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Social Security Experience Panels: Initial findings on the development of the Young Carer Grant

EQUALITY, POVERTY AND SOCIAL SECURITY

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Social Security Experience Panels: Initial findings on the development of the Young Carer Grant

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Introduction

Between February 2018 and August 2018, Scottish Government researchers held 16 focus groups with more than 50 young carers, to hear about their experiences and views on the development of a new grant for young carers in Scotland. This was part of the Social Security Experience Panels programme of research. This work is ongoing, with research planned to further engage with young carers who have registered to take part and work to encourage more young carers to get involved.

This report provides a summary of some of the key themes from this research to date. All quotes are from young carers who have attended a focus group.

Summary of key themes

Key themes emerging from the focus groups have included:

Understanding and connecting with terminology
Whilst most attendees felt that they understood or connected with the term “young carer” there was a lack of consensus about how this term could be defined, particularly in terms of the age bracket that it would refer to.

The impact of being a young carer
Participants described the impact that their caring role has on their lives – many felt that they didn’t have enough time for their education, to get a part time job, or for socialising. Others described mental health impacts including stress and anxiety.

Reaching out to young carers
Participants described an inconsistent picture of the support available to young carers across Scotland. This could vary greatly depending on individual schools and teachers. Young Carer Groups were seen as an important support mechanism through which the young carer could meet others in a similar position and learn new skills.

Eligibility: time spent caring
Some respondents said that they felt that 16 hours caring per week was “reasonable” in order to be eligible. Others said that they would find this very difficult to quantify or that it varies a lot.

Eligibility: duration of caring
Many respondents felt that 3 months was a “reasonable” amount of time for a young person to have been caring in order to apply for the grant, however some said it is difficult to say how long they have been caring, or felt that there should be some exceptions.

Applying for the grant

Key factors in making the application process as easy as possible included a short form, with easy language, and making sure the questions are easy and don’t repeat themselves. The form should also be available in a wide range of formats.

What would you spend it on?

There was a wide variety of things that young carers would spend the grant on. Many of the items were practical, including travel costs, clothes, or household items, and other suggestions included holidays or trips, socialising, and things for their family or cared for person.

Questions about the grant

Participants raised a number of questions or concerns about the grant. These include questions around the age criteria, number of people who can claim the grant in the household, number of people that you care for, and the amount of the grant.

Background and research methods

The Scottish Government is becoming responsible for 11 of the benefits previously 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. The Experience Panels are made up of over 2,400 people across Scotland who have recent experience of claiming at least one of the benefits that will be devolved to Scotland.

The Scottish Government is working with Experience Panel members to design a new social security system that works for the people of Scotland. As part of this work, Scottish Government researchers have met with young carer groups to hear about their experiences, and to invite them to join the Social Security Experience Panels work on the Young Carer Grant.

Sixteen focus groups were held between February and August 2018. These were held with existing young carer groups in locations across Scotland, and in most instances the participants of each group knew each other and received regular support from a dedicated youth worker or social worker. Most groups had between 5 and 10 participants. The fewest number of participants in a group was 3, and the highest number was 16.

Young carers were asked about their experiences and views in relation to the design of the new grant. In particular:

- What is a young carer?
- What is good about being a young carer?
- What is difficult about being a young carer?

These questions were used as prompts to discuss the language that should be used, the verification process, eligibility criteria, application processes, how we reach out to young carers, how the grant might impact on their lives, and any other questions or concerns that they have about the grant.

Flipcharts and post-its were used to facilitate discussion and to capture the views of less vocal or confident participants. A Scottish Government staff member acted as note-taker in each session. Due to practical and ethical considerations, the sessions were not recorded, so this analysis is based on these notes and flipchart responses.

Focus groups were held in a wide range of locations across Scotland, including in small town/rural areas and Highlands, and Islands, as well as bigger cities. Participants were between the ages of 12 and 25 and were all young people with current or recent experience of caring for someone. For those under the age of 16, parents or guardians were asked to give their consent for their child to participate, as well as the young person consenting themselves. Trained youth workers or social workers were present throughout all of these focus groups to provide support. A minimum of two Scottish Government staff were present at each session, including at least one social researcher. Research staff underwent safeguarding training to support this work with young carers.

It is important to note that at this stage, participants were all affiliated with a young carer group. Work to engage with young carers who are not part of a formal group will be part of the next stage of the research for the Young Carer Grant, and will be informed by the findings and lessons learned from this work so far.

Participants were invited to register for the Young Carers Experience Panel to stay involved in the work to design the new young carer grant. For those who chose to stay involved, their data is held in an encrypted file in a secure Scottish Government network folder, and is held separately from the wider Experience Panels data, unless they are over 16 and have requested to be part of the wider Experience Panels work also.

Understanding and connecting with terminology

Many of the young carers were familiar with this term and would use it to describe themselves or their role. Some felt very confident describing what this means, or had a description that they had used before with friends or in school.

However, understanding of the age criteria for young carers varied between groups. Some felt that a “young carer” was up to, or including the age of 18. Other felt that it would include people up to the age of 21 or 25. A number of participants stressed that many young carers are under the age of 16. Others commented that caring for someone doesn’t necessarily change or stop after you leave a certain age bracket.

Most participants associated the phrase “young carer” with caring for a family member. Some suggested that it could also be someone else – for example a partner, friend, or neighbour. Others felt that it is someone that you are really close to, or suggested that it was someone that you don’t feel that you have a choice on whether to care for them or not. Some suggested that it isn’t important *who* you care for, but rather it is what you do and the impact that it has on you.

> “I used to care for my upstairs neighbour, it can be other people outside your family. But you still have to be close to them in a sense.”

Some said that they didn’t always tell people that they are a young carer, or find it difficult to talk about with friends. Reasons for this included not wanting to be labelled or thought of differently, wanting to avoid questions about it, or feeling that their situation is “not normal”.

> I won’t always tell people what I’m doing – I might say I’m going to a dentist appointment.

A small number said that they did not identify with the term, and although they had caring responsibilities they would not describe themselves as a young carer. Some also said they preferred the term “young adult carer”, or just preferred “carer”, or said that it’s a “compromise” term but “can’t think of a better one”.

> “I prefer just a carer, young carers aren’t doing any less than an adult”

There was a lack of consensus about terminology used between different groups and even among different young carers within groups. In particular, this related to when participants would stop using the term “young carer” and instead described themselves as “young adult carers”. Some used the term “young adult carer” after young carers had left school. Others used this term from the age of 18. Some young people used the term “young adult carer” from the age of 16.

It is worth noting, however, that the focus groups so far have been with young carers who are affiliated with a group, most of which describe themselves using the language “young carer” or “young adult carer”. It is therefore possible that they are more familiar and comfortable with this language than those who have caring responsibilities but are not part of a group. More research is required in order to understand how comfortable those not affiliated with a group would feel using this language.

This was also something highlighted by many of the attendees, many of whom said that they did not describe themselves as a young carer until someone approached them about their caring role, or told them about the group. Some said that they had been caring for their family member for such a long time (or their whole life) that they were unaware that their situation was any different from their peers until this was made clear to them by a teacher, social worker, medical professional or other support worker.

In terms of the name for the grant, many participants felt that “Young Carer Grant” is a useful name as it says who it is for, but some felt it would be helpful to include more information about the age and eligibility criteria when advertising the grant in order to make it clearer who the grant is for. Others felt that if it was called something else then people would be able to apply without their friends knowing that they were a carer, and indicated a degree of stigma associated with the term.

The impact of being a young carer

A key theme from across the focus groups was participants describing a lack of time for socialising, for school work, and for other responsibilities outside of caring. Some also felt a time pressure to fit in all of their caring roles, and some felt unable to get part time work (like many of their friends have) due to caring responsibilities.

Some suggested that they felt “selfish” or “worried” when doing other things and not caring. This was described as being because they know the person they care for might be less happy or less well looked after when they are not there. Some said that they could never relax when away from the person they look after because they worry about whether they are needed, or are constantly checking their mobile phone to see whether the person they care for is ok. They felt guilty about doing things for them, like seeing friends, or even school work, when the person they care for might need help.

A number of young carers spoke about experiencing stress or their caring role having an impact on their mental health. Some spoke about challenges concentrating at school or with friends, in particular due to worrying or thinking about their cared for person or due to frequent phone calls with their cared for person. Many said that caring had impacted on their school or college work, including missing lessons, or being unable to complete homework. Some of the challenges were described as:

> “Watching the person you are looking after going through a difficult time”

> “Just thinking about them, instead of school”

> “Having to leave the person you care for to go out doing daily things like school/work”

Some also spoke about finding it difficult or upsetting to see someone you love dealing with an illness or disability, and spoke about feeling isolated from friends. Some also said that they weren’t able to get emotional support from their parents in the same way their peers do, because their parent is the person they care for, or having to put their parent’s emotional needs before their own.

> “Trying to juggle multiple tasks at once and feeling overwhelmed and worried”

A number of young carers also spoke about one of the good things about being a young carer being the closeness to their family or cared for person.

Some spoke about learning life skills, interpersonal skills, and becoming responsible and mature at a young age. This included gaining skills through caring, but also learning to care for themselves at a young age and being independent.

Reaching out to young carers

A number of young carers spoke about the value of their young carer group as a support network. This included creating a space for friendships and support with people that understand their situation, going on trips, and the support from youth workers.

Participants described a very varied level of support from their schools and colleges. Some had experienced very good support from school or from an individual teacher, where others said that their school didn't take it seriously or didn't understand.

> "Too many kids get no support in schools in my opinion - at primary school I got a lot more support but then when you move up there are loads more kids"

Some participants described how young carers may be afraid of reaching out for support for fear of involving social work or getting separated from their family. Other talked about a lack of recognition for young carers, in particular in terms of understanding the impact that caring has on them at school.

Many young carers suggested that reaching out to schools is a good way to reach young carers, but some noted that that some schools are more supportive to young carers than others. Other suggestions included:

- After school clubs/ youth groups
- Religious groups
- Sports clubs
- TV
- Social media (including snapchat/ Instagram/ Facebook/ Twitter)
- GP surgeries
- Child and Adolescent Mental Health Services (CAMHS)
- Informal networks (friends/ families)
- Organisations that provide support associated with particular disabilities or health conditions

Some suggested that it would be useful to have wider awareness raising campaigns with schools and medical professionals to support them to identify young carers and how to help.

Some also suggested that it would be helpful to use the application process for the grant as a way to raise awareness of the other support, like young carer groups, that might be available to someone in their local area.

Eligibility: time spent caring

Some young carers felt that 16 hours per week was a “reasonable” number of hours to spend caring in order to qualify for the grant, and that they would know that that included them or that they do many more hours than that. This included some who said that their caring hours fluctuate. Some felt that this number should be lower (for example 14 hours).

Other young carers felt that they would find it difficult to say how many hours per week they spent caring. Reasons for this included the number of hours fluctuating on a daily or weekly basis, not keeping a record of the hours they spend caring, and finding it difficult to define what would count as “caring”.

Others said that their caring role might change, for example if a sibling leaves home, and they may have to do more/less and wouldn’t know how to factor that in. One scenario that some felt should be clarified was if the person they cared for was taken into hospital – although they would no longer be providing the same care, they felt that the impact of the hospitalisation, and the number of hours spent travelling to the hospital to visit, should be considered.

“If my mum needs to talk to me, I don't set a timer. You're constantly caring, always on alert for silly things like handing a can of juice because they can't get up to get to things themselves. Even when you leave the house you're still on alert in case they call and you need to leave.”

“My role is changing, my sister is about to go to college, so I will have to do more.”

Some said that there are parts of their responsibilities, such as caring for a sibling, or housework, that they wouldn’t see as caring.

“Biggest issue is that some parents don't understand the caring role either”

“I would never have known until I came here.”

A number of young carers spoke about how they discussed their caring role with a worker when joining the young carers group, and that this process helped them to understand how much caring they do. Some said that this sort of support would be helpful in completing the application if this was one of the criteria.

“I thought I did less than 16 hours, but then sat down with my young carers worker and worked out I was doing over 40 hours.”

Some young carers said that it would be helpful to give examples of what counted as caring, including emotional support, but felt that it would be important to be clear that the list isn't exhaustive, or to include an "other" box. Some suggested that having an open text box for young carers to describe the sort of caring they do on a regular basis may be easier for people to answer than just yes/no questions.

Others had concerns that this might exclude some things that people do as part of their caring role and therefore put people off applying. Some felt that the impact – and in particular emotional impact – on the young person is more important.

"My Dad doesn't like being alone – I sit and talk to him and that helps him. He doesn't need me to do practical tasks, but he needs me there."

"If I'm worrying about it, I tend to think of myself as a carer. It's about the impact it has on me and my feelings rather than the workload."

Some participants suggested that this criteria may put off young people who have caring responsibilities who do not identify as a "young carer", who do not recognise what they do as caring, or who would find it difficult to calculate how much time they spend caring each week – including for the reasons outlined above.

Others felt that the grant should consider the impact of the caring responsibilities, more than the number of hours. Some felt, for example, that caring for someone for 2 hours per day could be just as demanding as caring for someone for 8 hours per day depending on the circumstances.

I don't think it should seem like a barrier - and to me it would seem like a barrier. I think it would put people off applying if it was a criteria

Eligibility: duration of caring responsibilities

Many young carers said that three months was a "reasonable" amount of time to have spent caring before being able to apply for the grant. Some felt that in practical terms, three months would allow time for the qualifying benefits to be in place, and that there should be limitations on who can get the grant.

"Because it's working with money, you can't just hand it to everyone."

However, some young carers were unclear about when their caring role would have started from. This included some wondering whether it would only count once you were part of a young carer group. A number of young carers said that they only realised that they were a young carer a long time into their caring role.

> “Difficult to know when I became a carer. I didn’t know that was what I was doing. It was just normal to me.”

Some young carers were concerned that the three month cut off might exclude some people, for example if someone’s situation changed quickly such as a severe accident or recent diagnosis, and that there should be exceptions to this.

It was felt by some that having someone write a statement to verify that you are a young carer would be better than having set criteria. Others felt that having to have someone verify it might put people off applying if they weren’t already connected to support services.

Applying for the grant

Key factors in making the form easy for young carers included being:

- Short (some said no more than 10 questions, others said 3)
- Easy language
- Available in different formats (i.e. computer, phone, tablet, paper forms)
- Don’t ask the same question multiple ways
- Types of question – multiple choice are easier than open text, with an open text option in case the options don’t work for you
- Some commented that tick box questions can be hard if you don’t feel like the answers fit your situation
- Accessible to everyone

A number of participants commented that there should be as few criteria and questions as possible. The questions should make it possible for people to fill in their situation without having to repeat themselves. Some felt that you shouldn’t have to prove that you are a young carer and this would make them feel like they are lying – they felt the form should be enough. Some had experience of helping parents complete difficult benefit application forms.

> “Mum has a lot wrong with her – she was awarded lifetime DLA and then had to switch to PIP - it was terrifying for her, I had to break it down for my mum and it made her feel stupid”

Some said if they weren’t sure how to complete a question, they would leave it blank, or just not apply. Some said that they would ask someone they know for help – for example from a family member or their young carer group leader. Very few felt they would use online support like webchat or a phoneline if they weren’t sure how to complete the form. They felt that because of this it was important that the form is as simple as possible.

In terms of the preferred way of applying, many of the young carers said that the most important thing is to have choice. Whilst some felt that it is easier to be able to apply online, others wanted the choice to be able to do a paper form – some said, for example, that this would make it easier to take along to their young carer group and get help to fill it in. Some suggested that paper copies of forms could be distributed to groups as a way of encouraging people to apply. Others felt that it was important to have the choice of face-to-face application channels – for example at a local job centre or through an organisation that can help fill it in.

Some participants felt that it might be useful to have a reference to back up the application, or that this could be an optional criteria. The reason given for this was that some people felt they would feel more confident completing the form if they had a worker helping them. Other suggested that the form should make it clear that you can get support to complete it.

Some young carers commented that it can be hard to get people like teachers or college staff to believe them about the responsibilities they have. Other young carers are worried about social work getting involved if they share what is going on at home, and that there is a lot of stigma and fear around families becoming separated. Some have had negative experiences of this happening. Others said that they were glad when social work did become involved because they got support.

Participants queried whether there would be a need to re-apply every year.

What would you spend it on?

There was a wide range of responses on the question of what young carers would spend the grant on. Many were keen to make it clear that they would use the grant in a “sensible” way.

> “I think adults think we would blow it – but that’s not right, we are sensible and we would get something that we really want, may save some and be sensible.”

Responses included (in no order):

- Travel costs (including bus passes, driving lessons, money towards a car/ car running costs)
- Socialising (including cinema passes, festivals/ gigs or trips with friends)
- Holidays
- Clothes
- Sport equipment

- Items for the house or household (i.e. kitchen equipment)
- Food for themselves or the household
- Improving their bedroom (i.e. redecorating, partitions to have separate space from siblings, new furniture
- Gifts
- Educational materials (i.e. books, uniform, shoes, computers and school necessities/equipment)
- Spending the money on the person they care for or other family member (for example a trip or gift, or respite care)
- Saving the money

Questions about the grant

A number of other questions and concerns relating to the Scottish Government's plans for the new Young Carer Grant come up over the course of the focus groups. These are outlined below.

Age
There was a concern from some young carers that the age criteria create a potential gap for people who cannot claim Carers Allowance due to being in education (i.e. college or university), but who are too old to claim the young carer grant. In particular it was noted that the grant would miss young carers aged 18 who are at college, and who often have to spend a lot on travel.

There was a concern from some participants about what support would be available to under 16s. Many felt that it would be valuable for at least the travel card to be available to young carers who are under 16.

Many participants felt that the travel card would be particularly beneficial. Some questioned whether this could be available to young carers outside of the 16-18 bracket.

Multiple carers
There was a question over whether more than one young carer in a household could apply for the grant (i.e. when there are multiple siblings providing care), or whether the payment could be split between them.

Some young carers felt that it would be fair to provide split grants, rather than one grant per young carer in a household, because there "isn't an infinite pot of money". They felt that one grant per cared for person felt fair. Others felt that the amount of care a person needs can be very variable, so it might be reasonable for 2 of more young carers to receive the grant if they each provide the required number of hours of care.

Caring for more than one person

Some young carers care for multiple people in their household and questioned whether the 16 hours could reflect caring for more than one person. Some also questioned how looking after siblings would be treated – for example looking after a sibling because their parent is unable to.

Grant amount

A small number of young carers noted that £300 per year isn’t a huge amount of money, particularly compared with someone who is working. Some also commented their families struggle financially because their parent(s) are unable to work.

> “Financial support for young carers is awful - a lot of young carers leave school so they can get the support. If you're in a home taking money off the person you care for it makes you feel bad. £300 a year is nothing, you won't survive. Even £20 a week would be better - you could get your lunch/bus.”

Some also suggested that it would be helpful to have the choice for the payment to be split, for example on a monthly or quarterly basis.

Summary

The young carers who participated in these focus groups shared some of the positives and challenges of being a young carer. This included a lack of time for education and socialising and mental health impacts, however the positives included building networks through the young carer groups and learning new skills. It was clear that the support received outside of young carer groups is variable.

Some of the key challenges include the difficulty that some young carers have in quantifying the amount of time they spend caring, or the duration of their care experience. Many felt it was “reasonable” to make sure the grant is going to the right people, but felt that these could be barriers to applying.

There was consensus that the application itself should be kept as simple as possible, but views also varied about the best way to support people to be able to complete this – for example having a support worker help or provide a reference for their application.

Next Steps

This work was carried out early in the design of the new Young Carer Grant to ensure that the voice of young carers in embedded from the initial decision making about what the new grant should be like – for example when drafting the regulations about how the grant should operate, and when formulating approaches to the operation of the grant with the people designing the service. We have invited young carers who participated to stay involved through the Young Carer Panel – this was optional for all participants. We are additionally looking to engage with young carers who are not part of a formal group and will use this research to help us do so effectively.

How to access background or source data

The data collected for this social research publication:
☐ are available in more detail through Scottish Neighbourhood Statistics

☐ are available via an alternative route <specify or delete this text>

☒ may be made available on request, subject to consideration of legal and ethical factors. Please contact socialsecurityexperience@gov.scot for further information.

☐ cannot be made available by Scottish Government for further analysis as Scottish Government is not the data controller.

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This document is also available from our website at www.gov.scot.
ISBN: 978-1-78781-344-1

The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

Produced for
the Scottish Government
by APS Group Scotland
PPDAS491566 (11/18)
Published by
the Scottish Government,
November 2018

Social Research series
ISSN 2045-6964
ISBN 978-1-78781-344-1

Web and Print Publication
www.gov.scot/socialresearch

PPDAS491566 (11/18)