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# **SOCIAL SECURITY EXPERIENCE PANELS - SELDOM HEARD PROGRAMME OF RESEARCH: CARERS AND CARE EXPERIENCED**



**Equality, Poverty and Social Security**



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# Summary

## Introduction

In 2017 Social Security Scotland set up Experience Panels to help in the design, delivery, oversight and review of Scotland's new social security system. These panels are made up of over 2,400 people who have experience of at least one of the benefits that have been, and will be, devolved to Scotland. As hard to reach and marginalised groups are less likely to be visible in the Experience Panels, we have set up a programme of research for 'Seldom Heard Voices' to ensure these voices are included in the design of social security services.

There are four groups identified as 'Seldom Heard' in this research. They are Mobile Populations, Vulnerable Groups, End of Life; and Carers and Care Experienced. For each group two waves of fieldwork are being undertaken.

This is the report for the first wave of the Carers and Care Experienced strand. The group is divided into the following sub-groups: care experienced; kinship carers, foster carers and adoptive parents; single parents; and young parents.

## Background

People from the carers and care experienced strand found information of benefits from a range of sources such as third sector organisations, online searches, word of mouth, benefit staff, public sector workers and health practitioners. Benefits they frequently applied for were Universal Credit, Child Benefit and disability benefits.

Some people from this strand highlighted positive experiences of support and guidance from third sector organisations, public sector workers and health practitioners. On the other hand, mixed experiences were highlighted concerning support from the Department of Work and Pensions (DWP) and Job Centre Plus staff.

This report highlights key barriers and challenges in accessing benefits faced by Carer and Care experienced strand people, as identified through analysis of survey responses, focus groups and qualitative interviews. The report also discusses enablers or potential improvements which may support increased benefit uptake among this group.

## **Summary Findings**

### **Barriers**

The research findings suggest that people from this group had difficulties accessing information on benefits. Lack of knowledge of the benefit system and of entitlement for specific benefits were experienced by many. They reported a lack of information and even misinformation of benefit eligibility based on their individual circumstances. Some even reported that information was not readily available or streamlined when they actively liaised with official government agencies.

People from this group also noted negative attitudes towards them when communicating with benefit advisors, work coaches and public sector workers. This was particularly the case when communicating with DWP and Job Centre Plus staff. These experiences led to many feeling stigmatised, judged and discriminated against.

A further challenge was faced when trying to complete application forms. Several reported that the structure and the wording of the application forms were prescriptive, complex and long. The closed (tick-box) questions did not allow them to convey the nuances of their particular circumstances. A few said they did not understand the language or jargon that was required to complete the forms correctly.

Disability Living Allowance and Personal Independence Payment application forms were highlighted as the most complex and difficult forms. Many reported that the long rigid format did not allow them to convey the fluctuating and nuanced nature of long-term and chronic health conditions.

Some told us that health assessments triggered stress. The main difficulties with the assessments were: the environment of suspicion, the restrictive nature of the questions and the assessors lack of qualifications meaning they could not identify the nuance of some health conditions. A few were critical of the frequency of reviews for conditions that were unlikely to change.

Long waiting times for award decisions and payments, changes to eligibility, interactions across benefits and overpayments led to a detrimental impact on household finances for some. This includes experiences such as getting into debt, rent arrears and the need to use foodbanks. In a few cases, these difficulties led to some experiencing constant stress and the intensification of mental health problems.

## Enablers

Positive experiences (enablers) and views on how the benefit system can be improved were identified by carers and care experienced people.

People from this group suggested that having a range of choices to get information, apply for benefits and to find guidance would improve access to benefits as it would take into account the different communication needs of different groups and their circumstances.

Many stressed the need for information on eligibility criteria, in particular, and for application processes to be consistent, comprehensive, clear and easy to understand. Several suggested that application forms should be worded in plain English, should be shorter with reduced duplication of questions. Many respondents and participants stated that forms should be designed with more flexibility so that clients can convey their specific circumstances. The information provided from agencies, public services and third sector organisations should be consistent following a joined-up approach.

Several highlighted the need for staff of benefit agencies to be appropriately trained in order to have a comprehensive understanding of benefits and interactions across

benefits. People wanted interactions with benefit staff to be based on a friendly, respectful, compassionate and empathetic approach.

Some suggested that health assessments should be carried out by medical professionals who have an appropriate understanding of long-term physical and mental health conditions. A few argued to reconsider the frequency of assessments for clients who have long-term conditions which are unlikely to change.

Some carers and care experienced people suggested that to simplify, prevent duplication and streamline benefit application processes, relevant information from the client should be stored.

Some suggested shortening waiting times between application and payment could help clients to avoid financial difficulties. Others mentioned that some flexibility around or a respite period for those experiencing changes in benefit entitlements could avoid people falling into difficulties.

Third sector organisations contributed to positive experiences with the benefit system. They are perceived as a good source of clear and comprehensive information.

# Introduction

The Social Security Experience Panels were established by researchers in the Scottish Government in 2017. Scottish Government researchers work with members to bring the voices of those with lived experience into the design of the new social security system in Scotland, as run by Social Security Scotland. There are groups of people with lived experience that are less likely to be represented on the panels, so the “Seldom Heard Voices” research programme was set up to address this gap. It ensures that groups who need to be treated with particular sensitivity and those who are marginalised or dispersed, also have a voice in designing Scotland’s social security services.

There are four groups identified as ‘Seldom Heard’ in this research programme. They are Mobile Populations, Vulnerable Groups, End of Life; and Carers and Care Experienced. For each group two waves of fieldwork are being undertaken.

This is the report for the first wave of the carers and care experienced strand. Blake Stevenson was commissioned by the Scottish Government to carry out the fieldwork which was undertaken between October and November of 2019. The analysis was carried out by Scottish Government researchers.

There are four sub-groups in this strand: care experienced people; kinship/foster carers and adoptive parents; single parents; and young parents under the age of 19.

The second stage of research is in progress at the time of writing and due to be published in 2022.



# Methods

The aim of the research was to engage with carers and care experienced people to better understand their experiences and views of benefits. Data were collected using an online survey, focus groups and interviews. There were a total of 59 survey respondents, 12 focus groups with 79 participants and 16 interviews.

The research explored the following themes:

- Finding out about benefits: experiences, barriers and enablers on getting information about benefits.
- Applying to benefits: experiences of the application processes and forms, barriers and views on improvement.
- Interacting with government agencies, support and advocacy organisations: experiences of support and difficulties when interacting with organisations to find out and apply to benefits.
- Views for preferences in the future.

Carers and care experienced people were recruited through engagement with national and local third sector organisations; including governing bodies and umbrella organisations for organisations that work with this group. In addition, social media platforms were used to recruit potential participants directly.

All the data collection was carried out by Blake Stevenson and was compliant with Social Research Association Ethical Guidelines, the Data Protection Act 2018 and the General Data Protection Regulation (GDPR). To ensure the research was ethically comprehensive, the following key mechanisms were applied: voluntary participation, informed consent, confidentiality and anonymity. Personal and sensitive data of participants was safeguarded and concealed. The data transferred to Scottish Government researchers for analysis was fully anonymised.

## Online survey

The survey, which ran during November 2019, was online only. It was not completed by a representative sample of carer and care experienced people. We refer to those who completed the survey as respondents throughout the report.

Most of the 59 respondents (59%) were care experienced people. Around a third (32%) were single parents. About a quarter (27%) belonged to the kinship/foster carers and adoptive parents sub-group. One in ten (10%) were parents under the age of 19.

**Table 1: Sub-groups survey respondents belong to (n=59)**

Sub-groups	%
Care experienced	59
Single parents	32
kinship/foster carers and adoptive parents	27
Young parents	10

The majority of survey respondents were female (84%) and white (95%). Around three-quarters of survey respondents (74%) were 44 years old or younger. Just below half of respondents (45%) were disabled or had long-term health condition. Just over one-quarter of respondents (27%) said they look after or care for someone because of ill health, disability or problems related to old age. Most survey respondents lived in an urban area (84%).

## Interviews and focus groups

Ninety-five participants took part in a total of 12 focus groups and 16 interviews. These were carried out between October and November of 2019. The same interview guide was used in both research methods. Focus groups and all but one

interview were recorded and transcribed<sup>1</sup>. We refer to those who came to focus groups and gave us interviews as participants throughout the report.

A £10 gift voucher was offered as a thank-you for taking part. Participants were also reimbursed travel expenses.

From the 95 participants, almost two-thirds (64%) were single parents, 31% belonged to the kinship/foster carers and adoptive parents sub-group, 15% were care experienced and 8% were parents under the age of 19.

**Table 2: Sub-groups participants belong to (n=95)**

	%
Single parents	64
Kinship/foster carers and adoptive parents	31
Care experienced	15
Young parents	8

The majority of participants were female (85%) and white (83%). Almost two thirds of participants (63%) were 44 years old or younger. Around one fifth (22%) were disabled or had a long-term health condition. Around one third of participants (34%) said they look after or care for someone because of ill health, disability or problems related to old age. Most participants lived in an urban area (92%).

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<sup>1</sup> One interview participant did not want to be recorded. Data from that interview is based on a summary of the interview rather than a full verbatim transcript.

# General experiences of benefits

Although our respondents and participants had some different and specific experiences we also found commonalities.

## Which benefits?

Table 3 sets out the proportion of respondents that had experience of each of the benefits. The three most common were: Universal Credit (UC) (52%), followed by Child Benefit (CB) (39%) and Personal Independence Payment (PIP) (33%).

**Table 3: Proportion of respondents applying for each benefit in previous three years (n=46)**

	%
Universal Credit	52
Child Benefit	39
Personal Independence Payment	33
Housing Benefit	30
Child Tax Credits	22
Cold Weather Payments and Winter Fuel Payments	20
Employment Support Allowance	17
Carers Allowance	15
Disability Living Allowance	13
Discretionary Housing Payments	11
Jobseeker's Allowance	9
Contributory Job Seeker's Allowance	9
Income Support	9
Sure Start Maternity Grant	9
Some powers in relation to Universal Credit	9
Severe Disablement Allowance	7
Working Tax Credits	7

Contributory Employment Support Allowance	4
Maternity Allowance	4

Similarly to respondents, participants had experience of most of the benefits shown in Table 3 and further of; Best Start Grant (BSG), Kinship Carer Allowance (KCA) and Pension Credit (PC). Most participants had experience of more than one benefit.

## Information sources

Table 4 sets out the sources of information for respondents. The most common source was 'Other organisations/professionals' (41%) which included third sector organisations, social workers, welfare rights officers, council staff, and health professionals. A third (33%) found information online themselves, whilst 20% said a Job Centre Plus advisor told them.

**Table 4: Thinking about the most recent benefits application you made, how did you find out about which benefits you are entitled to? (n=46)**

	%
Other organisations/professionals gave me information	41
I found information online	33
A Jobcentre Plus advisor told me	20
Friends/family gave me information	15
Other	9
I found written information offline (leaflets, flyers etc.)	4

Participants also mentioned a range of sources. Commonly stated sources were: third sector organisations, online searches, word of mouth, DWP and Job Centre Plus staff, public sector workers. A few of them mentioned health practitioners. Many of them used more than one source to get information about benefits.

Participants told us their first source of information was often relatives, friends, acquaintances and peer/service users.

**“[I got information] Just coming here [to support group], and then [name] who worked for CAB, she was really, really good. She knew everything about what kinship care payments were and what we were entitled to, so she came to the group and did bits and pieces and said you need to do one of those questionnaire things about your expenditure and benefits.”**

[Kinship/foster carer and adoptive parent, focus group]

Online searches were also a common way to look for initial information.

Respondents and participants who found information online commonly noted: UK and Scottish Government websites, internet search engines and social media websites. For some, websites and forums from third sector organisations were sources of information.

**“I’ve looked on Google...I look at the .gov websites and I’ve taken stuff from there”.**

[Single parent, focus group]

## **Ease of finding information**

Table 5 sets out how easy or difficult respondents found getting information on benefit entitlement, almost four-in-five (78%) respondents said it is quite difficult or very difficult.

**Table 5: How easy or difficult do you think it is to find out about which benefits you are entitled to? (n=59)**

	%
Very easy	2
Quite easy	20
Quite difficult	41
Very difficult	37
Total	100

Like respondents, the majority of participants also found getting information difficult. Both participants and respondents told us their difficulties stemmed from having no experience of benefits initially and so did not know where to look. When they did find information, it could be complicated and this was compounded by inconsistency across sources.

The small number of participants and the respondents who said finding information was easy, either had support from third sector organisations, public sector workers or benefit staff or said that finding information online was generally straightforward for them.

**“We spoke to [local third sector organisation]...It’s a third sector organisation for advocacy...they were [able to give all the information we needed] aye. They were very good..”**

[Kinship/foster carer and adoptive parent, interview]

## How did they apply?

When asked to think about what channel they used in their most recent application, just over half of survey respondents (54%) said they applied online. Three-in-ten (30%) completed a paper application. Only 2% applied face-to-face. Respondents who selected the ‘other’ option (13%) generally noted they had completed their application by phone (see Table 6).

**Table 6: Thinking about the most recent benefits application you have made, how did you apply? (n=46)**

	%
Online	54
Paper application	30
Other	13
Face-to-face	2
Total	100

Similarly, most participants mentioned the same channels of communication (i.e. online, paper application, face to face) when asked how they applied to benefits.

Around three-quarters (74 %) of survey respondents said applying was quite or very difficult. Table 7 below shows results in more detail. It highlights only 2% said the process was 'very easy'.

**Table 7: How easy or difficult did you find it to apply for benefits? (n=46)**

	%
Very easy	2
Quite easy	24
Quite difficult	24
Very difficult	50
Total	100

The small number of respondents who said applying for benefits was easy said that processes with some specific benefits - CB and Child Tax Credit (CTC) - were straightforward. Further, respondents who found it easy highlighted that it was because of the support they had from third sector organisations, public sector workers or benefit staff (more below).

Most participants also found applying for benefits difficult. Among the reasons cited for difficulties were: that they found application forms long and also repetitive which seemed unnecessary, that the application process could be complex and confusing, and further they could feel stigmatised or discriminated against. One final issue was that participants could feel unsure that they were following the processes 'correctly' which led to a feeling of insecurity.



Benefits participants mentioned as particularly difficult were UC and PIP. People who did not consider themselves computer literate, in particular, found the online UC application process difficult.

For those claiming PIP, difficulties mentioned included: the application form was repetitive, long and complex and so filling the form was challenging without support, and the assessments process was particularly stressful. Specifically, the application and assessment processes were found to be unable to capture appropriately the fluctuating nature of some health conditions.

As well as difficulties with the actual application process, participants and respondents found other aspects difficult. These included the long waiting periods before getting payment, the transition when moving to UC from other benefits with fewer conditions to entitlements; and the interactions of eligibility between UC and other benefits.

### **Support with information and application processes**

Some participants and respondents told us about positive experiences when they got support with information on benefits and further help with filling in application forms, assessments and appeals. This support mostly came from third sector organisations, public services workers and health practitioners.

Third sector organisations, in particular, those who advocate and work on the specific needs of carers and care experienced people (for example, Who Cares? Scotland, One Parent Families Scotland and Barnardos) along with support groups and service users in these groups; were highlighted as key support for finding information and with applications. In some cases, they made participants aware for the first time of benefits to which they might be entitled. A few participants said that without the support of these organisations, they would have not applied to benefits.

**“I didn’t know what benefits I could apply for, see until I came to One Parent Families Scotland, I didn’t know anything about any of the benefits I could apply for.”**

**“...a lot of us have found out about different benefits that we maybe don’t know about, but we should be entitled to. And it’s all down to this group”.**

[Single parents, focus group]

A handful of participants mentioned having a difficulty with long waiting times to get appointments with third sector organisations notably Citizens Advice and GEMAP. Despite this, the organisations were found helpful.

**“...there’s always Citizens Advice as well. They’re really good...They guide you in the right direction, for example with what charitable organisations [that] can help, what the charitable organisations can do for the child. They can give you a lot of information.”**

[Kinship/foster carer and adoptive parent, interview]

To a lesser extent, public sector workers and health practitioners provided useful information to participants and respondents, and further gave support with application processes. Participants mentioned getting help from social workers, welfare rights officers, housing officers, family nurses, health visitors and midwives. A small number of participants also received guidance and advice from support workers from schools and homeless services. Other participants criticised the lack of support from some public sector workers; in particular from social workers.

**“It was my welfare rights officer that told me about the Personal Independence Payment, and he did the application form in the house for me. I got knocked back but then he appealed it, and I got it then, so that was quite good that the welfare rights officer helped me with that.”**

[Single parent, focus group]

Participants had mixed experiences when looking for support from DWP and Job Centre Plus staff. A few had good Job Centre Plus advisors and work coaches who helped them find information; and supported them with completing application forms. Many others stated DWP and Job Centre Plus staff gave them confusing information, misinformation or no information about benefit entitlement. Some participants also indicated that they did not support them with application processes.

**“...the Job Centre Plus that I go to, whenever I go there with a problem or whatever I have, they give you the right information or way to go. Even if they can’t help, they tell you what to do and give you telephone numbers and stuff like that. To go and get help.”**

[Single parent, focus group]

**“...It seem liked everyone was sending me in different directions and nobody actually knew [...] The Job Centre Plus was the only source of contact that I had about benefits, nobody else had a clue. That left me stranded for ages until I got a family nurse.”**

**“A lot of [Job Centre Plus] staff don’t know what they are doing a lot of the time.”**

[Young parents, focus group]

Most support participants obtained was in the form of face-to-face interactions. However, there were some cases where support by phone was valuable. Online forums were also a source information and were used to make specific queries about benefits for a few participants.

## Key barriers with the benefit system

Common barriers experienced by carers and care experienced people in our research are presented below.

### Lack of existing knowledge and difficulty finding information

As set out above, people from the carers and care experienced strand often lacked knowledge of the benefit system in general, and knowledge about their potential entitlement in particular. This was compounded by difficulties finding the right information. These twin issues were a key barrier and could lead to participants and respondents missing out on or delaying benefits they were eligible for.

Participants and respondents also told us that when their circumstances changed, and there was a potential impact on benefit entitlement, once again the lack of knowledge and hard to find information became an issue that was experienced as a barrier.

**“As a foster carer, I am not sure what I would be entitled to for the child within my care, then moving onto being an adoptive parent. I can now apply but due to never using benefits in the past, I do not know what or if I am entitled to anything.”**

[Kinship/foster carers and adoptive parent, online survey]

Another issue experienced by the respondents and participants was potential misinformation. They told us that not only was the information not streamlined, but that they found Government websites, public sector workers, benefit staff and some third sector organisations could provide inconsistent information and incorrect information which compounded the confusion they felt. Participants felt that information supplied by DWP and Job Centre Plus staff should have been correct and consistent but a few of them were given conflicting, confusing and insufficient information.

**“Trusted organisations don't have the correct information to inform people.”**

[Care experienced respondent, online survey]

**“I'm still getting the medical certificates because I'm still unable to work. I wasn't told that I could be getting other things on top of this because of my mental health, and I've only been advised by the support worker here [support organisation] just now that there is other options out there that I could have been getting. They [Job Centre Plus staff] didn't tell me the options that they should have told me in the first place. It's their job to inform me that this is what I could have applied for.”**

[Single parent, interview]

Participants told us this inconsistency led to a tendency to distrust public sector workers to provide them all the information of benefits they could be eligible for. This distrust was experienced more typically when interacting with Job Centre Plus staff.

**“You're probably better off Googling it than asking at Job Centre Plus. So, things they say you're entitled to things that you're not entitled to. There's a lot of misinformation.”**

[Single parent, focus group]

## **Challenges with accessing the benefit system online**

There were mixed experiences concerning accessing information and applying for benefits online. Whereas some mentioned their online experiences as simple and straightforward, others highlighted barriers to accessing information and the application processes online.

Some did not have access to a computer or a smart phone so could not get online. Others had access but not the experience of using the internet. A small number of participants and respondents told us that when they did use the internet, online

searches did not help to find accurate or clear information on benefits they may be entitled to.

One issue was that some found government websites difficult to navigate, another that the information could be limited or confusing. Participants and respondents also reported they found digital services difficult because they were impersonal and they would prefer face to face.

Further, we found that some people experienced long delays waiting for information that they had requested online.

**“And everything is like online. Everything is online. And people aren’t geared up. A lot of people can’t do things online. You don’t get a face to face person.”**

[Kinship/foster carers and adoptive parent, focus group]

**“...the difficulty for people that can’t be online. It’s a barrier for a lot of people. You see a lot of people in libraries struggling with it.”**

[Single parent, focus group]

## **Stigma and distrust from official channels**

People from the carers and care experienced strand of research reported feeling stigmatised, judged and discriminated against by public sector staff.

Participants and respondents reported experiencing a negative attitude from some benefit advisors, work coaches and other public sector workers, when claiming benefits. This was particularly the case when communicating with DWP and Job Centre Plus staff.

Further, people reported feeling a lack of empathy and compassion when interacting with benefit staff, including staff who carried out work and health assessments.

The attitudes they experienced were not helped by the physical environment of Job Centre Plus which they found unfriendly and not welcoming.

Some in the research also distrusted that DWP and Job Centre Plus staff as mentioned above. They expanded on this distrust saying that benefit advisors did not have accurate and comprehensive knowledge about the various benefits and their eligibility criteria. In some cases participants and respondents found that DWP and Job Centre Plus advisors simply did not want to provide information and they perceived that this was put potential clients off claiming benefits, even if they were entitled to them.

All these experiences made some respondents and participants nervous, anxious, embarrassed and stressed. They reported that they had experienced a general negativity in the whole culture of the benefit system and this prejudice against claimants was a symptom of that. They worried that some claimants might not speak up or question the information provided by the benefit staff out of fear of being rejected or sanctioned.

**“The questions that were asked in my fit to work assessment really made my mental health a lot worse. But it’s not the questions, it’s the way they ask them. [...] And I’ve heard a lot of people say that, and it put me off going in the first place. And if I hadn’t been taken by my friend to go, I never would have gone and I never would have got the benefits because every time I set foot in the Job Centre Plus, I’ve felt very much like a number and very much beneath the staff. And the questions, everything, even to do with suicide, self-harm, they’re monotone, straight-faced, can’t even look at you.”**

[Care experienced participant, interview]

**“It’s so scary. You always feel like they are trying to trip you up. You feel guilty, for applying. They sometimes are so abrupt that you feel belittled.”**

[Care experienced respondent, online survey]

## Complexity of the application forms

People from the carer and care experienced strand reported difficulties with application forms.

Respondents and participants typically mentioned that the structure and the wording of the application forms were prescriptive, complex and long. The language and jargon was unfamiliar and the closed (tick-box) questions did not allow them to convey the nuances of their particular circumstances. Many also felt that the questions were repetitive and intrusive. A few noted that they did not understand some of the questions. These difficulties led to a perception in this group that the forms were designed to make it hard to complete the forms correctly.

Many relied on help to fill out the forms correctly and we found a few cases where participants had claims rejected because they did not have help to complete them. This was not to do with eligibility rather that without support they were not completing them correctly, as once they got support to complete the application form; their claims were accepted.

Altogether, the complexities led to an amount of effort, time, confusion and stress which led some to postpone a claim. A few also had second thoughts when it was time to reapply due to these barriers.

DLA and PIP application forms were highlighted as the most complex and difficult forms.

**“...the repetitiveness of it [the form] is very strange. And it’s very difficult, if you care for somebody who needs a significant amount of care, it’s quite difficult to put what that’s like in a box. They ask, is it one time a night, is it two times a night. Well sometimes yes and sometimes it’s six times a night they get up, sometimes it’s seven times. Sometimes it will only be two times. But there wasn’t a bit where you could actually write a narrative around that rather than tick a box...So, it’s quite scary to know where to put your tick, to accurately describe your role caring for this individual. It’s quite tricky, what do you want me to say here, because none of these really apply. He’s a human being, not a statistic, if that makes sense.”**

[Kinship/foster carers and adoptive parent, interview]



**“I’m entitled to disability for my son...it’s such a rigmarole and I’ve just not reapplied for it. My son’s got severe ADHD, ADD and Tourette’s, so he’s entitled to disability. But because he’s at a middle age where he’s 16 in a couple of weeks, I’d have to change it when he’s 16 to PIP. It’s disability for under 16, then it changes to PIP. And I was like, do you know what? I’m not even going to bother. And I am entitled to it and its quite a bit of money, and he used to get a bus pass and everything. It’s the form is massive. It’s about 60 pages long, you need letters from the ADHD doctor, you need to take it to their school and get them to confirm what he’s like at school. You need another family member as well, or somebody that you know, to say what the child is like. It’s like three or four people have to fill out a form about your own child.”**

[Kinship/foster carers and adoptive parent, focus group]

## **Challenges with health assessments**

Most participants and respondents who had health related assessments experienced embarrassment, anxiety, stress and humiliation.

They reported that Work Capability, DLA and PIP assessments were characterised by an environment of suspicion and scrutiny, and assessors lacked empathy and gave respondents and participants the feeling of being distrusted.

As assessors were not health professionals, many reported a perception that they were not qualified to identify some health conditions, in particular they lacked expertise to identify and recognise the varying nature of long-term and chronic illnesses. This led some participants and respondents to question why there was no recognition of the medical evidence they had already provided to the assessors.

This was compounded by, a similar issue reported with application forms above, the restricted nature of the closed (tick-box) questions they were asked in the assessment. Such questions left no room to capture the fluctuating nature of some health conditions.

In addition, a few people in the research found the questions unnecessarily intrusive and they were made to feel shame and embarrassment.

The research found that people were left with a feeling that assessors wanted them to fail and many highlighted that without the support from third sector organisations, they would have not been able to go through the assessments processes.

Finally for this issue, a small number of carer and care experienced people noted that assessment reports were inaccurate and one-sided. And some were critical about the frequency of reviews for some long-term health conditions that are unlikely to change or resolve.

**“I just don’t get how one person can sit there and judge you on one session by asking questions repetitively like you would do in a call centre, they read off these things and that is it”.**

[Single parent, focus group]

**“It’s almost like they’re undermining you, cause they’re trying to make out that you’re lying to them. They speak to you in a way like, ‘you’re not telling me the truth’”.**

[Kinship/foster carers and adoptive parent, focus group]

## **Long waiting times, changing benefits and overpayments**

Respondents and participants reported experiencing financial hardship due to long waiting times, changes in eligibility during transfer to new benefits, interactions across different benefits and overpayments. They reported precarious economic experiences such as getting into debt, rent arrears and the need to use foodbanks. In few cases, these difficulties led to some experiencing constant stress and the intensification of mental health problems.

Long wait times between applying and receiving benefits were commonly noted in relation to UC, disability related benefits, Tax Credits and KCA. These also occurred when people were transferred to UC. Participants told us that their only choice was to request advance payments which left them short when the payments came through. Further, when transferred some perceived that they received less money because of changes such as the benefit cap and the 'bedroom tax'.

A few also indicated that timescales to obtain decisions from assessments and appeals left people without any financial support during the long waiting period.

Interactions across benefits led to some people experiencing a reduction in the amount they received and even the termination of benefit payments.

Further, losing eligibility for some benefits due to being transferred to other benefits was not unusual. In some cases, benefit payments were stopped without the client being made aware of the changes.

One example of losing eligibility came from a student who reported being disadvantaged in the benefit system.

**“I’m a student so it’s a total mess. I’m hugely disadvantaged when it comes to benefits and different advisors say different things.”**

[Care experienced respondent, online survey]

Another source of financial difficulty was overpayments. Even where participants had provided information on their change of circumstances well in advance, they still had to pay the money overpaid through no fault of their own back.

**“The period you have to wait for a decision. I had to wait 5 weeks for a payment, I am a care leaver with no family support so this was really difficult. I was made to get into debt including with the Job Centre Plus with the advance payment you get to have to wait. So my payments are now reduced due to the advance payment I had no choice but to take to live.”**

[Care experienced respondent, online survey]

**“...the application time for any of these benefits, it’s absolutely ridiculously unrealistically long. I mean, eight weeks you need to wait for a reply? And sometimes if there’s a backlog, it can be 10-12 weeks. You try surviving on reduced benefits for 12 weeks, you know what I mean? I’ve never had to use foodbanks as much as I’ve had to use foodbanks this year. And it’s embarrassing, because I’ve always provided for my children as best as I can on the money that I get. I’m not the kind of person that likes going cap in hand and asking people for things.”**

[Single parent, interview]

# Enablers and views on improvement of the benefit system

Positive experiences (enablers) around the benefit system were also identified through the online survey, interviews and focus groups. Some also shared their thoughts on how the system can be improved. Key enablers and views on improvement are outlined below.

## Multi-channel access

Carers and care experienced respondents and participants suggested that having a range of choices to get information, apply for benefits and to find guidance would improve access to benefits as it would take into account the different communication needs of different groups and their circumstances.

It was clear that respondents would prefer to use different methods at different times as some chose multiple methods when asked about their preferences for getting information (see Table 8). Over half (56%) said they would want to get such information online, almost half (47%) also wanted the option of written information (such as leaflets or flyers) close to half (44%) selected 'other organisations or professionals' as an information source and around a third (31%) wanted their information to come from Job Centre Plus.

**Table 8: How would you prefer to get information about any benefits you are entitled to in the future? (n=59)**

	%
Online	56
Written information - written leaflets, flyers, etc	47
Other organisations/professionals	44
Jobcentre Plus	31
Friends/family	17

Newspapers/magazines	12
Other	3

When asked how they would like to apply for benefits (Table 9), most (56%) said that they would prefer online, about a third (34%), said they would like to apply face-to-face with the remaining 10% favouring paper methods.

**Table 9: What would be your preferred way to apply for benefits in future? (n=59)**

	%
Online	56
Face-to-face	34
Paper	10
Other	0
Total	100

Similarly, participants from the focus groups and interviews had a range of preferences for how to access information, how to apply for benefits and how to get support. These included: online, face to face, written information and telephone. For information in particular, a few suggested advertising through various channels such as radio and TV.

As for online sources of information, carers and care experienced people mentioned government websites and social media platforms as key. They did stress, however; that it was important for official websites to be clear and easy to navigate (more below).

Many also stated the need to offer written information in different forms such as letters through the post and information packs in the form of booklets and leaflets.

Participants and respondents would like to see written information in a variety of public places in order to reach the most people. They gave the examples of GP

surgeries, other NHS services, schools, libraries, housing offices, and benefits and social security offices.

Many suggested a comprehensive provision of information, support and guidance should be offered by benefit staff, to counteract the barriers set out above. In addition, several suggested that key workers from different services they interact with could act as enablers by providing information and support with application processes. These included: health professionals, social workers, support workers, teachers, financial advisors and welfare and housing officers.

Several mentioned their preferences for face-to-face and individual guidance and support with staff from benefit agencies. Many felt that with this support, they would be able to navigate application processes more effectively and be more confident that they had complete application forms correctly.

**“I’d prefer to do it face-to-face so they can advise you as you go along. The last thing I expected at my age was to be looking after a four and five-year-old, with all the panel meetings, and courts, I didn’t expect to be doing this at my time of life. So a wee bit more help would be good.”**

[Kinship/foster carers and adoptive parent, interview]

**“More face to face, personal and individual lead support & advice.”**

[Young parent, online survey]

A few people in the research highlighted the importance of providing information and guidance via home visits for some groups.

Ultimately, carers and care experienced people in our research stressed that in order for the different sources and channels of communication to be enabling as opposed to barriers and to ensure inclusivity and accessibility; it was necessary to provide the full range of options.

**“Online is nice because it’s convenient. Some people might find it more intimidating to sit in front of an official person and have to be interviewed by them, whereas it’s nice to be able to put everything you think down on a bit of paper and submit it without having to deal face-to-face with someone. But I also think it might be helpful to deal face-to-face with someone because I was confused about what to write for certain things. So, it might be better to have the option of doing it face-to-face so that you can talk it through with someone and pull out the relevant information.”**

[Single parent, interview]

**“Having a different way for applying cause everyone might like to do things differently.”**

[Care experienced respondent, online survey]

## **Consistent, comprehensive and streamlined information**

As well as being able to access information through different channels, respondents and participants stressed the need for information on, in particular, eligibility criteria and for application processes to be consistent, comprehensive, clear and easy to understand.

One suggestion was to set out clear directions, for different benefits, different circumstances and different support needs; for clients to follow. These routes could signpost people to information on benefit entitlements with their qualifying criteria and the available support for specific circumstances and situations. It was also suggested a checklist to review if the client is following all the steps appropriately.

**“Easy to understand information either in information booklets or online about what each benefit is and guideline as to who would be able to apply.”**

[Kinship/foster carers and adoptive parent, online survey]

Several suggested that application forms should be worded in plain English, should be shorter with reduced duplication of questions. Many respondents and participants stated that forms should be designed with more flexibility so that clients can convey their specific circumstances.



**“Make the forms more friendly, with less jargon.”**

[Kinship/foster carers and adoptive parent,, interview]

The people in the research thought that to avoid confusion and misinformation for the client all the information and support provided by staff from agencies, public services and third sector organisations should be consistent, simplified and streamlined. This joined-up approach would help people navigate the benefit system.

**“I think all the information you find online versus what you get through word of mouth needs to match up so there needs to be a training review in terms of Job Centre staff”.**

**“...it should be more joined up, they should talk to each other, more linked up.”**

[Single parents, focus group]

### **Knowledgeable and empathetic staff**

Many people in our research emphasised the need for staff of benefit agencies to be appropriately trained in order to have a comprehensive understanding of benefits and interactions across benefits. They thought such training would enable staff to give information and support with any circumstances a client can present with.

Benefit staff should also be well-informed about the particular difficulties endured by some people. This could include homelessness, difficult health conditions and all disabilities. In this way benefit staff would provide tailored and targeted support, and signpost services sensitively. Ultimately, people wanted interactions with benefit staff to be based on a friendly, respectful, compassionate and empathetic approach.

**“Train all front line staff on what being Care Experienced means and what that can mean for some of us.”**

[Care experienced respondent, online survey]

**“Talk to people face to face...look at individual situations...employ people in job centres that actually know what they are doing...not just pressing buttons until computer says no!”**

[Kinship/foster carers and adoptive parent, online survey]

Some respondents and participants also suggested that the general culture underpinning the design and delivery of the benefit system could be more empathetic and compassionate. A few mentioned the importance of challenging stigma around benefits.

**“...but if you are in the situation where you have to apply for things, you need some compassion.”**

**“Compassionate people. People that aren’t going to mock you.”**

[Single parents, focus group]

**“Treat people with dignity and respect.”**

[Care experienced respondent, online survey]

## **Assessments and renewals**

Concerning health assessments, some suggested that they should be carried out by medical professionals who have an appropriate understanding of long-term physical and mental health conditions. In this way, fluctuating and chronic health conditions would be properly considered for awarding benefit related benefits. Relatedly, few argued to reconsider the frequency of assessments for clients who have long-term conditions which are unlikely to change.

**“Have an actual doctor sitting in front of you that knows what the prescription that you’re getting prescribed, the way it affects your day-to-day life. An expert, somebody that cares. A doctor. Listen to your doctor, your doctor’s not giving you things for no reason.”**

**“...getting examined or assessed by a proper, and I’m going to stress that word proper, medical professional.”**

[Single parents, focus group]

**“I think that lifelong conditions should not be reassessed. The system should enable people not to reapply every year. The appeals process should be way easier.”**

[Kinship/foster carers and adoptive parent, interview]

Some mentioned that medical evidence provided by hospitals and GPs should be weighed heavier for health assessments and award decisions.

**“There’s doctor’s letters, there’s hospital letters and you still have to sit and degrade somebody.”**

**“Someone was saying to me... why do they have to put that all on the form when your doctor probably has all that information.”**

[Single parents, focus groups]

## **Storing information and evidence**

A few carers and care experienced people suggested that to simplify, prevent duplication and streamline benefit application processes, relevant information from the client should be stored. This would avoid the current practice of requesting information from clients who are already in the benefit system.

## **Reduce waiting times and more flexibility**

Participants and respondents suggested shortening waiting times between application and payment could help clients to avoid financial difficulties. Others mentioned that some flexibility around or a respite period for those experiencing changes in benefit entitlements could avoid people falling into difficulties and further more flexibility when having to pay back overpayments, loans and advance payments.

A few made suggestions to increase benefit payments or bring in new benefits for people in some specific circumstances, for example for young people who are care experienced to prevent them falling into destitution and homelessness. Few kinship carers stated that there should be an increase of KCA.

**“I think they could implement some sort of relief for that waiting period so people don’t get into debt because the numbers of people in debt and going into poverty is sky high in Scotland.”**

[Single parent, focus group]

**“...maybe some other types of benefits that are for the younger people that would help them through a rough time, because a lot of younger people nowadays are ending up unfortunately homeless or without a place to live...”**

[Care experienced respondent, focus group]

More generally, some indicated that due to benefit changes and the reduction of the value of payments, there should an overhaul on the system aimed to increase the amount of benefit payments to match the cost of living.

**“...what is the problem with raising what we actually get paid? Which hasn’t been raised for about 5 years...It would save a hell of a lot of hassle at the end of the day, without have to claim discretionary funds, and all these welfare funds.”**

[Single parent, focus group]

**“Give us the money to live on...The inflation is going up higher than what I can buy food at. Something’s gonna give. The Government is on about concluding austerity. Well now’s the time. If we’re gonna set up a new benefits system, now’s the time to start from the start and get it right for every person...”**

[Single parent, interview]

## **Key role of third sector organisations**

Third sector organisations, in particular those which advocate and work on the specific needs of carers and care experienced people; contributed to positive experiences with the benefit system. They are perceived as a good source of clear and comprehensive information. For many, they were also of fundamental support with application processes. Guidance and help from these organisations to complete applications forms correctly, attending assessments, tribunals and appeals was frequently praised by participants from focus groups and interviews.

**“...we have a charity in [location] called [name of local charity]...they know all about benefits and the benefits system and how it works and how you get awarded your points, and they’ll advise you and they also give you a representative to fight your case if it needs to go to a panel. So I went up to him and filled out the form to appeal the decision. They came back with a letter to say the decision had been appealed and refused, at which point I then had to fill out a form asking for it to be taken to an independent tribunal. And then I had to wait for the appointment for the tribunal. I had to go out to Glasgow to the tribunal. [name - representative from local charity] came with me, and he basically just fought my case for me and told them, explained to them why I needed the ESA and why I wasn’t fit for work at the moment. And about twenty minutes later, they came back with the decision and they just reinstated it”.**

[Single parent, interview]

## What's next?

The chart below summarises the barriers that carers and care experienced people faced, the corresponding enablers and suggested improvements and sets out the action Scottish Government and Social Security Scotland will undertake (or has already undertaken) to address these barriers.

Barriers	Enablers	Action
Lack of knowledge of the benefit system		<p>A general duty to promote the take-up of devolved benefits is enshrined in the <a href="#">Social Security (Scotland) Act 2018</a>. Social Security Scotland and the Scottish Government to date have published <a href="#">two take-up strategies</a> that set out all the activity and engagement being undertaken to ensure awareness of benefits improves.</p> <p>Social Security Scotland will build on these findings by carrying out further research to identify and explore how best to communicate and market benefits to hard-to-reach and marginalised groups. The results of this research will be used to</p>

		<p>develop bespoke communication and engagement plans to support communication activity.</p> <p>The findings from this research have been fed into the consideration to implement a joined-up approach to improve access to information and support, and the importance of providing a range of communication options, in the work to develop Scottish Carer's Assistance, the Scottish replacement benefit for Carers Allowance. The intention is for the new benefit to reach more carers, and help carers find out about the wider support which is available to them.</p>
<p>Challenges with access to the benefit system online</p>	<p>Multi-channel access to get information, apply for benefits and to find guidance</p> <p>Preferences for face to face service and importance of home visits for some groups</p>	<p>For the benefits that have been and will be devolved to Scotland Social Security Scotland will offer a range of ways to apply for the benefits they deliver including online, telephone, paper-based or face-to-face. Further applicants will be offered support when applying for disability benefits. This multi-channel approach will ensure that those who cannot or choose not to adopt digital methods will not become isolated through technology.</p>

		<p>The findings on the preference for face-to-face support will be fed into the development of the Local Delivery service in local communities across Scotland. This service will be person-centred by providing local presence to meet people’s needs in key locations where clients currently attend. Local delivery staff will provide pre-application advice and support to encourage people to take up the payments they are entitled to.</p>
<p>Difficulty finding information</p>	<p>Consistent, comprehensive and streamlined information</p>	<p>Social Security Scotland has introduced inclusive communication approaches in all its work working towards clear and accessible information, and a clear and transparent explanation of the eligibility criteria for each application form.</p>
<p>Stigma and distrust from official channels</p>	<p>Knowledgeable and empathetic staff</p>	<p>Social Security Scotland and Scottish Government have gone to great lengths to ensure that fairness, dignity and respect are embedded in the new system. <a href="#">Our Charter</a> was co-designed to ensure that what a good system looks like is set out in full. This system includes the need for staff to be knowledgeable and empathetic. The <a href="#">Charter Measurement Framework</a> (also co-</p>



		designed) monitors and reports on a yearly basis the progress being made against the Charter.
Complexity of the application forms (prescriptive, complex and long)	Application forms should be plain English and shorter and designed with more flexibility	<p>Social Security Scotland has introduced inclusive communication approaches in all its work including application processes, all systems and client/staff interaction.</p> <p>Further, the design of forms and application processes are undertaken in collaboration with people with lived experience of the benefit being devolved.</p> <p>Social Security Scotland has provided telephone and online services to advise clients on each aspect of the application processes.</p>
Challenges with health assessments (restrictive and unable to capture fluctuating	Assessments and renewals carried out by medical professionals. Reconsider frequency of assessments (for people with long-term health conditions unlikely to change)	These suggestions are aligned with the approach to supporting information being implemented by Social Security Scotland. This approach will consider using supporting information from the medical profession.

<p>and chronic conditions)</p>	<p>Medical evidence to weigh heavier for health assessments and award decisions</p>	
<p>Financial hardship due to long waiting times, changing benefits and overpayments</p>	<p>Reduce waiting times between application and payment</p> <p>More flexibility to pay back overpayment, loans and advance payments</p>	<p>Scottish Government is working with internal and external stakeholders to develop an Overpayments Policy that balances the need to treat people with dignity, fairness and respect alongside the Government's wider responsibilities to demonstrate responsible administration of public funds. One of the key principles of the overarching Overpayments Policy is that no individual will be knowingly pushed into hardship as a result of repayment. To achieve this principle, work is currently ongoing to develop a Hardship Policy, processes and guidance that is flexible enough to take into account the full circumstances, as far as they are known, of an individual to ensure they are fully supported in coming to an agreement on the best method of repaying their debt.</p> <p>Universal Credit is reserved to the UK Government, and as such Scottish Ministers do not have the required powers to affect delays in processing applications and getting first payments out to</p>

		<p>claimants. However, we have written to the UK Government on several occasions specifically to ask them to scrap the 5-week wait for a first payment of Universal Credit, amongst other much needed improvements, including replacing advance payments with non-repayable grants.</p> <p>We will continue to call on the UK Government to act on these recommendations.</p>
	Storing information and evidence	<p>Storing information from clients to prevent duplication is addressed by a new practice to gather information. This practice will focus on Social Security Scotland being able to proactively store information from the client since the start of application when that is possible. This will reduce the burden on the applicant.</p>
	Key role of third sector organisations (for information, advice and support)	<p>Scottish Government has published two <a href="#">take-up strategies</a> that include engaging with advocacy organisations to address barriers to benefit take-up. The findings from this research will inform a targeted approach with these specific groups for the</p>

		<p>implementation of interventions committed to in the Benefit take-up Strategy.</p> <p>The findings from this research will be used to inform stakeholder engagement which communicates changes on Social Security Scotland benefits. Activities include workshops which bring together a wide range of organisations. These workshops involve various teams across Social Security Scotland working with third sector organisations. This engagement will help organisations to provide relevant and accurate information on benefits and their eligibility to their clients.</p>
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Further to the next steps outlined above, Social Security Scotland will also undertake a full assessment of the impacts and corresponding actions required as part of their business planning and prioritisation process.

The Scottish Government is doing further research with Seldom Heard voices.

Blake Stevenson is doing a second wave of fieldwork with carers and care experienced groups. We will publish the findings in 2022. Participants are being recruited through national and local third sector organisations, including governing bodies and umbrella organisations for the sectors who work with carers and care experienced people.

## Annex A: Main challenges concerning specific sub-groups

All of the challenges and barriers reported above were experienced by all of the sub-groups in our study: young parents, care experienced people and kinship, foster carers and adoptive parents. Nevertheless some the challenges and barriers were more pertinent or were experienced more frequently for each of the sub-groups.

### Young parents

This sub-group reported general difficulties with accessing the benefits system.

#### Faced with confusion

Young parents reported facing confusion at the start of their benefit journey. They told us they lacked awareness of benefits and had limited knowledge of application processes.

**“Very hard to understand and follow everything [information] unless you understand what you’re looking for.”**

[Young parent respondent, online survey]

#### Inconsistent information and advice

The initial lack of awareness and knowledge was compounded by receiving inconsistent and, in many cases, contradictory information. A few reported getting misinformation from official sources. This manifested as being given information, and even payments, that they later found were incorrect. Overpayments could occur which caused financial difficulties when they have to be re-paid.

**“It’s like how am I supposed to know what I am getting? We were actually overpaid as well and we had to pay it back out of the next payments. But we didn’t know we were being overpaid... but then they [JCP staff] realised that actually, he’s [partner] a student and his income is from student loans, so they looked at it again and we had been overpaid... They really need to work on it for students. They really, really need to do that because like I was getting so much misinformation from different sources”.**

[Young parents, focus group]

## Lack of support

As well as this initial confusion and inconsistent advice young parents reported experiencing a lack of support when they reached out for help with benefits, despite asking repeatedly for help. They specifically mentioned this could be from Job Centre Plus staff and other official channels.

**“Like I can’t tell you how many times I have had to have an appointment and I have gone in [Job Centre] and they are like we don’t know why you are here, then I have gone away and then asked to come in again.”**

[Young parents, focus group]

## Care experienced people

This sub-group reported leaving care with no understanding of the benefit system or how it worked, and facing stigma and distrust when they applied for benefits.

## Lack of knowledge of the benefit system

Care leavers, particularly those leaving care aged 16, reported having minimal knowledge of, or experience, with the benefit system. They had no conception of what benefits were available or where they could get information on them.

**“I’m not sure if being homeless comes under the housing benefits... No, I haven’t [claimed housing benefits]...because I don’t have any understanding about it, I’ve never had my own house.” [Care experienced participant, focus group ]**

**“A lot of young people and care experienced young people don’t know which sites can tell you what your entitled too and therefore they never find out”.**

[Care experienced respondent, online survey]

A few stressed that their social workers had not provided them with information on benefits. And some only found out about benefits coincidentally during conversations with friends and relatives.

**“For the most part, you don’t know about these things, even when you need them. It’s usually afterwards, or at a point in time when someone else knows something about it. It’s not something that’s particularly common knowledge for the most part.” [Care experienced participant, focus group]**

Difficulties of not being eligible to benefits until they are 18 years old were also noted.

**“I can’t even claim anything when I’m near enough turned 18. I’m expected to pay my own way, but I’ve no idea how the Government is expecting people to do it...The system is set up in a way that as soon as you turn 16, you’re classed as an adult and you can’t claim any sort of benefit until you turn 18. So, what are you meant to do for those two years? I don’t understand what it is you’re meant to do. Are those two years meant to be a survival challenge?”**

[Care experienced participant, focus group]

### **Difficulties with application processes**

Care experienced people, as well as an initial lack of knowledge, found application processes difficult.

This sub-group found application forms challenging, PIP forms were frequently mentioned as the most difficult to complete, and a few indicated they had further difficulties because their specific individual circumstances. Some respondents and participants from this sub-group told us they relied on support from third sector organisations to complete forms.

**“The questions [were] quite difficult. I had to get support to fill in the PIP form and limited capability for work.”**

[Care experienced respondent, online survey]

**“Forms are really hard for me and especially because they are not designed for people with my type of difficulties”**

[Care experienced respondent, online survey]

Care experienced respondents and participants found the long-time between application and payment created financial difficulties. This was particularly when they did not have a support network to rely on when waiting for decisions and payments.

As a part of the application process, this sub-group found particular difficulties gathering together the evidence they needed to apply for benefits.



**“Providing the proof required can sometimes prove very difficult”.**

[Care experienced respondent, online survey]

**“...other hurdles would be access to information. For example, having your own birth certificate, or having some information from your doctor, stuff like that. It’s a lot of things you have to scrounge together. And a lot of people that move into flats or fall into homelessness don’t have a lot of those things, or access to a lot of those things easily. For example, if you lose your birth certificate, you can go to a Government building and pay about 60 quid for a new birth certificate... it’s kind of hard to come by if you don’t have an income.”**

[Care experienced participant, focus group]

### **Stigma and distrust**

Compounding the lack of knowledge and difficult application processes care experienced people reported being stressed, anxious, embarrassed by the attitudes of some staff working in the system. These attitudes frequently came from DWP and Job Centre Plus staff, respondents and participants reported that they experienced a lack of understanding or a lack of awareness of the specific circumstances faced by care experienced people. Many felt they lacked of empathy, a few experienced a wide-ranging negative culture within the benefit system toward people who rely on benefits.

**“I find the staff to be extremely short-tempered and obnoxious.”**

[Care experienced respondent, online survey]

**“Lack of empathy, understanding, knowledge.”**

[Care experienced respondent, online survey]

### **Kinship, foster carers and adoptive parents**

This sub-group suffered because of a lack of awareness of entitlement to benefits and grants for the children they cared for, confusion about whether they or the natural parents were entitled to benefits, and difficulties benefits for the disabled children they cared for.

### **Lack of awareness of benefit entitlement**

Kinship, foster carers and adoptive parents reported being unaware that they were entitled to benefits. They told us they frequently found out coincidentally when liaising with public sector workers, peer/service users or acquaintances. In some cases, specifically for Kinship Carer Allowance, respondents and participants did not claim for some time because they didn't know they were due a payment.

**“I never got any money for seven years because I didnae ken about it, it was somebody in the playground, another kinship carer, came up and said ‘you must be glad that the money’s gone up’, and I was like ‘what money? I dinnae get any money’...If someone hadn’t walked up to me, I would still be standing at the school gate, not knowing [about Kinship Carer Allowance]. It was another parent, another kinship carer that knew me, that came up and said. And if it wasn’t for her, I still wouldn’t have known.”**

[kinship/foster carers and adoptive parent, focus group]

### **Confusion about benefit entitlement**

In some cases, people reported to us that biological parents were still claiming benefits for the children that were now in their care. Often they were unsure who was entitled to the benefit and if it was them how they should go about getting it.

**“...his mum was still getting money and the social worker wanted it stopped and they said to me ‘you’ll need to apply for it’ and I said, she’s still getting it and they’re not going to pay [the] two of you. But they said, “she’s not entitled to that money, they’re not getting it.” Social work said, ‘you’re entitled to it, you’ve got the child’”.**

[kinship/foster carers and adoptive parent, focus group]

### **Access to official documents**

Collecting evidence for accessing some benefits acted as barrier for this sub-group, as official documents required for a claim could still be in the hands of biological parents or lost.

**I had to get the schools and nurseries to write letters as well to state the kids went to school and nursery for my Universal. I had to take in their birth certificates, which, I didn’t even have the girls’ birth certificates! Their mum**

**had them. So I had to then say to her, you need to give me the birth certificates, I need them. Otherwise I was going to have to pay to get them. And it was like three or four times I had to take all this paperwork in, just to justify-**

[kinship/foster carers and adoptive parent, focus group]

### **Difficulties with disability benefits**

Many kinship/foster carers and adoptive parents were looking after disabled children or a child with a long-term health condition. Once again there was a lack of awareness of the payments they were due, and some reported missing out.

Further, this sub-group experienced many problems with the application processes for PIP, DLA and Carers Allowance. Our participants and respondents found the application forms complex and assessments not able to take into account chronic and fluctuating illnesses. They also experienced an environment of distrust in assessments and appeals that left them with stress, anxiety and feelings of being undermined. One final issue was the frequency of reassessments, most especially when conditions were unlikely to change.

**“...my son has chronic long-term conditions. They’re not going to change. So, a two-year renewal process is just too short. I do get for some people, they might be in a short-term situation, but my son has complex needs and that’s not going to change... it’s the first time that I’ve claimed something- I found it really distressing and really, really challenging and I was quite shocked actually about how hard it is to get support.”**

[kinship/foster carers and adoptive parent, interview]

**“The other thing is when they sent you for medicals - the Department of Work and Pensions send you intermittently for medicals - I found that more stressful ... I think they should take time for the person to explain the actual situation they’re in, and all the knock-on effects that has on them.”**

[Kinship/foster carers and adoptive parent, interview]

A further issue for participants and respondents caring for a disabled child, was concern as they turned 16 years old because they had to move from DLA to PIP and a whole new application was needed.

## Single parents

Single parents suffered from misinformation and uncertainty, would not have been able to access their due without help and support, faced fear because of conditionality<sup>2</sup>, mental health difficulties because of stigma and financial difficulties because of benefit changes.

### Misinformation and uncertainty

Single parents experienced delays in payments that led to financial difficulties and a lack of certainty. They frequently reported that this stemmed from a lack of information or misinformation and guidance from DWP and Job Centre Plus staff.

**“When I knew I was moving over from income support to Universal Credit, in the run up, I was asking a lot of questions about it in the Job Centre, and every single time I was getting told ‘I don’t know, I don’t know, I don’t know’... that’s a huge uncertainty when people can’t even tell you what works.”**

[Single parent, focus group]

**“I’m back and forward to the Job Centre pretty regularly and I would assume that I’m being given all the information and all of the things that I’m supposed to have and that’s not information I got from them.”**

[Single parent, focus group]

### Need for support

Many single parents noted that third sector organisations were essential to them because of the lack of information and guidance from official channels. Information and active support was also accessed from support networks such as other service users, acquaintances and friends. Without this support, this group reported that they would not have known about eligibility and further, would not have attempted to apply by themselves.

**“I’m still getting the medical certificates because I’m still unable to work. I wasn’t told that I could be getting other things on top of this because of my mental health, and I’ve only been advised by the support worker here [third sector organisation] just now that there are other options out there that I**

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<sup>2</sup> Conditionality in this context refers to the link of accessing benefits/welfare rights/services and meet particular obligations (e.g. engage in job search activities). These conditional arrangements combine elements of sanction and support to have access/be eligible to certain benefits.

**could have been getting. They [DWP and JC staff] didn't tell me the options that they should have told me in the first place. It's their job to inform me that this is what I could have applied for."**

[Single parent, interview]

**"I didn't know what benefits I could apply for, see until I came to One Parent Families Scotland, I didn't know anything about any of the benefits I could apply for.... I've still got a long-term thing wrong with me and I dinnae know about even applying for PIP and [name of group member] told me to apply for it."**

[Single parent, focus group]

### **Conditionality and stigma**

Single parents were experiencing pressure because of having to look for work in order to access benefits, despite their all encompassing caring responsibilities. This conditionality, they reported was detrimental to their mental health, not least as they constantly felt under suspicion from the DWP and Job Centre Plus staff.

**"I'm sorry but I don't want to be claiming benefits, I don't want to be living on a certain amount a month, I really, really don't and I take no pride having to go sign in at the Job Centre, I feel they just must look at you and go 'come on get your act together'. I'm trying, I really am."**

**"I get embarrassed when I am walking into the Job Centre."**

[Single parents, focus group]

For many, experiences with the benefit system involved feelings of fear, embarrassment and stress. Attending the work-focused appointments and carrying out job-search activities were frequently dreaded. Some single parents complied to the conditions without questioning them out of fear of being sanctioned.

**"Nobody wants to be on benefits, we all want to work, but there's nobody to watch the wains...when you go in there [Job Centre], they think you don't want to work. That's not how it is, people just have different circumstances. The way they speak to you on the phone is atrocious. I know hundreds of different people are on benefits but going up to the Job Centre for me is a bundle of anxiety...And there's sanctions. Anything at all, then you're sanctioned. And the reason we're sanctioned is because we've got the wains. Even though we don't, because we've got all those commitments. If you miss**

**one hour of job searching, you're sanctioned for like 'you've done 34 hours searching but why haven't you done 36?', you're sanctioned."**

[Single parent, focus group]

A few mentioned that DWP and Job Centre Plus staff did not recognise the difficulties of being a sole carer, attending mandatory appointments and getting a paid job. Further, some highlighted that being unemployed was perceived negatively by the benefit system.

**"...one of my work coaches, he just didn't get it at all. It was a case of, 'you've been unemployed for twelve months, come on woman, you need to learn to juggle.' That was his words to me. He followed it on with 'me and my wife juggle, we work it out.' And I said, there you go, you and your wife. I'm on my own, I don't have anyone to juggle with. But that was the day I left in tears, because I thought he was going to sanction me. I was providing the proof, I was filling in the book, I was applying for anything that would be suitable in his eyes. I was applying for things I wasn't even qualified for so I had an extra thing that I could write in my book because it was the fear factor."**

[Single parents, focus group]

### **Financial hardship due to benefit changes**

Respondents and participants that had been transferred from Income Support or other benefits to Universal Credit and other benefit changes faced financial insecurity debt, rent arrears, a need to use foodbanks and get payday loans. The changes mentioned waiting times for the first UC payment, the benefit cap and the 'bedroom tax'. These difficult economic circumstances had also an impact in their mental health for a few.

**"I applied for Universal Credit from ESA last year. It was a nightmare. Just getting paid, the time it took. There was no money available until six weeks or so after my claim. The only support I had was the foodbanks...They give you a loan [advance payment], because they know how your rent arrears will clock up in that space of time while you're waiting for the money to get sorted. So they gave me a loan, and that loan had to be paid back every month at so much per month as well as deductions from Universal Credit as well, which left me just as bad as what it was before I started claiming in the first place. So it was a bit of a rigmarole."**

[single parent, interview]

## **Annex B: List of abbreviations**

List of Commonly used abbreviations in this report

BSG: Best Start Grants

CB: Child Benefit

CTC: Child Tax Credit

ESA: Employment and Support Allowance

DLA: Disability Living Allowance

DWP: Department for Work and Pensions

HB: Housing Benefit

JCP: Job Centre Plus

JSA: Job Seekers Allowance

KCA: Kinship Carer Allowance

PC: Pension Credit

PIP: Personal Independence Payment

UC: Universal Credit

## How to access background or source data

The data collected for this social research publication:

- Are available in more detail through Scottish Neighbourhood Statistics
- May be made available on request, subject to consideration of legal and ethical factors. Please contact [socialsecurityexperience@gov.scot](mailto:socialsecurityexperience@gov.scot) 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](http://www.gov.scot).  
ISBN: 978-1-80201-718-2

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

Produced for  
the Scottish Government  
by APS Group Scotland  
PPDAS985726 (12/21)  
Published by  
the Scottish Government,  
December 2021



Social Research series  
ISSN 2045-6964  
ISBN 978-1-80201-718-2

Web Publication  
[www.gov.scot/socialresearch](http://www.gov.scot/socialresearch)

PPDAS985726 (12/21)