their work allowance and work capability amount (Disability Rights UK 2024).

This is our best understanding of the universal credit system based on significant reading. If there are any errors, they are of our own omission.

Box 1 continued:

On 18 March 2025, the UK Government announced significant reforms to health and disability benefits in their Green Paper "Pathways to Work: Reforming Benefits and Support to Get Britain Working" (UK Government 2025). This will change the operation of Universal Credit across Great Britain, with fewer people likely to be placed in the LCW or LCWRA group. As yet there is not enough detail to know how it will operate in Scotland, or on the people we interviewed.

While there is not a cliff edge for disabled working people in UC (see Box 1) like there is in ESA, there is still a significant lack of clarity around what happens when individuals increase their hours or earnings, since the DWP can reassess a person's capability to work due to any change of circumstances. On top of this, many people with learning disabilities due to migrate from ESA to UC may not understand the differences between the two systems unless these are provided in an accessible format. And while the removal of the benefits cliff edge is a positive step, those who work above the work allowance will lose money when migrating to the UC system.

Our participants claiming ESA were facing some significant cliff edges which disincentivise what they should be incentivising. Migration to UC could leave these individuals worse off financially, and a lack of guidance around increasing hours or earnings is likely to continue to disincentivise progression in work. It is also possible that participants were worried about losing all benefits (including their additional cost benefits) due to working, though we did not look into this.

Barriers to entering employment

Participants in the sample faced many barriers to entering employment. Several participants discussed being faced with stigma or a lack of understanding of their disability by prospective employers. Some participants were told the business would need 'liability insurance' or have to pay extra to employ them. One participant was reportedly told by their Access to Work representative that individuals working less than 16 hours 'shouldn't really get Access to Work'. We were unable to find any evidence of part-time workers being ineligible for Access to Work in online guidance.

For those who had not worked before, employers asking what kind of support they might need was difficult. Participants were not sure what to say since they did not have previous experience of work. Some participants who had successfully entered employment had to self-advocate at various stages of the process in ways which may not be possible for many individuals with a learning disability.

The findings of this study in relation to barriers to work are reflected in many related pieces of research, including our previous work on learning disability employment (Fraser of Allander Institute 2021). People with learning disabilities struggle to enter employment due to myriad barriers. If successful in gaining a job, they are often restricted to low-skilled, low-paid roles at part-time hours due to hard caps on hours and pay which are tied to benefits. Fear of losing out on benefits often kept participants with learning disabilities in this study in these low-skilled, low-paid roles, or drove them to voluntary work where they could use their skills and experience more effectively.

The reforms announced by the UK Government in their Green Paper include a "right to try" in legislation so that people can be confident that an increase in income from earnings will not lead to a lead to a reassessment or award review. This is a positive step which should help with the issues raised in our interviews.

Social care, unpaid care and support from charities

Most participants received care and support from either support workers or unpaid carers. Some participants also received support from third sector organisations. The two most common forms of care which people were receiving were regular home visits from paid carers, and unpaid care from people with whom they lived. 10 participants received visits from support workers (some of these participants also received unpaid care). A further six were receiving unpaid care only. One person lived in independent supported living and had 24-hour access to support workers at home. Other types of care accessed by participants included day centres (two participants) and support from charities for people with learning disabilities.

Six participants who lived alone were not receiving any paid or unpaid care. Two of these participants said that they had received social care in the past, but it was stopped at some point. Out of the six participants who were not receiving social care, four said that they wanted or needed it.

One participant was unable to take full advantage of the number of care hours they were allocated through self-directed support, due to a lack of staff availability in the rural area they lived in.

One participant paid £250 per month on top of their self-directed support for their care as they were ineligible for the support they felt was required.

Participants received support for personal care and daily activities such as cooking. Some also received support with budgeting, sorting through letters and bills, making appointments, understanding complex information, and having someone to support them when going out. Participants were generally happy with their care when it was available. However, the supply was not always there – several participants discussed hours being cut or taken away entirely. Some of these participants were told this was due to staff shortages, while others were not given an explanation. Those with more control over their care, such as those on SDS option 1, tended to be more satisfied with their care (see Self Directed Support Options section for more information).

We found some participants had difficulties with different eligibility in different local authorities. One participant who had moved recently explained the following:

> *"I had put in for occupational therapy, but [Council A] said I was ineligible because I'm an owner occupier, but [Council B] said, 'You are eligible even though you pay private for your house and you're actually… you've bought your house. You can still get help because you've got a severe disability.' But they made that decision after speaking to me on the phone because I sound affluent… I sound like I've got money, but I don't." - Participant*

Those who could self-advocate tended to have better experiences than those who needed external support, as often this was not accessed. Independent advocacy provision also seemed to differ across local authorities.

Care charges

A number of participants mentioned non-residential social care charges having an impact on their overall sense of financial security. As we have found in this research, people with learning disabilities often face higher living costs associated with their disability, and charging for essential support inevitably creates additional financial hardship. In March 2021 following the Independent Review of Adult Social Care, the Scottish Government and COSLA launched a joint statement that committed to end charging for non-residential services as soon as possible (Scottish Government 2022). However, this has not yet been implemented.

Residential care

Our aim was to recruit individuals who were living in residential care, but we struggled to do so. Some organisations we approached explained that often the guardians of those in residential care were not available nearby, sometimes even living abroad. Without families present, we could not speak to those who were not able to give informed consent by themselves.

However, we did speak to the parent of one person living in independent supported living. We were not able to speak to the person with a learning disability because they were residing in England (the parent lived in Scotland). Because of this, the interviewee was subject to the English Court of Protection System, rather than the Scottish system of guardianship and SDS.

Under the English system, an individual must be given the status of "deputy" in order to deal with the financial affairs of another individual who has been deemed to have no capacity to do so themselves. In case of the participant who was interviewed there were many similarities between what they are required to do by the Court of Protection system and what they would have been expected to do under the Scottish SDS system – for example, the participant was required to keep financial records for the person they are financially responsible for. However, it seems that the English system is much more stringent in certain ways. The participant discussed the pressure of being subject to strict financial monitoring and the possibility of being subject to financial auditing by the UK Government.

Self-directed support options

All those eligible for social care in Scotland receive self-directed support (SDS). SDS has four options available:

- Option 1: Direct Payment. A cash payment is paid directly to the individual, or to a third party. The individual can use this payment to choose and control their support.
- Option 2: Individual Service Fund. The individual chooses what support they would like and the Local Authority (or an agency) holds their budget and makes the arrangements on their behalf.
- Option 3: Direct Service. The Local Authority selects the support and arranges it.
- Option 4: A Combination. The individual can choose to mix the above options to suit them. (Self-Directed Support Scotland, undated)

Three participants in this study were receiving SDS option 1. It was difficult to determine which SDS options the remaining participants were using, as SDS was not well understood by many participants. Participants generally knew that they did not manage their SDS money, so must have been on options 2-4. We expect many were on option 3 (direct service) as there was little evidence of participants asking their local authority for specific forms of care and support.

Those whose care was managed by the local authority tended to report more problems with their care than those on option 1. Participants discussed support worker shortages, and their support hours being cut or changed at short notice. Participants using option 1 had much more choice and control, but this option came with its own difficulties. Unpaid carers had to act as employers and keep a detailed record of finances: one unpaid carer paid an accountant to ensure that they were paying their support workers' national insurance contributions correctly.

Only one participant with a learning disability was using SDS option 1 without the help of an unpaid carer, and this was made possible due to independent advocacy. Option 1 made a significant difference to this person's care.

> *"Well, the other options were … and I was a bit petrified to do option one, to be fair, but the other options, you didn't get … it wasn't me that chose my hours, I had to work round whichever service came in to help me. So the way it was explained to me was, if I go with a service, yes, someone will definitely come in, but they will dictate the hours. So if I wanted to go to bed at say 10:00 o'clock, they would say, "Well, we'll be in between 7:00 and 9:00, so if they came in at 7:00, I'd be in bed at 7 o'clock at night, or sometimes even 6 o'clock at night. And even if I wasn't in bed, I had to be in my house for 7 o'clock, just in case, even though they might not turn up until 10:00. So it wouldn't have given me the life I wanted.*

> *Whereas this option I've got, I am allowed to be flexible, I've got all my staff on a group chat and I've got all their numbers, and I just message them and say, "I'm going to be doing such and such today, can you come in a bit later?" Or, "If you can't come in a bit later, can you just get on and do what needs doing in the house and I'll see you there?" And so far it's been amazing." - Participant*

However, the effort required to maintain option 1 may not be feasible for all people with learning disabilities. Some participants mentioned that they had declined when they were asked whether they wanted to manage their own SDS money: the prospect of managing their own care money was intimidating for many participants, particularly those who already struggled with budgeting or understanding their finances. For those who were nervous about managing funds, it seems that option 2 would be the ideal option since it offers greater control without financial responsibility. But without independent advocacy, many people with learning disabilities may not have the confidence or level of understanding to determine which option is best for them.

We are unsure how much detail participants were given when the options were explained to them by their local authorities. The SDS act includes a duty which requires local authorities to direct individuals to independent advice on SDS, but it is unknown if this information is provided in a format which people with learning disabilities can understand. The post-legislative scrutiny of SDS has highlighted issues with implementation of the legislation, particularly differences in assessment, delivery, and availability of services between local authorities (Health, Social Care and Sport Committee, 2024).

Does the adequacy of social care affect financial security?

One relationship we were interested in exploring was whether participants' perception of how they managed financially was better when they received adequate social care. Care is a benefit in kind, which means that money received from work or benefits may have less of a determinant on whether people feel able to live the life they want to, if care provision is adequate.

15 of 21 participants' experiences were in line with the hypothesis that adequate care may correlate with participants feeling they have enough money. Of the 6 participants whose responses did not align with this hypothesis, 4 felt they had enough money but not enough social care. This was mostly due to a lack of care resource in their local area or having care hours cut due to not being on SDS option 1 as discussed in the previous section. The two participants who were happy with their social care but not their money received unpaid care from family members.

This relationship does not prove causality but nevertheless is a useful indication of the interaction between the adequacy of social care and perceptions of money for people with learning disabilities. In terms of policy, this evidence shows that financial security is impacted not just by financial benefits, but also by benefits in kind received through public services such as social care.

However, it is important to note that adequate social care is not a substitute for adequate benefits, but instead an additional component which affects financial security. This relationship highlights the need for cross-government and agency working to maintain/improve the financial security of people with learning disabilities.

Conclusions

To conclude, we return to our research objectives. First, we aimed to gather evidence on the extent to which people with learning disabilities and their families are supported adequately financially. We found that across our sample, 14% of participants' households were in poverty. This rose to more than half of households (57%) when additional cost benefits were excluded. 70% of households did not meet the Minimum Income Standard when we included all benefits – this rose to 86% when additional cost benefits were excluded. Some participants reported they were happy with their money, but more said they did not have enough to live the lives they want to. And in some cases, participants were missing out on essentials.

Secondly, we wanted to understand the impact of the social security system on people with learning disabilities and their families. Many participants were worried or confused by the social security system, particularly where changes were being made, such as the planned migration to Universal Credit or the change from Personal Independence Payment to Adult Disability Payment. Participants were also concerned about the employment cliff-edge created by the conditions associated with limited capability to work. We found a lack of evidence of participants accessing independent advocacy for benefits.

Our findings on the inadequacy of benefits are echoed by a range of evidence and have been shown to apply to the disabled population of the UK, not just those with learning disabilities (see Work and Pensions Committee 2024 for a summary).

Finally, we gathered evidence on the impact of social care. Participants in our sample accessing social care were often unhappy with their social care provision. Several participants reported their hours being cut or taken away completely with little explanation given to them. There was a lack of understanding of the options included in Self Directed Support – only three participants were using option 1 which offers the most control, and two of these participants were supported by their unpaid carers to access this. We found that our participants were hesitant to use option 1 if they understood it due to having to manage budgets themselves. We found a correlation between those who felt their social care was adequate and those who had positive feelings about their money.

The experiences of our participants highlight the complexity of the social security and social care systems, and the negative impacts these systems can have when people with learning disabilities do not receive adequate support to interact with such systems. Below, we outline some options for improvement which we feel would improve the situations of those in our sample, and those with learning disabilities in Scotland more widely.

Our research concluded before the recent changes announced by the UK Government on disability and health benefits. Some of the changes announced should help with the issues raised, but others are likely to increase uncertainty and reduce entitlements. We note, where relevant, these issues below.

1. Better promotion and implementation of independent advocacy

While independent advocacy is now a legal right, this does not guarantee that people with learning disabilities are aware of it. Many of the issues faced by our participants, such as inadequate social care and confusion around benefits, could be tackled with the help of an independent advocate. Ensuring information about independent advocacy is provided reliably and in accessible formats to people with learning disabilities would go some way in reducing this issue. Furthermore, some advocacy services such as VoiceAbility can only provide advocacy related to Scottish benefits. People with learning disabilities require support to access both reserved and devolved benefits.

2. More accessible information on UC rollout and upcoming health-related benefit changes

Our participants were concerned about having to move to UC, but did not speak about this as an inevitable event. We did not discuss with them the mandatory migration deadline. If we did, we expect this would have caused significant distress for many participants. The UK Government's recent green paper contains several changes to health-related elements of UC, both good and bad, which may affect people with learning disabilities' financial situations and barriers to paid work (UK Government 2025). However, we still do not fully know how the changes will operate in Scotland. The changes are hugely complex, and from our research we can see that there is a lack of accessible explanations of how the current system operates, let alone the changes.

3. Exploration of ways to provide clarity on UC and employment with a disability

Those with a limited capability to work claiming ESA currently experience a cliff-edge in their benefits. All ESA recipients are due to migrate to UC by the end of 2026, which will mitigate this cliff-edge. The extent to which people can increase earnings from paid work under the current UC system without losing income from benefits is unclear. The UK Government reforms seek to clarify this by legislating for a "right to try" so that people can be confident that they will not lose benefit income if their earnings increase. This is a positive development, and we hope that it will reduce barriers to paid work for people with learning disabilities.

4. Support for existing recommendations for Self-Directed Support implementation

Our findings support the recommendations from the post-legislative scrutiny of SDS policy, with particular focus required on the needs of people with learning disabilities. This is a process which has judged the effectiveness of SDS implementation across Scotland and offered recommendations for improvements to the SDS system. There are many recommendations in the post-legislative scrutiny. Our research adds weight to the following recommendations on consistency of SDS implementation:

"During this scrutiny, the Committee has heard that there is a lack of national consistency in relation to information, advice and support to ensure fair and equitable access to social care through SDS. The Committee recommends that the Scottish Government issues further guidance to all HSCPs to ensure there is a significantly improved level of consistency in communication of information, definitions and use of language to describe SDS.

The Committee's scrutiny has revealed a lack of public awareness about what social care, and SDS, is and how it works. The Committee agrees with stakeholders that there should be an online one-stop resource for people who may need to access support with SDS and calls on the Scottish Government to establish such a service, accompanied by regular campaigns to promote it. This would be a huge benefit to people who require social care support and want to understand more about SDS." (Health, Social Care and Sport Committee, 2024, p. 42).

We agree that the consistency of information provided and provision across local authorities must be improved, including information in formats accessible to people with learning disabilities.

5. Wider, joined-up consideration given to improving financial security for people with learning disabilities and their families

The Social Security (Scotland) Act 2018 states that the social security system should contribute to reducing poverty in Scotland. If Scotland is to meet its poverty targets by 2030/31, action will need to be taken to boost the incomes of disabled families. This report has shown that there are many complex factors involved in ensuring financial security for people with learning disabilities and their families.

Over half of our participants were in poverty based on their income from work and their reserved income-related benefits ESA and UC. We also found that 70% of households did not meet the Minimum Income Standard, even with their additional cost benefits included. Though a Minimum Income Standard for disabled households has not been calculated, the Disability Price Tag 2024 report shows that disabled households need additional funds to meet the same standard of living as non-disabled households (Scope 2024). This means it is likely that many disabled families are missing out on things that others in society feel are important to a minimum decent standard of living. But our findings are not just about money. Better joined up support across government in the areas of social security, social care, independent advocacy and employability support would greatly benefit people with learning disabilities. Financial security for people with learning disabilities can be enabled by joined up support, where individuals and their families are supported to understand the different services they access, and where government departments and bodies work together on how services can better complement each other.

The UK Government reforms which seek to reduce additional element paid to disabled people in UC, and restrict who will receive it, will exacerbate these issues. Another key UK Government reform, which will tighten eligibility for PIP will not automatically apply in Scotland because the policy is devolved, but the Scottish Government will face a reduced budget from the UK Government to pay for the equivalent benefit (ADP) in Scotland.

If the Scottish Government keeps eligibility at the same level in Scotland, they will need to raise taxes or find savings from elsewhere in the Scottish budget. If spend is reduced elsewhere, our research shows how important it is to understand how this impacts across other areas of public services that support people with learning disabilities. Support from the social security system can be undermined if there is not adequate complementary support from other parts of the state.

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