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Social Security Experience Panels: Appointees



EQUALITY, POVERTY AND SOCIAL SECURITY



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Introduction

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

The Scottish Government is working with Experience Panel members to design a new social security system that works for the people of Scotland. From 24 June to 12 July 2020 Scottish Government researchers conducted a survey to help design the new appointee system for Social Security Scotland. This report outlines the findings from this survey. All quotes are from panel members taken from the survey responses.

The survey asked about people's experience of the appointees system in place in the current benefits system. It also asked about how the new process for having an appointee should work in Scotland, including in what circumstances someone might want to choose to have an appointee act on their behalf.

Summary

The first part of this survey looked at respondent's previous experience of acting as an appointee. Almost a third (31 per cent) of respondents had experience of being an appointee, either currently or in the past. Most of these were an appointee for either their child or another family member. Respondents described a range of disabilities and long term health conditions that had caused the requirement for an appointee, including learning disabilities, neurological conditions, mental health conditions, terminal illness or old age.

Almost two in five (38 per cent) said they had experience of a third party acting on their behalf, and more than one in ten had experience of an advocate acting on their behalf. Overall, most respondents said that the person or organisation helping them were able to help with some or all of the areas that they needed support with. However, respondents highlighted limitations in terms of the support available to them, either due to resource limitations or due to restrictions in what the DWP would allow. This was a

particular issue around the assessment and appeals processes where some felt that the person there to support them was unable to speak up for them or in support of them.

In the second part of the survey, respondents were asked about whether they would ever choose to become an appointee, or have an appointee act on their behalf. For these questions respondents were asked to answer in the context of someone who was not deemed to be lacking in capacity, but who would choose to have an appointee for another reason. Half (51 per cent) said that they might choose to become an appointee for a client of Social Security Scotland. The situations in which they would consider doing so included for a close friend or family member, particularly if that person became very ill or was struggling to cope with the benefit processes. Many also specifically mentioned they would choose to act as an appointee for an elderly parent or their child.

A number of respondents said they would want to be able to help if someone were unable to act for themselves. Some of the circumstances described may constitute situations where the adult in question were not deemed to be lacking in capacity, but where they were still struggling to cope with the benefits system. Examples of where this may be relevant included a range of disabilities or long term health conditions, challenges with communication or numerical skills, challenges with planning or organisational skills, challenges with technology, or difficult personal circumstances.

Seven in ten (71 per cent) respondents said that in the right circumstances they might choose to have an appointee act for them. Many said that they may choose this if their existing conditions progressed. In particular mental health conditions, conditions which impact memory or cognitive function, some physical conditions, fatigue, and conditions that impact their ability to complete paperwork. Some also said that navigating the current DWP benefits system can have a negative impact on their health condition due to the stress it can provoke. Others said that there may be difficult circumstances where they would want an appointee to act for them, such as worsening illness, hospital admission, or a traumatic life event.

Most (93 per cent) respondents who said they might choose to have an appointee act for them said that they would want the appointee to apply for a benefit for them. Two thirds (66 per cent) said they would want the appointee to receive all communications from Social Security Scotland on their behalf.

Fewer respondents said they would want the appointee to make decisions about their benefits (39 per cent) or receive the benefit payment (20 per cent). Some respondents were clear that they would still want to retain some control if they had an appointee.

More than two in five (44 per cent) respondents who said they might choose to have an appointee act for them said that they would want their partner or spouse to act as their appointee. More than half said “another close family member”.

Respondents were asked how Social Security Scotland should check if someone is suitable to be an appointee. If respondents said that they would never choose to have an appointee they were given the option to opt out of these questions, however most respondents opted to answer them. Just over seven in ten (71 per cent) said that there should be background checks and almost six in ten said that Social Security Scotland should visit them face to face. Many respondents felt that protecting the interests of the client should be the priority and highlighted that clients could be vulnerable to exploitation, coercion or abuse. Others felt that the process should be made as simple as possible for clients and appointees and that the level of checks required should depend on the circumstances.

Respondents were asked how frequently an appointee arrangement should be reviewed. Just over three in five (62 per cent) said that checks should happen when the client or appointee requests it. More than half felt that checks should happen if someone else asks Social Security Scotland to do so or raises a concern (56 per cent) or when the client’s benefits are changed or reviewed (54 per cent). Views on the frequency of reviews varied from those who felt that the burden on clients should be minimised by only reviewing if there is a concern, to those who felt more regular checks would be necessary to safeguard clients.

Respondents were asked how Social Security Scotland should review an appointee arrangement. Two thirds (67 per cent) said there should be a face to face conversation. More than half (52 per cent) said that a form should be submitted online or by email. When asked what should be looked at, most respondents were in favour of a broad range of questions being considered, relating to the client and appointee’s wishes, the appointee’s management of the role, and any changes of circumstances.

Overall, many respondents were very supportive of the proposal to offer the option for someone to choose have an appointee where they are deemed to have the capacity to make decisions. People felt that this would be valuable in a range of circumstances where someone was struggling to cope with the benefits process including a disability, ill health or difficult personal circumstances. Safeguarding the interests of clients was consistently highlighted as a priority, and some felt that consideration should be given for how to support clients who might feel they require an appointee but who do not have a close friend or family member in a position to support them. Others suggested that there should be guidance about the role of an appointee, and on what support might be available to them.

Background and Research Methods

About the appointee process and the proposals discussed in this research

An appointee is a person or organisation given the power by a social security agency to act on another person's behalf in all interactions with the agency. This includes a benefit application, communication with the agency, and receipt of payments. They are also responsible for reporting any changes of circumstances to the agency.

Under the current DWP benefits system an appointee is only put in place for adults who are regarded as lacking capacity to make decisions, or for children. This would usually only happen for an adult where nobody else already has the legal power to act for them, and would always be in place for a child.

In the Scottish social security system adults deemed to be lacking capacity will still be able to have an appointee. Children will also be able to have an appointee if no one who lives with them is already legally able to act on their behalf.

If they want to, appointees already in place under the current DWP system will remain in place as a client's benefit is transferred to Social Security Scotland.

In this survey, participants were asked if there were situations where they would want to be able to choose to have an appointee act for them, even if they didn't fall into the categories described above.

Annex A provides a copy of information given to survey participants to help them to better understand what is meant by an “appointee” and how the appointees process differs from other support available to clients when accessing benefits.

About the research

This report outlines the findings from a survey that took place in June to July 2020 with Experience Panel members to help design the system for appointees within Social Security Scotland.

This survey was sent out to all Experience Panel members who had given consent to be contacted by email. This was due to restrictions in place due to the Coronavirus (COVID-19) pandemic during the timeframe when the research was needed. During the Coronavirus (COVID-19) ‘lockdown’ staff working on the Experience Panels were unable to enter Scottish Government buildings to manage the usual alternative option of receiving surveys by post. It also took a number of weeks before infrastructure was in place to allow the Experience Panels helpline to operate with staff working from home. This survey could therefore only be completed online.

Participation in Experience Panels research is optional, and in this case 259 of the 1969 people invited chose to respond to the survey. This was a response rate of 13 per cent. The survey was written in straightforward language to ensure it was clear what was being asked. This survey combined closed ended and open ended questions to allow panel members to express their views in full.

Within the survey, respondents were asked about:

- Their previous experience of the appointee process in the existing benefits system.
- How the appointees process should work under Social Security Scotland.
- In what circumstances they may choose to have an appointee act on their behalf.

The Social Security Experience Panels are made up of volunteers from the Scottish population who have experience of at least one of the benefits that are coming to Scotland. The results of this work should be regarded as being reflective of the experience and views of the participants only, and are not

indicative of a wider population. Percentages are given only to provide a broad sense of the balance of opinion across participants.

About the participants

Information from the survey was added to information from the '*About Your Benefits and You*'¹ and '*Social Security Experience Panels: Who is in the panels and their experiences so far*'² surveys. The demographic data collected in these surveys was linked to the information supplied previously by participants.

However, linking was not possible where there was missing or unclear information. 202 respondents' data were linked to demographic information supplied previously.

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

Around 66 per cent of respondents whose data we could link identified as a 'woman or girl' and almost a third as a 'man or boy'. Half (50 per cent) were aged between 45-59 years old. Almost a third (32 per cent) were aged 60-79, and one in six (16 per cent) were aged 25-44.

87 per cent had a disability or long term health condition lasting 3 months or longer and 55 per cent had experience of being a carer. 45 per cent of respondents had experience of Carer's Allowance, 61 per cent had experience of Disability Living Allowance and 73 per cent had experience of Personal Independence Payment.

Almost eight in ten (78 per cent) respondents whose data we could link live in an urban area, and just over one in five (22 per cent) in a rural area.³

¹ Scottish Government (2017). *Social Security Experience Panels: About Your Benefits and You – Quantitative Research Findings*. [Online] Available at: www.gov.scot/Publications/2017/11/7769/

² Scottish Government (2018). *Social Security Experience Panels: Who is in the panels and their experiences so far*. [Online] Available at: www.gov.scot/Publications/2018/10/3083/

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

Experience of the current appointee system

The first part of the survey looked at respondents' previous experience of acting as an appointee. 31 per cent of respondents had experience of being an appointee, either currently or in the past.

Table 1: Experience of being an appointee for someone in their receipt of benefits (259)

Response options (select one)	%
Currently an appointee	22
Have been an appointee in the past	9
Never been an appointee	67
Prefer not to say	2

Among those who said they had experience of being an appointee, four in ten (41 per cent) said that they were an appointee for their child, and a third (34 per cent) were an appointee for "another family member" (other than those listed in table 2).

Table 2: Who respondents were appointees for (n=80)

Response options (select one)	%
My child	41%
Another family member	34%
A spouse or partner	15%
A friend	5%
A client/ I was an appointee in a professional capacity	3%
Someone else	2%

Respondents said that they acted as appointees to support a disabled child, an adult family member, or another adult who lacks capacity to manage their benefits. Respondents described a range of disabilities and long term health

conditions that had caused the requirement for an appointee. These include learning disabilities, a range of neurological conditions, mental health conditions, terminal illnesses and the effects of old age. Dementia was frequently cited as a reason.

“Mum had dementia [...] so when we claimed AA for her [...] it was actually a helpful DWP officer who suggested it would be more appropriate to start off the new claim as appointee rather than have to switch later on - good advice!”

Respondents were asked whether they had past experience of someone acting on their behalf. Almost two in five (38 per cent) respondents said that they had experience of a third party acting on their behalf. More than one in ten (12 per cent) said that they had experience of an advocate acting on their behalf.

Table 3: Experience of someone acting on their behalf when accessing benefits (n=255)

Response options (select all that apply)	%
A third party	38%
An advocate	12%
An appointee	5%
A Power of Attorney	1%

Overall, most respondents felt that the person or organisation who acted on their behalf were able to help with some or all of the areas they needed support with.

A number of respondents highlighted limitations in what the person or organisation were able to do for them, either due to resource limitations, or due to restrictions in what DWP would allow. In particular this was highlighted as being an issue around assessments and the appeals process. Others suggested that it was difficult to put in place arrangements with DWP for someone to act on their behalf with regard to their benefits.

“They were told they could not act or speak on my behalf.”

“I would have liked to have someone I could talk things through with rather than just someone who did things on my behalf. I did not "lack capacity" in the normal understanding of that term...but I lacked the emotional energy to deal with any of the process/system and the lack of income.”

“As third party it was difficult getting permissions. Much easier as appointee. Great system.”

A small number of respondents described incidents where they felt they had been misrepresented by an organisation or legal representative who they had trusted to act for them, and felt that they had lost benefits that they should have been entitled to because of this.

Some respondents also said that setting up an appointee arrangement had been difficult.

“It was difficult to actually access benefits initially, particularly via telephone. Felt I had to jump through hoops just to be able to access things for the family member I was helping (took 5 weeks to be sent a form) I believe this was to ‘stall’ the process.”

Among those who had an advocate or third party act of their behalf (not as an appointee), responses were very mixed as to whether the person or organisation was able to do everything they needed help with. The experiences described ranged from having someone checking over a completed application, through to being supported or guided through the whole application, assessment and appeals process. Many highlighted positive experiences of this.

“They were able to explain, support and guide me through the necessary benefits and paperwork/forms when I was not in a position to do so myself.”

“They sorted matters out & helped me understand. They managed better than I ever would have to get matters sorted.”

However, a number of respondents highlighted limitations in organisational capacity or an individual staff member’s ability to help.

“In most instances whoever I have asked to help has been able to support me. I’ve either had to write giving permission or give verbal consent. When I have not been able to do this they have been able to get very little help from DWP.”

Some said that the fact that the person or organisation was unable to speak for them was a barrier to getting the support they felt they needed. In particular, people said that the person there to support them at tribunal stage had not spoken up for them, or in support of them.

“They were unable to speak up for me or interject and query decision making.”

The need for appointees

Becoming an appointee for someone else

Survey respondents were asked to think about people who are capable of acting, but who due to difficult circumstances would wish for an appointee to act on their behalf.

Table 4: Whether respondents might ever choose to become an appointee for a client of Social Security Scotland who is capable of acting (n=257)

Response options (select one)	%
Yes	51%
No	25%
Unsure	24%

Respondents who said they might choose to become an appointee for someone who was capable of acting were asked in what situations they would ever choose to do so.

Many respondents said that they would consider doing this for a close friend or family member, particularly in situations where this person became very ill, or was struggling to cope with the benefit process. A number of people said that they would take on this role for an elderly parent, or for their spouse, while others said that they would (or already do) act on behalf of their child.

“If my mother or father begin to lose the ability to have independent living and require a formal representative to act on their behalf”

Some respondents said they would want to be able to help if someone was unable to act for themselves. It was unclear whether they felt that these circumstances would be covered by the existing appointee process which puts an appointee in place for an adult if they are deemed to be lacking capacity.

However, a number of examples were provided which may constitute situations where an adult may be considered to have capacity, but who would still struggle to navigate the benefits system.

Examples given included some learning disabilities, mental health conditions, conditions which impact on communication or numerical skills, and conditions which impact on organisational or planning skills. Other circumstances given included someone who struggles to use technology, if someone didn't speak English, or if someone was going through a difficult personal time.

“Maybe due to inability to communicate by phone or in person. Where the person would not manage their benefits effectively and spend it on special interests”

“In the case of someone who quite aware of what is happening and could make decisions, but is:

- a) afraid to act on their own,
- b) has a seeing or communication difficulty,
- c) a family member who is aged,
- d) confused by officialdom and 'jargon',
- e) someone who asks for control to be delegated for any other reasons.”

A number of respondents highlighted particular health conditions where someone may find it helpful to have an appointee act for them. This included autism, dyslexia and other neuro-diverse conditions, mental health conditions, stroke, Parkinson's Disease, dementia, degenerative conditions and terminal illness.

“If someone I know needs help and perhaps was suffering mental health problems like myself. Claiming benefits when suffering mental health problems was really not helpful when I was at my most ill.”

A number of respondents simply said that they would be happy to act as an appointee if asked, or if asked by someone close to them. Whilst others said they would only want to take on this role if there was no-one else in a position to help. A number of people said it would depend on their own ability or capacity to help, for example if their own health condition was stable.

“Short-term, very specific issues if the person I am closest to were unwell and couldn't manage the process. Even in this type of situation, I would need to consider what I myself could manage, as it may be better to help the person think through the issues but to involve someone else to act as an appointee.”

Choosing to have an appointee act for you

Respondents were asked about whether, and in what circumstances they might choose to have an appointee act for them. 71 per cent of respondents said that they might choose to have an appointee.

Table 5: Might respondents ever choose to have an appointee (n=257)

Response options (select one)	%
Yes	71%
No	29%

Many respondents described having existing conditions that are progressive or degenerative. They felt that as their condition progresses they may want to have the option to have an appointee act on their behalf. Conditions which can affect memory or cognitive function were frequently mentioned, as were mental health conditions and some physical conditions – particularly those which impacted on their ability to manage application forms or paperwork. This included conditions which affect eyesight, dexterity, chronic pain or induce fatigue.

“My own health has been deteriorating for the last decade and I can imagine that in another decade I may not be able to do what I am doing now. I would ask for help if help was needed. I think it is important that people feel they can ask for this and it not be either an embarrassment or an inconvenience.”

“If I felt unable to look after my own affairs but still met the criteria for capacity. I would like to have the choice to allow me to opt to use an appointee. This could be a long or short term arrangement depending on circumstances.”

A number of respondents felt that their condition was already at a stage where having an appointee would be valuable.

“If I was feeling 'extra' unwell (or even 'ok'), I would dearly like to hand responsibility over to someone else to complete as much of the process as possible without my input. After more than 25 years of having a progressive condition, the benefits claiming process is seriously detrimental to my health - both mental and physical.”

A number of respondents described how dealing with the current DWP benefits system can have a negative impact on their health condition due to

the stress of navigating the system, and felt that they may at times want an appointee to act on their behalf to mitigate this. Others spoke about not having the “emotional energy” to deal with the benefits system, or described struggling to “cope” or navigate the process.

“At times of illness where I am exceptionally anxious and dealing with social security agencies would severely impact my health and well-being.”

“Where people are struggling with medicals and having their appeals turned down when they are clearly ill [...] generally helping people to know what they are entitled to”

Respondents also described a number of difficult circumstances in which they may want an appointee to act for them. These included a traumatic life event, times of extreme stress, an illness (such as a worsening of a mental health condition), a bereavement, or a hospital admission.

Responsibilities of an appointee

Survey participants who said they might choose to have an appointee act for them were asked what they would want an appointee to do for them. More than nine in ten (93 per cent) said that they would want an appointee to apply for a benefit for them. Two thirds (66 per cent) said that they would want the appointee to receive all communications from Social Security Scotland on their behalf.

Table 6: What respondents would you want the appointee to do for them (n=181)

Response options (select all that apply)	%
Apply for a benefit	93%
Receive all communications from Social Security Scotland	66%
Make decisions about your benefit	39%
Something else	23%
Receive the benefit payment	20%

Among respondents who said that they would want the appointee to do “something else” for them, many said they would want help accessing information to help them to make decisions or for the appointee to help them to understand what’s happening with their benefits and give guidance. They

also said they would want an appointee to assist with benefits paperwork and keep records for them.

Others said they would want an appointee to assist them with, or accompany them to assessments, or act on their behalf at tribunal.

Some respondents were clear that they would still want to retain some control if they had an appointee, and would not want that person to “take over”. They would want the appointee to help them to come to their own decisions, rather than the appointee making decisions unilaterally.

“Consult with me about my benefits, then pursue a course of action that has the best possible outcome for me.”

Who should be the appointee

More than two in five (44 per cent) respondents said that they would want their partner or spouse to act as their appointee. More than half (54 per cent) said “another close family member”.

Table 7: Who respondents would want to act as an appointee for them (n=180)

Response options (select all that apply)	%
Another close family member	54%
My partner/ spouse	44%
A paid professional	38%
A friend	20%
Someone else	14%

Among those who said “someone else” many listed a voluntary organisation such as Citizen’s Advice Scotland, or professional such as a healthcare worker. Some also suggested someone in a position of authority such as a union worker or their MP. Others said that it would need to be someone who they could trust or who knew about their needs or health condition.

Setting up an appointeeship

Respondents were asked about the process for setting up an appointee. If they did not think they would ever choose to have an appointee they were given the option to skip this set of questions. Responses to this question were mixed. Just over three in ten (31 per cent) said they would want a member of staff from Social Security Scotland to visit them at home, and just over a quarter (26 per cent) saying they would want the appointee to contact Social Security Scotland for them.

Table 8: How respondents would want to nominate an appointee (n=250)

Response options (select one)	%
I would want a member of staff from Social Security Scotland to visit	31%
I would want my appointee to contact Social Security Scotland for me	26%
By phoning Social Security Scotland	18%
By writing to Social Security Scotland	10%
I would want to visit Social Security Scotland's local office	2%
Another way	13%

Among those who said that they would want to appoint an appointee “another way”, responses included a visit at home with the appointee present, by email or online, or by completing a form or writing to Social Security Scotland. Some suggested that written confirmation should be provided to both the appointee and the client, and some suggested that proof of identification should be required.

The survey explained to respondents that Social Security Scotland has a duty of care to clients, and that it needs to make sure that clients are not exploited if someone is appointed to act for them. It also needs to keep processes as simple as possible and not put in place any unnecessary burden on clients, particularly if they might be going through a difficult time. With this context, survey respondents were asked how Social Security Scotland should check if someone is suitable to be an appointee.

Just over seven in ten (71 per cent) said that there should be background checks and almost six in ten said that Social Security Scotland should visit them face to face.

Table 9: How Social Security Scotland should check if someone is suitable to be an appointee (n=248)

Response options (select all that apply)	%
There should be background checks	71%
Social Security Scotland should visit them face to face	59%
The appointee should have to provide a reference	46%
Social Security Scotland should speak to them over the phone	25%
None of the above/ in another way	22%

Those who said that Social Security Scotland should use another way of checking whether someone is suitable to be an appointee suggested a statement from the client about why they chose the appointee, a written plan for how the appointee arrangement should work, by talking to the client, or by using video chat with both parties. Others suggested there should be robust checks in place including background checks, or that there should be legal documents in place such as a PVG check, or a Power of Attorney. However, it is worth noting that if a Power of Attorney were in place, the client would not also require an appointee arrangement in order for that individual to act on their behalf.

When asked to explain their answer, many respondents felt that protecting the interests of the client should be the priority, with some highlighting that a client may be vulnerable to exploitation, coercion or abuse. Some respondents felt that the checks in place should depend on the circumstances of the individual client and appointee, or their relationship. For example, some felt that if the appointee were a close family member, or if they were well known to the client, then a background check should not be necessary, but they would expect this to be in place for a professional or a volunteer if they were to act in this capacity.

“I think if someone was an MP or a professional, references and background checks would be sufficient. If it was a friend, I would expect there to be a face to face meeting (with me too).”

“If it's a parent or spouse I don't think it's necessary to check as the person knows them well but if it's another family member or a friend the background may need to be established as some people may befriend others to deliberately take advantage of them”

Others felt that background checks should always be in place to safeguard vulnerable clients.

“As that individual will be taking on a role that is for the safety and health of that person and will deal with personal issues the person must be checked that they have not got a criminal record.”

In describing the background checks they felt should be in place, a number of different types of checks were cited. These included police or criminal record checks (such as PVG), financial background checks (for example for debt or past evidence of fraud or financial crime) and checking the domestic abuse register.

Many respondents were in favour of face to face interviews as a means to assess the suitability of an appointee. They felt that this would help to ensure that the appointee was acting in the best interests of the client, was able to do the role, and would allow Social Security Scotland to make sure that the client was not being coerced into making the appointment. Others felt these conversations should be able to be done remotely, for example using video conferencing, or over the phone.

“A face to face interview for appointee action is the safest way to ensure that both the appointee and benefit claimant are protected and the full role of the appointee is explained in detail”

A number of respondents felt that all possible checks should be in place to protect the client – including interviews, references and background checks. However, some respondents felt that the priority should be minimising the burden or stress felt by clients. Some pointed out that a face-to-face conversation could be very difficult for some clients.

“My brother wanted me to be appointee which currently is a long drawn out process where someone has to visit and decide if the person has capacity or not. For my brother this process was extremely daunting as part of his

disability is being unable to communicate with strangers. This left him very anxious in the build-up. I think it would be easier to reach a decision without having to meet face to face and safeguarding can be put in place by doing background checks and seeking written permissions.”

A number of respondents felt that the client’s decision to appoint should be viewed as enough, without further checks being necessary.

“The appointee is of greatest import to the applicant. They hold safety, reassurance and often mean a great deal to the person applying. Their very selection by the applicant and contact details ought to suffice when complete strangers wield life changing circumstances at their whim and will.”

“If I was to ask someone to act as an appointee for myself I would be mortified if you then asked that person to prove something. How could I ask someone for help if it was to be an inquisition into their life to help me?”

Reviewing an appointeeship

How often should appointee arrangements be reviewed

Respondents were asked how frequently an appointee arrangement should be reviewed, and could select multiple options. Just over three in five (62 per cent) said that checks should happen when the client or appointee requests it. More than half felt that checks should happen if someone else asks Social Security Scotland to do so or raises a concern (56 per cent) or when the client’s benefits are changed or reviewed (54 per cent).

Table 10: How often Social Security Scotland should check both clients and appointees are happy to continue (n=250)

Response options (select all that apply)	%
When the client or appointee requests it	62%
If someone else asks Social Security Scotland to do so or raises a concern	56%
When the client’s benefits are changed or reviewed	54%
Every year	40%
Every two years	20%
Another time	6%

Suggestions for “another time” included more frequent checks such as every three or six months, and also others who felt it should be less frequent, such as every four years. Others suggested it should be reviewed when the client goes through a change in their health condition or circumstances.

When asked to explain their views on how often appointee arrangements should be reviewed, responses were varied and often polarised. There were those who felt there should only be a review if a concern was raised about the appointment, whilst others argued that regular reviews, annually or even more regularly, were critical to safeguard clients.

Among those who argued for less frequent reviews, respondents felt that the burden placed on clients and appointees through review processes should be minimised, that there is already “enough paper work” and minimise “unnecessary stress”.

“No need to keep on checking up if people are happy with the arrangement.”

“Dealing with disabilities is tiring and stressful. It's important to have checks in place but these need to be at a level which doesn't become a burden.”

Many argued that rather than fixed timescales for reviews, this should be dependent on the needs of the client. For example, a client may wish to specify how long they wish the appointee arrangement to last, or it might make sense for an appointee arrangement to last for the duration of a benefit award. Some felt individual circumstances should be considered – for example it could be very disruptive for a review to happen in the middle of a redetermination or appeal process.

“A periodic check is sensible. However, the frequency should be determined partly by the turnaround of decisions. It would be unhelpful to bring about an end to an appointee role in the middle of an unresolved issue, only to have to take action to reinstate the person.”

Many respondents were in favour of a regular review cycle, with most of these respondents supporting an annual review, and some supporting a two-yearly review. Many felt that this regular review should be supplemented by reviews being scheduled if any concerns are raised, or if there was a change of circumstances.

Respondents felt that regular reviews are important to make sure that any change of circumstances are picked up and to make sure that the client/appointee relationship is working well. They felt that this would also help to protect clients from exploitation, abuse or coercion.

“The relationship can legitimately change in time, so checking in on the status is of course important. However unnecessary contacts from authority cause panic and are intrusive. A simple question at the points described above would be adequate for all parties.”

“The situation should be constantly under review. An appointee is for exceptional circumstances. If it's a long-term situation, the appointee and client should have the chance to say they want to stop or are unhappy with the situation.”

Some pointed out that a client may not always be aware or able to say if they are being exploited or abused and that checks should take that into account.

“Safeguarding is the most important thing here, so checking whenever there is any sort of doubt raised, or change in benefits is essential, and not just a tick box, wrongdoing, or anything in doubt needs to be acted on immediately.”

How should Social Security Scotland review an appointee arrangement

Respondents were asked how Social Security Scotland should review an appointee arrangement. Two thirds (67 per cent) said there should be a face to face conversation. More than half (52 per cent) said that a form should be submitted online or by email.

Table 11: Methods Social Security Scotland should offer to check that clients and appointees are happy to continue (n=249)

Response options (select all that apply)	%
A face to face conversation	67%
A form submitted online or by email	52%
A phone conversation	43%

A form submitted by post	43%
Another way	7%

A number of those who said they would want checks to happen “another way” suggested video calls as an alternative way of have a face-to-face conversation with clients and appointees. Others emphasised the importance of giving options and prioritising the needs of the client and the appointee. Some suggested more detailed checks should be in place, such as speaking to social work, medical professionals, or other professionals involved with their case, checking how payments have been managed, or “spot checks” on how the arrangement is working.

What should be looked at as part of the review?

When asked what should be looked at as part of a review of an appointee arrangement, most respondents were in favour of a broad range of questions being considered, relating to the client’s and appointee’s wishes, the appointee’s management of the role, and any changes of circumstances.

Table 12: Areas that respondents felt should be looked at as part of a review of an appointee arrangement (n=248)

Response options (select all that apply)	%
Any changes to the client’s wishes	93%
Whether the client is happy with their level of involvement	86%
Any concerns about the appointee’s ability to do the role	86%
Any significant changes to the client’s health	84%
Whether the client is happy with how their case is being managed	82%
How the benefit payments are being managed	76%
Any changes to the appointee’s wishes	76%
Something else	9%

For those who said that “something else” should be looked at as part of the review, suggestions included whether the appointee has the ability or capacity to do the role and whether both parties are happy to continue. Others were concerned about having procedures in place to capture when things go wrong, including if the client incurs significant debt or if there are concerns about the

conduct of the appointee. Some felt that reviews should not add any stress or burden to the client.

Wider feedback and concerns

Many respondents were very supportive of the proposal to offer the option for someone to have an appointee where they have capacity to make their own decisions. They felt that this would offer flexibility and could be beneficial to people in a range of situations, such as a time of crisis, ill health or progression of an illness. Some felt that the current definition of “lacking capacity” is very strict, and that there are people who fall short of that definition but who struggle to cope with managing things like benefits applications, appeals, and even day to day finances. Others felt that all clients should be alerted to this option to avoid people struggling without support.

“It should not rely on legal lack of capacity on an ongoing basis but should be accessible to anyone going through a difficult time due to bereavement, mental health issues, physical illness”

“I wouldn't normally be considered to require an appointee but I would really like one. I think it would make things much less stressful for me.”

Some argued that thought should be given to the role that professionals and voluntary organisations could play in acting as appointees. In particular, for people who do not have a trusted friend or relative who could act for them.

“I think should be separate paid posts set up in these organisation that people turn to when need help, but so often have to wait considerable amount of time to get someone to help usually too late as form or dispute has to be done in a timeframe. So people who don't have a family/friend to take this on don't get left without.”

Some respondents felt strongly that there should be strict safeguards in place to protect vulnerable clients. Some suggested, for example, that spot checks should be made to make sure that the appointee is fulfilling their responsibilities appropriately. Others felt that payments should not be made into appointees' bank accounts.

“Both from professional and personal experience I think the appointees system is essential. However safeguards need to be in place; ideally the payments should always be made to the claimant.”

A number of respondents highlighted the need for clarity on the role of an appointee, and raised concerns about the burden placed upon appointees, especially if they are also the person's carer.

"I think the role of the appointee should be made very clear at every stage of the appointment process so that there is no doubt about their role and responsibilities."

"The level of support and work required of an appointee who is dealing with an ill family member is more than say a friend or an organisation. What I mean here is that someone with some emotional distance can deal with another level of paperwork pretty easily. Their capacity to understand the difficulties and nuances of another's life very limited. For the well being of the ill person you must have the well-being of the appointee."

Next Steps

The Scottish Government will continue to work with the Experience Panels in the development of Scotland's new social security system.

The content of this report will be used by the Scottish Government and Social Security Scotland to inform the development of guidance for appointees. It has provided insight into the circumstances clients think having an appointee would be helpful, the safeguards that should be put in place, including when and how appointeeships should be reviewed.

The insights in this report will also inform the legal framework required. This will be established in the Social Security Administration and Tribunal Membership (Scotland) Bill.

Annex A: Information provided to survey participants about the appointee process

About Appointees

What is an appointee?

An appointee is a person or organisation given the power by a social security agency like DWP or Social Security Scotland, to deal with a person's benefits for them.

An appointee has more power than a welfare rights representative or advocate. They can do all the things the person would normally do for themselves. An appointee not only helps the person to apply for a benefit, they act on their behalf and receive payments on their behalf. They are also responsible for reporting any changes of circumstances to the agency.

What is the current system for having an appointee?

Under the current DWP benefits system an appointee is only put in place for adults who are regarded as lacking capacity to make decisions, or for children. This would usually only happen where nobody else already has the legal power to act for them.

What is going to change in Scotland?

In the Scottish social security system adults lacking capacity will still be able to have an appointee. Children will also be able to have an appointee if there is no one who lives with them who is already legally able to act on their behalf.

If they want to, appointees already in place under the current DWP system will remain in place as a client's benefit is transferred to Social Security Scotland.

We would like to know if there are situations where you would want to be able to **choose** to have an appointee act for you, even if you don't fall into the categories described above. For example, this might be an option someone would want if they were going through difficult circumstances such as a serious illness.

We would like to know how you think this should work.

Some definitions:

There are lots of ways that someone can get help to access the benefits system. To help with the rest of this survey we have created a list of definitions of some of the main ways you might get help. This list was also attached to the email inviting you to take part.

Appointee: An appointee is a person or organisation given the power by DWP or Social Security Scotland, to deal with an individual's benefits for them. They will handle applications, decide where the benefit is paid to, and report changes of circumstances.

Advocate: A specially trained person who helps and supports a disabled person to express their views and wishes in the process of claiming benefits.

Attorney: A person or organisation that has been given legal authority by the individual to manage specific aspects of their affairs. This could include their finances and property, or other matters such as where they live or what medical treatment they get. One example is that someone might choose to put this in place at the early stages of a degenerative condition, if they are worried that they may lose the capacity to make decisions for themselves. Setting up a Power of Attorney requires a lawyer and you have to pay a registration fee.

Guardian: A person or organisation that has been granted specific powers by a court to act on behalf of an adult who is legally regarded as lacking capacity. This could include their finances and property, or other matters such as where they live or what medical treatment they get.

A Third Party: A third party could be a friend, family member, carer or an organisation providing support to you. They can help you to make an application. If you give consent they can then make enquires, receive information about your benefit and deal with any appeal. They cannot receive information instead of you, but they can receive the same information as you. They will not receive your benefit for you.

Third Sector Support Organisation: Third sector organisations can provide expert advice about your entitlement to benefits and will often provide representation at tribunal hearings. An organisation can act as a Third Party or as an Appointee, Attorney or Guardian if they have either been given consent by you, or legal powers to act for you.

Local Delivery: Social Security Scotland staff can provide one to one support, help people to understand what devolved benefits they are entitled to and help them to complete applications. Local delivery staff cannot act on your behalf or represent you.

Annex B: About the Participants

Information from the survey was added to information from the '*About Your Benefits and You*⁴' and '*Social Security Experience Panels: Who is in the panels and their experiences so far*⁵' surveys. The demographic data collected in these surveys was linked to the information supplied previously by participants as part of the longitudinal data set for this project. The following demographic information is given to give context to the findings from the survey.

Not all responses were linked in this way. Providing identifying information is optional in all of our surveys. So linking was not possible where there was missing or unclear information from the survey responses. It was also not possible where participants had not previously supplied us with the relevant demographic information. 202 respondents' data were linked to demographic information supplied previously.

Around two thirds of respondents whose data we could link identified as a 'woman or girl' (66 per cent) and a third (32 per cent) of participants identified as a 'man or boy'.

Table 1: Gender of survey respondents (n=202)

Gender	%
Woman or girl	66
Man or boy	32
Identify in another way	1

Half of respondents whose data we could link were aged between 45-59 (50 per cent).

⁴ Scottish Government (2017). *Social Security Experience Panels: About Your Benefits and You – Quantitative Research Findings*. [Online] Available at: www.gov.scot/Publications/2017/11/7769/

⁵ Scottish Government (2018). *Social Security Experience Panels: Who is in the panels and their experiences so far*. [Online] Available at: www.gov.scot/Publications/2018/10/3083/

Table 2: Age of survey respondents (n=201)

Age group	%
16-24	1
25-44	16
45-59	50
60-79	32

Almost nine in ten (87 per cent) respondents whose data we could link had a disability or long term health condition lasting 3 months or longer. Details of the types of condition are in Table 3 below.

Table 3: Disability or long term health condition experienced by respondents (n=202)

Disability or long term health condition (n=147)	%
Another long term condition	67%
Chronic pain lasting at least 3 months	57%
A physical disability	55%
A mental health condition	25%
Deafness or severe hearing impairment	9%
Blindness or severe vision impairment	6%
A learning disability	3%

More than half (55 per cent) respondents whose data we could link had experience of being a carer.

Table 4: Caring responsibility of respondents (n=202)

Caring responsibility	%
Carer for one or more children who are disabled or have a long term health condition	15%
Carer for one or more adults who are disabled or have a long term health condition	43%
Care for an adult due to older age	19%

Of the respondents whose data we could link, more than three quarters (78 per cent) live in urban areas⁶. Respondents took part from 30 of the 32 Local Authority areas.

Table 5: Location of respondent (n=199)

Location	%
Urban	78%
Rural	22%

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

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

Benefit experience	%
Personal Independence Payment	73%
Disability Living Allowance	61%
Carer’s Allowance	45%
Cold Weather Payment	35%
Winter Fuel Payment	35%
Attendance Allowance	20%
Severe Disablement Allowance	14%
Funeral Expense Assistance	8%

More detailed demographic information on the Experience Panels as a whole can be found in ‘*Social Security Experience Panels: Who is in the panels and their experiences so far*’⁷.

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

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

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



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