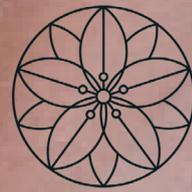




University of
Strathclyde
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ACORNS TO TREES

SUPPORTING THE MEANINGFUL INTEGRATION OF ADULTS
WITH LEARNING DISABILITIES INTO MAINSTREAM SOCIETY



Fraser of Allander Institute

Learning disabilities and the value of
unpaid care

September 2021

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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. The FAI is a leading academic research centre focused on the Scottish economy.

The analysis and writing-up of the results was undertaken independently by the FAI. The FAI is committed to informing and encouraging public debate through the provision of the highest quality analytical advice and analysis. We are therefore happy to respond to requests for factual advice and analysis. Any technical errors or omissions are those of the FAI.

Executive summary

People with learning disabilities draw on different types of support to enable them to live rich and fulfilling lives. But the support given by unpaid carers is often overlooked and undervalued.

It is important to understand the extent and nature of unpaid care delivered to people with learning disabilities and the interaction between caring roles, family finances and wellbeing. Delivering on the Scottish Government's pledges to build a wellbeing economy with inclusive growth at its heart will be impossible without this understanding.

The success of these economic priorities will be measured on the ground, so we surveyed unpaid carers of adults with a learning disability. We found that:

- On average, the support delivered by each unpaid carer in our sample would have cost the taxpayer £114,000 per year to deliver equivalent care. The provision of unpaid personal care alone delivered the taxpayer an annual saving of £55,000 for each carer in our sample.
- Total hours of unpaid care provided per day ranged from 8 to 16 hours for those cohabiting with the person they provide care for, and 5.5 to 8.5 hours for those who provide unpaid care for an adult with learning disabilities that lives elsewhere.
- Unpaid caring roles for adults with learning disabilities differ from what might be expected. Personal care, such as support with washing, dressing and eating, comprised only part of the care delivered. Not to be overlooked is the impact of providing other essential care, such as supervision to ensure safety, assisting with leisure activities, providing transport, ordering medications, and liaising with health and social care staff. This means that the unpaid carers in our sample got little genuine downtime.
- Caring responsibilities limit unpaid carers' opportunity to earn income through employment, leaving them more reliant on the social security system for support, which is often insufficient. Just over half the unpaid carers in our sample had household income below or around the poverty line.
- The unpaid carers in our sample generally scored far lower than the national average on wellbeing measures. This was particularly notable for measures of loneliness and burnout.
- Because learning disabilities are by definition lifelong, the impact of caring responsibilities for family members (especially parents) can differ from other caring roles, such as caring for an elderly relative. The lifelong caring commitment creates a loss of agency and limits the long term choices unpaid carers can make.
- When asked for their priorities for better support, all but one of the unpaid carers in our sample wanted more respite and services for the person they care for. This points to a social care system that is not doing enough to support people with learning disabilities and their families.
- During the Covid-19 pandemic, unpaid carers have filled in the gaps left by the care system, leaving many exhausted. None of the unpaid carers in our sample have seen support return to pre-pandemic levels, even as Scotland moves "beyond level 0". With no clear plan for a return to normality, unpaid carers are facing an uncertain future.

1. Introduction

People with learning disabilities draw on support in different ways throughout their lives. For many, the most impactful support they receive comes from unpaid carers, usually parents or other family members.

Because learning disabilities are by definition lifelong and the fact that it is often parents who provide unpaid care as their children become adults, the nature of caring responsibilities can differ from other caring roles, such as caring for an elderly relative. It is therefore important when thinking about policy to better support unpaid carers to consider unpaid carers of adults with learning disabilities as a distinct group.

This report adds to the evidence base on this and analyses the extent and value of unpaid care provided, as well as the impact that this has on carers' lives, wellbeing and financial prospects. This is the latest instalment of our [programme of work](#) looking at how adults with learning disabilities are supported in Scotland. It extends our focus from individuals to families and raises questions about how we, as a society, support people with learning disabilities and their families to live fulfilling lives as equal citizens.

“Unpaid carers are the mortar in the wall. We’re there, we’re essential, but we’re hidden.”

Unpaid carer from FAI focus group

Clearly, the support given by unpaid carers has value in that it enriches their loved one's life and ensures their safety. However, because it is an activity that does not result in a transfer of money, it is not part of measures such as GDP, nor are full-time unpaid carers deemed active in the labour market. This means that the contribution of unpaid carers can often be overlooked and undervalued. In this report, we use economic techniques to estimate an economic value of the support provided by a sample of unpaid carers of adults with a learning disability.

The difference that unpaid carers make to people with learning disabilities is often invaluable and life changing and we do not claim that the true value of this care can be reduced to a financial sum of money. But demonstrating the economic value of unpaid care enables us to illustrate the cost savings to the public purse that it generates and systematically puts into context the work that unpaid carers do, often with little recognition.

We also analyse the wellbeing and financial circumstances of households where unpaid care is provided to someone with a learning disability.

“People find it hard to believe but I’m literally there for my son 24 / 7. If I had a break, I honestly wouldn’t know what to do because it’s become a way of life. I’d love to just go for a coffee with a friend, but I haven’t done that for 3 or 4 years.”

Unpaid carer from FAI focus group

This report could not be more timely, as we emerge from the Covid-19 pandemic and consider how to “build back better”. As Covid-19 restrictions forced care packages to be withdrawn, reduced or changed, families stepped in to fill the gaps. So we also asked our sample of unpaid carers to reflect on their experiences since the beginning of the pandemic and for their priorities for the future.

How we reached our conclusions

The conclusions of this report are drawn from primary research methods that involve unpaid carers of an adult with a learning disability in Scotland participating in a survey. Participants completed a time use diary on an anonymous basis, as well as a questionnaire that asked for information about their household finances and the wellbeing of the unpaid carer. Further details on these are presented in Annex A.

As well as the rich data that the time use diaries and questionnaires provided, a focus group was held with a selection of unpaid carers of adults with a learning disability. This enabled unpaid carers to describe their experiences, and how providing unpaid care affects their lives, in their own words. It provided another source of evidence (qualitative data) and complements the analytical approach described above. A case study of one unpaid carer is profiled in section 7.

The sample used in this study is not representative of the population of unpaid carers of adults with learning disabilities, which means that results cannot be extrapolated. However, they provide an insight into the lives of the unpaid carers that we surveyed and illustrate the level of public expenditure savings that they contribute on an individual basis.

Even if the sample were representative, extrapolating results across the population would still be difficult, as there is no widely agreed estimate of how many people live with a learning disability in Scotland and how many of them receive unpaid care.

2. Results at a glance



2 to 8.5 hours

The unpaid carers in our sample who live with the person they care for delivered **2 to 8.5 hours** of **personal care** alone per day.



8 to 16 hours

The unpaid carers in our sample who live with the person they care for provided between **8 and 16 hours** of **total care** per day.



53%

53% of household income for the unpaid carers in our sample was from the **social security system**.

£114,000



The average cost of care delivered by each unpaid carer in our sample would have been **£114,000** without their contribution.

55%



55% of our sample of unpaid carers had income **below or close to the poverty line**.

£35,000



On average, the living wage equivalent for the personal care provided by our sample of unpaid carers was **£35,000** each.

72%



72% of the unpaid carers in our sample **reported feeling lonely**, compared with the most recent national average of **20%**.

Source: FAI survey of unpaid carers and the Scottish Health Survey 2020

3. The economic value of unpaid care

In order to understand the extent and value of unpaid care provided to adults with learning disabilities, we asked a sample of unpaid carers of adults with a learning disability to complete a diary on a selected day. We then translated the time spent on unpaid care into an economic value.

We took two different approaches. First, we estimated the attributable wage if those providing unpaid care were paid the living wage for the hours of care provided. Secondly, we estimated the replacement cost if the services were provided by the state rather than by unpaid carers. The latter is likely to be larger than the former due to the cost of overheads alongside labour costs.

We received a total of 17 time use diaries. Results are broken down into the different types of care activities that unpaid carers relayed.

Box 1: Types of care delivered

Personal care

The type of care that could be termed ‘personal care’ which includes help with washing, dressing, eating and immobility support¹. We assume this type of care would require a paid home carer in the absence of an unpaid carer.

Examples of personal care activities

- Help washing and dressing
- Food preparation and support eating meals
- Assistance with mobility
- Providing medications
- Help with therapy exercises

Other essential unpaid caring activities at home

Unpaid carers provide a much wider range of support than personal care in order to safeguard health and wellbeing. These may be activities where they are supporting leisure activities or being present in the same room at all times to ensure the person they are caring for is safe and well.

In addition, there were many instances where the unpaid carer was ‘on call’ even when they were engaged with other activities such as cleaning, cooking or even sleeping with an eye and an ear out in case they were needed suddenly. Unsurprisingly, this meant that few unpaid carers had any genuine downtime.

This type of care provision is essential and highlights how the role of an unpaid carer might differ from many people’s expectations – providing personal care, such as help washing and dressing, is only part of the story.

Examples of other essential caring activities

- Supervising family member to ensure safeguarding in the home

- Being ‘on call’ whilst engaging in other activities
- Assisting at organised leisure activities, such as art classes
- Managing and organising care
- Liaising with health and social care staff
- Transport to and attendance at medical appointments

In the absence of the type of unpaid care described, we have assumed there would need to be a suitable alternative in place, likely in some sort of supported accommodation.

Additional unpaid care even for those in supported accommodation

Based on responses we received from unpaid carers of those who already lived in supported accommodation, unpaid care may reduce but not cease. Family members still spent time providing direct care such as shopping for food, checking on whether medications have been taken, spending time trying to understand problems and concerns, responding to emergencies overnight, and liaising with care professionals.

We assume that, in the absence of this unpaid care, a higher level of support would need to be provided within the supported living environment.

Hours of unpaid care provided

Hours of **personal care** provided for those cohabiting with the person they cared for ranged from between 2 hours and 8 and a half hours on the day they filled out the survey.

In the situations with lower levels of unpaid personal care, the adult that was being supported was able to do many activities such as dressing and eating cold items independently, but still needed some support with personal care such as showering, organising medication and cooking. Those providing higher levels of personal care were involved in all personal care activities.

There was no explicit indication from any of the survey responses that a social care worker was coming into the home to provide personal care. This raises questions over the coverage of “Frank’s Law” that promised free personal care for all those who need it².

Adding on **other unpaid caring activities at home** raised the hours of care for all households, with the range extending from 8 hours to 16 hours on the day in question.

“It doesn’t stop when they go to bed. It’s changing sheets in the night, sickness, nightmares. And for me, it’s every night.”

Unpaid carer from FAI focus group

For adults who live in supported accommodation, families reported between five and a half and eight and a half hours of **additional unpaid care** on the day they filled out the survey. The higher figure here was due to a call out during the night.

In the case of one unpaid carer, the day in question was during a weekend visit home from an adult care home. The level of unpaid care provided on that day was significant with supervision all day.

The economic value of care

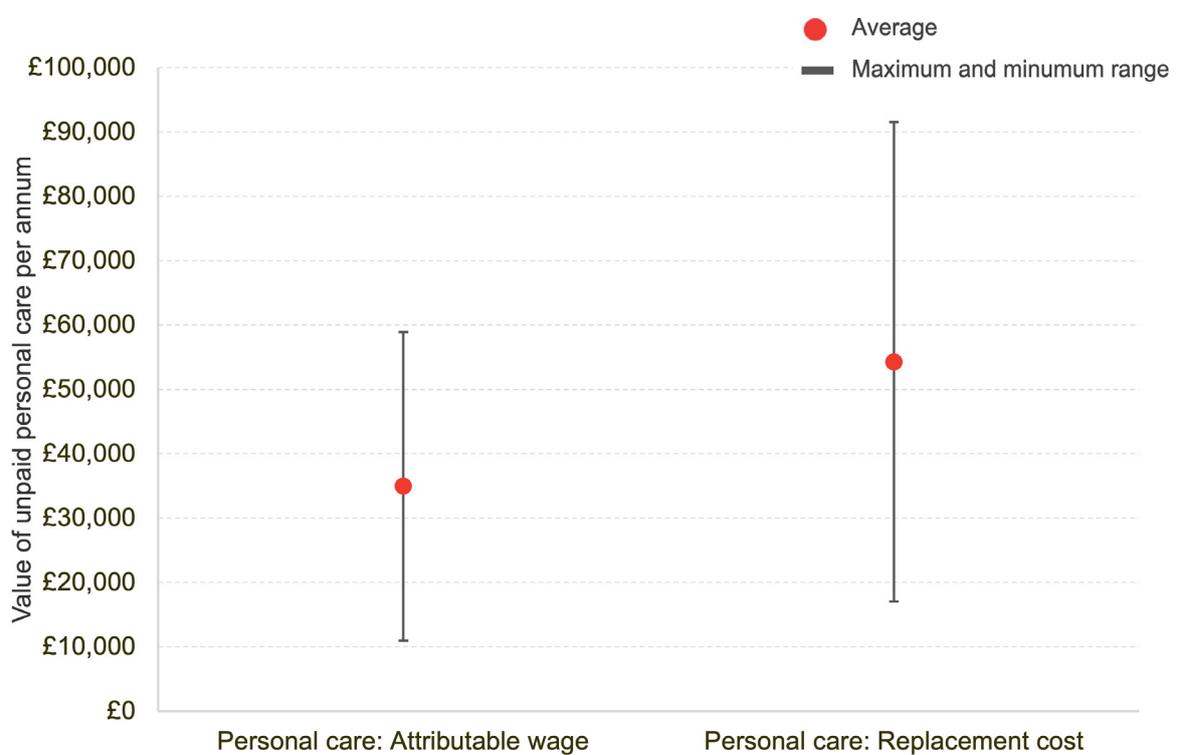
Personal care was an identified caring activity of all of the unpaid carers who cohabited with the person they provided care for.

The average value of personal care, if hours of care were to be paid at the living wage, is estimated at £35,000 per year based on the average of those we surveyed.

The average replacement value for this care, if it had been provided by a paid for home carer, is estimated at £55,000 per year based on the average of those we surveyed.

Chart 1 shows these average figures, alongside the minimum and maximum figures, which gives an indication of the range of estimates based on the survey responses.

Chart 1: Average, maximum and minimum values of unpaid personal care



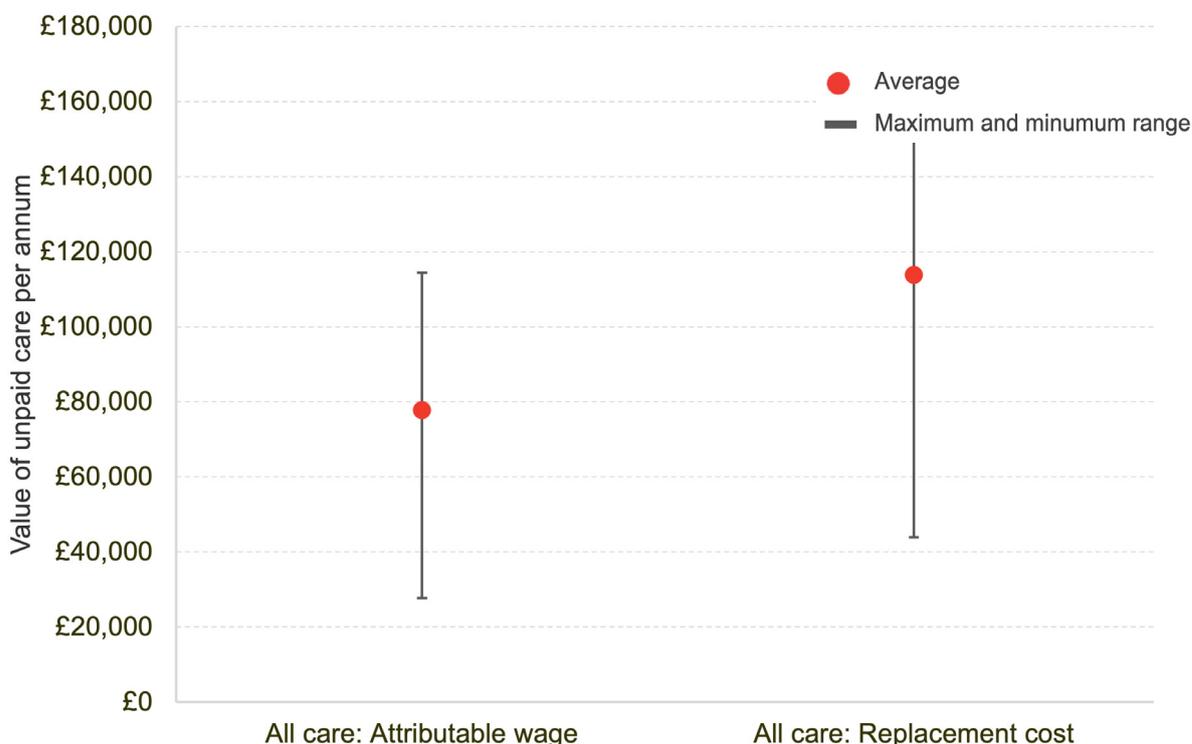
Source: FAI survey of unpaid carers

Adding on **other essential and additional care**, the average value of care, if hours of care were to be paid at the living wage, is estimated at £78,000 per year.

Assuming that in the absence of this unpaid care the person with a learning disability would need to transfer into supported accommodation or have their care package in supported accommodation increased, the average replacement cost is estimated at £114,000 per year.

Both the attributable wage and replacement value of unpaid care clearly represent significant sums of money and highlight the extraordinary, and often unrecognised, contribution that unpaid carers of adults with learning disabilities make.

Chart 2: Average, maximum and minimum values of all unpaid care



Source: FAI survey of unpaid carers

This research also shows how the caring roles of unpaid carers of adults with a learning disability are not homogeneous. Across our sample, there was a range of hours provided and cost savings to the public sector delivered, as shown above. As well as this, participants reported several different types of caring activities.

Some caring roles were more ‘hands on’ with more hours spent assisting with personal care and help during the night. Others involved more supervision and support around the house whilst engaging in day to day activities, such as helping with gardening, watching TV and exercising.

This variety of caring responsibilities reflects the fact that people with learning disabilities themselves are clearly not homogeneous, come from a variety of backgrounds and have different needs in terms of the type and level of care that supports them to live a fulfilling life.

This point should not be overlooked by policy makers, as they seek to understand how to better support unpaid carers – there is no one approach or policy that will deliver for everyone.

4. Unpaid care and family finances

The caring commitments outlined above limit unpaid carers' ability to sustain employment and earn income. In order to understand the financial impact of unpaid caring responsibilities, we asked survey respondents about their family finances. We received sufficient information from 11 surveys to estimate their household income.

Overview of sources of income

When reviewing time use diaries and financial information together, it was clear that unpaid caring responsibilities limited carers' ability to work. All those who reported not being able to work were women. Those that did have the opportunity to work relied on the support of family or paid-for care.

Of the total income reported in our sample, around half was in the form of benefits, highlighting the importance of the social security system to the livelihoods of unpaid carers. It should be noted that these figures were calculated and reported before the forthcoming reduction of Universal Credit (UC) and tax credits by £1,040 per year will be implemented. However, most of the benefit income for those with a learning disability in our survey was in the form of the legacy benefit, Employment and Support Allowance (ESA), and therefore did not see the uplift at the start of the pandemic that those on UC and tax credits received.

4/5 of our sample live with the person they care for and therefore recorded the benefits both received for the adult with learning disabilities and others in the household. All adults with learning disabilities received either Personal Independence Payments (PIP) or Disability Living Allowance (DLA). For reference, the level of entitlement depends on an assessment for both the daily living and mobility part of PIP, which pays up to £7,912 per year.

4/5 of adults with learning disabilities received ESA, which pays between £3,884.40 and £5,933.20 per year depending on which premiums apply.

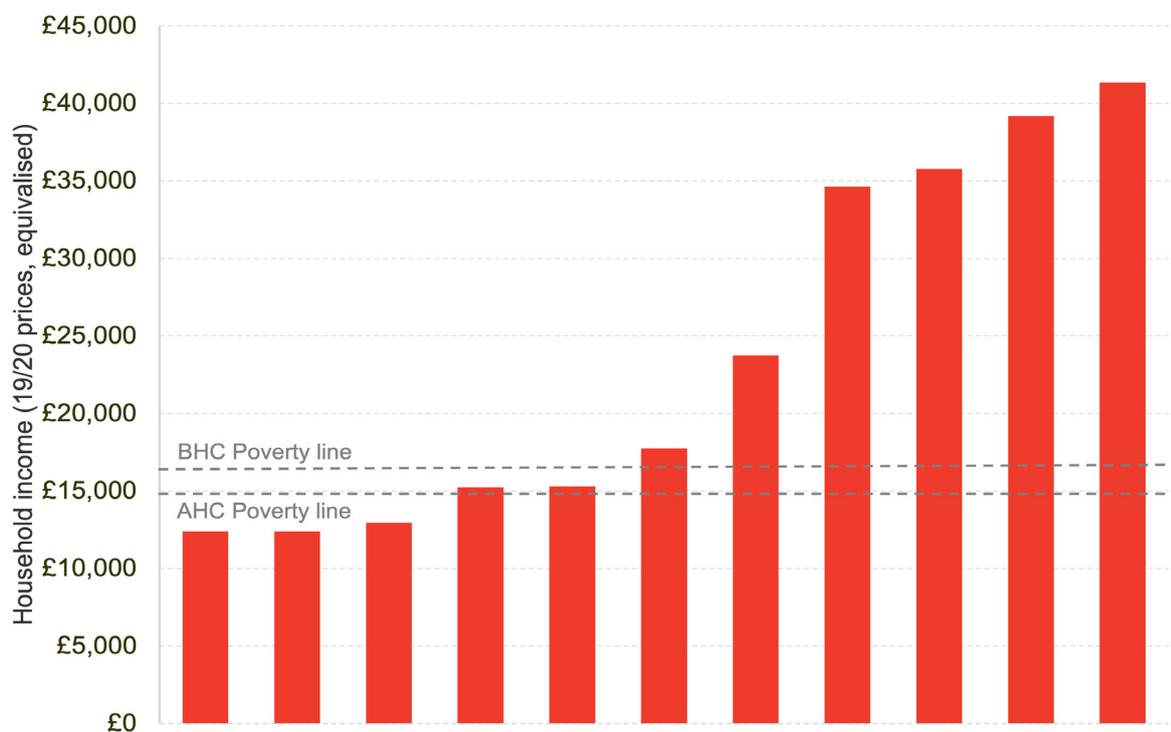
Two thirds of unpaid carers in our sample received Carer's Allowance. There were some households that received Carer's Allowance but not ESA and vice versa. Carer's Allowance in Scotland pays £67.60 per week and a twice-yearly supplement of £231.40.

Using the information provided, we were able to compare our sample's household incomes to markers of low income in Scotland. The results of this, along with commonly understood poverty lines are shown in Chart 3.

Just over half of survey respondents had income below or around the poverty line. All these households were within the first or second income decile. Analysis below suggests that the biggest contributing factor to low incomes is the inability to work full time due to caring commitments.

Furthermore, it should be noted that these figures have not accounted for the additional costs associated with disability. This means that the families in our survey are likely to have a lower standard of living than their income might suggest if an equivalent household, but without a family member with a learning disability, had a similar income.

Chart 3: Household income of survey respondents and the poverty line



Note: All incomes are equivalised to account for family size. BHC Poverty and AHC Poverty refer to Before Housing Cost income and After Housing Cost income. See Annex A for full description of how this analysis was conducted.

Source: FAI survey of unpaid carers

Unpaid carers below or close to the poverty line

Of those households in our sample that were below or close to the poverty line, two thirds had some paid for care provision on at least some days.

One unpaid carer was able to do some paid work during the hours when care was provided, but described that much of the time when her son was away from the home was spent ordering medical supplies and organising his finances and appointments. This person was in receipt of Carer's Allowance.

Another carer had had to stop (self-employed) work temporarily to look after the person they provide unpaid care for when they became ill and even though the person they care for lives in supported accommodation, the care required from them as family member (including shopping, checking in to make sure they are eating, and responding to calls in the night if something happens) takes many hours out of the day. This person was not in receipt of Carer's Allowance.

In another case, the unpaid carer lives part-time with the person they care for, and lives on private pension income. When the person they care for is at home, they require full time assistance. This person was not in receipt of Carer's Allowance.

Only one mentioned a small amount of support from a day centre that the person cared for attends, but described that was different before the pandemic when the person cared for was out almost all

of the week, along with 8 hours of home care paid through Self Directed Support (SDS). Due to a combination of factors, the person that is cared for is now home most of the week and issues with the carer agency has meant that other options are being looked at for homecare.

The remainder had no paid care provision. They reported that they provided unpaid care mostly themselves with some support from family members. These households were in receipt of Carer's Allowance, ESA and PIP.

Unpaid carers currently not at risk of poverty

Around a third of households in our sample were relatively far away from the poverty line. These households had equivalised, and actual, household income of £35,000 and above and fell somewhere between the 6th and 8th income decile. All households had at least one family member working full time or retired having worked.

One household was in between this higher income cohort and the low income cohort, with income somewhere around the 3rd or 4th decile. The carer in this household was retired, with some private pension income.

Future implications of constraints on work for unpaid carers

It is clear from our analysis that adequate paid work is not compatible with unpaid care for the primary unpaid carer. This has implications in the here and now, and also in the future.

One financial impact of providing unpaid care, which this study cannot measure, is the change in carers' long-term earnings outlook due to caring commitments. This cannot be captured by analysis of static income figures and is difficult to reliably measure. This effect is particularly relevant to unpaid carers of someone with a learning disability, as this is by definition a lifelong condition that requires ongoing support.

"I used to have a well paid career and a lot of interests, but I can't follow those because of my caring role. And it doesn't stop when you retire."

Unpaid carer from FAI focus group

Another aspect is the loss of agency around potential earnings due to caring commitments. Given the lifelong nature of learning disabilities and the associated caring commitments from parents, this also limits many unpaid carers' ability to build a pension. It also limits unpaid carers' tax and national insurance contributions. The result is that social security income comprises a large portion of total household income for unpaid carers, who are themselves limited in how much they can contribute to the social security system.

5. The wellbeing of unpaid carers

As well as measuring the financial position of families that provide unpaid care to an adult with a learning disability, we also measured the wellbeing of unpaid carers. The Scottish Government have stated that building a wellbeing economy is a top priority and is a founding member of the Wellbeing Economy Governments group.

“Building a Wellbeing Economy is a top priority for the Scottish Government. This means building an economy that is inclusive and that promotes sustainability, prosperity and resilience.”

Scottish Government³

Questions around wellbeing were drawn from the Scottish Government’s National Performance Framework (NPF)⁴ and the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS). The NPF sets out what kind of country the Scottish Government wants to build and informs the public on what their priorities are. One such priority is to *“increase the wellbeing of people living in Scotland”*.

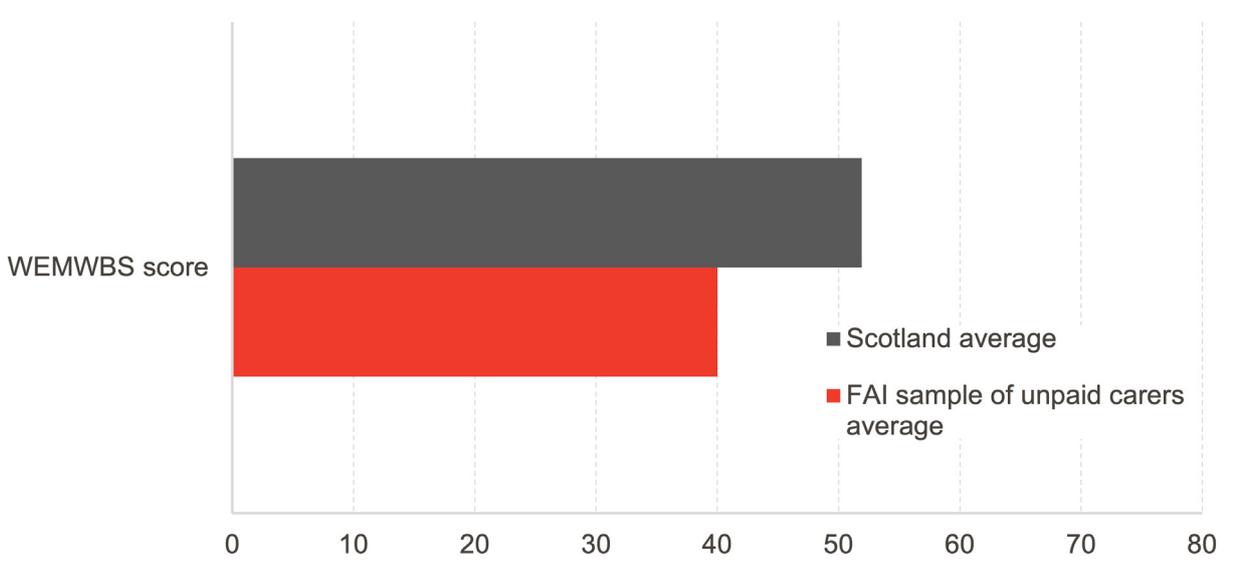
The NPF includes a range of National Indicators, against which progress can be measured and authorities held accountable. Many of these indicators are based on responses to the annual Scottish Household Survey or Scottish Health Survey. There is no standard definition of wellbeing, and measuring this abstract concept can be subjective. Using the wellbeing-related indicators in the NPF provides us with measurable benchmarks that are formally recognised as national priorities. The results from our sample can be compared against the national average of these indicators in the NPF to provide insight into how the wellbeing of unpaid carers that we surveyed compares with the general population.

The WEMWBS *“were developed to enable the measuring of mental wellbeing in the general population”*⁵. The scales were developed by academics primarily from the University of Warwick and the University of Edinburgh and provide another rigorous benchmark against which we can compare the mental wellbeing of unpaid carers of adults with a learning disability.

The scales ask participants to respond to positive statements about their mental state on a scale of 1 to 5, with 1 being *“none of the time”* and 5 being *“all of the time”*. Statements include *“I’ve been feeling useful”* and *“I’ve been feeling interested in other people”*. The statements are designed to *“cover both feeling and functional aspects of mental wellbeing”*⁶.

The average WEMWBS score in our sample was 40. This compares to a score of 51.9 recorded in the Scottish Health Survey field work in August/September 2020⁷. We received 18 surveys that included responses to wellbeing questions.

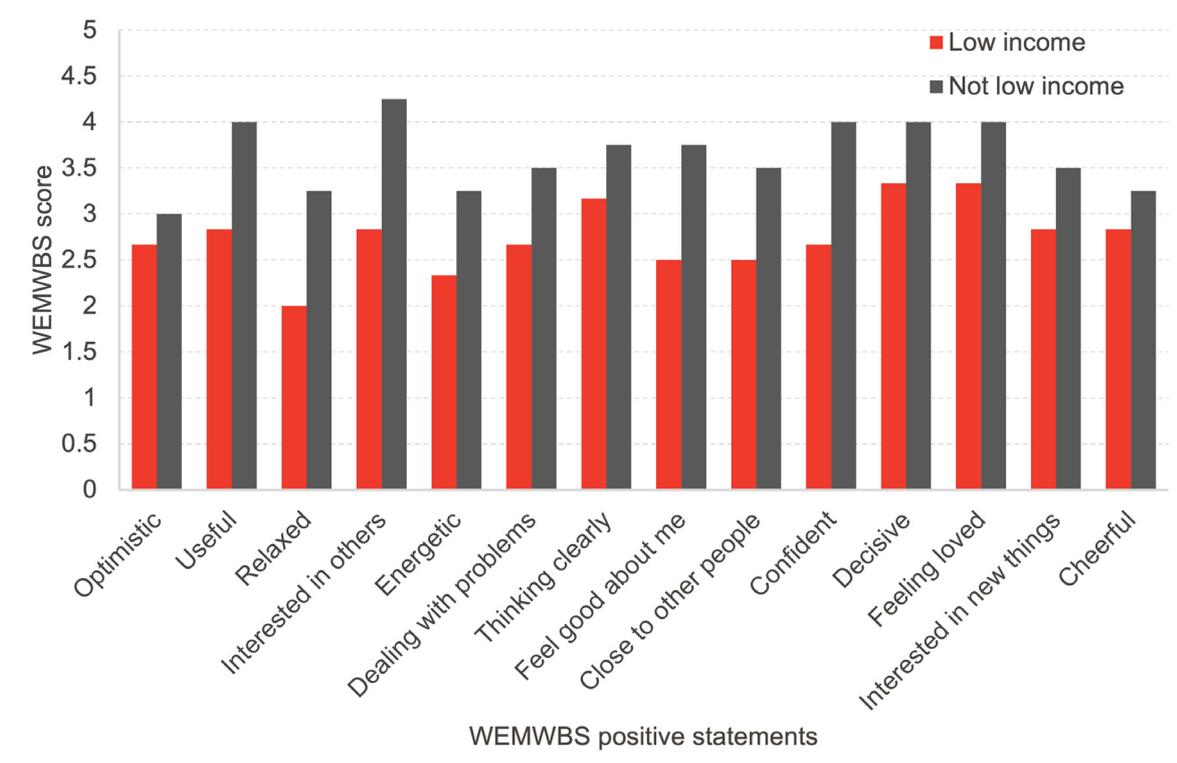
Chart 4: WEMWBS scores



Source: FAI survey of unpaid carers and Scottish Health Survey

The average WEMWBS score recorded for survey respondents who provided income information showed that those in low income had a score of 38.5, compared to 51 for those not in low income. This suggests that income has a bearing on wellbeing scores, and this may be driving lower wellbeing amongst the sample.

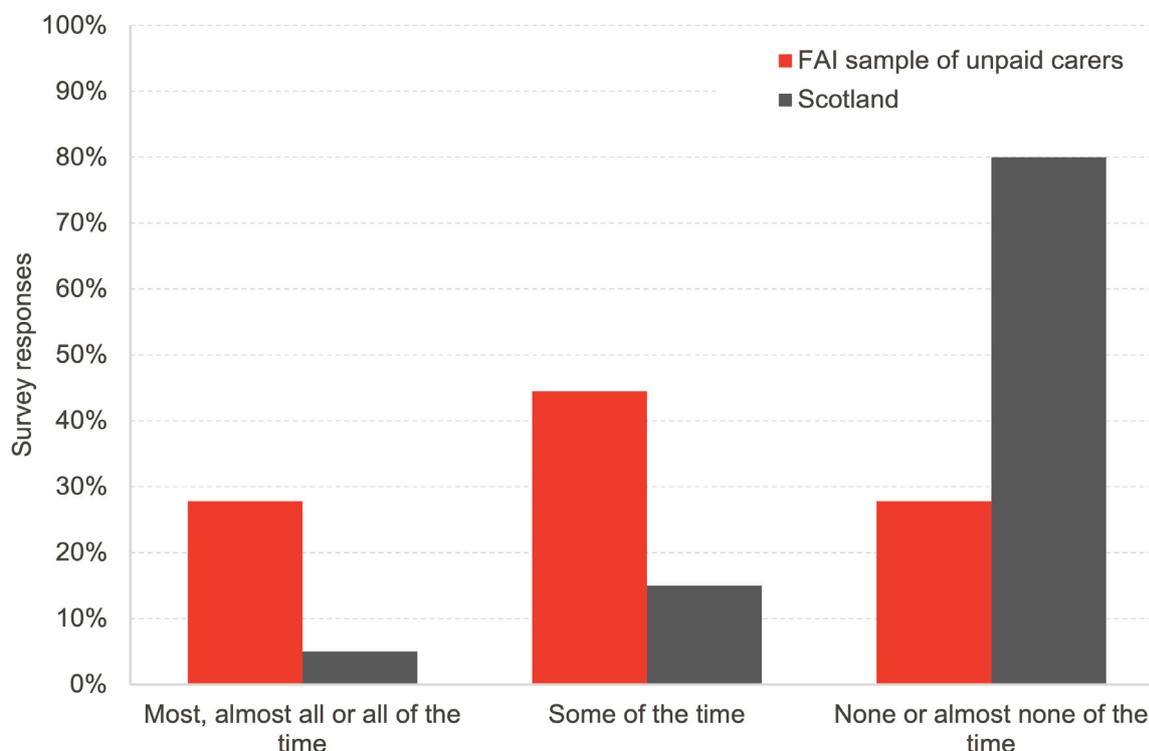
Chart 5: Income and WEMWBS score



Source: FAI survey of unpaid carers

We also asked our sample of unpaid carers a question that measures loneliness and social isolation.

Chart 6: “How much of the time during the last week have you felt lonely?”

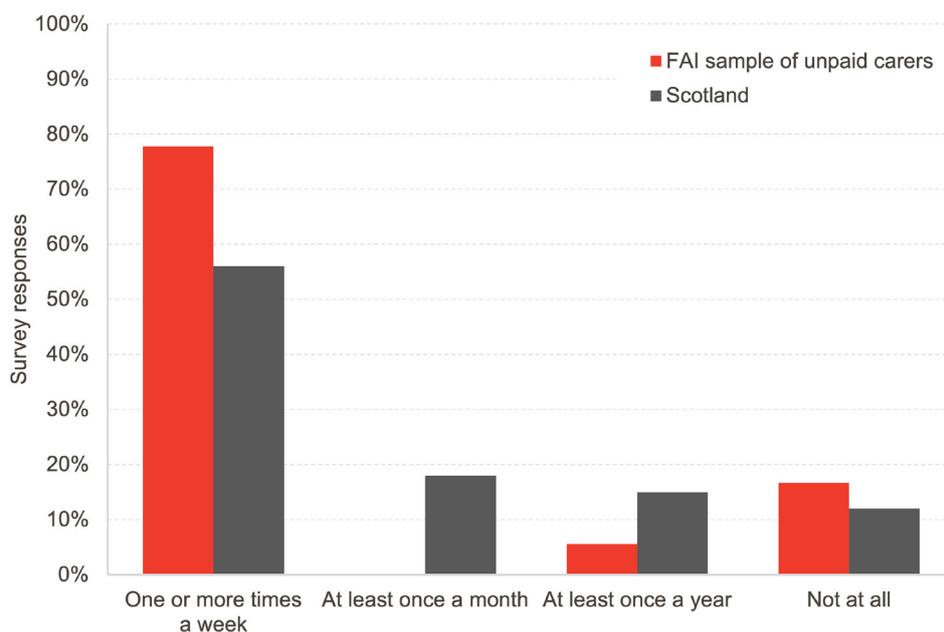


Source: FAI survey of unpaid carers and Scottish Health Survey

The key performance measure in the NPF is the percentage of adults answering “*some, most, almost all or all of the time*” and the most recent Scottish Health Survey in August/September 2020 produced a result of 20%⁷. This compares with 72% of our sample of unpaid carers of adults with a learning disability.

Another indicator that was selected as a measure of wellbeing in the NPF regards outdoor leisure visits. The key performance indicator is the proportion of adults making one or more visits to the outdoors per week, taken from the Scottish Household Survey. The unpaid carers in our sample are more likely to visit the outdoors than the national average, with 78% doing so at least once per week, compared with 56% of the national average⁴. It should be noted that the most recent Scottish Household Survey was conducted in 2019, before the Covid-19 pandemic.

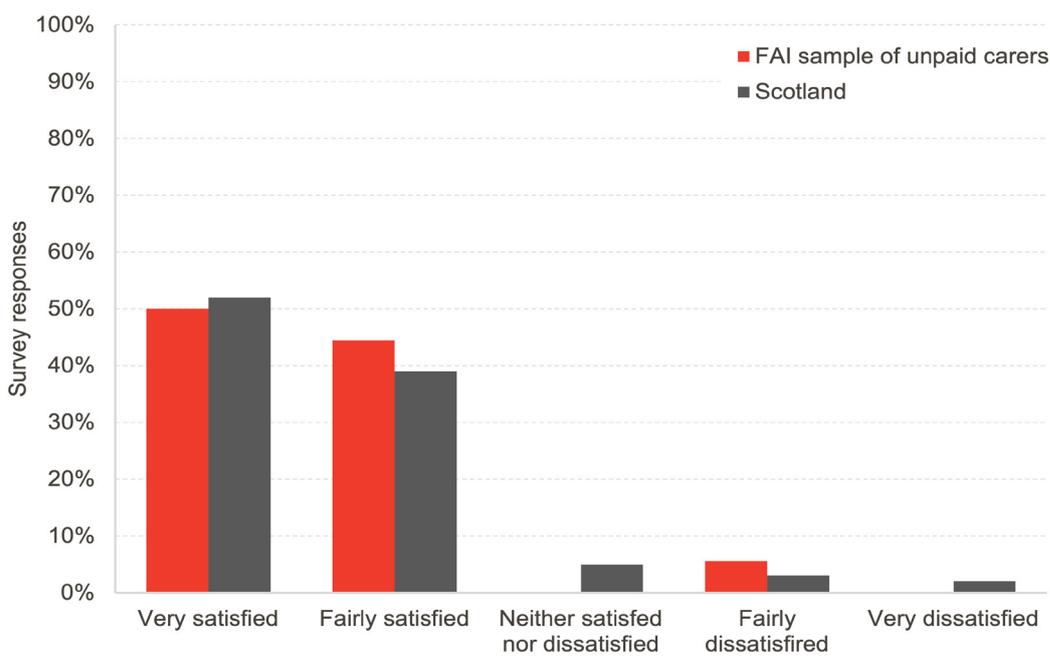
Chart 7: “How often, on average, have you taken visits to the outdoors for leisure and recreation in Scotland in the last 12 months?”



Source: FAI survey of unpaid carers and Scottish Household Survey

We also asked unpaid carers about their accommodation. The national performance indicator for this question is the percentage of adults who are either very or fairly satisfied with their house or flat. Our sample and the national average (taken in 2019) produced similar results, with 94% of our sample and 91% of the national average⁴ reporting that they are satisfied with their house or flat.

Chart 8: “On the whole, how satisfied or dissatisfied are you with your house/flat?”



Source: FAI survey of unpaid carers and Scottish Household Survey

Whilst some of our survey results are compared with surveys conducted before the Covid-19 pandemic, there is clearly an overall gap in wellbeing scores between the national average and the unpaid carers in our sample. It is striking that there are some elements of wellbeing where the gaps are more significant. This is particularly the case when asked about loneliness, energy and burnout, being optimistic about the future and feelings of self-worth.

In order to deliver on the promise of building a wellbeing economy, better support for unpaid carers is clearly needed.

“You do it because you love your child, but all I want is to be supported and valued. It would make a huge difference to my life if I could just be listened to.”

Unpaid carer from FAI focus group

It should be noted that these results do not compare unpaid carers’ present wellbeing with a time before they provided unpaid care, meaning that it does not measure the wellbeing impact of becoming an unpaid carer. In any case, many other factors that determine wellbeing will have changed since the participants in our sample became unpaid carers, so it is difficult to pinpoint the impact on wellbeing of becoming an unpaid carer. However, we can conclude that the wellbeing of unpaid carers in our sample is below the national average.

Many survey respondents and our focus group described in their own words the ways in which providing unpaid care impacts their wellbeing. Some clear themes emerged:

- The wellbeing of the person they care for is central to the wellbeing of the unpaid carer. When asked for their priorities for increased support, many unpaid carers asked for more services for adults with learning disabilities that would enable a greater degree of independence, rather than more direct assistance for carers themselves.
- Many unpaid carers in our sample reported facing exhaustion and burnout, especially in the wake of the Covid-19 pandemic.
- Some unpaid carers reported a sense of social isolation, which existed before the Covid-19 pandemic, and is backed up by the survey responses above.
- Most unpaid carers indicated a sense of lacking control and agency over their lives, due to the restraints that caring responsibilities place on their time.

Assessments of need

Unpaid carers are often eligible for some support through the social care system. In order to access this support, an Adult Care Support Plan, commonly referred to as a carer’s assessment, must be completed by their local authority. These are a legal entitlement for anyone who provides care and are designed to identify the support that carers need to sustainably carry out their caring role. We asked our sample of unpaid carers whether they have received such assessment of their needs.

We asked three questions around assessment of need for both the unpaid carer and the adult with learning disabilities. The results are displayed in Diagram 1.

Diagram 1: Assessments of need

Have you (as an unpaid carer) ever received an assessment of needs from your local authority?



Have you (as an unpaid carer) received an assessment of needs since March 2020?



Has the person you care for received a reassessment of needs since March 2020?



Source: FAI survey of unpaid carers

During our focus group, there was a feeling amongst some unpaid carers that these assessments amount to little and are a “tick box exercise”.

“I had to give up a career due to my caring role. I did a carer’s assessment but there was absolutely nothing in terms of additional support or resources for me for my family. It was just a tick box exercise. I just assumed that’s what a carer’s assessment is.”

Unpaid carer from FAI focus group

“There’s no point having a carer’s assessment. Mine was completed and I qualified for extra support but there isn’t any replacement care available. I was given a massage voucher, but I can’t take time away from my family to use it.”

Unpaid carer from FAI focus group

It was also striking that different members of the focus group received very different levels of support from their local authority depending on where they lived. This raises questions about the consistent application of guidance and available funding for supporting carers in their demanding roles.

Future support

We asked the unpaid carers in our sample what additional support they would like to see put in place for unpaid carers. One commonly reported priority for further support was increased pay for those working in the care sector. Around 3/10 commented that Carer’s Allowance is too low and eligibility

too restrictive (for example, state pension recipients are not eligible).

However, by far the clearest conclusion was that all but one respondent demanded more respite and services for the person they care for, both in terms of the variety and extent of support available. This was particularly notable amongst families that have made use of the direct payments option under Self Directed Support (SDS), which allows individuals to manage their own care within a given budget. These survey respondents reported a lack of options to spend the SDS budget on.

“I’ve read all the relevant legislation and it all looks great and really empowering. But in reality, it just doesn’t happen because the resources fall short.”

Unpaid carer from FAI focus group

6. The Covid-19 pandemic

The Covid-19 pandemic has upended many peoples' lives and it is important to understand the ways in which it has impacted unpaid carers. Many unpaid carers were already facing difficult circumstances before the pandemic, so were vulnerable to a significant adverse change in the support they receive.

To better understand the impact of the pandemic, we asked survey respondents and our focus group to describe in their own words their experiences since March 2020 and the support that they've received over that time.

The most obvious impact reported was the sudden withdrawal of support services for adults with a learning disability, meaning unpaid carers were left to fill in the gaps. A UK-wide study found 81% of unpaid carers have taken on more responsibilities during the pandemic⁸.

A commonly reported phrase was a “fight” or “battle” with the very system that is designed to support unpaid carers and their families. Some respondents noted a sense of “abandonment” at the very time when they needed support the most, and that this has had a significant detrimental impact on their mental health and wellbeing.

“This whole pandemic has shown what unpaid carers do for society. Authorities have to pull their socks up and listen to us, to understand what we do and what we've given up.”

Unpaid carer from FAI focus group

Before the pandemic, many unpaid carers used the time their loved one spent at formal services, such as day centres or time with a paid carer, for respite purposes. None of our respondents reported a return to normality and several voiced fears that support services that have been closed and/or restricted won't return in full.

This is one of the most concerning aspect of this research. Covid-19 restrictions inevitably caused disruption on all aspects of society, but as Scotland moves “beyond Level 0”, there appears to be no plan for a return to normal levels of care, leaving unpaid carers facing an uncertain future.

“It was difficult before Covid, but now everything has changed. There's so much uncertainty about the future and you never get a clear answer.”

Unpaid carer from FAI focus group

On the other hand, it was interesting to note that some unpaid carers in our sample felt that life has changed little since before the pandemic. Those unpaid carers that reported little change in their daily lives unanimously gave the reason that they already felt socially isolated before the pandemic.

Impact on care recipients

Whilst many unpaid carers have struggled through the pandemic, the primary concern for everyone involved in this research was the wellbeing of the person they care for. Some respondents were in the process of transitioning their family member to a more independent form of living, in preparation

for a time when they won't be around to provide support. The average age of unpaid carers in our sample was 57.

Some unpaid carers reported that their family member with a learning disability had lost all progress towards that goal. For example, their care recipient might have lost skills that took years to learn. This problem is exacerbated by a lack of suitable accommodation for people with learning disabilities, with some carers in our sample reporting that they had been waiting years for their loved one to find a home suitable for their long term needs. The result is continued reliance on unpaid carers.

The implication of these findings is that there won't simply be a "return to normal" for many families, and that as we emerge from the pandemic, the level of need will increase, placing more demand on unpaid carers and a social care system that is already under strain.

Our sample size was relatively small, but the conclusions to be drawn are clear and consistent. Unpaid carers have been left to fill in the gaps in the care system, placing them under enormous strain. They are now facing an uncertain future, without a clear plan for the reopening of support systems, even as Scotland moves "beyond Level 0".

7. Case study

Throughout our programme of work on support for adults with learning disabilities, we have been keen to hear the voices of those with lived experience, as an addition to the evidence base. Here, we present a case study that brings to life in personal terms what some of the data presented in previous sections tells us. The names of those involved have been changed.

Katie and Laura's story

Laura is an unpaid carer of her sister, Katie, and her story highlights some of the challenges faced by families of people with learning disabilities, but also the support that is available.

Laura's sister, Katie, has autism and a learning disability and requires constant support throughout the day. Katie previously lived near her mother in England but following an incident with her care provider and health concerns for her elderly mother, Katie and her family took the opportunity to move her closer to her wider family in Scotland. At the end of 2020, Katie moved in with Laura.

On a typical day, Laura assists Katie with her personal care, for example washing and dressing, prepares meals with Katie's help, eats with Katie and assists with Katie's mobility. She also supervises Katie whilst undertaking leisure activities, such as arts and crafts, watching TV or completing a jigsaw. Laura is also keen to take Katie out every day, whether that be to the gym, swimming, coffee, walking or going for a drive. When discussing her average day, Laura pointed out the importance of routine and structure for Katie's wellbeing.

Laura's unpaid caring role was supposed to be temporary, until a care package in Katie's new local area could be arranged. However, their situation has continued for over 10 months, with Katie's family left on their own to support her. Laura relied on the support of her family, a flexible employer and reduced hours at work to provide the care that Katie needs.

"If you were in a job that didn't offer that flexibility, you'd be absolutely scuppered."

Laura, unpaid carer

Laura was hoping for temporary help with caring for Katie but was desperate for her not to be placed in a respite facility or shared accommodation, as past experiences have been distressing for Katie, who can exhibit behaviour that challenges.

"All the wonderful things she's achieved around her independence would just disappear (in shared accommodation) because she won't have that level of care and support. All we wanted was help for 5 hours, 2 days a week on a temporary basis but that support wasn't available."

Laura, unpaid carer

Laura is not eligible for financial assistance through the social security system but additional financial help is not what would improve her situation most. Laura's main concern was getting the right support package for Katie to give her family respite, knowing that Katie is safe and supported.

But getting that care package for her sister has been a “battle” for Laura.

“Social services just weren’t engaging with us at all. The minute we said we’d like support for Katie in a single tenancy, like she had previously, that was a massive issue for them because they’re trying to push for cheaper shared tenancies.”

Laura, unpaid carer

A “battle” with the care system

Throughout this research, we have heard multiple family members of someone with a learning disability describe a “battle” against the very system that is supposed to support them. When asked why her experience arranging a care package for Katie was so challenging, Laura suggested two reasons.

The first is that Katie moved from out of area. Laura described being “left in limbo”, with no preparation for Katie’s arrival and no case worker assigned until Katie had moved to her new local authority area. Even then, Katie was not assigned a case worker until Laura raised a complaint with her local MSP. Katie did live in the area previously, but all records of her engagement with local learning disability services have been lost.

The second is that the care package most suitable for Katie is unusual, in that the “standard” route for most people in Katie’s position would be a placement with a care provider in shared accommodation. Katie’s family want to organise and manage Katie’s care through direct payments and organise a single tenancy for her, which she has previously had. On paper, the social care system is supposed to offer this flexibility.

“They promote the Keys to Life and the person being at the heart of everything, but it’s just not the case. It’s about money.”

Laura, unpaid carer

Laura describes constantly chasing her local authority for information, asking questions without receiving a response, being repeatedly asked to provide evidence of Katie’s situation, managing Katie’s finances, applying for guardianship, raising a complaint with her MSP, all whilst providing unpaid care for her sister with no support during a pandemic.

When asked about the impact on her wellbeing and mental health, Laura noted that whilst day to day life can be “a struggle”, the most difficult aspect was the fear and uncertainty around Katie’s long term care.

10 months since Katie moved to Scotland, she has now been offered a single tenancy and her family can start building a care package around her by, for example, hiring a paid personal assistant to support Katie.

Laura stressed that she was only able to navigate the system and arrange Katie’s care with the support of ENABLE Scotland and a personal contact at Cornerstone, both charities that assist people with learning disabilities and have expert knowledge of the social care system and families’ rights. She was also feels “lucky” that Katie now has a great social worker.

8. Conclusion

This report provides evidence that underlines the key roles that unpaid carers play in our society. The contribution of unpaid carers of adults with a learning disability is particularly significant on a day to day basis, but also due to their often lifelong commitment. It is therefore important to put this commitment into context and understand the interaction between caring responsibilities, family finances and wellbeing, in a way that is specific to unpaid carers of adults with learning disabilities.

In this report, we analysed how a sample of unpaid carers of adults with learning disabilities spend their time and calculated an economic value for the care they provided. This does not reduce their contribution to a financial sum of money – it puts into context the role that unpaid carers play and illustrates the cost to society if the same role were played by the state rather than unpaid carers.

We also asked our sample of unpaid carers about their family finances, which operate differently to most other households due to the restrictions that a lifelong caring role places on the choices they can make and their potential for paid work, along with the resulting increased reliance on the social security system. We also broadened our range of economic indicators to look at the wellbeing of unpaid carers too.

We found that, on average, the support delivered by each unpaid carer in our sample would have cost the taxpayer £114,000 per year to deliver equivalent care. Those that live with the person they care for spent between 8 and 16 hours providing care in one day.

The loss of agency that lifelong caring commitments create limits unpaid carers' ability to work. Just over half the unpaid carers in our sample had household income below or around the poverty line and overall, they had a relatively high degree of reliance on the social security system. Their wellbeing scores were also lower than the national average, particularly on measures of social isolation and burnout.

These findings are particularly relevant as we turn attention to a future beyond the Covid-19 pandemic. Unpaid carers have filled in the gaps left by the care system and all of those in our sample have yet to see the support they receive return to pre-pandemic levels. As Scotland begins a new parliamentary term and focus turns to the challenges we will face in the future, the role of unpaid carers should not be overlooked.

This report is the latest instalment in our programme of work looking at how adults with learning disabilities are supported in Scotland to live secure, fulfilling, independent lives. This is a complex question with a lot to piece together, which is why we have published our work in stages. By extending our focus to look at the families of people with learning disabilities, this report demonstrates the vital role that they play, but also the pressure that is placed on them due to a lack of support from society's network of support systems.

It is clear that the status quo is not sustainable. Support needs are likely to increase for adults with learning disabilities and unpaid carers. As we emerge from the pandemic and begin a new parliament, many will be looking to policy makers for a deliverable plan to meet those needs.

Annex A: Methodology

Surveys that included a time use diary and questionnaire were sent to our sample of unpaid carers of adults with learning disabilities between June and July 2021. Before this, ethics approval for the research was granted by the University of Strathclyde's Ethics Committee, in line with the University's procedures. Participants were compensated with a shopping voucher, but the value was not considered material enough to affect any aspect of participants' involvement.

As noted above, the analysis presented in this report is based on a small, self-selected sample and there is no way of verifying whether this is representative of the population of unpaid carers of adults with learning disabilities. The results should therefore be taken as illustrative, rather than representative.

The economic value of unpaid care

The time use diary asked participants to record what they were doing throughout half hour intervals of a day that represented as close to typical as possible. Participants logged their primary activities alongside any additional caring responsibilities they might have been doing, for example supervising their care recipient whilst preparing a meal.

We took a dual approach to calculating the monetary value of this time.

1. The attributable wage if those providing unpaid care were paid the living wage (£9.50 for 2020/21⁹) for each hour of 'active' care provided.
2. The replacement cost if the services were provided by the state rather than by unpaid carers.

The replacement cost was calculated by taking the number of hours of care provided in the time use diary of each participant and applying this to a benchmark cost of care. These costs were taken from Unit Costs of Health and Social Care 2020¹⁰, which is a comprehensive and widely used study of health and social care unit costs in England. This includes estimates of the cost of staff time plus salary on costs, overheads and travel time. The values in this publication related to 2019/20. In the results, we adjusted these values to 2020/21 prices.

The replacement cost in Scotland may vary, for example due to the expectation of payment of the real living wage and/or longer journey times for some home carers in remote rural areas. However, in the absence of Scottish data, we have assumed that the margins of difference will be fairly small, and within an acceptable margin of error/uncertainty inherent in this type of analysis.

Different methodological approaches were used to assign an economic value to each type of care provided, with all figures based on the Unit Costs of Health and Social Care 2020 study referenced above.

Personal care

The replacement cost for a home carer was estimated to be in the region of £28 - £31 per hour in 2019/20, depending on day of the week and time of day. For this analysis, we chose the mid-point of this range.

Other essential unpaid caring activities at home

Supported living costs vary, depending on different levels of care and the staff costs that are required. A low level of support is 30 hours a week (£1,010/week including overheads in 2019/20), and high is 100 hours a week (£1,981/week including overheads in 2019/20). We have assigned a level of need to each person in our survey, depending on the level of personal care plus other essential unpaid caring activities, that are received currently at home.

Additional unpaid care even for those in supported accommodation

It is difficult to assign a value to this type of care as it is unclear what the counterfactual would be. We have assumed that a higher level of need would need to be assigned to the adult with a learning disability and the cost of their supported accommodation would increase. The replacement value we have assumed is the difference between the estimate of the cost of supported accommodation at the highest level of need and the lowest level of need (£518/week in 2019/20). This is no doubt a simplification, but appeals more than the alternative of assuming no additional cost, implying the level of care and the subsequent wellbeing of the adult with a learning disability is reduced.

Analysis of family finances

Questionnaires asked for information on main sources of income (from earnings and from pensions) and whether or not means tested and additional costs benefits were claimed by someone in the household. The information was asked for on a voluntary basis, and not all respondents supplied information.

The questionnaire also asked for information on the number of adults and children in the household, and ages. This allowed us to impute income from child benefit and the state pension. A household income figure was calculated, deflated and equivalised so as to be comparable with the Scottish Government's published statistics on the poverty line.

Because the questionnaires were anonymous, we did not want to ask for information on council tax as this would potentially allow participants' local authority location to be visible to us. For council tax, we therefore use an assumed amount, using a series of assumptions:

- The Scottish average council tax in 2019/20 was £1,147.
- All families living with the person they care for should be entitled to a discount (their council tax is charged one band below) and we have based the amount on the difference between each band A – D (£138.16).
- People with learning disabilities are likely to be a 'disregarded' person in relation to council tax so single person discount should apply where there are only 2 people in the household.
- Where it is clear that council tax relief would also apply (i.e. due to the carer claiming a passported benefits) this has also been applied.

The household income was compared to the relevant, equivalised, relative poverty line in 2019/20 for each household. A second calculation, with PIP and DLA excluded from income, was also performed to look at whether removing these additional benefits move additional households into poverty.

Annex B: References

- 1 [*'Personal care overview'*](#), Care Information Scotland
- 2 [*'Frank's Law announcement'*](#), Scottish Government
- 3 [*'Wellbeing Economy Governments overview'*](#), Scottish Government
- 4 [*'National Performance Framework national indicators'*](#), Scottish Government
- 5 [*'The Warwick-Edinburgh Mental Wellbeing Scales overview'*](#), Warwick University Medical School
- 6 [*'Measuring wellbeing'*](#), What Works Wellbeing
- 7 [*'Scottish Health Survey 2020'*](#), Scottish Government
- 8 [*'Unseen and undervalued 2020'*](#), Carers UK
- 9 [*'What is the real living wage?'*](#), Living Wage Foundation
- 10 [*'Unit Costs of Health and Social Care 2020'*](#), Personal Social Services Research Unit

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