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Social Security Experience Panels: Carer benefits



EQUALITY, POVERTY AND SOCIAL SECURITY



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Introduction

The Scottish Government is becoming responsible for some of the benefits currently delivered by the Department for Work and Pensions. As part of the work to prepare for this change, the Scottish Government set up the Social Security Experience Panels. Over 2,400 people from across Scotland who have recent experience of at least one of the benefits coming to Scotland registered as Experience Panel members during the launch in 2017.

The Scottish Government is working with Experience Panel members to design a new social security system that works for the people of Scotland. From 2nd December to 23rd December 2019, Scottish Government researchers conducted a survey to help design carer benefits in Scotland. This report outlines the findings from this survey. All quotes are from panel members taken from the survey responses.

The survey asked about people's experiences of applying for and receiving the existing Carer's Allowance benefit. It also looked at how a new benefit for carers of more than one disabled child or young person under the age of 18 should be designed. The questions were informed by responses to the 2016 consultation on Social Security in Scotland. The survey also built on work carried out in 2019 to hear feedback from more than 100 carers through the Scottish Government's Carer Benefits Advisory Group. This work looked at the proposed extra payment for carers of more than one disabled child. The Scottish Government estimates that there are around 1,900 people in receipt of Carer's Allowance in Scotland who have caring responsibilities for more than one disabled child (under the age of 18).

Summary

The first part of the survey looked at the design of the new benefit for carers of more than one disabled child under the age of 18. Only 11 per cent of respondents (a total of 26) said that they care for more than one disabled child, so the findings should be considered in that light, and should not be considered representative of wider populations.

Most respondents said that they would want to receive a leaflet about the new payment with their Carer's Allowance Supplement letter or receive a letter

specifically about the payment with an application form.¹ Many also wanted to receive information via a carers' organisation or see information on social media. Most respondents said that they would want to apply for the new benefit online.

Respondents felt that the application should be short and simple, with space for them to write in information about their circumstances. They felt it should be written in plain English, that questions should be clear about their purpose, and that applicants should have support to complete the application if they need it.

Carers may need to confirm each year that they care for more than one disabled child to receive the new benefit. Half of respondents said they would want to confirm this via email and around a third by letter.

Some respondents commented that the payment should have wider eligibility. This included for carers of more than one of their children at any age, including after they turn 18. Others felt that there should be additional support for those who care for more than two disabled children, and that there should be support for parents with disabled children regardless of whether they receive a qualifying benefit. Panel members were also asked for their thoughts on what the new benefit should be called. There were a range of responses, most of which indicated that the name should include the term "carer", and refer to "children" or "families".

The second part of the survey asked about respondents' experiences of applying for Carer's Allowance. Almost three in ten respondents found out about Carer's Allowance through family or friends. One in five found out about it through DWP.

More than half applied for Carer's Allowance using a paper form and a third applied online. If they were to apply again, more than six in ten said that they would apply online. Around half of respondents said that they applied for Carer's Allowance sometime after the person they care for started receiving the qualifying benefit.

¹ Carer's Allowance Supplement is an extra payment for people in Scotland who get Carer's Allowance on a particular date. Carer's Allowance Supplement is paid 2 times a year.

Respondents were asked what worked well about the application process. Responses included finding the process quick and straightforward, helpful staff and being able to apply online.

When asked what did not work well, respondents highlighted the reliance on qualifying benefits as a cause of stress, the repetition of questions and lack of clarity in the application form, the waiting period for payments, and coming across errors in the process. Some also highlighted a lack of awareness about the availability of Carer's Allowance and the need to make it more accessible. Overall, 60 per cent of panel members described their experience of Carer's Allowance as "good" or "very good". However, a number of problem areas were also identified. These included the payment amount, which was felt to be much too low, and gaps in payments, for example when the person cared for is in hospital.

Most respondents also felt that the eligibility criteria were unfair. In particular, the rules around working or studying while receiving Carer's Allowance were felt to limit people's ability to improve their situation and were not felt to be reflective of the reality of carers' daily lives. Respondents also felt that it was unfair for Carer's Allowance to stop at pension age, when the caring responsibilities continue.

Finally, they commented that it was hard to understand how Carer's Allowance would impact other benefits, and felt it was unfair that if you receive Carer's Allowance other payments would reduce, often by the same amount.

Background and Research Methods

This report outlines the findings from a survey that took place in December 2019 with Experience Panel members to help design carer benefits in Scotland.

This survey was sent out to 696 panel members who have experience of Carer's Allowance. Participation in Experience Panels research is optional, and in this case 244 people chose to respond to the survey either online, over the phone or through the post. This was a response rate of 35 per cent. The survey was written in straightforward language to ensure it was clear what was being asked. This survey combined closed ended and open ended questions to allow panel members to express their views in full.

Within the survey, respondents who currently care for more than one disabled child or young person under the age of 18 were asked about:

- Thoughts on how to apply for a new benefit for people caring for more than one disabled child or young person under the age of 18.
- Naming the benefit.

All respondents were asked about:

- Their experience as a carer.
- Their experience and views of applying for Carer's Allowance.

The Social Security Experience Panels are made up of volunteers from the Scottish population who have experience of at least one of the benefits that are coming to Scotland. The results of this work should be regarded as being reflective of the experience and views of the participants only, and are not indicative of the wider Scottish population. Percentages are given only to provide a broad sense of the balance of opinion across participants.

About the participants

Information from the survey was added to information from the '*About Your Benefits and You*² and '*Social Security Experience Panels: Who is in the panels and their experiences so far*³ surveys. The demographic data collected in these surveys was linked to the information supplied previously by participants. However, linking was not possible where there was missing or unclear information. 147 respondents' data were linked to demographic information supplied previously. 219 respondents data were linked to information they had already supplied about the benefits that they have experience of.

The following demographic information is given to give context to the findings from the survey. More detailed information about participants is available in Annex A.

Around two thirds (68 per cent) of respondents whose data we could link identified as a 'woman or girl' and a third as a 'man or boy'. More than half were aged between 45-59 years old.

Two thirds had a disability or long term health condition lasting 3 months or longer and almost nine in ten had experience of being a carer. A quarter had

² Scottish Government (2017). *Social Security Experience Panels: About Your Benefits and You – Quantitative Research Findings*. [Online] Available at: www.gov.scot/Publications/2017/11/7769/

³ Scottish Government (2018). *Social Security Experience Panels: Who is in the panels and their experiences so far*. [Online] Available at: www.gov.scot/Publications/2018/10/3083/

experience caring for one or more children who are disabled or have a long term health condition. Almost all respondents had experience of Carer's Allowance and around two thirds had experience of Disability Living Allowance (70 per cent) and Personal Independence Payments (64 per cent).

Almost three quarters (73 per cent) of respondents whose data we could link live in an urban area, and just over a quarter (27 per cent) in a rural area.⁴ Scottish Government statistics show that the proportion of people who provide care is slightly higher in the most rural areas compared to the most urban areas of Scotland.⁵

Designing a new benefit for carers of more than one disabled child

The first part of the survey looked into the design of a new benefit for carers of more than one disabled child or young person under the age of 18.

Respondents were first asked whether they care for more than one disabled child. The majority of respondents (89 per cent) did not care for more than one disabled child. Those who did (11 per cent) were asked further questions on how they would want to apply for this new benefit and the name of the benefit.

Table 7: Experience of caring for more than one disabled child (n=242)

Caring for more than one disabled child	%
No	89
Yes	11

This was a total of 26 respondents. The findings in the rest of this section should be considered in the context of the low response numbers for this set of questions. Percentages are included to provide a sense of the proportion of responses only, and these should not be considered to be representative of any wider population.

⁴ 17 per cent of the Scottish population lives in a rural area. Scottish Government (2018) *Rural Scotland Key Facts 2018* [Online] Available at: <https://www.gov.scot/publications/rural-scotland-key-facts-2018/>

⁵ 9.9% of people living in UR6 (most rural) and 9.8% in UR5 provide care, compared to 9.1% in UR1 (most urban) and 9.6% in UR2. Scottish Government (2015) *Scotland's Carers* [Online] Available at: <https://www.gov.scot/publications/scotlands-carers/pages/6/>

Respondents who care for more than one disabled child were asked where they would want to see information about the new benefit. The most popular response was for information on this benefit to be sent as a leaflet with the Carer's Allowance Supplement letter (85 per cent). This was followed by being sent a letter specifically about this to you with a short application form (77 per cent). Being sent information through a carer's organisation was another common preference (69 per cent).

Some participants mentioned a few other ways information could be sent to them. These include GP clinics, schools and health centres.

Table 8: Finding information about the new benefit (n=26)

Information available	%
Leaflet in with Carer's Allowance Supplement letter	85
Letter specifically about this to you with a short application form	77
Via carer's organisation (in person, email, post)	69
Social media	54
Community hubs	27
Other	19

Respondents were asked how they would want to apply for the new benefit. The most common response was online (65 per cent). The second most popular way was through a paper form (19 per cent).

Table 9: How respondents would want to apply (n=26)

Application channel	%
Online	65
By paper form	19
By phone	8
Face to face with someone helping me	4
Other	4

Some respondents said the application form should be able to be completed through any channel.

“I think you should be able to apply online, via normal mail, and over the phone”.

It was also suggested that support should be available for people completing the form online or over the phone.

“An advice line or live chat system where an agent can help the applicant through the process”.

Short and simple

Respondents were asked how Social Security Scotland could make the application work for them. The majority of respondents felt that the application form should be short and simple.

“The shorter and simpler the form the better”.

“The form needs to be in plain English, easy to understand with short concise questions”.

Respondents explained that this was because their caring responsibilities take a lot of their time. Keeping the application short would indicate that Social Security Scotland values carers' time.

“Make it simple to fill out. I care for [multiple] disabled children so I don't have time to fill out lots of information”.

“Make it short and simple. Time is something carers have very little of and it can be off putting having big complicated forms to fill in”.

Some respondents felt that the application form should not to have too many tick boxes, and instead have open text boxes where they would have space to write information.

“Don’t have too many tick boxes as so many of these don’t really ask the right questions. Give boxes where additional information/fuller explanations can be given”.

“Make the questions straightforward with space to add details personal to your own situation as everyone will have different needs”.

Some participants suggested that Social Security Scotland should use the information it already has about clients to keep the application as short as possible. They suggested that this could include information about the benefits already received by the applicant and their children to automate the process.

“If it’s basically automatic dependent on providing evidence of the two children you care for, then I think the only information requested should be identity details of claimant [and] identity details of children. The shorter and simpler the form the better”.

Respondents also said that it would be helpful to ensure people are able to complete the form in their own time and come back to an application once they have started it.

“Having the ability to save it part way through would be advantageous as I often don’t have a lot of time to sit down to plough through the lengthy forms. I also find that they take their toll on me mentally as well”.

Wording of the application

Respondents said that to make sure the application form is easy to understand, the wording of the questions should be in plain English and straightforward. They felt it should be clear from the question what information is needed, without the applicant needing to get external support to complete it successfully.

“Word the questions so people understand what they are being asked so they can fill out without worry or pressure”.

“Ask the questions you want to know instead of expecting the applicant to know how to word their answer. Be direct. This should make it easier for applicants to fill in the form without having to ask for help from charities”.

One respondent suggested making sure the wording of the questions doesn't stigmatise applicants.

"It needs to be worded in such a way that it does not make the carer feel that they are begging for help".

Naming the benefit

Respondents were asked for suggestions for what they thought the new benefit should be named. Most respondents felt the new benefit name should include the word "carer". Many suggested a name that also included a reference to children or families. Some suggested a name that alluded to it being a supplement or addition to the existing Carer's Allowance payment, or a "support". 18 unique name suggestions were submitted. Two of these names were suggested twice. These were "Carer's Benefit" and "Carer's Support". The variety of responses can be seen in Annex B.

Confirmation of caring

With this new benefit, carers may need to confirm each year if they are still caring for more than one disabled child or young person under the age of 18 to continue receiving the benefit. Respondents were asked how would they want Social Security Scotland to get in touch with them to confirm this. Half of the respondents (50 per cent) would want Social Security Scotland to confirm this through email. The second most popular response was through letter (35 per cent). 8 per cent said they would want a text message, 4 per cent said they would want to be contacted by phone and 4 percent gave another answer.

Table 10: How Social Security Scotland should get in touch to confirm caring role (n=26)

Communication channel	%
By email	50
By letter	35
By text	8
By phone	4
Other	4

Entitlement to the benefit

When asked if there was anything else they would like to tell us about the new benefit or application process, many respondents said that this benefit should not be exclusively for those caring for children or young people under the age of 18. Instead, it should be available to parents whose children requires care at any age, including if their children are now adults.

“Just because they become 18 doesn’t mean they automatically stop needing care”.

“I think it should go beyond age 18. My eldest son will be 18 next year and I will still have the exact same caring responsibilities as now. The fact he turns 18 doesn’t lessen the amount of caring I have to do”.

Some respondents felt that further support should be for available for carers who have more than two disabled children.

“There should be an additional payment for each additional child”.

“It needs to recognise that there are families where there are more than two disabled children in the family. I have [multiple] children with [a health condition]. Two have additional disabilities and they receive DLA, but all [of my children] need care”.

Some respondents suggested that the criteria for receiving Carer’s Allowance and Disability Living Allowance are too restrictive. They felt that this new benefit should be available to carers of disabled children, regardless of whether they have been successful in receiving these existing benefits.

“Since I started work three years ago I have been in almost constant dispute with the Carer’s Allowance unit over my claim. Despite being well under the threshold I have only received Carer’s Allowance for two months out of the three years. Therefore I do not receive Carer’s Allowance Supplement and presumably would also not receive this benefit.”

“I feel it should take into account people caring for disabled children who have been refused DLA yet have clearly got disabilities and paperwork from doctors etc to prove it.”

Experience of applying for Carer's Allowance

The second part of the survey asked panel members about their experience of applying for Carer's Allowance and changes that they feel are needed to the Carer's Allowance application process when it moves to Scotland. Panel members were asked about their experience as a carer and their views of applying for Carer's Allowance. This section was asked of all 244 respondents.

Respondents were asked how they found out about Carer's Allowance when they first applied for it. A third of respondents (34 per cent) found out about Carer's Allowance through other avenues not mentioned in the table below. Among these "other" responses, many had found out about Carer's Allowance through a health or social worker or a third sector organisation. This included third sector organisations which support or advocate for people with a specific health condition, and local support groups. Others had spoken to Citizens Advice Scotland, or had received advice from a Welfare Rights service. Some had heard about Carer's Allowance through their work or by doing research online.

From the categories listed in the survey (set out in the table below), respondents mostly found out about Carer's Allowance through family or friends (29 per cent) or from DWP (20 per cent).

Table 11: How respondents found out about Carer's Allowance (n=244)

Means of finding out	%
Other	34
Family or Friends	29
DWP	20
Local Carer's Centre	11
Social Media	6

Respondents were asked how they applied for Carer's Allowance. More than half of respondent said they applied through a paper form (53 per cent). One third of respondents applied online (33 per cent).

Table 12: How respondents applied for Carer's Allowance (n=240)

Application channel	%
Paper form	53
Online	33
Through a support organisation	6
Face to face	3
Other	4

Respondents were asked how they would want to apply if they were doing it again. More than six in ten respondents would want to apply online if they could do it again (61 per cent). Nearly two in ten respondents said they would want to apply using a paper form (16 per cent). There were a few respondents who said they would want to apply through a support organisation (14 per cent) or face to face (seven per cent).

Table 13: How respondents would apply if they were applying again (n=241)

Application channel	%
Online	61
Paper form	16
Through a support organisation	14
Face to face	7
Other	2

Respondents were asked at what stage they applied for Carer's Allowance, in relation to when the person they care for applied for the qualifying disability benefit (such as Personal Independence Payment). Almost half of respondents applied for Carer's Allowance sometime after the person they cared for started receiving the qualifying benefit (49 per cent). More than three in ten respondents applied for Carer's Allowance when the person they cared for started receiving the qualifying benefit (33 per cent).

Table 14: Stage at which respondents applied for Carer's Allowance (n=240)

Application stage	%
Same time as they were applying for the qualifying benefit	9
When they started receiving the qualifying benefit	33
Sometime after they started receiving the qualifying benefit	49
Can't remember	9

What worked well about the Carer's Allowance application process

Respondents were asked what they thought worked well about the Carer's Allowance application process.

Quick and straightforward application process

Many of the respondents said that they thought the application process was quick and straightforward to follow, and that they faced no delays in hearing the result of their application or receiving payments. Some also commented that it was helpful that their payments were backdated.

"The process of applying was easy. I heard very quickly about the decision and it was paid on time".

"It was easy to fill out, and when they needed extra information they phoned me and it was dealt with there and then. I then received my first payment a few days later".

Respondents commented that they had time to fully understand what was needed before applying for Carer's Allowance. Compared to other benefits, respondents felt that the process for applying for Carer Allowance was much simpler.

“Carer’s Allowance is one of the only benefits which are stress free, hassle free and easy to do”.

Helpful staff

A number of respondents said they found staff to be helpful when completing the application. Respondents said they were able to receive support to complete the application process, either from staff, or by going through a support organisation – for example a local carers centre.

“It was dealt with and processed quite quickly. And when I needed to call someone they were very understanding and helpful”.

“Form was clear to complete and if I had to phone they are always helpful”.

Online application process

Many respondents said they felt that having the application process online made applying for Carer’s Allowance easier, quicker and minimised the need to provide additional documentation.

“The fact that it was simple to do online, it was easy and hassle free. The response was fair timing and the letters are easy to read and understand”.

“Easy to apply- there are no difficult questions. It’s quick to apply if doing it online. There is no need to send in any additional evidence, other than proving part time students status and wage slips if earning under the threshold”.

Respondents said that by having the application online helps reduce stress with documents being sent over the post.

It also helps with worries about posting things in- there’s rarely ever a problem, but with documents as important as these you do tend to worry about what ifs”.

What did not work well about the Carer's Allowance application process

Reliance on qualifying benefits

A number of respondents highlighted that while the application for Carer's Allowance in and of itself hadn't been difficult for them, they had faced significant challenges and distress in applying for a qualifying benefit which had therefore also prevented them from receiving Carer's Allowance.

"I did have to wait until DLA came through and it would have helped to have it before. My son's diagnosis took a long time and in that time I had to sign on and look for jobs when it would have been incredibly difficult for me to hold down any employment because of my caring responsibility. This caused me stress and financial hardship. Perhaps a recognition that carers can be carers while they wait for diagnosis would help."

Repetition of questions in application

Some respondents said they felt the application process repeated the same questions, which some found to be stressful.

"You are asked repeatedly what sort of care you provide it gets overwhelming for most people".

They also felt that some of the questions were unnecessary to ask.

"A lot of stupid questions that had no relevance to looking after the person I am caring for".

Unclear application information

A few respondents said that the application form should be clearer in informing people what benefits stop them from receiving Carer's Allowance.

"Losing some of other benefits once accepted for Carer's Allowance".

“Maybe state what alternate benefits preclude you from receiving Carer’s Allowance”.

A few respondents also said the application form was not clear for people who have varying conditions.

“This ties into a wider problem with the DWP, wherein it doesn’t account well for conditions that are variable”.

Waiting period for payments

While some respondents said that they received their first payment quickly, many others felt that it took too long for the application to be processed and to receive Carer’s Allowance.

“The wait for it to be approved and the allowance to actually be paid”.

“Length of time to be informed [of] result”.

A few respondents said that they had to wait between 11-13 weeks to receive a response on their application.

“The delay in processing. A standard 13 week processing time is stunningly bad”.

“Waiting 11 weeks before I got a decision. 11 weeks of no income whatsoever”.

Accessibility and awareness

Many respondents felt that Social Security Scotland should ensure that applying for Carer’s Allowance is accessible for everyone and that people are made aware of their entitlement. Some people said that it had taken them a long time to find out about Carer’s Allowance and realise that they would be eligible.

Respondents felt that applications and correspondence should be conducted through people's preferred communication channel – whether that is online, on paper, over the phone, or another way.

“Don't assume everyone can or wants to do things online, there should always be an option to do things offline”.

It was suggested that it would be valuable to have someone to call who could help them complete the application.

“Maybe having someone on a helpline or being able to apply over the phone would maybe help too as paperwork doesn't work for everyone”.

Errors in the application process

A number of respondents described experiencing processing errors with their application. This included applications being lost and needing to repeat answers.

“The organisation claimed they lost the paperwork. I had to call daily for updates. The application repeated the same questions over and over and were difficult to answer.”

“I had to re-apply due to DWP error.”

Some respondents suggested that staff were not equipped with the knowledge or skills to help applicants or process the application. Others highlighted experiences where their payment had been miscalculated, for example due to errors in the dates they are recorded as being eligible for payment. Respondents also said there was a lot of duplication of paperwork like letters.

“However there is quite a lot of bureaucracy, pedantry, and stupid mistakes made by the CA Unit such as making incorrect calculations relating to dates.”

“An awful lot of letter duplication which is a waste of resources and money!”

Experience of receiving Carer's Allowance

Respondents were asked about their overall experience of Carer Allowance. Six in ten respondents (60 per cent) felt their experience was 'very good' (22 per cent) or 'good' (38 per cent). One in ten respondents (10 per cent) said that their experience was 'bad' (eight per cent) or 'very bad' (two per cent).

Table 15: Experience of Carer's Allowance (n=241)

Experience	%
Very good	22
Good	38
Neither good or bad	29
Bad	8
Very bad	2

Low payment amount

While many respondents said that the application was straightforward, many also expressed the view that the amount given for Carer's Allowance is too low.

"It's an allowance in name only. We're on duty 24/7, not 9 till 5".

Respondents said that even with Carer's Allowance, they still had to find different avenues to get money for necessities such as food, gas or rent.

"My big problem with it is that it just doesn't provide much to live on, even with my mum's disability benefits taken into account. We've had to borrow a lot of money from friends and family recently - not for luxuries, but to make sure we can top up the gas or get food enough to last us until we get money in".
"While the money is helpful, it's not enough to survive on or even make rent".

Respondents pointed out that for the amount of hours required to receive the benefit, the payment is lower than someone working minimum wage. Some also highlighted that in reality, many carers work many more hours than this, and indeed some are effectively "on call" at all times.

“I was working it out recently, and even combining my Carer’s Allowance, my Income Support (as I’m a full-time carer) and the Scottish Government’s CA Supplement, I still only get less than half what minimum wage would be in my age bracket”.

Some respondents also highlighted how gaps in Carer’s Allowance payments (for example if the person that is cared for is in hospital) can lead to shortfalls in income which are difficult to manage, particularly in what can already be a stressful time.

“When my son is in hospital for more than 4 weeks I lose carers and am made to sign on and look for work, it’s a difficult enough time without going through this and no sympathy for what is going on. Again when you re apply it takes even longer to receive the benefit back.”

Similarly, people who have cared for more than one person experienced issues if the person named on their Carer’s Allowance application dies, and they need to reapply for to continue to receive Carer’s Allowance for the other person they care for.

“I had been my Dad’s carer for ten years, he died, so I had to reapply to be my Mum’s carer. 11 weeks of no income what’s so ever, housing benefit suspend - with my current housing association sending me weekly eviction notices despite me writing to them beforehand telling them of the situation and that I would not get a decision for at least 10 weeks.”

Working or studying while caring

Most of the respondents said that the eligibility requirements for Carer’s Allowance are unfair if they work part time.

“Carer’s Allowance is far too inflexible. It makes trying to work a nightmare, as if one earns a single pound over the limit, the entire week is voided. It should be based on hours and allow someone to work 16 hours so as to be able to access tax credits”.

Respondents said that Carer’s Allowance should not be affected by their work as many carers fulfil the criteria for hours spent caring even when working (particularly part time workers). Some also argued that they should not be limited to how much they earn and that this earnings cap may be effectively trapping people in low-wage jobs.

“Carer’s Allowance should be paid regardless of income. The care I give my child is the same whether I earn minimum wage or not. I have been penalised because I earn more an hour, not because I work more. I work between school hours but my job is well paid so doesn’t seem quite fair! Carer’s Allowance should not be means tested and certainly not because I have a good job”.

Respondents also highlighted that it was confusing and a significant administrative burden to have to update DWP with their hours worked and earnings, and calculate whether that will stop their payments in a given month. In particular, this was seen as burdensome when their income surpassed the threshold by very small amounts.

It was also pointed out that a carer may be the only person in a household with the ability to work, and may have the responsibility of supporting the household with those earnings, whilst also providing care.

“Many carers have no choice but to work as they are supporting more than themselves - either another disabled adult or a disabled child. Their caring responsibilities do not stop because they are working a few hours every week. It unfairly penalises people on low incomes.”

Respondents felt it was unfair that people cannot receive Carer’s Allowance if they are undertaking further or higher education.

Carer’s Allowance is pitiful and restrictive. As a full time carer I cannot even take a night class even just for my mental health. Distance learning for pleasure only applies if it is not worth credits. It takes away the ability to be normal in society and seems nonsensical. It is discriminatory. I feel my rights have been taken away and my access to lifelong learning is denied to me.

“I am going to university next year. I will be at university only a few days a week although because of this I will lose my Carer’s Allowance. My caring duties don’t stop. I don’t stop becoming a Carer when I am at university. I think it’s unfair that I can no longer receive the extra help and support. I have [multiple] children that are disabled”.

Carer’s Allowance beyond pension age

A few respondents said that Carer’s Allowance should not stop when carers reach pension age, as caring responsibility continues on. Respondents

described having to rely on their own pension to look after the person they care for. Respondents said they feel demoralised with Carer's Allowance stopping at pension age.

"I'd like to see the carer's benefit extending to as long as the person you are caring for is still alive and you are still doing the caring required. This stopping at pension age is a joke".

"Often carers don't know Carer's Allowance stops with payment of state pension even though caring role continues. It is confusing and feels as if you are being undermined".

Impact on other benefits

Some respondents said that it was hard to understand the impact that receiving Carer's Allowance could have on other benefits that you are eligible for. They felt it was unfair that if you receive Carer's Allowance other benefits could be reduced, so the benefit payment become negligible.

"I was shocked when my income support was reduced £ for £ ie cancelling out carers allowance. That seems quite wrong, given the amount of energy and time spent caring."

"The knock on effect on other benefits was confusing. My income support has been reduced as a result of Carers Allowance, so instead of a benefit that is additional to my income, it has only increased money coming in by a small amount as most of it is clawed back via Income support."

Eligibility criteria

Some respondents commented that the eligibility criteria related to the number of hours of caring are too restrictive. For example, if a person cares for more than one person they wouldn't be eligible if their caring hours for each person individually were lower than 30 hours, even where their total number of hours caring exceeds the threshold.

Similarly if two people share a caring role, they cannot both apply for Carer's Allowance, even if both care for more than 30 hours per week. Respondents felt these restrictions were prohibitive.

“what about two carers who share caring equally and both care for (say) 24 hours each - or a single carer caring for two disabled people e.g. parents, neither of whom quite meets the higher dependence threshold? That's where the attendance allowance: paid to the disabled person, is in some ways fairer.”

Next Steps

The Scottish Government will use these findings, along with wider research with carers and the organisations who support them, to inform the design of the new support for people caring for more than one disabled child. It will also be used to inform the development of the future Scottish replacement for Carer's Assistance. The Scottish Government will continue to work with people with experience of the benefits system in the development of Scotland's new social security system.

Annex A: About the Participants

Information from the survey was added to information from the ‘*About Your Benefits and You*⁶’ and ‘*Social Security Experience Panels: Who is in the panels and their experiences so far*⁷’ surveys. The demographic data collected in these surveys was linked to the information supplied previously by participants as part of the longitudinal data set for this project. The following demographic information is given to give context to the findings from the survey.

Not all responses were linked in this way. Providing identifying information is optional in all of our surveys. So linking was not possible where there was missing or unclear information from the survey responses. It was also not possible where participants had not previously supplied us with the relevant demographic information. 147 respondents’ data were linked to demographic information supplied previously. 219 respondents data were linked to information they had already supplied about the benefits that they have experience of.

Around two thirds of respondents whose data we could link identified as a ‘woman or girl’ (68 per cent) and a third (31 per cent) of participants identified as a ‘man or boy’.

Table 1: Gender of survey respondents (n=147)

Gender	%
Woman or girl	68
Man or boy	31
Identify in another way	1

⁶ Scottish Government (2017). *Social Security Experience Panels: About Your Benefits and You – Quantitative Research Findings*. [Online] Available at: www.gov.scot/Publications/2017/11/7769/

⁷ Scottish Government (2018). *Social Security Experience Panels: Who is in the panels and their experiences so far*. [Online] Available at: www.gov.scot/Publications/2018/10/3083/

More than half of respondents whose data we could link were aged between 45-59 (54 per cent).

Table 2: Age of survey respondents (n=147)

Age group	%
16-24	1
25-44	20
45-59	54
60-79	25

Two thirds (67 per cent) of respondents whose data we could link had a disability or long term health condition lasting 3 months or longer. Details of the types of condition are in Table 3 below.

Table 3: Disability or long term health condition experienced by respondents (n=147)

Disability or long term health condition (n=147)	%
A physical disability	39%
Chronic pain lasting at least 3 months	50%
Another long term condition	48%
Deafness or severe hearing impairment	9%
Blindness or severe vision impairment	7%
A learning disability	7%

Almost 9 in 10 (86 per cent) respondents whose data we could link had experience of being a carer. A quarter (26 per cent) of these had experience of caring for one or more children who are disabled or have a long term health condition.

Table 4: Caring responsibility of respondents (n=147)

Caring responsibility	%
Carer for one or more children who are disabled or have a long term health condition	26%
Carer for one or more adults who are disabled or have a long term health condition	69%
Care for an adult due to older age	20%

Of the respondents whose data we could link, almost three quarters (73 per cent) live in urban areas⁸. Respondents took part from 28 of the 32 Local Authority areas.

Table 5: Location of respondent (n=138)

Location	%
Urban	73%
Rural	27%

Almost all (96 per cent) had experience of Carer's Allowance. Seven in ten (70 per cent) respondents whose data we could link had experience of Disability Living Allowance and two thirds (64 per cent) had experience of Personal Independence Payment.

Table 6: Respondents' benefit experience (n=219)

Benefit experience	%
Carer's Allowance	96%
Disability Living Allowance	70%
Personal Independence Payment	64%
Cold Weather Payment	35%
Winter Fuel Payment	28%
Attendance Allowance	20%
Funeral Expense Assistance	11%
Industrial Injuries Disability Benefit	2%

More detailed demographic information on the Experience Panels as a whole can be found in '*Social Security Experience Panels: Who is in the panels and their experiences so far*'⁹.

⁸ 17 per cent of the Scottish population lives in a rural area.

Scottish Government (2018). Rural Scotland Key Facts 2018. [Online] Available at: www2.gov.scot/Resource/0054/00541327.pdf

⁹ Scottish Government (2018). *Social Security Experience Panels: Who is in the panels and their experiences so far*. [Online] Available at: www.gov.scot/Publications/2018/10/3083

Annex B: Benefit name suggestions

The list below is of benefit names suggested by respondents in the survey for naming the new benefit looking into Carer's of more than one disabled child.

18 unique name suggestions were submitted. Two of these names were suggested twice. These were "Carer's Benefit" and "Carer's Support".

- Carers benefit (2)
- Carers Support (2)
- Carers Supplement
- Multiple Child Carers Allowance
- Carers Plus
- Children and Young People Allowance
- Carers Allowance, I believe this would just be a fair and reasonable adjustment to the existing benefit.
- Family's carers allowance
- Carers plus support payment
- Caring for disability Support
- Carers Security
- Carers support allowance
- Parent or Guardian carers support payment/supplement
- Multiple Carer Benefit
- Carers support fund
- Care for more
- It should be similar to the current to avoid the applicant being confused with other benefits.
- Carers Allowance plus



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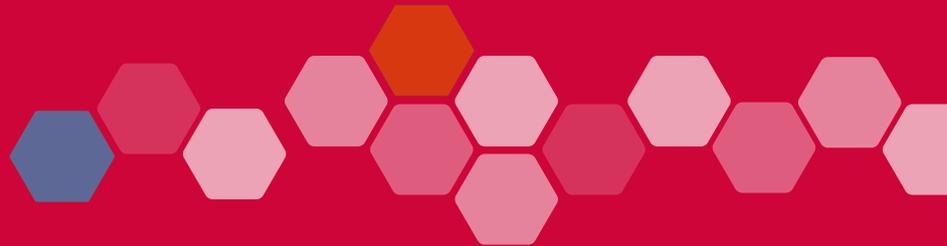
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