

Independent Review of Adult Disability Payment (ADP)

Analysis of responses to a public consultation and call for evidence

Final Report

November 2024

Contents

Executive Summary	1
1. Introduction	7
2. Take-up of Adult Disability Payment	13
3. Eligibility check.....	27
4. Pre-application support for Adult Disability Payment applications	33
5. Rules about who can get Adult Disability Payment.....	43
6. Fluctuating Conditions	61
7. Decision-making	67
8. Re-determinations.....	75
9. Review periods and indefinite awards	81
10. Processing times.....	88
11. Changes in people’s circumstances	93
12. Other considerations.....	98
13. Conclusion	101
Appendix A: Public Consultation Questions	103
Appendix B: Call for Evidence Questions	113
Appendix C: Summary of Engagement Events	117
Appendix D: Daily Living Activities.....	118

Executive Summary

Adult Disability Payment (ADP) was launched on 29 August 2022 and is one of fifteen payments that Social Security Scotland (SSS) delivers. Adult Disability Payment has replaced Personal Independence Payment (PIP) for disabled people of working age in Scotland. To understand people's experiences with Adult Disability Payment during the first year of delivery, the Scottish Government has commissioned an Independent Review of Adult Disability Payment, chaired by Edel Harris OBE, which began in February 2024.

The lived experiences of disabled people, people with a long-term health condition and people with a terminal illness will guide the review. There were three possible avenues for public participation: a consultation, a call for evidence and engagement events. In total, 84 consultation responses were received from 80 individuals and 4 organisations and 36 responses to the call for evidence were received from 29 organisations and seven individuals. The Independent Review organised nine engagement events across Scotland which were attended by 19 individuals and 28 organisation representatives¹.

Public consultation of this kind means anyone can express their views; individuals and organisations interested in the topic are more likely to respond than those without a direct or known interest. **This self-selection means the views of respondents do not necessarily represent the views of the entire population.**

Overview

A range of views were expressed in responses. Many gave positive feedback about Adult Disability Payment and Social Security Scotland, speaking highly of some staff interactions, describing feeling respected during the application process and welcoming the lack of medical assessments. However, respondents also suggested changes they felt would encourage more people to apply for Adult Disability Payment, improve the efficiency of the application process, ensure the breadth of conditions and impacts are considered in decision-making and ensure clients continue to be treated fairly. Key suggested improvements are highlighted in the following summary.

Awareness of ADP

There were concerns across all strands of engagement that awareness of Adult Disability Payment remains low. It was frequently suggested that Social Security Scotland publicise Adult Disability Payment through media channels and use more community networks, including GPs, community link workers, and social care workers, to help make people aware of their eligibility. A recurring suggestion was for greater acknowledgement of the key role of the third sector in providing information and individualised support to help people understand their eligibility and apply for Adult Disability Payment.

Reasons cited for the lack of uptake of Adult Disability Payment included a lack of awareness of eligibility, stigma around receiving disability benefits, previous negative experiences with Personal Independence Payment, and stress related to the application

¹ The events were held in Aberdeen, Cowdenbeath, Dundee, Edinburgh, Glasgow, Inverness, Perth, Stirling and one virtual event. A summary of the location and number of attendees at each event is provided in Appendix C.

process, particularly the length of the application form. Providing individualised support, an improved process, and ensuring fair treatment of applicants were highlighted as ways to encourage uptake.

Pre-application support

Respondents generally supported a more detailed eligibility check, suggesting it could save people the time and energy of applying if they knew they did not qualify. A few suggested that any eligibility checker must capture the full range of qualifying conditions to ensure people were not wrongly advised. However, some preferred the current approach as they felt sufficient information already existed to help people understand whether they are likely to be entitled. Criteria recommended for inclusion in an eligibility checker included the impact of disabilities or conditions on daily life, information about daily living and independent living, emotional wellbeing and cognitive state, assistance needed to complete tasks, and financial circumstances.

Clients reported mostly positive experiences with the Local Delivery Service (LDS) and Independent Advocacy Service. However, reported usage of both services was low with one in ten (11%)² using Local Delivery Service and fewer than one in ten (6%) using the Independent Advocacy Service. Many acknowledged that greater awareness of these services was needed. Recommended improvements to the services from both the consultation and call for evidence included improved staff training, better communication such as dedicated telephone lines, greater interaction with third-party organisations, and reassurance about the impartiality of the advice offered.

Accessibility was a recurring theme in all aspects of Adult Disability Payment processes. Calls were made to improve accessibility by considering the needs of people with different conditions, for example neurodiverse or visual impairments, and those in seldom-heard groups who may require translation or interpreter support.

Daily living activities and the ADP application form

Views on the clarity of the daily living part of the Adult Disability Payment application were mixed. One third (35%) agreed that the rules for the daily living part of Adult Disability Payment are easy to understand, 48% disagreed and 17% were unsure. Reasons for disagreeing included the use of unclear terminology and difficulties relating the activities to real life, fluctuating conditions or specific conditions like Long COVID, ME/CFS, autism spectrum disorder, or mental health conditions. Respondents recommended clarifying the rules and simplifying the language to make the daily living part easier to understand. Others suggested using more illustrations, while event participants emphasised the importance of accessible support for applicants.

The vast majority (87%) indicated that people with certain conditions might find it difficult to receive points for any one or more of the daily living activities. The most common view in comments was that people with certain conditions could struggle to be considered adequately under the existing daily living activities, including a belief that the current activities were too focussed on physical disabilities. Others thought their conditions were

² All percentages referenced in this executive summary are percentages of consultation respondents who answered the corresponding closed question. Full data is provided in the report.

too difficult to describe and felt they would struggle to highlight the impact of their conditions within the existing activities.

Respondents suggested making changes to the activities in the daily living component to ensure they: gather relevant information about a wider range of conditions, including those who currently feel they are not represented in the application process; consider the broader impacts of a condition on daily living; reflect people's lived experience of real-life scenarios; and reduce confusion around fluctuating conditions. There were also calls for greater transparency about the allocation of points across the activities.

Views about the clarity of the reliability criteria were also mixed. One third (33%) felt the reliability criteria are easy to understand, just under half (45%) felt they are not, and one quarter (23%) were unsure. Those who felt they could be clarified recommended that a 'reasonable time period' be better defined and proposed using more examples to improve applicants' understanding. Participants at the consultation events shared similar views but also suggested other changes to enhance understanding of the reliability criteria. This included referencing the reliability criteria in or at the start of the Adult Disability Payment application form and explaining reliability and the 50% rule on any initial communication.

Two thirds (68%) felt the daily living part of the Adult Disability Payment application is effective at helping Social Security Scotland understand a person's daily living needs; 11% felt it is 'very effective', 20% 'effective' and 37% 'somewhat effective'. The remaining third (32%) felt it was not effective. Among those who felt the form was somewhat or not effective, the most common theme in comments was that the daily living part of the application was overly rigid. Others felt that it did not reflect certain conditions or capture all relevant information or evidence. Similarly, event participants frequently described the application form as long, daunting, exhausting, and too difficult, and highlighted the need to consider the emotional impact on clients of completing a long and complex application. Frequently raised suggestions included reducing the complexity of the application process and considering whether shorter application forms, clearer questions and simpler language can be used, and providing more examples and case studies of how the rules apply in practice.

Fluctuating conditions

Seven in ten (70%) felt the daily living activities do not allow the impact of fluctuating conditions to be accounted for adequately. Both respondents and event participants suggested that people may find it hard to describe the impact of their fluctuating conditions, with the Adult Disability Payment application form viewed as being too rigid and inflexible, with little opportunity to describe nuance or the impact of multiple conditions.

Mixed views were expressed about the fluctuating conditions section of the Adult Disability Payment application form. Some consultation respondents found it confusing or felt it did not consider the impact of bad days on life and wellbeing. In contrast, some others commented that the section allowed them to adequately represent their conditions.

Respondents suggested changing the 50% rule, with suggested alternatives including a 30% rule or a sliding scale depending on the impact of fluctuating conditions on daily life. Considering the wider impacts of how completing a task can affect a person's life was also recommended as a change.

Decision-making and re-determinations

Three fifths (60%) felt the Adult Disability Payment decision-making process is effective in understanding a person's daily living needs, with some comments outlining positive experiences. However, 17% found it 'not very effective' and 24% 'not effective at all'. Reasons for this included that the process would benefit from a more qualitative and individually focused application form which more effectively captures details about a person's condition and lived experience. Others felt that their supporting information was ignored in the consideration of their application.

Another theme reiterated throughout the consultation and engagement events was that Social Security Scotland staff would benefit from more training to better understand certain conditions and the impact they have on people's lives, therefore ensuring effective decision-making and potentially reducing inconsistencies in decision-making.

Among the few respondents who had a consultation as part of the decision-making process, most had them on the telephone and typically indicated that the consultation happened at a time convenient for them. Few provided qualitative feedback about the consultations. Those who did said that they felt the practitioner was polite and clear in their intent. Suggested improvements provided by a few respondents included greater clarity that the consultation could be held in a way that best suits the person applying.

Four fifths (80%) of those who had received a decision understood it. In open comments, however, some described confusion about their award and the points they received, often reflecting disagreement with the decision. This was also reflected in the call for evidence, where respondents highlighted instances where decisions appeared to be inconsistent with supporting information. Calls for better and more personalised communication about decision-making was a key theme in both consultation and call for evidence responses. This included calls for clearer communication about how points had been allocated and decisions made, and information being delivered in a method that best suits the client, such as large font format.

One quarter (26%) had asked for a re-determination. Those who had provided feedback on what worked well, including the ability to submit personal statements and being able to provide supporting information in multiple formats. Others highlighted concerns about long timescales for a decision. Event participants had experienced stock phrases in re-determination decisions, expressing a concern that this indicated the decision-making or communication was not unique to each applicant. Others suggested that applicants be allowed to review their full application before a re-determination.

Call for evidence respondents noted that the re-determination process could be confusing for some. Some organisations highlighted that their clients were not well informed about the Adult Disability Payment process and were not aware that points could be removed during a re-determination process, for example. Others cited confusion about the process as a reason people did not seek re-determinations. Negative impacts on wellbeing and lengthy timescales were mentioned as other reasons clients may not seek re-determinations. Similar reasons were given for why clients may not seek an appeal.

Review periods and change of circumstances

Two fifths (65%) had experienced an Adult Disability Payment review. Those who had were positive about the lack of face-to-face assessments during a review and felt that communication leading up to a review was clear. However, reducing the waiting time to hear about review outcomes and more communication through text or email were mentioned as areas for improvement. Respondents typically favoured using longer review periods, suggesting these would reduce clients' stress and anxiety and provide greater financial stability. A few questioned why permanent or deteriorating conditions were still given review periods or called for greater use of indefinite awards for such conditions.

Fewer than one in ten (7%) had received an indefinite award. Those who had described positive improvements to their quality of life as a result. This included improved access to care, financial stability, and reduced stress about future Adult Disability Payment applications. These positive impacts were also reflected in call for evidence responses. However, call for evidence respondents requested clearer award and indefinite award letters, while a few consultation respondents noted the confusion they had experienced due to receiving their first payment before their award letter.

One third (32%) had reported a change of circumstance to Social Security Scotland. While two fifths (39%) of those who had felt they had been treated with dignity, fairness and respect, fewer than one in ten (8%) felt they had received regular updates. Only a few respondents provided further details about their experience. Some spoke highly of the assistance they received, although it was not always clear which organisation had provided the assistance. Shortening response times and better communication about the status of their change of circumstance were suggested as improvements. Other suggested improvements included clearer guidance on submitting a change of circumstance, providing more details about what needs to be included in the change of circumstance, and integrating all benefit systems to help those applying get the assistance they need with less paperwork.

Processing times

Three in ten (29%) received a decision about their application within three months, 42% between three and six months and it took six months or more for three in ten (30%). While consultation and call for evidence respondents emphasised that shortening processing times would improve applicants' experience, they also noted that better communication could alleviate some anxiety. Respondents suggested email or text updates or a dashboard for applicants to monitor the progress of their application or re-determination, as well as making it easier to contact Social Security Scotland for an update. Shorter processing times were also called for to minimise financial harm to clients.

Call for evidence respondents highlighted several groups who they felt were adversely affected by long processing times. These included people needing to access other disability benefits, such as a Blue Badge or a mobility device through the AVE scheme, carers who were struggling financially, those with mental health conditions, those with degenerative cognitive conditions and lone parents.

Next Steps

The responses to the consultation and call for evidence, and in particular the lived examples provided by individuals who receive Adult Disability Payment and those who have supported people to apply, will provide valuable and informative evidence for the Independent Review to draw on when considering its recommendations.

1. Introduction

Background

Adult Disability Payment (Adult Disability Payment) launched on 29 August 2022 and is one of fifteen payments that Social Security Scotland (Social Security Scotland) delivers. Adult Disability Payment has replaced Personal Independence Payment (Personal Independence Payment) for disabled people of working age in Scotland.

An [Independent Review of Adult Disability Payment](#), chaired by Edel Harris OBE, began in February 2024. The review will consider people's experiences of the first year of delivery of Adult Disability Payment, as well as the eligibility criteria. An advisory group of 10 members has been convened to provide guidance, expertise, and scrutiny to the Chair to ensure the effectiveness, fairness, and integrity of the review. The Advisory Group includes disabled people and people with experience of disability, and people who work for organisations that support disabled people.

The Scottish Government has asked the Independent Review to look at:

- The activities and descriptors that determine entitlement to Adult Disability Payment, including how these apply to disabled people with fluctuating conditions.
- People's experiences of applying for, receiving or challenging a decision about Adult Disability Payment or undergoing a review, including unsuccessful applicants.
- Consultations process and Adult Disability Payment-specific guidance for practitioners and decision-making guidance to ensure a rights-based model of social security is being applied.
- Considering initial priorities capable of early action that do not require changes to the application, decision-making or service delivery, where those changes offer value, are deliverable and useful regardless of any longer-term changes.

This consultation will be used to assist the Chair of the Independent Review make recommendations about Adult Disability Payment. The review will also consider the recent analysis of responses to the [consultation on the eligibility criteria for the mobility component of Adult Disability Payment](#), the work with [Social Security Experience Panel Members on the eligibility criteria for the mobility part](#), and the [evaluation of supporting information](#) which was undertaken by the Scottish Government as part of its disability benefits evaluation strategy.

An interim report identifying any initial priorities, which do not involve substantive changes to service design and are capable of early action, is planned for November 2024. A final report will be provided from the Independent Review to the Scottish Government by July 2025.

Overview of engagement activity

The Independent Review aimed to take an inclusive and transparent approach to engaging with disabled people and stakeholders. This report combines responses and evidence gathered across three strands of engagement which ran from 28 June to 30

August 2024; a public consultation, a call for evidence and stakeholder engagement events. Details of each of these elements are provided below.

Public consultation

The [public consultation](#) was mainly meant for people with lived and living experience of accessing – or trying to access – Adult Disability Payment. The consultation contained 46 open and 40 closed questions which sought respondents' views on 12 aspects of Adult Disability Payment. Given the availability of existing evidence noted above, the consultation (and call for evidence) did not cover the mobility component of Adult Disability Payment or the gathering of supporting information to support an application. A full list of consultation questions is provided in Appendix A.

In total, 84 consultation responses were received from 80 individuals and four organisations. These individuals typically left shorter responses to questions relevant to their own personal experiences, suggesting how it could have been improved.

Call for Evidence

The [call for evidence](#) was primarily intended for organisations, and included 21 open questions which aimed to gather data and evidence to inform the Review's recommendations. It provided an opportunity for all interested parties to provide specific feedback in relation to the areas identified in the Review's Terms of Reference as being a focus for the Review. The call for evidence did not ask questions about the eligibility criteria or fluctuating conditions for Adult Disability Payment, but these were included in the consultation and events. A full list of the call for evidence questions is provided in Appendix B.

A total of 36 responses were received from 29 organisations and seven individuals. These respondents typically left longer, detailed responses, outlining their perspectives on the first year of Adult Disability Payment. The call for evidence paper noted that evidence cited in responses need not be limited to evidence published academically. Given this, responses highlighted a range of evidence, including ongoing research studies and internal organisation data about different stages of the Adult Disability Payment application and decision-making process. In many cases, organisations had collected feedback from their own stakeholders. As well as a few instances of survey data, some organisations used quotes and case studies to evidence the points raised in their responses and to illustrate the lived experience of the individuals they support.

Stakeholder engagement events

The Independent Review organised nine engagement events with stakeholders to provide a more accessible opportunity for people to contribute. Following a short introduction by the Independent Review's Secretariat, these events were independently facilitated by The Lines Between. The events were structured around key stages of applying for Adult Disability Payment: awareness of Adult Disability Payment and pre-application support; the eligibility criteria; asking about daily living needs; and getting a decision. While questions were asked about these areas, the events were open forum to allow participants to expand on their areas of interest.

In total 47 people attended eight in-person events across Scotland and one online event. This comprised 19 individuals and 28 organisation representatives. A summary of the location and number of attendees at each event is provided in Appendix C.

Consultation and Call for Evidence respondent profile

In total, 120 responses were received from 117 unique respondents³. Almost all were submitted via the online consultation platform, Citizen Space. Those received in an alternative format, for example, an email or PDF document, were reviewed separately by the research team. The table below shows the number of each type of respondent.

Respondent type	Number of consultation respondents	Number of call for evidence respondents
Individuals	80	7
Organisations	4	29
- Third sector – health / disability	2	14
- Third sector – campaigning / umbrella body	1	5
- Third sector – information and advice	0	5
- Local authority (inc. advice services)	1	3
- Education and research	0	2

Analysis approach

The Lines Between was commissioned to provide a robust, independent analysis of the responses to the consultation and the call for evidence, and of the notes from consultation events. The main purpose of this analysis is to understand the full range of views expressed and, where possible, using closed questions to quantify how many respondents hold particular views. This report provides a thematic analysis of responses based on the analysis approach outlined below.

Reflecting the number and knowledge of respondents, it is not practical to detail every response in this report; some, especially organisations, shared lengthy submissions reflecting their subject matter expertise. Full responses, where permission for publication was granted, can be found on the [Scottish Government’s consultation website](#).

Quantitative analysis

The consultation included 40 closed questions, though not all respondents answered every question. This report presents the results of the closed questions **based on those who answered each question**. Each results table shows the:

- Number of respondents **in the total sample** selecting each response (blue row).
- Percentage of **the total sample** selecting each response (grey row).

³ Data checks identified three respondents who had responded to both the consultation and call for evidence. As this was a valid approach, both responses were kept in each case.

- Percentage response **among those who answered each question**⁴ (white row). Please note that the row percentages may not add to 100% due to rounding.

Qualitative analysis

Qualitative analysis identifies the key themes across responses to each question. The research team developed a draft coding framework based on a review of the consultation questions and call for evidence and a sample of responses. During the coding process, new codes were created if additional themes emerged.

In a small number of instances where a response received via email or in a PDF document contained information that did not align with specific questions, analysts exercised judgment about the most relevant place to include this material for analysis purposes.

The analysis also included notes collected by The Lines Between at the nine engagement events. These discussions aligned closely with the themes arising in the formal responses received via Citizen Space and have been weaved into the analysis presented in this report. Additional or unique perspectives raised in events have been highlighted.

Where appropriate, quotes from a range of the consultation and call for evidence responses are included to illustrate key points and provide useful examples, insights and contextual information.

When reviewing the analysis in this report, we would ask the reader to consider:

- Public consultation of this kind means anyone can express their views; individuals and organisations interested in the topic are more likely to respond than those without a direct or known interest. **This self-selection means the views of respondents do not necessarily represent the views of the entire population.**
- Given the composition of each sample, themes evident in the consultation responses were mostly raised by individuals, and those in the call for evidence raised by organisations. However, where differences between the views of individuals and organisations were evident in qualitative responses, these have been noted.
- While qualitative questions allow respondents to elaborate on their views, not all respondents choose to answer, with those who do providing varying levels of detail. The qualitative analysis can therefore only be based on the information provided by those who commented. In particular, because Adult Disability Payment was only launched two years ago, only a small proportion of respondents have experienced parts of the process such as review and change in circumstances, meaning the numbers answering these questions are smaller.
- Many call for evidence responses did not provide the types of evidence sought by the Independent Review; indeed, some highlighted the lack of available evidence. Instead, responses frequently took the form of more traditional consultation responses where organisations used their own internal data and information from stakeholders to illustrate their views. Where possible, information provided about the

⁴ The need to maintain respondent confidentiality means it is not possible to present the quantitative data broken down by individual and organisation.

nature of data or evidence used to inform their submission has been noted. Similarly, a few individuals who responded to the call for evidence were confused by the repeated requests for evidence. Their responses reflect their own experiences and have been analysed alongside other call for evidence responses.

- Some points, such as the need for more communication or shorter timescales, were raised repeatedly across the questions. Where these are related to specific stages of the process, the points are presented under the relevant questions. Where themes or issues did not align with specific questions, analysts exercised judgement about the most relevant place to include each theme to avoid repetition. Similarly, some points for discussion in the engagement events did not have corresponding consultation or call for evidence questions and have therefore been noted in the most suitable chapters.
- While the focus of the engagement was on understanding experiences of Adult Disability Payment, some respondents provided evidence from stakeholders that explicitly described experiences of Personal Independence Payment, or in some cases it was unclear if a respondent was referring to Personal Independence Payment or Adult Disability Payment. Instances where previous experiences provide a useful comparison and provide insight into how Adult Disability Payment is different have been included as appropriate.

Weight of opinion

This report presents the themes identified in responses to each question from most to least commonly mentioned, outlined using the sub-headings under each question. All themes, including views shared by small numbers of respondents, are covered; a view expressed by a very small number of respondents is not given less weight than more general comments shared by a majority.

Similarly, all responses have an equal weighting. We recognise this means a response from an individual has the same weight as the response from an organisation which may represent many members, but this approach ensures all views are presented.

Qualitative analysis of open-ended questions does not permit the quantification of results. However, to assist the reader in interpreting the findings, a framework is used to convey the most to least commonly identified themes in responses to each question:

- The most/second most common/prevalent theme; most frequently identified.
- Several respondents; more than 10 respondents, a recurring theme.
- Some respondents; between five and nine respondents, another theme.
- A few / a small number; fewer than five respondents, a less commonly mentioned theme.
- Two/one respondents; a singular comment or a view identified in only one or two responses.

When referring to notes from the engagement events, we have referred to points raised in one event, a few events i.e. two or three events, and in multiple events i.e. more than four.

Report structure

This report is structured around the stages of the Adult Disability Payment application and decision-making process. For each stage, the analysis of responses to the consultation questions is presented and then followed by relevant responses from the call for evidence. Analysis of the discussion at consultation events has been included at the most appropriate points throughout. In one instance where discussion did not align directly to consultation or call for evidence questions, it has been presented separately in Chapter 5.

The report structure is as follows:

- Chapters 2 to 4 presents an analysis of responses about the process leading up to the Adult Disability Payment application. This includes awareness of the benefit, the eligibility check and the pre-application support.
- Chapters 5 to 7 examine views on the rules and criteria that govern the Adult Disability Payment decision-making process.
- Chapters 8 to 11 present the analysis of comments about the process of receiving a decision, communication around the decision and processing times.
- Chapters 12 and 13 consider other experiences with Adult Disability Payment, such as the process of reporting a change in circumstances.
- Chapter 13 concludes the report.
- There are three appendices for readers to refer to the consultation questions (Appendix A), the questions posed in the call for evidence (Appendix B), and the overview of the consultation events (Appendix C).

2. Take-up of Adult Disability Payment

The consultation paper explains that take-up means how many people who are eligible for a benefit actually receive it. The Scottish Government and Social Security Scotland wish to encourage take-up of benefits and have a range of strategies designed to improve take-up. Although there is no separate benefit-specific take-up strategy for Adult Disability Payment, this is something that the Scottish Government may consider in future. This chapter presents the analysis of responses to questions which sought views on the most effective ways to help people find out about Adult Disability Payment, and what else could be done to increase Adult Disability Payment take-up.

Key findings

- There were concerns across all strands of the engagement that awareness of Adult Disability Payment remains low. Respondents and participants at events suggested that Social Security Scotland publicise Adult Disability Payment through media channels and use more community resources, including GPs, community link workers, and social care workers to help make more people aware of their eligibility. Third-sector organisations were considered a reliable source of information and support about Adult Disability Payment and the application process.
- Reasons cited for the lack of uptake of Adult Disability Payment included a lack of awareness of eligibility, including people who thought their work status disqualified them from applying, stigma around receiving disability benefits, fear related to previous negative experiences with Personal Independence Payment or Disability Living Allowance or the possibility an award may diminish, and stress related to the application process, particularly the length of the application form.
- Providing individualised support, an improved process, and ensuring fair treatment of applicants were highlighted as ways to encourage uptake.

Consultation

How effective do you think the following methods could be at helping people to find out about Adult Disability Payment?

How effective do you think the following methods could be at helping people to find out about Adult Disability Payment?	Very Effective (%)	Effective (%)	Somewhat Effective (%)	Not very effective (%)	Not effective at all (%)
Q1A. Advertisements for Adult Disability Payment (television, social media/online, newspapers etc) (n=81)	25	27	25	11	12
Q1B. Working with organisations like charities to inform those who use their services about Adult Disability Payment. (n=82)	37	24	26	9	5
Q1C. Running events within communities to inform people about Adult Disability Payment. (n=82)	23	16	30	13	17

Across these three questions, respondents who answered were most likely to believe that working with organisations such as charities would be the most effective way to inform people about Adult Disability Payment. Almost nine in ten (87%) felt this would be effective to some extent, and 37% 'very effective', compared to 77% effective to some extent and 25% 'very effective' for advertisements and 72% effective to some extent and 23% 'very effective' for community events. Similarly, across engagement events, participants highlighted supports provided by charities, community groups and support networks as many people's main source of awareness about Adult Disability Payment.

Q1D. Do you think there is anyone who might be left out by these methods? Please give reasons for your answer.

Those not accessing media

Two thirds of consultation respondents suggested groups who might face barriers to finding out about Adult Disability Payment. Several mentioned people not who do not or cannot access media as being at risk of not hearing about Adult Disability Payment. Reasons for a lack of access included low literacy skills, both digital and written, lack of internet access and people's conditions or disabilities affecting their ability to access media or information. Some respondents highlighted difficulties for people unable to leave their home in accessing information. At one stakeholder event it was highlighted that not everyone reads or understands official letters.

"There are some people who do not have access to the internet, who also are perhaps not proficient in reading and or writing, and who perhaps have some sort of learning issue might not have the assistance and or help to be able to access these application forms." – Individual

Everyone could experience barriers

Several felt it was possible that anyone could struggle to find out about Adult Disability Payment, a view endorsed in a few engagement events, where a general lack of awareness of Adult Disability Payment among the public was highlighted by participants. Individual respondents often highlighted their own challenges finding out about Adult Disability Payment, and one organisation noted they dealt with many people who had not heard about it.

Those who believe they are not entitled

Not thinking Adult Disability Payment applied to them was another reason some felt could be a barrier to finding out about Adult Disability Payment. The main explanation given was that working people may not think they are entitled. Those who did not identify as disabled were also highlighted. At one engagement event, this latter group was considered to include, for instance, those living with long-term conditions who did not realise these were capable of being considered disabilities. One consultation respondent suggested a "much wider ranging publicity campaign is needed" to address this issue.

Other groups that could experience barriers

Some felt people with learning disabilities or older people may experience barriers in finding out about Adult Disability Payment, while a few suggested people with mental health issues, hidden disabilities or those with physical / sensory issues. Other non-disability related groups that might experience barriers included people who find it difficult to access events, those in residential or insecure housing, those with English as a second language, and carers of 18+-year-olds or young people leaving school. Homeowners, or those who live independently with less professional contact, might also experience barriers according to participants in engagement events.

Q1E. Are there any other methods that might help people find out about Adult Disability Payment? Please give reasons for your answer.

Two thirds of consultation respondents left a comment in response to Q1E. The three most prevalent themes were that it would be useful to have greater media coverage, distribution of information via health and social care and direct support from a professional. These themes were also reflected across engagement events.

Greater media promotion

The most prevalent theme was that greater media coverage would help promote Adult Disability Payment. Suggestions included raising awareness through television, newspapers, radio, social media and other online channels, potentially as part of a national campaign. One suggested optimising search engines so Adult Disability Payment messaging would be directed towards disabled people. Conversely, recognising that some people do not see themselves as disabled, suggestions were made in engagement events to promote Adult Disability Payment as a support for those who need help with daily living tasks and not focusing on their disability.

The need for more promotion was also a recurring theme at subsequent questions Q1F and Q2, with similar suggestions being made as well as calls for the distribution of leaflets and sending letters directly to potentially eligible people.

Promote through health and care

Distributing information, such as leaflets and posters, in places potentially eligible people were likely to access was seen as a way to raise awareness of Adult Disability Payment. Several held this view, including the Health and Social Care Alliance Scotland, #MEAction Scotland and event participants. Respondents suggested places that could distribute Adult Disability Payment information, including hospitals, health centres, GP practices, care providers, disability charities or services, carer centres, Jobcentres and foodbanks.

“Leaflets advertising ADP could be in waiting rooms/areas.” - The Neurological Alliance of Scotland (NAoS)

Direct approach from a professional

Information from a professional in contact with those who may be eligible for Adult Disability Payment was advocated by several individuals. Professionals suggested by respondents included GPs, nurses, other health professionals, psychologists, social

workers and Jobcentre staff. One felt welfare rights advisors should visit people before they are discharged from hospital, with a call in one consultation group for information to be provided at the earliest opportunity, such as at the point of diagnosis.

“I think that people may benefit from someone taking the time to go through the literature and explain in a way that they'll be able to understand. I think GP surgeries are good places to target.” – Individual

Other suggestions

Some suggested promoting Adult Disability Payment in buildings or places accessed by the public. These included libraries, community centres, leisure facilities, supermarkets or bus shelters.

A few felt information could be sent to people's home addresses. Singular comments were that existing client information could be used to contact people and that there was a need to provide a range of formats to cater for the different ways people access information.

Q1G. What reasons do you think might mean someone may be unwilling to apply for Adult Disability Payment?

Unsure it applies

Over four in five consultation respondents commented on why someone may be unwilling to apply for Adult Disability Payment. Several respondents felt that people may be unsure if Adult Disability Payment is a benefit that applies to them. Reasons given included that people may not see themselves as disabled, that they believe their condition doesn't make them eligible, they believe Adult Disability Payment is not available to people who work, or that they may have never received benefits previously and are therefore unaware of Adult Disability Payment.

“Not wishing to use resources they don't feel entitled to, and not 'identifying' as disabled.”
– Individual

Too complex or stressful

The second most prevalent theme was that the application process for Adult Disability Payment is too stressful, complex or difficult and some people would require help to overcome these challenges. The application process was also highlighted as challenging during engagement events, with participants noting it was difficult to complete without support. Event participants described it as distressing, overwhelming, embarrassing and uncomfortable to answer questions about limitations and struggles over again. One felt the application process was not accessible enough to people with certain disabilities or health conditions, such as those who were neurodivergent, who would find it difficult to apply. Some felt the process could be overwhelming or exhausting. More detail about the application process is provided in Chapter 5.

Too intimidating or accusatory

Perceptions of people being judged or accused of lying, or fear of the process, was raised by several. Negative feelings were expressed, such as fear, degradation, and humiliation, but also embarrassment in “being made to feel like you are begging for something”, as an individual noted. At engagement events, fears of being under the scrutiny of officials, fears it may affect other benefits or the mental health impacts of dealing with official systems, such as having to meet deadlines, were also highlighted. Commonly raised issues included a lack of trust that people would be treated with respect and dignity.

In multiple engagement events, participants acknowledged that these feelings were often a legacy of some people’s past experiences of Personal Independence Payment and that Social Security Scotland’s approach was a significant improvement. However, at one engagement event, it was felt that the tone of Social Security Scotland was becoming more like Department for Work and Pensions (DWP) over time; for example, decision letters becoming more likely to use DWP-style wording. Given this, the need for people to be believed and treated in a friendly, supportive way was emphasised by respondents and event participants.

“The portrayal of the harsh critical system where someone judges you to be okay when you live with pain constantly and your doctors agree, yet an unqualified person has the final say on whether or not you are sick or ill enough.” – Individual

A dislike of sharing personal information or a perception that the process was intrusive was also raised by some. A few raised that they felt the questions were not relevant or a fear of being investigated.

Negative experiences of previous system

Several felt negative experiences of applying for Personal Independence Payment, or hearing about these, may impact willingness to apply for Adult Disability Payment. Similarly, being unsuccessful when applying for Personal Independence Payment was felt to have the potential to put people off applying for Adult Disability Payment.

Form or process is too long

The length of the application form and the decision-making process were reasons given by several as to why people might not apply for Adult Disability Payment, a view also raised across engagement events. Most comments were about the application form being too long, though a few commented on the overall process being too long, such as taking too long to reach a decision or that phone interviews could be lengthy.

Fear of being rejected or of losing benefits

Some, including Mental Health Advocacy Project (West Lothian) and #MEAction Scotland, highlighted that a fear of not receiving an award or of losing benefits following an unsuccessful application were reasons why people may not apply for Adult Disability Payment.

Other issues

Other varied reasons why people may not apply for Adult Disability Payment were given by several, including a perceived lack of consistency in decision-making or that the process was not fair, not wanting to be labelled, not wanting “government interference” in their lives, difficulties obtaining supporting information and a perception that many Adult Disability Payment applications were not being awarded.

Q1F. What do you think the Scottish Government could do to help people who know Adult Disability Payment exists but are unsure if they should apply or might be unwilling to apply?

Q2. Do you think there is anything else that could be done to encourage people to apply for Adult Disability Payment?

Almost seven in ten consultation respondents answered Q1F and over four fifths Q2. While the emphasis of the questions was slightly different, there was significant overlap in respondents’ comments to both questions. To avoid repetition, the analysis of both questions has been combined below.

Individualised support to help people to apply

By far the most prevalent theme in responses to Q2 was the need to help people to apply through encouragement or support. Referring to, and accessing, one-to-one support through a support agency was the most prevalent theme in response to Q1F, and this point was raised repeatedly across engagement events, where support to complete a form was recommended, with the suggestion that people should not try to complete it alone.

Specific points included that it was felt more engagement was needed with “those who are at risk”, to make it easier for a third party to represent a person, or that specialised mentors or health professionals could encourage people to apply. However, some organisational representatives at engagement events highlighted the resource required in support organisations to assist people effectively.

“Personally, I filled out the first part online, and then didn't fill out the second part until someone from SSS called me to ask if I was planning on filling it out, answered my questions, extended my deadline, and offered me an appointment with someone to support me with filling it out, so do keep doing that! It was very effective.” - Individual

Help people understand they could be eligible

Suggestions were made by several consultation respondents on ways Adult Disability Payment could be promoted to those who might not realise they are eligible. Most commonly, easy ways to get initial information and ask questions were called for, such as through a helpline, information points or email help. Suggested messages for communication included counteracting stigma with positive messages, listing the eligibility criteria clearly on advertisements and highlighting the benefits of receiving Adult Disability Payment. A few felt that reducing waiting times, on the phone for instance, would help encourage applications.

Improve the process

At both questions some gave suggestions for improving the application process as a way to encourage Adult Disability Payment applications. Suggestions included shortening the form or making it less complex, allowing people with life-long conditions to automatically qualify, giving people access to their own medical notes and having better communication with applicants. Providing updates as people move through the decision-making process was also suggested at multiple events.

Ensure the approach treats people fairly

Comments on the approach taken by Social Security Scotland staff were given by some. Recommendations were made that staff should treat people with dignity and respect and that staff should believe what applicants say. One suggested a lived experience panel could be part of the decision-making process to allow better understanding of the nature of disability and its impact. Another suggested:

“Training in the condition for assessors. If people with ME/CFS [Myalgic Encephalomyelitis or chronic fatigue syndrome] knew that assessors understood the condition and are therefore more likely to make a fairer assessment, it would help reassure that there is less chance of stigma or rejection.” – #MEAction Scotland

Some also felt that reassuring people they would be treated with dignity and respect would encourage people to apply. This view was supported by participants at engagement events who suggested promotional literature could signpost to the Social Security Charter or highlight there is no face-to-face assessment, to counter perceptions that Adult Disability Payment is like Personal Independence Payment.

Other discussion at engagement events

At engagement events, the need to ensure Adult Disability Payment is accessible to people whose condition or situation could impact their ability to apply was highlighted. Participants’ suggestions for improvements included providing information in alternative formats including Easy Read, video and audio versions, or ensuring the application process was accessible to seldom-heard groups and those who experience digital exclusion.

Other suggestions included making it clear that people who work can qualify, that applying for Adult Disability Payment does not affect other benefits, that it is not means-tested or taxable, and that the online application form includes a ‘save and return’ function.

The name of the benefit was considered in some engagement events, with mixed views on whether to retain Adult Disability Payment or to replace it with something emphasising the payment’s potential to provide support, such as Adult Independence Payment (similar to Personal Independence Payment for PIP).

Call for Evidence

The [Social Security Scotland Charter](#) specifically states that the Scottish Government will ensure as many people as possible get the benefits they are entitled to. This includes making a particular effort to reach people who are most likely to be excluded.

Q1A. Thinking about take-up of Adult Disability Payment for seldom-heard groups, what evidence exists about levels of awareness and barriers to awareness of Adult Disability Payment amongst seldom-heard groups?

Several respondents to the call for evidence either provided more detail in their responses to the first few questions of the call for evidence, or were more likely to answer the earlier questions than later questions. For this reason, the analysis below goes into more detail than other later sections of the call for evidence analysis. Reflecting the level of detail and evidence provided in some responses, it is not possible to present all the information submitted within this report. Full responses to the consultation, where permission for publication was granted, can be found on the [Scottish Government's consultation website](#).

General lack of awareness

Around three quarters of call for evidence respondents commented at Q1A. Several described a general lack of awareness of Adult Disability Payment among their stakeholders and clients. For example, Homeless Network Scotland provided examples of their clients who were neurodiverse and struggling to understand which benefits might be most appropriate for them. MECOPP (Minority Ethnic Carers of People Project) and Feniks noted that their clients who did not speak English were less aware of Adult Disability Payment or more confused about their eligibility due to receiving information through word of mouth rather than official channels.

Considered ineligible

A misconception that certain groups are not entitled to Adult Disability Payment was a barrier to greater awareness of the benefit for some. This was particularly highlighted by organisations who worked with people with cancer and those who were terminally ill.

“Whilst some respondents were not aware of ADP and other benefits available to them, the majority believed that they would not be eligible for benefits, and in many cases, this was because they did not think that their cancer diagnosis qualified them for assistance. This demonstrates not only a failure in awareness and communications around the benefits available to everyone, but also in ensuring specific groups are aware that they, because of their specific condition, are eligible to claim them.” - Young Lives vs Cancer

Stigma

The stigma of receiving benefits and therefore the need to raise awareness of and learn more about the support available was mentioned by some, including SAMH (Scottish Association for Mental Health) and Homeless Network Scotland. The Coalition for Racial Equality and Rights (CRER) and MECOPP highlighted evidence that showed connection between cultural beliefs and uptake of social security benefits.

“A Money & Pension Service report highlighted that some potential applicants who were aware and otherwise able to apply were reluctant to do so due to their cultural beliefs, and stigma about being ‘on benefits’. Similarly, within the Eurofound review, potential recipients were keen to highlight they could ‘manage’ and in the Young Carer interim evaluation, it was noted that there was some ‘initial reluctance’, where carers felt they should not receive the payment as there were others who would need the money more. The increased impact of benefits stigmatisation within some cultures was noted by a number of reports, with many feeling it was charity, only for the most in need rather than a right or entitlement. Within this vein, some respondents believed any payments should only be spent on the absolute essentials, so would instead prefer to have less income to spend and live freely. This stigma can be exacerbated by past negative experiences with public service staff, adding to feelings of exclusion.” - Coalition for Racial Equality and Rights

“In some cultures, discussing disability or seeking financial benefit might carry stigma or be seen as undesirable, further discouraging them from applying.” - MECOPP

Awareness levels among specific groups

LGBT+ Welfare and Assets Project at the University of Stirling cited their own research with 110 people who applied for benefits in the last eight years, alongside a statistical analysis on the proportion of people identifying as LGB who applied for/received benefits.

“We also found that ADP benefited from a “good glow” being associated with the Scottish Government. The Government was seen (at the time) as being LGBT+ friendly and progressive, and thus people believed the system would be. PIP was associated with the Conservative UK Government and their attacks on LGBT+ people. Our fieldwork was carried out in 2021/22.” - LGBT+ Welfare and Assets Project at the University of Stirling

Throughout the call for evidence, the Coalition for Racial Equality and Rights noted that there was not enough available evidence or research detailing the experiences of uptake of social security benefits among BME (Black and Minority Ethnic) communities, noting this was also highlighted in recent ScotCen research commissioned by the Scottish Government. While they cite Social Security Scotland’s client equality and diversity data release for June 2021-March 2023, which would suggest Adult Disability Payment uptake for BME communities is lower than average, that data is complicated by the transfer of the payment from DWP to Social Security Scotland during that period.

“Unfortunately, there is a significant lack of information on the experiences of Black minority ethnic (BME) people who are applying for ADP, as well as on BME people with disabilities in Scotland and their access to benefits. CRER continues to highlight the issues with evidence in Scotland and advocate for better data collection by ethnicity, higher standards for public sector data, and proactive plans to fill these gaps in data and evidence. The lack of data severely limits the ability to implement effective policy and accurately evaluate its impact.” - The Coalition for Racial Equality and Rights

Q1B. Thinking about take-up of Adult Disability Payment for seldom-heard groups, what evidence exists about the particular barriers to application facing people in specific seldom-heard groups?

Accessibility

Around three quarters of call for evidence respondents commented at Q1B. Several noted that they were aware of accessibility issues causing barriers to applying. A few spoke of language and literacy barriers, particularly for those who did not speak English or who were recent immigrants to the UK; this was also noted as a concern at engagement events. A few others highlighted bureaucratic confusion and no access to easy read documents for some who have neurological or memory conditions or those with learning difficulties or learning disabilities. LGBT+ Welfare and Assets Project at the University of Stirling gave evidence of a research participant receiving communication that was addressed using incorrect pronouns, which they felt were exclusionary.

Digital exclusion was also mentioned by some who noted that there were many in seldom-heard groups who did not own or had trouble accessing computers. For example, One Parent Families Scotland highlighted that many single parents do not use computers but rely on their mobile phones for digital connection. They suggest that due to “the levels of benefit income, even having enough credit in their phone can be impossible and will delay or prevent them applying.”

Complex process

Perceptions of the different stages of the Adult Disability Payment application process, from a long and overly complex form to multiple approval stages to a long waiting time for an award, were mentioned by some as a barrier to applying.

“Those in seldom-heard groups have likely overcome many barriers in their lives already, so it is unlikely to be one particular barrier that prevents them from applying, but ‘barrier exhaustion’. They may have found it difficult to get information about benefits in the past; not known how to apply; needed support to apply but none was available; felt embarrassed or stigmatised; and are additionally already dealing with so much that they just don’t have the energy to fight for something they are entitled to.” – Age Scotland

The Communication Inclusion People noted the perceived complexity of the process was particularly challenging for those experiencing communication disadvantage. Young Lives vs Cancer, Feniks and Alzheimer Scotland all mentioned that the complexity of the process made it almost impossible to apply for Adult Disability Payment when a person was very ill, whether mental or physical, acute or terminal.

“Furthermore, a cancer diagnosis brings with it immediate financial and emotional challenges that can last for years. Given this, many patients are focused on their treatment and health, rather than applying for financial assistance that may take months to be approved. They may also not be well enough to engage effectively in the application process. Efforts to streamline the process of applying for ADP and expedite the approval of applications must be made and better support patients such as young people with cancer.” - Young Lives vs Cancer

Provision of assistance

Acknowledging the difficulties often faced by applicants, including those in seldom-heard groups, some respondents noted that barriers to accessing support, whether provided by the third sector or pre-application assistance provided by Social Security Scotland, could also be a barrier to applying. Social isolation was mentioned by MECOPP as both a barrier to awareness and a barrier to applying. Organisations such as Cerebral Palsy Scotland noted that those who do not have relationships with GPs may struggle with awareness or to get the supporting information necessary to receive an award.

Previous negative experiences

A small number highlighted that their clients' negative or traumatic experiences with a Personal Independence Payment application under the DWP made them hesitant to apply for Adult Disability Payment. Respondents suggested more communication emphasising the distinction between the two would be beneficial.

Q2A/B. In relation to Adult Disability Payment, can you provide evidence about any initiatives or activities that have measurably increased awareness of take-up?

Three fifths of call for evidence respondents commented at this question. While many provided anecdotal descriptions of activities and initiatives that they feel have increased uptake, respondents did not cite research or data that consider the issue on a larger scale.

Promotion

Some highlighted the importance of increased promotion. VoiceAbility highlighted an increased interest in Adult Disability Payment evident through monitoring of their social media channels, which showed high levels of engagement with the material about Adult Disability Payment. MS Society Scotland also noted increased take-up due to promotion of the benefit on their social media channels.

The Coalition for Racial Equality and Rights highlighted research from the Poverty and Inequality Commission that used unique communication strategies to target priority groups:

“The communications addressed universal barriers but were tailored with specific messages for each audience. The evaluation of the campaign found that 77% of parents in the priority family groups recognised the campaign and 76% of them acted due to seeing the campaign. We don't know if there was any variation in impact for minority ethnic or BME families, but the results are encouraging for targeted SSS communications. Messaging seeking to target BME groups should be tailored to the needs and cultures of different communities, rather than producing a generic BME alternative.” - Coalition for Racial Equality and Rights

Reaffirming the importance of addressing the needs of different groups, the Communication Inclusion People noted the success of the Inclusive Communication Action Plan 2022-2025, which they worked on with Social Security Scotland.

Parkinson's UK Scotland heard from stakeholders that they purposefully timed their new applications or change of circumstances forms to ensure they were considered under Adult Disability Payment rather than Personal Independence Payment. They suggest that emphasising the differences between the two payments and that the payment has now been devolved has worked positively to increase take-up.

Outreach through healthcare settings

Evidence provided by a few respondents emphasised the importance of outreach through GP practices and other healthcare settings, either through signage or direct outreach.

“During the financial year 2023-24, 6,280 people received advice from a CAB adviser embedded in a health care setting, from an adviser working on an outreach basis in a health setting or having been formally referred to a CAB from a health setting. The potential value of this approach in relation to reach, take-up and awareness is indicated by looking at what advice is given: 37% of the advice provided to this group of people concerned both components of Adult Disability Payment. The equivalent figure for the network as a whole is 26%.” - Citizens Advice Scotland Social Policy

Third sector organisations

The capacity of third-sector organisations to increase the take-up of Adult Disability Payment was mentioned by some. A few noted Adult Disability Payment applications could follow on from their clients having welfare benefits checks, a service offered by many third-sector support organisations. A few others suggested that they provided trusted advice to their clients, something that allowed them to speak about Adult Disability Payment and other benefits. FAIR Ltd. noted that their staff are well trained, which allows them to provide advice and information services that will support take-up. They, along with Epilepsy Scotland, expressed a view that more people would be willing to apply for Adult Disability Payment if Social Security Scotland provided a trusted organisation list or accreditation for agencies that assist people with the application, re-determination and appeals process.

Q3. Can you provide specific examples of the factors that affect whether someone chooses to apply for Adult Disability Payment or chooses not to apply?

Application form

The vast majority of call for evidence respondents answered Q3. Many provided examples or anecdotal evidence of when the length or complexity of the Adult Disability Payment application form made their clients decide not to apply for Adult Disability Payment without assistance. A few others mentioned that some clients had trouble identifying or articulating their daily struggles.

“Interviewees articulated the often overwhelming complexity of the ADP journey, and the challenges of providing the depth of information required.” - Citizens Advice Scotland Social Policy

“The length of the application continues to be a factor. Although the application form is well written and presented, it is extremely long and takes a huge amount of time to complete. As mentioned in our response to the prior question, previous negative experiences when applying for benefits are also a factor impacting on choosing to apply again for something new.” – Age Scotland

Not only is it the length of the form that can pose a challenge, but some mention that clients find it difficult to represent their experiences accurately in the application form. Communication Inclusion People also suggested that the application does not allow people to use their preferred or comfortable method of communicating when completing the form. Views on the application form are detailed more fully in Chapter 5.

“When a benefit check with one of our Social Welfare Specialists identifies an individual is eligible to claim ADP, we have a 100% take up record of them going on to make a claim - with the guidance and support of one of our specialists. After completing and submitting the ADP application form, nearly every person has reported they would not have been able to cope with their claim without our expert help and support. In our experience, contact with the Multiple System Atrophy Trust Social Welfare Service and subsequent discussion about possible entitlement then provides the person with confidence and assurance that a claim is justified and appropriate. Without this, the claim might not be made at all. This is because we have expert awareness of how MSA affects people and how this dovetails with ADP entitlement.” - Multiple System Atrophy Trust

Previous negative experiences

Several respondents cited evidence from stakeholders of fear or mistrust of the benefits system due to negative experiences during an application for Disability Living Allowance (DLA) or Personal Independence Payment. A few emphasised that people expressed a new willingness to apply for Adult Disability Payment due to their understanding it had been devolved to the Scottish Government.

A few respondents spoke about the difficulty their stakeholders faced when describing their limitations or ‘worst day’ examples of their conditions. Other noted that a fear those descriptions may not be believed was also stopping people from applying.

“Another contributing factor to whether people apply for ADP or not is the fear of not being believed or being rejected. While we have generally had positive feedback on the differences between ADP and PIP there is still some reticence to believe the systems are different.” – MS Society Scotland

Stigma

Stigma was mentioned as a factor that impacts a person’s decision to apply for Adult Disability Payment. Points raised here have been included in the analysis of Q1A above.

Impact on mental wellbeing

Considering the complexity of the Adult Disability Payment application form and process and previous negative experiences when applying for benefits payments, some

respondents highlighted that clients or stakeholders had decided not to apply for Adult Disability Payment because of the potential negative impact it could have on their mental wellbeing.

“Some women didn’t believe they could survive the ADP application process. They described how living with a debilitating mental health condition was exhausting.” - University of the West of Scotland

Difficulty gathering supporting information

Some cited a concern among potential applicants that they would not be able to prove their disability or health condition. This was either due to an application form they felt did not represent their condition or a lack of interaction with medical services, which they felt may make gathering supporting information difficult⁵.

“Difficulties in proving disability can also be a factor in choosing whether or not to apply. For some individuals, particularly those with "invisible" disabilities (e.g., mental health issues, chronic pain, or fluctuating conditions), proving their disability to meet the criteria for ADP can be difficult. The requirement for medical evidence or documentation can discourage them from applying, especially if their condition isn't well-documented by healthcare professionals or there is a long waiting list or there is no availability to meet their doctors.” - MECOPP

“In addition, we know that a lack of evidence of eligibility due to delays or lack of action in diagnoses via healthcare systems (which is often experienced in mental healthcare) can impact on choices to apply for ADP” – Age Scotland

Lack of support and assistance

Having support from family, health professionals and community or third-sector advocates was an important factor in encouraging application for Adult Disability Payment, according to a few respondents. This included getting support with the application form, but also advice about the different stages of the Adult Disability Payment application process.

⁵ It should be noted that under Social Security Scotland, an application for ADP should normally be accompanied by one piece of supporting information. However, it does not need to be medical or from a GP. It can include information from health and social care workers, therapists or occupational therapists, to name a few.

3. Eligibility check

Social Security Scotland has an online suitability checker that allows people thinking of applying for Adult Disability Payment to check if they meet the basic requirements. It does not tell someone if they are likely to get Adult Disability Payment because of their disability or health condition.

The Independent Review sought views on whether a more detailed eligibility check should be introduced to ask questions about a person’s daily living and mobility needs and to help them know if they are likely to be eligible for Adult Disability Payment.

Key findings

- Respondents generally supported a more detailed eligibility check prior to applying, suggesting it could save people the time and energy of applying if they knew they did not qualify. A few suggested that any digital eligibility checker must capture the full range of qualifying conditions to ensure people were not wrongly advised.
- However, some individuals preferred the current approach as they felt sufficient information already existed to help people understand whether they are likely to be entitled.
- Criteria that were recommended for inclusion in an eligibility checker included the impact of disabilities or conditions on daily lives, information about daily living and independent living, emotional wellbeing and cognitive state, assistance needed, and financial circumstances.
- There were mixed views on whether people considering applying for Adult Disability Payment would need help to complete an eligibility check. Those who thought they would, suggested that assistance be provided by advice or welfare rights workers, family members, or advocacy and support workers.

Q3A. In your view, would it be helpful to have a more detailed eligibility check before filling in the application form?

Q3B. Please explain your reasons.

Respondents	Yes	No	Don't know	No answer
No. of respondents (n=84)	37	25	21	1
All respondents (%) (n=84)	44	30	25	1
All answering (%) (n=83)	45	30	25	-

Among those who answered, 45% felt it would be helpful to have a more detailed eligibility check before filling in the application form. Three in ten (30%) did not believe this would be helpful and one quarter (25%) were unsure.

It will help people understand if they qualify

Four fifths of consultation respondents left an open comment to explain their answer. Among those expressing a view, support was mixed but a majority were positive. The most

prevalent theme, raised by several who supported the suggestion, was that a detailed eligibility check prior to applying would help people understand if they qualified for Adult Disability Payment. It was viewed that this would be helpful because it would save people time and energy, provide concise and clear information on eligibility, extend access to people who might not otherwise have applied or signpost those found not to be eligible, and be objective as it would be computer based. The need to ensure any check captures the full range of qualifying conditions was emphasised by a few. One organisation suggested it would help check residence, e.g. EU National competent state.

“Provide as much information as possible, in a succinct and simple format, on eligibility criteria so that people with limited energy can work out in advance whether it is worth their while going through the application process.” – #MEAction Scotland

“It would save people time if they can see they would be unlikely to be entitled to adult disability payment.” – Individual

Problems with an eligibility checker approach

Concerns about using a checker to determine eligibility were raised by some, including the results being incorrect, that it could put people off applying or that it was unsuitable for capturing fluctuating conditions. Issues with the current checker were highlighted by a few. These included:

- The ‘how to apply’ section having too high a reading age, without an accessible version offered.
- No questions that relate to disability or long-term conditions⁶.
- A perception that the questions such as age, residence / nationality or benefit receipt are “meaningless” or “over-simplified”.

It will help reduce stress and anxiety

Some felt a more detailed eligibility checker could reduce stress and anxiety associated with making an application, or waiting until a decision was made. A checker was perceived as less stressful for people, as it would save them having to make a full application if it was apparent they would not qualify. Comments from a few about making a full application described the process as “daunting”, “time-consuming”, “horrendous”, or that questions were repetitive.

“This would also help people in the community feel more comfortable by being able to do this in their own time.” - Individual

Ensures application is worthwhile

Knowing the application was more likely to be approved, and avoiding negative emotions associated with an unsuccessful application, were reasons given by some individuals for using a more detailed eligibility checker. Knowing an application was more likely to be

⁶ Though it should be noted another organisation disagreed with this suggestion (coded to another theme).

successful was felt to be a way of encouraging applications, for instance, by giving people assurances the energy and time required would be worthwhile.

“It is a huge form to fill in and a checker to begin would let you know whether it was worth expending all your energy.” – Individual

Current approach is preferable

Some individuals felt the existing arrangement should be retained, with those who expressed a view opposing the proposal. These comments reflected that much more detail would be needed in order to determine eligibility accurately than could be collected via an initial check. One felt sufficient information already existed to help people decide if they were eligible to apply.

Could become confusing / too complex

Using a more detailed eligibility checker could increase stress for applicants, according to some respondents. Reasons given included having to repeat the process when applying or if symptoms impacted cognitive ability. Two noted this could put people off applying. In answer to Q3C, some emphasised the need to keep the checker simple while some suggested basing eligibility on medical evidence supporting information instead of using a checker.

Specific suggestions

Some left specific suggestions. These included that the eligibility checker should be accessible, basic, optional or mirror eligibility checking tools used by other independent financial support agencies. One organisation called for the checker not to focus on disabilities.

Other comments

Some left general comments on the need for clear and concise information, such as putting the eligibility criteria in clear and simple English at the front of the application form and using relevant or explicit questions to benefit those with certain conditions. A few commented the proposal could put people off applying or that it was unhelpful if it added to the length of the process. Conversely, one felt that the proposal could speed up processing times as people who were not eligible would be less likely to apply.

Q3C. If you said “yes”, what questions do you think the eligibility checker should ask?

Two fifths of consultation respondents commented at Q3C. A wide range of suggested areas that an eligibility checker could cover were identified across comments.

Impact of disability

The need to ask about how disability impacts people in their daily lives was mentioned by some, including the Neurological Alliance of Scotland. Suggestions were made for questions on aspects such as pain, cognitive functioning, cumulative impacts and the consequence of undertaking activities.

“Changes to recent health that have impacted your life. I have Long COVID and it has drastically impacted on my life. Disability comes in many forms that may not affect mobility but impact on a person’s ability to work, such as brain function.” - Individual

Disability or conditions

Some individuals felt that a person’s disability or long-term condition should be asked about, with one suggesting questions should be tailored to different types of disabilities or conditions to ensure they were relevant.

Daily living or living independently

A similar proportion highlighted that questions on daily living should be asked. Areas suggested included aids and adaptations, time taken to undertake tasks, tasks that can be undertaken independently or with support, and ability to access community facilities.

“It should clearly state can you reliably and repeatedly perform a task. It should ask can you undertake certain tasks. Simple ‘yes’ or ‘no’ or ‘do you need assistance?’ Ask how long it takes to walk a certain distance, undertake a task such as dressing, make a meal etc. Include things like being incontinent as you can’t get to the toilet in time, not washing because it’s too difficult, eating ready meals. How long does it take to put your shopping away? Can you hang your washing up or Hoover? – ‘How long does it take?’ is a very good indication on general ability.” – Individual

Emotional wellbeing or cognitive state

A few felt questions should ask how someone’s condition impacts their wellbeing or cognitive abilities, though comments were brief and did not expand further.

Carers or assistance needed

Including questions on carer support, or the impact on carers, was raised by a few. Suggested questions included “Do you have help?” and “Do you need help to carry out personal care or activities essential for your health or day to day living?”.

“How it also impacts on people around them who may have to take over the tasks they did, or how others have had to step in to help with care.” - Individual

Employment and finance

A small number of respondents suggested asking clear and concise questions on employment or finances such as on income, savings and benefits. Although in some instances this may highlight a misunderstanding that eligibility is linked to working status, others felt that including questions about whether an applicant worked and what activities they could do could help improve understanding whether their needs meant they could be eligible for Adult Disability Payment.

Other comments

A few suggested other questions including questions on social interaction or inclusion in the community, or relating to best/worst days such as “Do you have more bad days than good days?”

Q3D. If you said “yes”, please consider what the potential advantages/disadvantages would be on people thinking about making an application for Adult Disability Payment.

Over a third of consultation respondents commented on Q3D. In line with comments to Q3B, the most prevalent view was that a detailed checker could help save time and effort for people not meeting the eligibility criteria, as they would know not to apply. As a result, these views were incorporated in the analysis of Q3B.

Benefits associated with being awarded Adult Disability Payment, such as financial support and an ability to reduce working hours, were highlighted by some individuals as advantages of a checker. Although not made explicit by respondents, this most likely relates to a checker having the advantage of encouraging Adult Disability Payment applications among those who appear to qualify.

A range of comments were left by one or two respondents. These included that some people will still need encouragement to apply, that a detailed checker would be fairer, that the proposal could increase Social Security Scotland efficiency by reducing waiting lists and speeding up processing times, that people may not include relevant information and miss being awarded points when they should have, or that it could become too complex.

Q3E. Would you need help to complete an eligibility check?

Q3F. If you said “yes”, who would you ask to help you?

Respondents	Yes	No	Don't know	No answer
No. of respondents (n=84)	30	27	18	9
All respondents (%) (n=84)	36	32	21	11
All answering (%) (n=75)	40	36	24	-

Two fifths (40%) of those answering indicated they would need help to complete an eligibility check. One third (36%) said they would not and one quarter (24%) were unsure.

Advice or welfare rights worker

Four in ten consultation respondents left an open answer indicating who would help them to complete an eligibility check. Some individuals cited an advice or welfare rights worker as being the person who would assist them. Citizens Advice Scotland was the main service mentioned, though money advice services were also suggested.

“As have already done this would ask Citizens Advice, before that would have asked wife as did not know of other options.” – Individual

Family member or spouse

A similar proportion of respondents commented that they would ask their spouse or a family member e.g. parents to assist them complete a checker.

Advocacy or support worker

Assistance from an advocacy service or local support service for people with disabilities or their carers to help complete a checker, such as charities, were mentioned by a few.

“Help should be available from such organisations such as Veterans charities, SCLD and NAS (Scotland) and Scottish Autism, Down Syndrome Scotland. Also there will be independent advocates available to assist. Reason to ask for this is the ability of the person applying to be able to complete even a simple form. There are many people out there with learning disabilities that require access to different types of ways to complete forms such as Easy Read or MAKTON to name only a few.” - Individual

Other people who could assist

A few suggested a health professional might assist them to complete a checker. A few also suggested people other than relatives or organisations, such as a friend or neighbour. Two suggested a Social Security Scotland appointee could assist them, while one suggested a carer could help. One felt there was no-one they would contact for support while another felt who they asked would depend on what the check involved.

4. Pre-application support for Adult Disability Payment applications

This chapter explores experiences with two new services created by the Scottish Government and Social Security Scotland to assist people in applying for Adult Disability Payment.

The Local Delivery Service (LDS) works in every local authority in Scotland, providing people with support with their Adult Disability Payment application. Advisers are trained and can work with people at times and in places that suit them, for example, at a person's home, at a venue in the local community, in a hospital or prison, on a telephone call or on a video call.

The Scottish Government has also provided funding for an Independent Advocacy Service. They have appointed VoiceAbility to deliver this service. More information on both these services can be found in the consultation and call for evidence papers.

As noted below, awareness and usage of both services among consultation respondents was relatively low, and therefore a limited number of comments were provided. Although some individuals described their experiences, it was often unclear what type of support they had received or whether they had been supported by the Local Delivery Service or the Independent Advocacy Service. In some cases, it is possible they were referencing interactions with case managers or other Social Security Scotland staff.

Key findings

- One in ten (11%) consultation respondents reported they have used the Local Delivery Service and one fifth (19%) of those who had not used the service were aware of it. Fewer than one in ten (6%) consultation respondents had used the Independent Advocacy Service. Many acknowledged that greater awareness of these services and what they do was needed. Recommendations for outreach included greater advertising, social media outreach and more information on the Social Security Scotland website.
- Consultation respondents who used the Local Delivery Service reported a positive experience with their adviser and appreciated that the meeting could be held in a preferred location. Similarly, those who had used the Independent Advocacy Service felt that they had been fairly treated. A few consultation respondents mentioned long wait times and trouble accessing these services as barriers to uptake.
- Participants at engagement events described more mixed experiences. Some described the staff as helpful and personable, while others highlighted difficulties with the referral process and trouble getting appointments.
- Call for evidence responses also provided feedback on the pre-application services and support. A few reported that the services worked well. Others suggested the following changes: improved staff training, better access to help such as dedicated telephone lines, greater interaction with third-party organisations; and ensuring the impartiality of the advice offered.

Consultation – Local Delivery Service

Question	Yes (%)	No (%)	Don't know (%)
Q4A. Have you ever used the Local Delivery Service provided by Social Security Scotland to help you with something to do with Adult Disability Payment? (%) (n=82)	11	88	1
Q4B. If you said “no”, are you aware of this service and the support it offers? (n=73)	19	79	1
Q4C. If you said “yes”, did you feel that you were treated with dignity, fairness and respect? (n=23)	43	17	39

One in ten (11%) consultation respondents who answered reported they have used the Local Delivery Service for help with something to do with Adult Disability Payment. Among those who had not used the Local Delivery Service, one fifth (19%) indicated they were aware of the service and the support it offers, while the remaining two fifths were either unaware or unsure.

Among those who answered Q4C, 43% felt they had been treated well, though 39% were unsure. However, the number of respondents answering this question was higher than the number who reported they have used the Local Delivery Service. It may be that these respondents misunderstood this question, which came early in the consultation, and were answering in relation to the application process more generally. Others may have misunderstood the instruction and responded if they had answered ‘yes’ to Q4B.

Q4D. If you said “yes”, how easy was it to access the Local Delivery Service?

Q4E. Please provide reasons for your answer.

Respondents	Very Easy	Somewhat easy	Neither	Somewhat difficult	Very difficult	No answer
No. of respondents (n=84)	3	3	7	2	2	67
All respondents (%) (n=84)	4	4	8	2	2	80
All answering (%) (n=17)	18	18	41	12	12	-

Among those who answered Q4D, there were mixed views on ease of accessing the Local Delivery Service. One third (36%) felt it was easy, one quarter (24%) difficult and 41% neither. Again, more respondents answered this question than indicated they had used the Local Delivery Service at Q4A. It is possible that some answered because they found it difficult to access the Local Delivery Service and therefore did not use it. Others, however, may have been confused about whether they were answering in relation to ‘yes’ they had used the Local Delivery Service (Q4A), or ‘yes’ they felt they were treated fairly (Q4C).

Lack of awareness

A quarter of consultation respondents provided an open comment at Q4E. Most commonly, respondents highlighted a lack of general awareness of the Local Delivery

Service or expressed confusion about how it worked and the services they offer. This sentiment was echoed at multiple engagement events.

“I am not aware of these organisations and I feel they should have been promoted more as I know a lot of family and friends are definitely not aware of these types of help.” – Individual

Positive experience

Some respondents described their positive experience of making an appointment with the Local Delivery Service. They found making an appointment straightforward and noted that the Local Delivery Service advisor met them at their preferred location for their meeting.

Multiple appointments

While happy with their experience with the Local Delivery Service, a few respondents highlighted that because their Adult Disability Payment application was very long they required multiple appointments with the service. While there were issues with the length of the process, these respondents were happy with the flexibility of Local Delivery Service advisors in assisting them.

Long wait times

Two mentioned that long wait to start using the service meant that they were unable to seek assistance from the Local Delivery Service and used other resources instead. Two respondents noted difficulty contacting the Local Delivery Service. One spoke of long waiting times on the phone, which led them to hang up on the call, and another mentioned that they felt the Local Delivery Service in their local authority was understaffed and unable to provide the needed assistance.

Experience of the Local Delivery Service among event participants

There were mixed views of the Local Delivery Service among event participants. One described receiving helpful support from their Local Delivery Service after they had encountered difficulties with their application and felt this support should be offered proactively by Social Security Scotland rather than waiting until problems arise. One organisational representative commented that when the information, advice, and assistance provided by the Local Delivery Service are accurate the service works well. Staff were described as personable and helpful, and less adversarial than DWP. Organisational participants at one event also appreciated that someone from their Local Delivery Service had come to speak to them and signposted them to useful courses.

Conversely, some described negative experiences such as a difficult referral process, difficulty reaching staff on the phone, a lack of available appointments, staff lacking experience, training and knowledge, and a request to meet with someone along with their carer not being taken into consideration.

Q4F. What do you think would help make people more aware of this service and the help it provides?

Just under half of consultation respondents provided an open comment at Q4F. The most prevalent theme, mentioned by many, was that Social Security Scotland should increase and improve the promotion of the Local Delivery Service. This was mentioned quite broadly without specifying the best channels or recommending any particular methods for promotion. However, many respondents agreed that the service sounded beneficial.

“More advertising of these organisations and how they help. This sounds a fantastic way to help people and a more supportive way and should be more promoted to the community and to the wider public.” - Individual

Several respondents did, however, suggest options for promotion. Some recommended social media and some others thought that advertising the service on the Social Security Scotland website, on all Adult Disability Payment-related mailings and in community settings, such as GPs surgeries, would be most effective.

Consultation – Independent Advocacy Service

Question	Yes (%)	No (%)	Don't know (%)
Q5A. Have you ever used the Independent Advocacy Service provided by VoiceAbility to help you with something to do with Adult Disability Payment? (n=81)	6	93	1
Q5B. If you said “no”, are you aware of this service and the support it offers? (n=75)	15	85	0
Q4C. If you said “yes”, did you feel that you were treated with dignity, fairness and respect? (n=15)	47	0	53

Only 6% of consultation respondents who answered said they had used the Independent Advocacy Service for help with something to do with Adult Disability Payment.

Among those who had not used the Independent Advocacy Service, 15% were aware of the service and the support it offers, while the remaining 85% were unaware.

Among those who answered Q5C, 47% felt they had been treated well, with the remaining 53% unsure. However, the number of respondents answering this question was higher than the number who claimed to have used the Independent Advocacy Service. It may be that these respondents misunderstood this question and were answering in relation to the application process more generally. Others may have misunderstood the instruction and responded if they had answered ‘yes’ to Q5B.

Q5D. If you said “yes”, how easy was it to access the Independent Advocacy Service?

Q5E. Please provide reasons for your answer.

Respondents	Very Easy	Somewhat easy	Neither	Somewhat difficult	Very difficult	No answer
No. of respondents (n=84)	4	2	3	0	0	75
All respondents (%) (n=84)	5	2	4	0	0	89
All answering (%) (n=9)	44	22	33	0	0	-

Among those who answered Q5D, two thirds (66%) felt it was easy to access the Independent Advocacy Service and one third (33%) were neutral. Again, a few more respondents answered this question than indicated they had used the Local Delivery Service. It is possible that these respondents may have been confused about whether they were answering in relation to ‘yes’ they had used the service (Q5A), or ‘yes’ they felt they were treated fairly (Q5C).

One in six consultation respondents provided an open comment at Q5E. The most prevalent theme was uncertainty about the Independent Advocacy Service and what it offers. These respondents had not heard of the service before responding to this consultation. Two others mentioned they had not used it but did not clarify if that was because they had not heard of it or did not need it. One respondent described an instance where a friend had been able to get an appointment, but it was too late for her to meet the deadline for a re-determination.

Q5F. What do you think would help make people more aware of this service and the help it provides?

Two-fifths of respondents provided an open comment at Q5F. The most prevalent theme, mentioned by many, was a request for more promotion of the service generally. Some suggested that the Independent Advocacy Service could be publicised on social media, TV, radio, and at local council offices, Jobcentres, community centres, GPs surgeries and at Citizens Advice Bureaux around Scotland. Some others suggested that direct links to the service be provided on the Social Security Scotland website, as well as in all communication about Adult Disability Payment.

Two respondents noted the importance of correct staffing levels to ensure that the level of service being offered via the Independent Advocacy Service is deliverable. As with Local Delivery Service, this related to the respondent’s difficulties contacting the service via the telephone.

Call for Evidence

Thinking about the pre-application services provided by Social Security Scotland, can you provide specific examples of:

Q4A. Parts of those services that are working well?

Q4B. Parts of those services that don't work, are confusing or could be further improved?

Just under half of call for evidence respondents commented at Q4A and just over half commented at Q4B. In these initial questions, respondents covered all aspects of pre-application services, including those delivered by Social Security Scotland.

Working well

A few respondents emphasised that Social Security Scotland staff were helpful when their clients called with questions. One Parent Families Scotland and MS Society Scotland specifically mentioned Local Delivery Service staff as providing positive input into their client's application. MECOPP and Citizens Advice Scotland emphasised that home visits are a very useful aspect of the services provided by the Local Delivery Service. They noted that face-to-face visits often helped clarify a person's needs and helped those people who did not or could not communicate on the phone.

In terms of accessibility, Feniks and Age Scotland noted the success of the language support and interpretation services offered by VoiceAbility and Social Security Scotland respectively. Another anonymous organisation mentioned that the online application submission process is working well for those who have access to computers and a certain level of digital literacy.

Improved staff training

Some felt that improved staff training is required, particularly to address a lack of awareness of certain conditions and the impacts they have on daily living. References to improved staff training included the services provided in the pre-application process, i.e., the Local Delivery Service and VoiceAbility, as well as case managers and staff working the phone lines at Social Security Scotland. For example, Cerebral Palsy Scotland noted that one in four people with Cerebral Palsy are unable to speak. They use alternative methods for communicating, including high-tech aids, and often feel that Social Security Scotland staff are not able to communicate with them successfully.

In response to Q5B, Epilepsy Scotland and FAIR Ltd, mentioned they would not necessarily recommend people to the Independent Advocacy Service as they believed the service could not offer the same level of support that they provide to their clients, due to having less knowledge or experience of either certain conditions or procedural advice. Similar concerns were raised in the engagement events. Participants spoke about receiving inaccurate advice from the service and feeling that staff lacked experience and a limited understanding of case law.

“People do not need an advocate who cannot advise. This needs to be looked at. Funding needs to be diverted to advice services for disabled people. The term advocacy is not being used in the correct way and it [is] not the correct service to access benefits. People need Welfare Rights Advice to access their rights and entitlements.” – FAIR Ltd.

Better access

Improved access to Social Security Scotland staff through dedicated telephone lines was suggested, as respondents mentioned that lines were often busy with very long waiting times. An anonymous organisation noted the importance of phone access for those who struggled with digital literacy.

Other respondents mentioned clients having difficulty contacting the pre-application services. Citizens Advice Scotland held a round table held with stakeholders which noted that there should be alternative referral pathways to enable organisations, like CABx around Scotland, to refer their clients directly to the pre-application services or to improve the provision of drop-in sessions in communities.

Other improvements to communication mentioned by a single individual respondents included better tracking of the application process, an application dashboard, and a concern that pre-application support does not work for people who do not have access to a telephone or do not like answering the telephone.

Impartiality

Another specific point mentioned by MS Society Scotland was a concern about the impartiality of the pre-application services that are funded by either Social Security Scotland or the Scottish Government, which increased mistrust in the services provided. Mistrust of the Independent Advocacy Service was also mentioned during the engagement events for the same reasons mentioned above. Participants noted that they and the people they support expressed greater confidence in approaching third-sector organisations, which they thought were more likely to consider their best interests. There were calls to make it clear that the Independent Advocacy Service delivered by VoiceAbility is independent from Social Security Scotland.

Interaction with third-party organisations

One Parent Families Scotland and one anonymous organisation emphasised the importance of providing implicit consent to advocacy organisations, in the same way as it was used for Personal Independence Payment under the DWP. One Parent Families Scotland also suggested that Social Security Scotland develop a transfer pathway with local third-sector organisations for those who may not feel comfortable using the Local Delivery Service or VoiceAbility due to fears of impartiality.

Lack of awareness and experience

Some could not provide evidence because their clients and research participants did not have experience or awareness of pre-application services. As with comments from consultation respondents, more promotion of the services was recommended.

Q5A. What evidence exists about the impact of Social Security Scotland’s Local Delivery Service in supporting people making an application for Adult Disability Payment

Positive impacts

The most prevalent theme in response to Q5A was that evidence highlights that the Local Delivery Service has provided a number of positive impacts for those applying. While a few respondents recounted positive experiences more generally, a few others mentioned specific aspects of the service that worked. These are listed here from most to least prevalent:

- The MS Society Scotland and SAMH, who both spoke with key stakeholders in preparation for this consultation response, suggested that the LDS reduced the stress of applying for some respondents.
- The MS Society Scotland also noted that they heard feedback that the LDS was helpful in gathering information for the application that the person may not have considered relevant.
- SAMH noted that it also assisted those who may struggle with digital exclusion as LDS staff members were able to collect information orally.

“The local delivery team were described as helpful in mitigating the distress caused by completing the ADP application, particularly where the applicant has a history of trauma. For example, link worker staff stated that people that use our services had told them that the volume and detail of information required in an application for ADP can be triggering, especially those who are writing down the symptoms they experience as a result of trauma. One person we support felt unable to have the physical copy of their evidence and application form within their house as seeing their experience in written form was triggering for them. This has been mitigated with support from the local delivery service, as the service can visit applicants and take evidence for the application orally.” – SAMH

Accessibility issues

One Parent Families Scotland and SAMH have both heard from key stakeholders that timely access to the Local Delivery Service could be difficult, although they noted that experiences varied across the country.

Less commonly mentioned themes:

The following concerns were mentioned by a small number of respondents:

- Issues surrounding identity checks, particularly for people working with addiction services or living in temporary accommodation.
- Child Poverty Action Group in Scotland noted that one stakeholder mentioned instances where people had applied and received a decision based on inaccurate application information. They believed that their application did not reflect what they had communicated to the Local Delivery Service staff member. They suggested that the Local Delivery Service provide applicants with the option to access their completed application.

- Participants in one event mentioned that some of the people they support may not want another professional involved in their application and highlighted the challenges they face having to retell their story multiple times.

Lack of awareness

As mentioned at the previous question, some respondents cited a lack of awareness of the Local Delivery Service among their stakeholders, or a lack of uptake of the service so far. This limited their ability to provide evidence at this question.

Q5B: What evidence exists about the impact of the Independent Advocacy Service in supporting people making an application for Adult Disability Payment.

Just under one third of respondents provided a comment at Q5B. However, some noted that due to limited awareness and uptake of the service, they could not provide evidence at this question. Others described what worked well or less well with the Independent Advisory Service, with these comments included in the analysis of responses to Q4A and Q4B above.

Q6. What evidence exists about what factors influence people approaching third sector or other public sector services for support with Adult Disability Payment?

Over two thirds of call for evidence respondents provided a comment at Q6. While organisations did not provide specific examples of existing evidence they contributed their understanding of the factors that lead people to their own, other third sector or other public sector services for support with Adult Disability Payment. These are listed below from most to least prevalent:

- Application literacy and assistance: respondents spoke of clients coming to their benefits services due to digital literacy issues, language barriers or confusion regarding the application wording.
- Accessibility: people who struggle to get through to the Local Delivery Service or Independent Advocacy Service often turn to their local third-sector or local authority teams for assistance.
- Knowledge: respondents noted that their services are often used due to their experience with the Adult Disability Payment application process or due to their insight into specific conditions which can help with the Adult Disability Payment application.
- Trust: organisational respondents noted that they work with many potential Adult Disability Payment clients on other issues and have already established trust with them, their families or their communities. In some cases, new contacts have come via word of mouth due to prior known successes with the Adult Disability Payment application. In contrast, Glasgow City Council noted that they may be approached due to a mistrust of Social Security Scotland.
- Re-determination or appeal assistance: Others noted that some people turn to third sector organisations or local authorities after they have had their initial application refused.

- Stress and anxiety: one individual and Citizens Advice Scotland suggested that people turn to their services due to the stress of the application process or previous trauma associated with Disability Living Allowance or Personal Independence Payment applications.
- Media and advertising: Age Scotland noted that after media stories about Adult Disability Payment, they often receive general enquiries about Adult Disability Payment on their helplines.

5. Rules about who can get Adult Disability Payment

Rules that decide whether someone is entitled to Adult Disability Payment are called the eligibility criteria. Adult Disability Payment is made up of two parts, a daily living component and a mobility component. As a separate [consultation of the mobility component](#) was conducted recently, this aspect of the eligibility criteria was not considered in this exercise. More information about the daily living component is provided in Appendix D.

Two sections of the consultation covered the rules about who can get Adult Disability Payment and asking about a person's daily living activities. This was also a focus of much of the discussion at the engagement events. However, because there was significant overlap in the themes evident in responses about these issues, analysis of both sections has been combined into this chapter to minimise repetition. It should be noted that questions about the eligibility criteria were not asked in the call for evidence.

Many respondents considered the rules, the nature and wording of the daily activities, and how these are asked about in the Adult Disability Payment application form, as one in the same. Where possible, a distinction has been made between themes related to the activities and about filling in the Adult Disability Payment application form.

Key findings

Daily living activities

- Views on the clarity of the rules for the daily living part of Adult Disability Payment were mixed. One third (35%) of consultation respondents agreed that the rules for the daily living part of Adult Disability Payment are easy to understand. Just under half (48%) disagreed and 17% were unsure. Reasons for disagreeing included vague terminology, difficulties relating the activities to real life, and difficulty applying them to fluctuating conditions or other specific conditions like Long COVID, ME/CFS, autism spectrum disorder, or mental health conditions. Respondents recommended clarifying the rules and simplifying the language to make the daily living component easier to understand. Others suggested using more illustrations, while participants at events emphasised the importance of accessible support for those applying.
- The vast majority (87%) indicated that people with certain conditions might find it difficult to receive points for any one or more of the daily living activities. The most common view in comments was that people with certain conditions could struggle to be considered adequately under the existing daily living activities, including a belief that the current activities were too focussed on physical disabilities. Others thought that their conditions were too difficult to describe and would struggle to reflect the impact of their conditions in the existing activities.
- Consultation respondents suggested making the activities more inclusive of all conditions, including fluctuating conditions, and ensuring that the criteria reflect the needs of those who currently feel underrepresented by the application process. There were also calls for greater transparency about the point allocation.

- Another theme reiterated throughout the consultation and engagement events was that Social Security Scotland staff would benefit from more training to better understand certain conditions and the impact they have on people’s lives, therefore ensuring effective decision-making.

Reliability criteria

- Consultation responses about the clarity of the reliability criteria were also mixed. One third (33%) felt the reliability criteria are easy to understand, just under half (45%) felt they were not, and one quarter (23%) were unsure. Those who felt they could be clarified recommended that a ‘reasonable time period’ be better defined and proposed using more examples to improve applicants’ understanding.
- Participants at the consultation events shared similar views but also suggested other changes to enhance understanding of the reliability criteria. This included referencing the reliability criteria in or at the start of the Adult Disability Payment application form and explaining reliability and the 50% rule on any initial communication.

ADP application form:

- Two thirds (68%) of those who answered felt the daily living part of the Adult Disability Payment application is effective at helping Social Security Scotland understand a person’s daily living needs; 11% felt it is ‘very effective’, 20% ‘effective’ and 37% ‘somewhat effective’. The remaining third (32%) felt it was not effective.
- Among those who felt the form was somewhat or not effective, the most common explanation in comments was that the daily living part of the application was overly rigid. Others felt that it did not reflect certain conditions or capture all relevant information or evidence.
- Similarly, event participants frequently described the application form as long, daunting, exhausting, and too difficult, and highlighted the need to consider the emotional impact on clients of completing a long and complex application.

Daily Living Activities

Q6A. Do you agree or disagree that the rules for the daily living part of Adult Disability Payment are easy to understand? You can check the [Adult Disability Payment information page](#) if you need a reminder of the rules.

Q6B. Please give reasons for your answer, outlining which parts you think are easy or difficult to understand and why.

Respondents	Agree	Disagree	Don’t know	No answer
No. of respondents (n=84)	28	39	14	3
All respondents (%) (n=84)	33	46	17	4
All answering (%) (n=81)	35	48	17	-

One third (35%) of consultation respondents who answered agreed that the rules for the daily living part of Adult Disability Payment are easy to understand. Just under half (48%) disagreed and 17% were unsure.

Vague or unclear terminology and questions

Over four fifths of consultation respondents left an open comment to explain their answer, mostly highlighting difficulties people could have in understanding the rules. Several, most of whom disagreed the rules were easy to understand at the closed question, felt the rules were not clear enough. This view was endorsed across multiple engagement events.

Reasons given for difficulty understanding included, in order of prevalence:

- Questions being vague, contradictory or unclear.
- Being unable to understand the rules generally.
- Questions being too similar or repetitive.
- The thinking behind questions not being given, so unsure how to answer.
- That it is unclear what 'reliably and repeatedly' mean in practice.
- That illustrative examples were needed.

"The questions are very repetitive, and I sometimes feel that they are this way to try and catch a person out, because you can ask two different questions, but they amount to the same answer. This confuses me." – Individual

Difficulties relating the activities to real life

People finding it hard to see how the activities relate to their own lives was an issue raised by several consultation respondents, including three organisations. Most commonly, it was noted that support was needed to help people describe their situation or the impact of their condition effectively within the context of the activities, or that relevant daily activities were not included.

"However, I feel that it can be difficult to articulate how my conditions affect me on a daily basis. I know this is something that others struggle with too, from reading experiences of others on social media, forums etc." – Individual

The most prevalent theme in comments at Q13B (What other issues with the daily living activities do you think need to be considered?) was suggestions for other activities to be included. Respondents suggested that sleep, engaging socially and managing unplanned events could be included. Participants at engagement events suggested additional areas could be housekeeping, IT literacy, quality of life, communication support, filling in forms, being part of a community, whether assistance is needed to take medication and the impact of medication side effects. Calls were made at engagement events for the eligibility criteria to be more aspirational or modernised.

“These are a direct copy from PIP and contain a lot of ambiguity... Modern daily living has changed a lot since these were put together. There should be a complete review.” - The Neurological Alliance of Scotland

Event participants also expressed the view that more detail was needed to help understand aspects of daily living activities that are already in the application, including managing washing and bathing, managing toilet needs, and preparing food. They felt greater emphasis should be placed on how people complete those tasks and the impact it has on them, rather than whether they can be completed.

To illustrate, two organisations raised issues with the preparing food activity, with #MEAction Scotland reflecting it was unclear if all the tasks involved in achieving an activity are considered in the application form or decision-making process. They highlighted that tasks involved with this activity included preparation and clearing up of equipment, utensils, work surfaces, washing up, drying and putting away after each meal, washing, cleaning the area and paying for food items in a shop, with all that entails, including getting there and back and waiting to pay. Participants at engagement events also added that more points should be awarded if the only food an applicant can prepare is of poor nutritional value.

At a few events it was reported to be hard to gain points for ‘communication skills’ and a review of this was suggested. One organisation raised that a person with learning disabilities can score zero points for ‘reading and understanding questions’, as they can read, but this did not capture difficulties comprehending or acting on the information.

Difficulties for people with fluctuating conditions

People with fluctuating conditions were considered by several to be likely to find the rules difficult to understand. Most commonly, individuals explained how variable and unpredictable symptoms made it difficult for them to complete the form accurately. Greater guidance was called for, for instance, providing more clarity on what constitutes an ‘acceptable standard’ and ‘reasonable time period’, on whether people should consider their best or worst day, and how to explain the impact of pain. More detail about the rules in relation to people with fluctuating conditions is provided in Chapter 6.

“I suffer from Long Covid and my condition fluctuated depending on how much I actually do. I work and have to take to my bed after as my body is in so much pain but I try to get through my day in pain. It’s very difficult to try to explain that to somebody.” - Individual

Easy to understand the rules

The rules and questions were considered easy to understand by some, though two felt the section on fluctuating conditions needed further work. Comments were brief and tended not to explain why they felt the rules were easy to understand. Two felt the rules were clear; for instance, one was able to tell from the criteria that they were eligible while the other felt people should “know what they can and can’t do 50% of the time or more”. Another attributed this to having had support to help them apply.

“I do think the daily living sections allow for the applicant to fully explain their condition on many different aspects of the day and helps to show the reviewer what daily life is like on the simple things such as food, clothing, washing, socialising etc.” - Individual

Difficulties for people with certain conditions

Difficulties certain people may have in understanding the rules, notably those who do not have physical disabilities, were noted by some. A few highlighted specific conditions that could impact someone’s ability to understand the rules, included ME/CFS, Long COVID, autism spectrum disorder, and mental health conditions.

In response to Q13C (Are there any other things you would like to tell us about the daily living part of Adult Disability Payment?) comments included how neurological conditions or memory issues could impact how well applicants can describe how they have completed the activities in the months before the application. It was also suggested that mental health and the ability to do things independently should be considered more in the application.

Q6C. How could the rules around the daily living part be made easier to understand?

Around six in ten consultation respondents left an open comment on Q6C. However, there was a significant overlap with responses to Q7A (If there was an opportunity to change the rules for the daily living part of Adult Disability Payment, what changes would you make?), which was answered by seven in ten respondents. The analysis below therefore presents themes raised by respondents about improving understanding, while themes about wider changes to the rules for the daily living part are presented under Q7A.

Give more detail or clarify the rules

The most prevalent theme was to provide more detail or clarification of the rules around the daily living activities. Respondents raised the need for clearly stated rules, such as to list what is included in each activity, expanding on definitions like ‘acceptable standard’ and asking more in-depth questions about “cooking, bathing, walking or getting out”.

“By asking how it affects them on maybe two out of five days, or something similar. People sometimes get flustered or are unable to understand what is being asked by the question. To have a clear question would help more.” – Individual

A few respondents also recommended that people with lived experience of different conditions, or from different target groups, participate in a redraft of the criteria, application and communication of Adult Disability Payment to ensure that it meets the expectations and captures the necessary information accurately.

Simplify the language

The need for simpler language on the form was highlighted by several individuals, and was raised across engagement events, as a way to make the rules around daily living easier to understand. Comments were received such as the need to ‘word it better’, ‘explain in simple terms’ and to use plain English.

Illustrate the rules more

Some suggested providing more examples of activities, to illustrate how the rules should be interpreted. A few felt that visual aids, including videos or pictures, could be beneficial.

Accessing support

Participants across multiple engagement events raised the importance of applicants accessing support to understand how they fit the descriptors, what case managers are basing their judgements on, and how they can best evidence their abilities and needs in their applications. In a few events, organisational representatives highlighted the skills they need to encourage applicants to share details about their condition and the preparatory work involved in supporting clients with an application such as researching the condition. Organisational participants at a few events noted that training from Social Security Scotland had been beneficial in understanding how best to complete an application form, though others felt they had learnt from experience.

Q8C. Do you think that people with certain conditions might find it difficult to receive points for any one or more of the daily living activities?

Q8D. Please give reasons for your answer.

Respondents	Yes	No	Don't know	No answer
No. of respondents (n=84)	67	1	9	7
All respondents (%) (n=84)	80	1	11	8
All answering (%) (n=77)	87	1	12	-

The vast majority (87%) of those who answered Q8C indicated that people with certain conditions might find it difficult to receive points for any one or more of the daily living activities. Most of the remaining respondents were unsure (12%).

Conditions that may not be considered adequately

Almost seven in ten respondents left an open answer to explain their answer. Several suggested people with certain conditions that may find it more difficult to gain points. These included those with mental health conditions, learning difficulties, neurological conditions such as ME/CFS, neurodivergent individuals and those with ADHD or Long COVID. In addition, it was suggested that features or symptoms of those conditions could result in people having a limited understanding or clarity about the daily living activities and how they applied to them, potentially leading to points not being awarded.

“People with conditions such as ME/CFS, rheumatoid arthritis etc. which are variable will suffer as they may not meet the 50% rule. There are also conditions that are uncommon and rare, that are misunderstood and discounted (e.g. ME) or cover a wide range of disability (such as autism). These tend to need a specialist to understand how things affect the individual.” - Individual

Difficulties describing certain conditions

The difficulty in being able to adequately describe conditions, or their impact, in the context of the daily living activities was highlighted by several individuals. Comments often drew on personal experiences. Some felt the rules or questions were too rigid to allow people to fully articulate how their conditions impacted them. For instance, while it may be possible to achieve an activity, the consequences of doing so were not taken into account. Two felt describing the impact of their disability was emotionally challenging.

“Speak to me, listen to me, understand my conditions. I feel I don't fit boxes, so I'm dismissed & not taken seriously. It's upsetting & undignified.” - Individual

“I have postural tachycardia syndrome which means I am OK as long as I don't stand up. When I do I faint. I don't know where that would fall with the 50% rule as I am not unconscious more than 50% of the time, but I'm at risk 100% of the time.” – Individual

Other considerations should be included

Several left suggestions for other aspects that should be considered within the daily living section. These included, as described previously, pain, energy, fatigue and medication side-effects, for example. This is explored more under Q7A below.

The current approach works

Some stated they agreed that the current activities allowed for the impact of fluctuating conditions to be accounted for. Views included that as long as people were treated as individuals and able to articulate any impacts, then the current approach would work.

Too focused on physical disabilities

A perception was expressed by a few that the form or decision-making process were overly focused on those with physical disabilities. Respondents felt this made it harder for others to be awarded points, as the questions were not aligned to their situation. It was felt those with mental health conditions would experience this in particular, and a view raised in a few events was that the current eligibility criteria are not accurately capturing the needs neurodivergent individuals or those diagnosed with mental health conditions such as anorexia or bulimia. It was suggested during one engagement event that a mental health question could be included alongside each activity.

One consultation respondent explained that completing the form was difficult when there were “so many factors that can impact on mental health issues”. One called for an overhaul of the questions to make them more relevant:

“If your dopamine and serotonin systems are disabled, so you don't want to do anything, and you are so totally exhausted that you can't even bring yourself to think about doing anything, it is not easy to get points, because you don't need help, because you don't want to do anything anyway... The whole basis of the questions is the 'disabled' person with mobility or sensory impairment. The whole way the questions are framed needs to be rethought.” – Individual

Q7A. If there was an opportunity to change the rules for the daily living part of Adult Disability Payment, what changes would you make (if any)?

Make changes to benefit people with specific conditions

According to several respondents at Q7A, changes to the rules for daily living could make it easier for people with specific conditions to apply for Adult Disability Payment.

Conditions identified by respondents included multiple sclerosis, diabetes, ME/CFS, Long COVID, neurological disorders, autism spectrum disorder, mental health conditions e.g. schizophrenia, learning disabilities, communication difficulties, and people with visual impairment. More detail about people with certain conditions is provided under Q8C/D below.

“Make it more disability friendly, easier to read. Not literal. Autistic people can find the literal questions hard to deal with and think there is nothing wrong when often there is.” – Individual

Ensuring the rules can be interpreted by, or reflect, the needs of those with certain conditions was highlighted by some. These comments suggested the application form questions and process should be worded or structured to include activities that take account of the range of circumstances faced by people in daily life. The need for the application to better capture symptoms was highlighted, such as asking for more information about pain, fatigue, side effects of medication, cognitive ability and lack of motivation. As noted above, there were also calls to include more questions related to mental health, or the impact of mental health on undertaking daily tasks.

“Reliability is a really important criterion for people with energy impairment conditions (ELCI), but it’s problematic because the energy required to perform any of the activities draws upon the same limited supply of energy, and doing one activity means there is less energy for another activity. Reliability refers to someone who is so exhausted after preparing breakfast that they can’t eat it, or they cannot prepare lunch too. Or someone with ELCI might be so exhausted after preparing breakfast that they can’t get dressed or have a shower. The cumulative impact of activities needs to be recognised, and the need to take into account the full spectrum of activities (e.g. preparing food + washing + dressing). The impact should take into account a range of factors including fatigue as well as delayed fatigue (one symptom of post-exertion symptom exacerbation) as, with people with ME/CFS, the onset may be 48-72 hours or more later.” – #MEAction Scotland

At a few events, participants highlighted the need to avoid using a deficit-based model, and instead use more questions grounded in a social model. This would consider how barriers presented by daily life impact independent living, rather than focusing on limitations due to disabilities. This was felt useful in helping a wider range of people to believe Adult Disability Payment could apply to them and avoid having to think about worst days or perceived personal limitations.

Make changes so it reflects fluctuating conditions

Another prevalent theme, aligned to the above, was for changes to make it easier to describe fluctuating conditions. Points made in these comments included that people are

individuals and applications should be considered on a case-by-case basis, that the questions should better reflect daily living and that cumulative and wellbeing impacts should be considered.

No change needed

A few individuals felt the daily living rules did not need to change. One felt the taking nutrition question was “worded most appropriately as it gives clearer examples”.

“I believe changes with the system are not what is needed. Only understanding and patience within the process and the people involved.” – Individual

Transparency over points allocation

Calls for greater transparency in how points were allocated were also made in a few events. It was noted that the descriptors used to allocate points and the reliability criteria are not currently included anywhere in the Adult Disability Payment application form. It was suggested that the descriptors should be included on the application form, or that there should be an option to download them, to help people understand the points system and why they are being asked the questions. In turn, this may enable them to understand what information about their condition and needs is relevant or helpful to include in their application.

Q7B. If you suggested changes, who do you think might be better off?

People with disabilities or eligible people that apply

Half of respondents left an open comment, with several suggesting that the person with a long-term condition or disability would benefit from changes made to the daily living section. Singular suggestions for who may benefit included those just under the threshold for an award currently, those who struggle with paperwork, and “working households who happen to have a disabled family member”.

“Everyone who has just been diagnosed with either an illness or disability. People who become disabled are usually hit very hard financially by the impact of their disability. Also their independence is affected. But the hardest impact is definitely financially.” - Individual

People with specific conditions

Several respondents felt changes to the daily living section would benefit groups with specific conditions, as described above under Q7A.

Myself, or everyone

A perception that changes would benefit everyone or ‘people like me’ was raised by some. Singular comments on why this was the case included that it would give a better understanding of daily challenges faced by applicants, it would improve financial wellbeing and it would better accommodate those whose situations cannot be categorised easily.

People with fluctuating conditions

Some noted changes to the rules for the daily living part of Adult Disability Payment to better capture the changing nature of symptoms would benefit those with fluctuating conditions, though comments were generally brief. One felt it was important for case managers to have better understanding of the highly variable nature of some conditions.

Q7C. If you suggested changes, who do you think might be worse off?

Fewer than half of respondents left an open comment in Q7C.

No-one will be worse off

Several felt no-one would be worse off from suggested changes to the daily living section; this was by far the most prevalent theme. Respondents tended not to give further detail, though singular comments included that further resources or training may be needed to achieve the changes.

People who don't fit the criteria

Those who would not qualify, or those making fraudulent applications, were considered by some as likely to be worse off from changes to the daily living rules. Again, comments were brief.

People who did not receive an award

A few felt people in certain situations could be worse off. Two were of the view that people whose case managers did not fully understand their fluctuating conditions would be worse off, as they may not be awarded Adult Disability Payment. Other singular comments included those who were dependent on Adult Disability Payment and subsequently found not to qualify or those who had a poor relationship with a GP or consultant.

Reliability Criteria

Q9A. Are the rules around an activity needing to be completed safely, to an acceptable standard and within a reasonable time period easy to understand?

Q9B. If you said "no", what would you change to make them easier to understand?

Respondents	Yes	No	Don't know	No answer
No. of respondents (n=84)	26	36	18	4
All respondents (%) (n=84)	31	43	21	5
All answering (%) (n=80)	33	45	23	-

One third (33%) of consultation respondents who answered Q9A felt the reliability criteria are easy to understand. Just under half (45%) felt they were not and one quarter (23%) were unsure. Fewer than half of consultation respondents left an open comment to explain changes they would make to the reliability rules to make them easier to understand.

Further define ‘reasonable time period’

The need to further define ‘reasonable time period’ so it could be more easily understood was recommended by some. Reasons given included that this was a subjective concept which could pose challenges for those who found ambiguity difficult.

Make the reliability criteria clearer

Some left brief general comments that the reliability criteria could be clearer. Singular comments included the criteria being hard to understand, the need to provide definitions for terms used and questions feeling repetitive in the absence of clear explanations. The need for more clarity was also raised at a few engagement events.

Use more examples

Using examples to illustrate conditions and their impact was suggested by some. Similar calls were made at engagement events, such as for improved explanations, case studies people can relate to and more examples of how descriptors apply when someone has a mental health condition or is neurodiverse. Comments included that examples should be specific or given for each daily living activity. #MEAAction Scotland called for the use of an example of someone with an energy limiting condition.

The reliability criteria should reflect real life

A few felt changes should be made to enable better, or more consistent, account to be taken of people’s actual lives. This was viewed as necessary as people may interpret the reliability criteria differently, based on their subjective experience:

“What you classify as safe and timely I don’t. Is taking thirty minutes to get to the toilet a safe and timely manner when I end up wetting myself or worse? It takes every ounce of strength I have, to go to the toilet. Yet for an able-bodied person they CANNOT imagine how wiped out I am after a simple task they can do in 30 seconds.” – Individual

Comments on the reliability criteria at engagement events

While the concept of reliability was noted to be helpful at one event, participants at a few events felt this lacked clarity on the Adult Disability Payment application form. At one event, concern was expressed that if applicants do not understand what is meant by ‘reliably’, they might answer ‘yes’ to one of the activities and move on to the next activity when in fact they may not be able to do the activity reliably and a significant amount of information about their needs and condition could be omitted from their application. This same issue was highlighted by an anonymous organisation in their call for evidence response who had received similar feedback from their stakeholders. This respondent additionally noted that this confusion and lack of information could potentially lead to incorrect awards if the case manager is unable to apply the criteria in all decisions.

At another event, the need to increase applicants’ awareness and understanding of the reliability criteria and the 50% rule before starting the application process was identified, although it was recognised that too much information could overwhelm the applicant. There were suggestions to:

- Reference the 50% rule and reliability criteria on promotional material.

- Explain reliability and the 50% rule in the initial letter to applicants and during any initial phone call with a Social Security Scotland advisor, to help people determine if they should apply.
- Explain at the start of the application form how reliability and the 50% rule are being used to understand people’s condition and the impact it has.

Other suggestions made in events to increase understanding included to:

- Restate the reliability criteria – i.e. safely; to an acceptable standard; repeatedly; and within a reasonable time period” – more often throughout the application form.
- Have boxes next to each activity to describe what is ‘reasonable’ to expect e.g. to not be in more pain.
- Change the wording to ‘reasonable’ to reflect that it is not always possible to be ‘reliable’ due to the weather, lack of aides etc.

The ADP application form

Q12A. How effective do you think the daily living part of the Adult Disability Payment application is at helping Social Security Scotland understand a person’s daily living needs?

Q12B. Please give reasons for your answer.

Respondents	Very Effective	Effective	Somewhat Effective	Not very effective	Not effective at all	No answer
No. of respondents (n=84)	8	15	28	13	11	9
All respondents (%) (n=84)	10	18	33	15	13	11
All answering (%) (n=75)	11	20	37	17	15	-

Two thirds (68%) of those who answered felt the daily living part of the Adult Disability Payment application is effective at helping Social Security Scotland understand a person’s daily living needs; 11% felt it is ‘very effective’, 20% ‘effective’ and 37% ‘somewhat effective’. The remaining third (32%) felt it was not effective.

Overly rigid

Just under two thirds of consultation respondents provided an open comment to Q12B. Of those, the most common theme was that the questions in the daily living part of the Adult Disability Payment application are too rigid to fully capture a person’s daily living needs. Respondents noted that due to the specificity of the questions or the tick-box nature of the application, they felt not all details about activities were gathered.

“Again, it is the 1-size-fits-all approach. I can make a cup of tea. I cannot remember when or where I put it. But that does not matter. The box is ticked.” - Individual

Another individual thought it was important to emphasise the form was not asking about the type of condition or disability a person has, but rather how it impacts their life.

“Forms to be more detailed, explain that it’s not what conditions you have, but how it impacts on daily living and mobility. Simplified questions that explain the qualifying criteria.” - Individual

Effective

Some shared that they felt the daily living part of the application effectively captured their experiences. These respondents noted that the application covers a range of day-to-day activities and gives space to allow people to explain their situation. The prompts were also mentioned as useful by a few.

“Plenty room to explain your situation and good prompts on the application form to remind you of things that may be relevant that you’d otherwise maybe have forgotten to mention. People with mental health issues especially can experience brain fog/confusion/overwhelm so prompts are really helpful.” - Individual

Not reflective of certain conditions

A small number thought that this aspect of the application was geared more toward people with physical disabilities and that more consideration should be given to those with fluctuating, mental health, or neurological conditions. They did not provide any further detail as to why or how.

Does not capture all the information

A few thought this section of the application was not effective in capturing their lived experiences. For example, two respondents suggested that it include space to explain the impact completing the activities had on wellbeing and energy levels. Another two thought that the application should acknowledge the difficulty some may feel in speaking about their conditions, particularly those who were newly diagnosed.

“Also, people who have a disability or illness can and do have severe anxiety or distress in a social situation, and some do feel embarrassed by their condition. A one [size] fits all unfortunately is too often the standard when it is far from that.” - Individual

Challenges associated with a deficit-based model or people not recognising or disclosing their difficulties was raised at multiple events. Participants highlighted that people may find it difficult to think about their ‘worst day’ or open up about their difficulties. They may have developed coping strategies which means they do not always perceive themselves as having a disability, or may interpret the questions differently than others due to the ambiguity of the questions. One example given was of people reporting that they can cook a simple meal, when in fact they need support to do this safely or are unable to prepare a nutritional meal. Another example is that an applicant may answer that they leave home when they only do this twice a year to visit their GP. The particular challenge for people with fluctuating conditions to recognise or convey their support needs was mentioned in a few events, given that their ability to do things might vary at different points in time.

Comments on the application form at engagement events

While the consultation included Q12A/B above which specifically explored the daily living part of the Adult Disability Payment application form, the form was one of the four main areas of focus at the engagement events. To ensure the themes raised and discussed at events are described fully, these have been presented separately in the following section.

Perceptions of the physically and emotionally demanding nature of making an Adult Disability Payment application, and the importance of people being supported to manage the process and to complete the form well, were mentioned in all events. The main points of these discussions are summarised below.

Emotional considerations

When considering the emotional impact of applying, event participants highlighted that they or the people they support reported feeling uncomfortable, distressed, overwhelmed or embarrassed. It was noted that, because the questions lead people to consider their limitations, it can be challenging for an applicant to face what they cannot do, or how their life has changed. For example, people with mental health conditions were identified at one event as being at risk of finding the application process stressful, or that being asked the questions could trigger paranoia. Participants also highlighted how they need to be careful when asking questions of applicants when supporting them to complete the form.

Related to this, a small number of consultation respondents suggested that assistance be given to people who find speaking about their conditions difficult or who have had previous negative experiences with their conditions being dismissed. Two specifically mentioned challenges with GPs and medical professionals accurately understanding their lived realities, which made them more worried about their Adult Disability Payment application.

Length of the application form

The application form and process were described by event participants as daunting, exhausting, long and difficult. The specific impact on people whose conditions mean they experience difficulties with concentration, brain fog or fatigue was highlighted, with concern expressed this may lead people to “give any answer just to get the process over and done with”. Concerns were also raised about those whose first language is not English due to translators needing to understand nuances and jargon. It was suggested that the application form explicitly encourage people to draw on the support of family members, professionals or advocates when completing the form to make sure they are representing themselves effectively. There were also suggestions to increase the support available to people during the application process such as:

- Providing opportunities to have a conversation with someone instead of filling in a form, or to establishing a specialist team within Social Security Scotland offering face-to-face appointments to take away the stress linked to form filling.
- Increasing resources to, and availability of, community support services to enable them to offer more assistance to those applying.

The strengths of the form, such as the value of free text questions and space for elaboration at the end, the straightforward layout and sensible grouping of questions were

noted in a few events. However, improvements to the application form were suggested in multiple events. These included, in no particular order:

- Including more open questions and space for free text responses throughout.
- Multiple choice questions for those who struggle with handwriting.
- Improvements to colour contrasts on the paper version to increase accessibility for those with visual impairments.
- Reviewing the use of language through a neurodiversity lens to support understanding of the questions.
- Providing different versions of the form, for instance a condensed version without photos specifically for support organisations so that it is easier to navigate.
- Less high-quality paper and binding to make this easier to fit into an envelope to return along with supporting documents.
- Making it easier to un-staple and copy the forms, as the booklet format means support organisation staff spend significant amounts of time scanning individual pages so they can be saved on their organisation's client databases.

At a few events there were mixed views about whether to shorten the application form by, for example, removing or having pictures in a separate document. However, the pictures and easy read information were recognised as being beneficial for supporting people's understanding and breaking up dense text, making the form more accessible for people with concentration difficulties or a learning disability. Concern was expressed about having to navigate two forms and that separating the pictures into a different document would exclude some people.

Paper vs online applications

The advantages and disadvantages of both paper and digital application options were discussed at a few events, typically concluding that it was helpful to have both to meet different needs. One consultation response suggested a responsive online form that takes answers into consideration and provides relevant follow up questions.

Challenges with digital and IT applications were raised in a few events, however. There were reports of technical issues with the submission portal and problems uploading online applications due to file size, with advisors having to scan these in two or three parts or reduce image quality. There were reports of fewer open text questions on the online form, compared to the paper form. It was highlighted that people can often forget their Government Gateway logins and passwords. There was also concern at one event that online applicants do not automatically get a copy of their application and may struggle to remember their responses if needed for a re-determination. There was acknowledgement that Social Security Scotland sends a copy if requested, but some felt this should be automatic or there should be a button online to request a copy. There was also a call to have audio-visual features on the online form to support people who are visually impaired.

Other considerations

Q13A. Are there any other issues with the daily living part of the Adult Disability Payment application that have not been captured above?

Respondents	Yes	No	Don't know	No answer
No. of respondents (n=84)	24	19	28	13
All respondents (%) (n=84)	29	23	33	15
All answering (%) (n=71)	34	27	39	-

One third (34%) of those who answered indicated that there are other issues with the daily living part of the application. However, two fifths (39%) were unsure.

Q13B. If you said “yes”, what other issues with the daily living activities do you think need to be considered?

Q13C. Are there any other things you would like to tell us about the daily living part of Adult Disability Payment?

In line with the results of the closed question, just over a quarter of consultation respondents provided further considerations at Q13B. In addition, just over one quarter commented at Q13C. In most instances the points raised aligned with themes already covered earlier in this chapter and have been included under the most relevant question. The below therefore presents other themes arising here and throughout this chapter about Social Security Scotland staff training, other views on the Social Security Scotland workforce and comments about the wider decision-making process.

Social Security Scotland staff training

The most prevalent theme in responses to Q13C, mentioned by a few respondents, was that staff need more training to better understand certain conditions and the impact they have on people’s lives, therefore ensuring effective decision-making. This point was reiterated throughout the consultation and engagement events.

Specifically in relation to the daily living activities, respondents noted that any changes made to the daily living part of the Adult Disability Payment application needed to be reflected in the medical literacy of case managers who review the applications. Similarly, a few respondents at Q7A highlighted the need to ensure staff have a detailed understanding of different conditions and how they impact people, or are using active listening skills. Two respondents noted concerns that case managers are not reading or understanding their supporting information from medical professionals.

“Only that the decision-makers seem to be the issue, not the application itself. I don’t know if the decision-makers are production oriented or quality oriented. It needs to be kept in mind that they are making life-changing decisions that affect real people” - Individual

Wider contact with staff during the application process was described positively in a few engagement events. However, challenges and suggestions for improvements were also

raised. Levels of knowledge and training across Social Security Scotland were felt to be inconsistent. There was a suggestion that Social Security Scotland case managers and those in client facing roles have more condition specific training to hear about new conditions, which could prevent clients having to repeatedly explain their condition or symptoms. An example was given of an individual receiving six calls with six different practitioners for one application and having to repeat the same information to each one.

One event participant expressed a view that fewer Adult Disability Payment applications were being awarded as Social Security Scotland staff gained more experience. This meant their organisation was having to support more re-determinations than had previously been the case. They called for improved training and institutional knowledge to help minimise inconsistencies in decision-making.

Comments about Social Security Scotland workforce at engagement events

A range of other comments about Social Security Scotland staff, not necessarily related to training, were noted across engagement events. These have been summarised below.

There was a call for better collaboration and communication between Social Security Scotland staff and other professionals. This includes them having a known point of contact in Social Security Scotland to resolve issues, clearer internal escalation routes, greater recognition of implicit consent built into the advisor relationship, and an improved process for third-party organisations to send in their consent mandate. For example, one organisation ticked the box for mandate for one year, but after the application took longer they could no longer speak to Social Security Scotland; while this highlighted the need to request a five-year mandate, they called for greater flexibility.

A few others also suggested that the workforce and the resourcing to handle Adult Disability Payment administration should be increased to positively impact processing times and allow case managers to thoroughly read and respond to applications. An organisational participant at one event noted that a single telephone line for all services made it difficult to get through to the necessary services. They acknowledged the simplicity and accessibility of a single number for all queries, but practically that meant long wait times and confusion for those calling. Another noted that there were no easily accessible escalation routes for queries or clear referral pathways. While another acknowledged they do exist, they felt these would be very difficult for individual applicants to use. It was also felt that the system should recognise some people experience difficulties using the phone or speaking to people.

A few event participants noted that paper forms have sometimes gone missing even though their organisation has a record of postage or where a Social Security Scotland advisor has previously referenced having the documentation.

Wider decision-making process

The second most prevalent theme in response to Q6C – how could the rules around the daily living part be made easier to understand? – was that some respondents called for wider changes to the decision-making process beyond considering daily living.

Suggestions included using Occupational Therapists more effectively to assess peoples needs, to “overhaul” or “scrap” the rules, to integrate Adult Disability Payment with NHS

systems so “doctors and consultants treating the patient are the decision-makers” and to treat private medical supporting information the same as public-sector supporting information.

In response to Q13C, few individuals left mixed comments on using points to determine awards. One organisation noted:

“Overall, the ALLIANCE are not convinced that a points and deficits based model of assessing a person’s daily living needs is the best approach to determining eligibility for disability payments. As such, we would encourage the review to consider alternatives to the current points based system for determining eligibility for ADP. Whilst a points based system may be easy to administer, it does not necessarily sit well with a human rights based approach to social security or with the provision of adequate support. Whether fairly or not, people may perceive a points based system to be rooted primarily in controlling costs for the government, rather than ensuring the right support is given to disabled people. In particular, there is potential for serious psychological distress where individuals fall only marginally short of a required number of points, risking giving the sense that they are “disabled, but not disabled enough” to justify support.” – Health and Social Care Alliance Scotland

Alternative ways of assessing daily living needs were suggested at a few events. These included:

- More of a clinical decision-making process to avoid situations where people request a re-determination or appeal because they are one point away from an Adult Disability Payment award.
- Removing the need to apply, or alternatively fast-tracking or simplifying applications for those with certain conditions such as loss of sight and hearing, amputation, MS, autism, and other conditions that are progressive or will not improve, in the same way as for those with terminal conditions.
- Social Security Scotland being more proactive in the first stage of the application at understanding whether a person is eligible and giving certain conditions a shorter form or a different way of applying.
- Basing Adult Disability Payment upon Disability Living Allowance using a qualitative approach drawing on the social care assessment of England and Wales and their 9 wellbeing points.

6. Fluctuating Conditions

This chapter examines respondents' views about the fluctuating conditions section of the Adult Disability Payment application form and how these are considered. Social Security Scotland defines fluctuating conditions as disabilities or conditions that can change frequently. These may include conditions like asthma, epilepsy, Chronic Obstructive Pulmonary Disease (COPD), bipolar disorder, or post-traumatic stress disorder (PTSD). The application form provides guidance for clients to understand how the rules for Adult Disability Payment are applied for people with fluctuating conditions. While the fluctuating conditions can also affect mobility, this is covered in a previous [separate consultation about the mobility component of Adult Disability Payment](#).

Key findings

- Seven in ten (70%) consultation respondents felt the daily living activities do not allow the impact of fluctuating conditions to be accounted for adequately. Both respondents and event participants suggested that people with fluctuating conditions may struggle to describe the impact of their fluctuating conditions, with the Adult Disability Payment application form viewed as being too rigid and inflexible, with little opportunity to describe nuance or the impact of multiple conditions.
- Mixed views were expressed about the fluctuating conditions section of the Adult Disability Payment application form. Some consultation respondents found it confusing or felt it did not consider the impact of bad days on life and wellbeing. In contrast, some others commented that the section allowed them to adequately represent their conditions.
- Respondents suggested changing the 50% rule, with suggested alternatives including a 30% rule or a sliding scale depending on the impact of fluctuating conditions on daily life. Considering the wider impacts of how completing a task can affect a person's life was also recommended as a change.
- While respondents typically felt that any changes made to the fluctuating conditions sections would improve clients' outcomes, a small number raised concerns including that a longer application that could be more difficult to complete and increased costs for the Scottish Government.

Q8A. Do the current daily living activities adequately allow the impact of fluctuating conditions to be accounted for?

Q8B. Please give reasons for your answer.

Respondents	Yes	No	Don't know	No answer
No. of respondents (n=84)	9	55	15	5
All respondents (%) (n=84)	11	65	18	6
All answering (%) (n=79)	11	70	19	-

Seven in ten (70%) consultation respondents who answered felt the current daily living activities do not adequately allow the impact of fluctuating conditions to be accounted for. One in ten (11%) felt they did, and one fifth (19%) were unsure.

The activities do not account for fluctuating conditions

Almost seven in ten consultation respondents left an open comment giving reasons for their answer. Several individuals felt that the daily living activities did not adequately account for the impact of fluctuating conditions, with this view endorsed across multiple events. Commonly the challenges of describing or measuring fluctuating conditions was highlighted, and were highlighted across multiple engagement events. Two respondents commented on the 50% rule, with one perceiving it was not inclusive, and the other, that it was unfair. Discussion in the engagement events suggested this was because a person may not reach the 50% threshold, but still have significant needs some of the time. An example was given of people with a visual impairment experiencing fluctuations linked to the season or time of day, which is not taken account of under the criteria. There were calls for a better way of capturing the needs of this group, although the risk of making the criteria more complex was acknowledged at one event.

“It is not possible to measure the frequency of the fluctuating condition and its impact. People will either fill it in based on their worst day (even if that day is only once a month) or they will under describe their level of difficulty.” - Individual

A few felt it was difficult for people to describe fluctuating conditions, or their impact, using the current approach, potentially leading to receiving less support than they are entitled to.

“As outlined in our response to other questions, we believe individuals with fluctuating conditions may struggle to describe how they are impacted in the way the form suggests. This may lead to some people receiving less support than they should be entitled to, and it may dissuade others from completing their application in the first place.” - Health and Social Care Alliance Scotland

The activities do not capture uniqueness

The daily living activities were considered insufficient for capturing the individual nature of people’s conditions and circumstances, according to several individuals. The Adult Disability Payment application form was viewed as being too rigid and inflexible, with little opportunity to describe nuance or the impact of multiple conditions. This view was also raised at multiple events, with calls for ‘sometimes’ to be added as a category in addition to ‘yes’ and ‘no’, and for more opportunities to leave open comments around how activities are undertaken, such as tasks requiring assistance and how long they take. One highlighted that conditions impact people differently and felt this should be recognised:

“Too often people are asked as if their illness/disability follows a rule. Everyone, no matter who they are, has had an illness, from something as simple as a cold or flu. They do not follow a rule, nor are they exactly the same as others. Person A may have a cold that’s lasts 2 days, but Person B may have a cold that’s lasts 4 days. People are unique and are individuals and they should be treated as such.” - Individual

Comments on best and worst days

Several commented describing their best or worse days. The most common view was that people would describe their worst days to gain points. Two individuals called for ‘worst days’ to be asked about directly on the application form. Others commented on having some good and bad days and felt that this should be acknowledged in decision-making.

Q10A. How effective do you think the fluctuating conditions sections of the application form are at helping people to describe their daily living needs?

Q10B. Please give reasons for your answer.

Respondents	Very Effective	Effective	Somewhat Effective	Not very effective	Not effective at all	No answer
No. of respondents (n=84)	1	12	15	24	17	15
All respondents (%) (n=84)	1	14	18	29	20	18
All answering (%) (n=69)	1	17	22	35	25	-

Among those who answered, three fifths (60%) felt that the fluctuating conditions section of the application form is ineffective at helping people to describe their daily living needs; 35% felt it is ‘not very effective’ and one quarter (25%) that it is ‘not effective at all’. While the remainder felt it is effective to some extent, most of this group felt it was ‘somewhat effective’ (22%) or ‘effective’ (14%), rather than ‘very effective’ (1%).

Confusing

Just under two thirds of consultation respondents commented at Q10B. The most prevalent theme was confusion over the fluctuating conditions section of the application form. Respondents were unsure what the prompts were asking, unsure what they were meant to convey in this section, and one respondent noted they did not know there was a section of the application that considered fluctuating conditions. Two respondents asked for clearer details and one suggested the use of words like “fluctuating”, “fluctuates” or “fluctuation” to clarify the experiences the section was addressing.

Similarly, at multiple engagement events the 50% rule was described as confusing, complicated, unclear and “not translating well to people filling in the form”. Participants felt the rule was difficult for both applicants to quantify and for case managers to apply. The small size of the open text box for both the 50% rule and the reliability criteria was also identified at one event as barrier to understanding, as this leads applicants to think that case managers do not require a lot of information.

No consideration of impact of bad days on life and wellbeing

Some felt that the fluctuating conditions section was ineffective at capturing the continued impact of bad days on a client’s life and wellbeing in the longer term.

“Doesn't score someone if they have two bad days a week, even though those two days have a massive impact.” – Individual

“It is not possible to hold down a job if you are bed bound 20% of the time, yet you wouldn't qualify for support if this was the case.” - Individual

The way conditions can fluctuate either rapidly over short periods of time or extremely, leaving people fine one moment and bedbound the next, was mentioned by some. They felt these rapid or extreme changes were not accounted for in the guidance or application form. A few noted how this can make reporting fluctuating conditions difficult. One noted that the experience of fluctuating conditions is so individual or specific to each condition that it makes a single understanding of them, as requested in the application, ineffective.

Not reflective of certain conditions

A concern that the application form did not capture all conditions well was referenced by some. While some respondents spoke universally, expressing a view that the section was too rigid in presenting a single idea of fluctuating conditions, others mentioned specific disabilities or conditions they felt were excluded from the application questions. These included: non-physical disabilities, Long Covid, Functional Neurological Disorder (FND) and other neurological conditions.

Difficulty describing impacts

A few respondents found it difficult to describe the impacts of their fluctuating conditions within the application form. Although they did not provide any further details on how to improve the application form to collect this, one respondent noted a positive experience with the Local Delivery Service who helped them articulate the impact of their condition well.

“How can another individual who is assessing you possibly understand my condition and how it fluctuates. It is one of the hardest things for me to describe the intensity of my pain. How do I apply that to a piece of paper?” - Individual

Positive comments about fluctuating conditions sections

In contrast, some respondents felt that the fluctuating conditions section of the application form representing people's conditions or disabilities and allowed them to reflect on their individual circumstances. Respondents liked the examples provided in the application and felt there was ample space to describe conditions. Singular comments were received about the experience of applying, of feeling accepted when admitting having good as well as bad days or being able to describe how a condition uniquely impacted them.

“The daily living activities goes over many aspects of one's day and so there is ample opportunity to talk about how one's condition affects their life in even the simple small details. This helps paint the picture for the reviewer to fully understand the daily life of who is being reviewed.” - Individual

One noted that while they found the application easy to fill out, there was still concern about how a case manager may interpret the information provided.

Q11A. If there was an opportunity to change any specific parts of the rules around fluctuating conditions as part of the daily living activities, what changes would you make (if any)?

Change the 50% rule

Just over half of respondents provided an answer at Q11A. Of those, there were two equally prevalent themes. The first was a suggestion to change the 50% rule. Suggestions included changing the guidance to a sliding scale depending on how often or how severely a condition impacts a person's life, or to make it a 30% rule rather than a 50% rule.

“The ALLIANCE have consistently called for the 50% rule to be scrapped... Although daily living and mobility are considered separately, the same logic applies to both in relation to fluctuating conditions. We believe this approach may not give an accurate indication of the impact of a person's condition. Whilst the 50% rule applies both to stable and fluctuating conditions, the negative impacts of this approach may be most strongly felt by people living with fluctuating conditions. The nature of fluctuating conditions is such that it may not be possible for people to predict or estimate how frequently they will be impacted. Understanding how people are impacted on their worst days would likely be more useful, both in terms of determining support that may be necessary and reassuring applicants that their experiences are valid and will be taken into account.” – The Health and Social Care Alliance Scotland

Consideration of impacts of daily activities

An equally prevalent theme emphasised the importance of asking about the impacts of daily activities on people with fluctuating conditions rather than just asking whether certain tasks can be accomplished. This could include considering the pain arising during or after the activity, the necessary recovery time and pain relief needed to recover.

“Each daily living activity needs to include a reference to fatigue and delayed fatigue post-activity e.g. how do you feel afterwards? And what impact does doing this activity have on your ability to do other activities?” - #MEAction Scotland

Others suggested changes

A few respondents provided other suggested changes to the rules around fluctuating conditions which are listed here from most to least prevalent:

- A dedicated part of the application form for people with fluctuating conditions, including different ways of gathering evidence supporting information such as a diary of bad days.
- Make application wording clear that fluctuating conditions are recognised and considered.
- Provide more assistance to help those with fluctuating conditions fill out the form correctly.
- Ensuring that any revisions to the application form are developed with input from those with lived experience of fluctuating conditions.

Case manager training

While not directly answering the question, others mentioned the need for case managers to receive more thorough training around specific conditions, including fluctuating conditions, to help them understand the impact the life and wellbeing of the client.

Q11B. If you proposed changes, what positive impacts could these have, and for who?

Just over two fifths provided a comment at Q11B. The most prevalent theme was a belief that the changes would provide improved outcomes for those with fluctuating conditions. Some suggested it could lead to more points and therefore higher Adult Disability Payment awards, which could improve financial security for those with fluctuating conditions. A few suggested that it could improve the quality of life by allowing those with fluctuating conditions to have the correct help organised for when bad days occur.

Some thought that the changes would provide those with fluctuating conditions a sense that their voice had been heard and considered. They emphasised that the changes suggested were necessary to ensure those clients with fluctuating conditions were taken seriously and treated with dignity and respect. A few noted that it would allow people to fully comprehend their conditions and the impact on their lives.

“This would help people to actually looking more at how their condition affects them in order to have a better understanding of their abilities in doing things that the forms are asking. This would then help the accessor to understand more about that person and therefore to help in making a decision.” - Individual

An outcome mentioned by a small number was that the application with the additions mentioned would be fairer and lead to fewer re-determinations and appeals.

Q11C. If you proposed changes, what negative impacts could these have, and for who?

Just over one third of respondents provided a comment at Q11C. The most prevalent theme by far was that the suggested changes would lead to no negative impacts for those with fluctuating conditions.

Two individuals suggested that the changes may make Adult Disability Payment more costly for the Scottish Government as more people could qualify or be awarded a high rate. Two respondents suggested the changes could lead some clients to lose points and either not qualify or lose their award; however, they did not explain how this would happen.

One respondent each mentioned the following themes:

- There was concern that adding more elements to the application may make the application more difficult to complete.
- Similarly, there was a suggestion that the application could become more confusing.
- One respondent noted that any increased contact with Social Security Scotland staff to clarify aspects of fluctuating conditions may cause greater amounts of stress among clients.

7. Decision-making

This chapter analyses responses to questions about of Social Security Scotland's decision-making process for awarding Adult Disability Payment. Social Security Scotland provides both clients and case managers with guidance for consideration of environmental, cultural and social factors. This is to ensure consistency and fairness during the decision-making process.

In contrast to Personal Independence Payment, Social Security Scotland requires one piece of supporting information from a formal source, such as a social care assessment, medical report, or prescription list. Social Security Scotland uses consultations with a Social Security Scotland practitioner to help gather more information about the application and assist practitioners in the decision-making process. Consultations can take place over the phone, by video call, at a local public venue or in the person's home. A person is only invited to take part in a consultation when there is no other practical way to understand their needs and only covers the areas of the application that Social Security Scotland needs more information about.

Key findings

- Three fifths (60%) of consultation respondents felt the Adult Disability Payment decision-making process is effective in understanding a person's daily living needs, with comments outlining positive experiences. However, 17% found it 'not very effective' and 24% 'not effective at all'. Reasons for this included that the decision would benefit from a more qualitative and individually focused application form which more effectively captures details about a person's condition and lived experience. Others felt that their supporting information was ignored in the consideration of their application.
- Among the small number of respondents who had a consultation as part of the decision-making process, most had them on the telephone, and respondents typically indicated that the consultation happened at a time convenient for them. Few provided qualitative feedback about the consultations. Those who did said that they felt the case manager was polite and clear in their intent. Suggested improvement provided by a few respondents included greater clarity that the consultation could be held in a way that best suits the person applying.
- Four fifths (80%) of those who had received a decision understood it. In open comments however, some described confusion about their award and the points they received, often reflecting disagreement with the decision. This was also reflected in the call for evidence, where respondents highlighted instances where decisions appeared to be inconsistent with supporting information.
- Better communication about decision-making was a key theme in both consultation and call for evidence responses. This included calls for clearer communication about how points had been allocated and decisions made, and information being delivered in a method that best suits the client, such as large font format.

Consultation

Q14A. How effective do you think Social Security Scotland’s decision-making process is with regards to understanding a person’s daily living needs?

Q14B. Please give reasons for your answer.

Respondents	Very Effective	Effective	Somewhat Effective	Not very effective	Not effective at all	No answer
No. of respondents (n=84)	5	13	25	12	17	12
All respondents (%) (n=84)	6	15	30	14	20	14
All answering (%) (n=72)	7	18	35	17	24	-

Mixed views were evident among those answering Q14A. While three fifths (60%) felt the decision-making process is effective in understanding a person’s daily living needs, 35% felt the process is ‘somewhat effective’, with 7% indicating they find it ‘very effective’. Conversely, 17% found it ‘not very effective’ and 24% ‘not at all effective’.

Ineffective: more qualitative, person-focussed experience needed

Just over two thirds of consultation respondents commented at this question. The most common theme was that a more qualitative and individually focused application form would improve the effectiveness of capturing a person’s daily living needs. Some felt the application form did not capture the details about their condition and their lived experiences. This included neurodiverse and people with non-physical conditions or disabilities. A few suggested that the form was too rigid, not allowing clients to explain specific aspects of their daily living that are different from the areas highlighted in the application.

“It is impossible to share the full range of information required to provide a comprehensive understanding of someone’s daily living needs. As such the decision will always be subjective.” – Individual

Others thought that consultations or calls with case managers, where case managers could ask for clarification and where clients could explain their daily living in detail, may have helped capture their lived reality more effectively. In contrast, a few others who spoke to a case manager felt their information was not captured accurately and suggested better staff training would make the process more effective.

Effective: positive experience with services

In contrast, several respondents felt that the decision-making process was effective. Respondents explained that they found the award letters clear and comprehensive in including all the information provided by the client. They also noted higher levels of trust in the Adult Disability Payment process compared to Personal Independence Payment and felt the process was more respectful.

“The award letter explained perfectly why I received points for each section and although it was really upsetting and quite shocking to read that back about myself and realise the seriousness of my conditions, I felt that they did it with understanding, compassion and most importantly respect. Something I never received from PIP. I actually cried reading my PIP letter and felt sick to my stomach. My ADP letter, although hard to read those things about myself, they said nothing derogatory or discriminatory about me.” - Individual

Ineffective: further information was ignored

Some respondents suggested that supporting information was ignored in the consideration of their application. In some cases, the supporting information was provided directly by the client and in other cases, the client felt that their health care professionals were never contacted by Social Security Scotland to gather supporting information.

Q15A. Have you received a decision on an application for Adult Disability Payment?

Respondents	Yes	No	Don't know	No answer
No. of respondents (n=84)	54	21	3	6
All respondents (%) (n=84)	64	25	4	7
All answering (%) (n=78)	69	27	4	-

Overall, 69% of those who answered indicated they had received a decision about their application. One quarter (27%) had not and 4% were unsure.

Q15B. If you said “yes”, were you invited to take part in a consultation as part of applying for Adult Disability Payment?

Respondents	Yes	No	Don't know	No answer
No. of respondents (n=84)	7	55	10	12
All respondents (%) (n=84)	8	65	12	14
All answering (%) (n=72)	10	76	14	-

While Q15B was intended for those who answered ‘yes’ at Q15A, a larger number of respondents left a response. Respondents who had not received a decision may have answered as they had not (yet) been invited to a consultation. Among those who answered Q15B, one in ten (10%) indicated they have been invited for a consultation; three quarters (76%) had not and 14% were unsure.

Q15C. How did the consultation take place?

Respondents	By telephone	Other	No answer
No. of respondents (n=84)	7	1	76
All respondents (%) (n=84)	8	1	90
All answering (%) (n=8)	88	13	-

Among the small number of respondents who had been invited to a consultation and answered Q15C, most (88%) had a telephone consultation.

Q15D. Did the consultation take place at a convenient date and time for you?

Respondents	Yes	No	No answer
No. of respondents (n=84)	6	2	76
All respondents (%) (n=84)	7	2	90
All answering (%) (n=8)	75	25	-

Among the small number of respondents who had been invited to a consultation and answered Q15D, three quarters (75%) indicated it was convenient for them.

Q15E. What worked well about the consultation process?
 Q15F. What worked less well about the consultation process?

Fewer than one in ten respondents provided a comment to Q15E and Q15F.

What worked well

The most prevalent theme was that clients found practitioners helpful and consultations less stressful than expected. Two respondents noted that the people they spoke with, whether that was case managers clarifying application points or healthcare professionals undertaking a consultation, were kind. One individual noted that they appreciated the lack of medical assessments, and another felt the phone call they had was efficient.

“The lady was very polite, explained fully why she was calling and didn't keep me for too long. She only asked one question, and it wasn't intimidating or anxiety inducing.” - Individual

One respondent mentioned that they appreciated the flexible consultation format, and another found that speaking to a person was helpful.

What worked less well

A small number of individuals noted that they did not like telephone consultations. One noted they were unaware at the time that they would have been able to have a consultation in another way. Another found it difficult to explain and remember details when discussing their condition over the telephone. Another did not like the consultation as they felt it was painful to go back over their daily living information.

“I am autistic and find telephone calls very distressing, I was not given another option or aware I could request this.” - Individual

Other comments about consultations

At Q15J, which asks about changes to the decision-making process, a small number of respondents requested that consultation be used more often to avoid re-determinations or

appeals. They expressed a view that issues which impacted their award outcomes could have been avoided if they had been queried in the first place. Two others also suggested improving the consultation process by ensuring the clients felt listened to and respected.

While event participants were asked about consultations, few participants or those they supported had experienced a consultation with Social Security Scotland staff as part of the decision-making process. The difference between Personal Independence Payment and Adult Disability Payment was highlighted in one event, where it was felt that Social Security Scotland case managers were helpfully trying to make a decision without a consultation where possible. In the same event the professional backgrounds and level of medical knowledge of the consultation practitioners was queried, and Social Security Scotland was urged not to subcontract this activity to local councils.

Organisational representatives at one event requested being kept up to date with data around consultations, such as why people were invited to a consultation, how many are being conducted, and how many clients had support from an advice agency about consultations. They felt this would be beneficial in knowing what information had been omitted in the original application, improving the application advice they give to clients, and potentially reducing Social Security Scotland staff's workload by reducing the need for consultations further.

Q15G. Did you understand the decision?

Respondents	Yes	No	Don't know	No answer
No. of respondents (n=84)	36	6	3	39
All respondents (%) (n=84)	43	7	4	46
All answering (%) (n=45)	80	13	7	-

Four fifths (80%) of those answering understood the decision they had received, 13% did not and 7% were unsure. The number of respondents answering this question was lower than the number who indicated they had received a decision, but this may reflect confusion about whether the question was asking about the decision or the consultation.

Q15H. Did you need support to understand the decision?

Q15I. Please explain your answer.

Respondents	Yes	No	Don't know	No answer
No. of respondents (n=84)	5	35	3	41
All respondents (%) (n=84)	6	42	4	49
All answering (%) (n=43)	12	81	7	-

Reflecting levels of understanding, four fifths (81%) of those who answered did not need support understanding the decision. However, one in ten (12%) did.

Confusion about the decision

Just under a quarter of consultation respondents commented at Q15I. The most prevalent theme in response to this question was confusion about why the client received the points they were awarded, often reflecting disagreement with the decision. While some did not explain further how they needed support to understand the decision, others had used family members or advocates to understand how the award was decided. One respondent, for example, saw that their GP was unaware of the impact of their condition upon their life and therefore did not provide sufficient supporting information. Another highlighted their confusion about their award.

“I didn't know why I scored 5 points previously for depression, then with depression and ADHD I scored zero.” - Individual

Positive comments

Some provided positive comments about the clarity of communication around their award. Others said they understood the decision letter because it was jargon-free, did not include legal language, and was very detailed.

“The decision responses were clear and concise. Using evidence submitted via present and past (both consultations and previous awards). The decision took into account my disabilities and how they would affect me on a daily basis. I feel the reviewer understood the information I submitted and was fair in their decision.” – Individual

Q15J. What could have been changed about telling you what the decision was? What do you think the impact of that change might be?

Better communication

Almost one third of consultation respondents provided a response to Q15J. The most prevalent theme in responses was for improvements to communication to help clients clearly understand the decision. This included a desire for more feedback on the application, with respondents feeling that the letter was too short and did not include personalised or specific information about their case. Improving the personalisation of the communication in the award letter was also highlighted at stakeholder events. Another recommended clarifying the language by using declarative statements, and this was reiterated at almost all engagement events. Another suggested that phone calls could be used alongside or in lieu of award letters to help clients better understand the decision.

Some of these challenges were highlighted in mixed views expressed in engagement events. There was a call for a summary sheet with the decision and key points on one page to improve clarity, as well for providing clear reasons for the decision to help support organisations explain the reasons for the decision to applicants they are supporting. However, participants at another event felt that the decision letter is clear, with the first page explaining the decision and breaking down the points and descriptors. This was contrasted to Universal Credit, where no explanation of the rationale for decisions is given, and Social Security Scotland were praised for supporting people's understanding of how

the decision has been made and providing information should a re-determination be needed.

In an interview with a stakeholder, the RNIB noted that details about required communication formats were not passed over from DWP to Social Security Scotland during the transition, which meant that some received decision communication in an inaccessible format.

“I need font size 40, this was recorded on my files with DWP, but this information wasn’t shared with Social Security Scotland when I transferred onto ADP from PIP. It would be helpful if this type of information was shared between the agencies dealing with my benefits.” - RNIB

One respondent noted that they received their first payment before they received official notification of their award, which they found confusing. This was also reflected in engagement events where participants spoke of instances where they were worried about their award and, while starting to receive the payment was good, it did not help ease their concerns about the process.

Timescales

Some respondents noted that the timescales for decision-making were too long. The processing times for Adult Disability Payment are explored in more detail in Chapter 10.

Call for Evidence

Q8. Thinking about when a decision on an Adult Disability Payment application is made, do you have any evidence about how clearly the reasons for the decision are explained to the person?

Clearer communication needed

Just over half of call for evidence respondents answered Q8. The most prevalent theme in responses was that communication about how decisions are reached needs to improve and be more transparent. Respondents noted this for a range of reasons. Often, respondents suggested that award letters are not clear enough in explaining why points have been awarded or not awarded.

Others suggested that, from their perspective as advocates or welfare specialists who see several award letters, they can identify different types of inconsistencies in decisions. For some, the reasons behind individual decisions seem inconsistent, while others notice inconsistencies across client experiences. These respondents felt that the wording of the decision as well as the reasons behind decisions lack consistency.

“When discussing reasons for appealing with appellants we often find that they are unclear on why certain points were not awarded based on their conditions or limitations, also the reasons can be inconsistent. For example, if points are awarded for difficulty in the bathroom with standing but not carried over into the kitchen when preparing a meal people are unclear as why this is so when it is the same difficulty. The decision does not explain the difference in its reasoning.” – Glasgow City Council

“The reasons for the decision are clear, however, they are also inconsistent. We are aware of decisions made with regards to some claimants with similar circumstances can vary. With the inconsistent decision-making it leads to further additional workload through appeal processes.” – Epilepsy Scotland

A few organisations requested that more information about the points and descriptors be provided to clients with their awards letter to clarify exactly what was awarded and why.

Decision inconsistent with supporting information

A small number of respondents highlighted that while the reasons for the decision were clear, they did not align with the information provided in the application.

“We have had mixed feedback from people with MS in relation to how decisions have been explained to people. In response to a recent survey that the MS society conducted 14 out of 28 (50%) respondents in Scotland said they didn’t think that the report they received gave an accurate reflection of their MS ... There was further evidence of these inaccuracies on people’s decisions among the people we have spoken to in preparation for this response.” - MS Society Scotland

Participants at a few events also advocated for greater transparency around the decision-making process. This included being provided with more information about how points have been allocated, what case managers are basing their decisions on, the professional background of case managers and their level of training and medical knowledge, how much they consult Social Security Scotland medical personnel to inform decisions, the weighting given to different types of supporting information and if the decisions are peer-reviewed.

However, at a few events Adult Disability Payment decision-making was described as an improvement on that of Personal Independence Payment. It was described as less adversarial, and it was welcomed that Adult Disability Payment is paid while a re-determination is being considered and that Adult Disability Payment seems to place more weight on supporting information from families, GPs and support workers.

8. Re-determinations

This chapter explores experiences of re-determinations and the appeals process. The right to ask for a decision to be looked at again is called a re-determination. People have 42 calendar days to ask for a re-determination, although in some cases Social Security Scotland can accept a late re-determination request. Re-determinations can be submitted online or by paper form, and once Social Security Scotland receives the re-determination request, they have 56 calendar days to make a new decision. If Social Security Scotland does not complete a re-determination process within the allocated 56-day period, a person has a right to appeal directly to a First-Tier Tribunal.

Key findings

- One quarter (26%) of consultation respondents had asked for a redetermination. Respondents provided some feedback on what worked well, including the ability to submit personal statements and being able to provide evidence in multiple formats.
- Others highlighted concerns about timescales. A few noted they were waiting on re-determination decisions. Participants at consultation events had experienced stock phrases in re-determination decisions that indicated the messaging was not unique to each applicant. Others suggested that applicants be allowed to review their full application before a re-determination.
- Call for evidence respondents noted that the re-determination process could be confusing for some. Some organisations highlighted that their clients were not well informed about the Adult Disability Payment process and were not aware that points could be removed during a re-determination process, for example.
- Others cited confusion about the process as a reason people did not seek re-determinations. Negative impacts on wellbeing and lengthy timescales were mentioned as other reasons clients may not seek re-determinations. Similar reasons were given for why clients may not seek an appeal.

Consultation

Question	Yes (%)	No (%)	Don't know (%)
Q16A. Have you ever asked for a decision on an Adult Disability Payment application to be looked at again through the re-determination process? (n=74)	26	73	1
Q16B. If you said "yes", do you feel that you were treated with dignity, fairness and respect? (n=24)	17	46	38
Q16C. Did you receive regular updates about what was happening? (n=16)	19	69	13

One quarter (26%) of those who answered had asked for a re-determination; three quarters (73%) had not and 1% were unsure.

Among those who answered Q16B, 17% indicated they had been treated well, 46% had not and 38% were unsure. The number of respondents answering this question, and the level of 'don't know', suggests that a few respondents who had not asked for a re-determination answered this question. They may have considered or contacted Social Security Scotland about a re-determination but not proceeded with it, or may have misunderstood the question and answered in the context of their contact with Social Security Scotland.

Among those who answered Q16C, over two third (69%) of those who had asked for a re-determination indicated that they had not had regular updates about it. One in five (19%) felt they had and 13% were unsure.

Q16D. What do you think worked well about the re-determination process?

Just over one in ten consultation respondents provided an open comment at Q16D. Among this small number of respondents, the most common theme, in contrast to the question, was dissatisfaction with the re-determination process. A few respondents expressed frustration with the timescales, noting that they are still waiting to hear about their re-determination. One organisation provided similar feedback.

A few respondents provided positive feedback about the re-determination process. Two individuals noted that they liked having the flexibility to provide supporting information in multiple formats. Both respondents provided personal statements alongside their re-determination, which they thought captured the state of their condition accurately. One individual reflected positively about their treatment during the re-determination process. Another individual thought that offering an online form made the process more accessible.

"The re-determination process was dealt with dignity, with compassion and fairly. Using evidence provided and no misinformation. I was informed throughout the process." - Individual

Individuals at engagement events also noted positive experiences with re-determinations, especially compared to similar experiences under Personal Independence Payment. Participants appreciated Social Security Scotland's flexibility in providing additional time to complete re-determinations and thought that it is clear how to request re-determinations.

Q16E. What would you change about this process?

One in ten provided a comment at Q16E. The most common theme, including the only organisational response, was a request to improve the re-determination timescales. Respondents felt they were taking too long and could be handled more efficiently.

"It should be much more urgent (my claim is now in its 7th month), and updates should be frequent." - Individual

Two individual respondents requested improved communication throughout the process, including updates on the status of the re-determination. One of those respondents noted that they would like it to include the chance to speak with a case manager about their

condition. Another individual thought it would be beneficial to allow the submission of new supporting information dated after the original application if that would allow the client to show new diagnoses or conditions.

At a few engagement events, participants from organisations described seeing more communication from Social Security Scotland that contained stock phrases and acronyms that indicated the messaging was not unique to each applicant or considering the applications fully. Another area for improvement raised during the events was a request to allow people to see their full application before a re-determination.

Two individuals noted that they would not change anything about the process as they had positive experiences. One noted they felt they had been treated with dignity and respect throughout the re-determination process.

Call for Evidence

Q9. Do you have any evidence about how well-informed people feel during the re-determination process?

One third of call for evidence respondents answered Q9. Among those responding, some highlighted that the process was confusing. For two, the confusion was related directly to the complexity of the language and phrasing. For example, two respondents noted their clients did not know what “re-determination” meant. This was also reflected at engagement events where organisational participants noted client confusion around the word and what it meant for their application.

A small number felt that the clients they helped were not well informed about the Adult Disability Payment process and struggled to understand the decision letters sent to them. Respondents therefore felt that their organisation’s support was needed to help their clients get through the re-determination process.

Two organisations highlighted a concern that clients were unaware there was a chance that points could be removed during a re-determination process. They thought that Social Security Scotland should make all the possible outcomes clearer to clients.

“We have noted on occasions that at the appeal stage, points that were awarded on the initial claim have been removed in the re-determination process without a full explanation. This is confusing for appellants and undermines their trust in the process.” – Glasgow City Council

Q10. Can you provide specific examples of factors that influence whether a person will request a re-determination of a decision made on an Adult Disability Payment application?

Just over half of respondents answered Q10. They provided a range of factors, both positive and negative, that influence whether a person will request a re-determination. These are listed below, from most to least prevalent. Evidence provided by respondents took the form of stakeholder feedback that respondents had gathered through their own

engagement events, case studies created by organisations about their clients' experiences with Adult Disability Payment and individual experiences.

Reasons for seeking a re-determination

- Social Security Scotland case managers incorrectly interpreted the information provided in the application.
- Support from outside agencies enables clients to feel confident in asking for a re-determination.

Reasons preventing people from seeking a re-determination

- The client found the process confusing and did not seek a re-determination in the right timeframe or was unable to seek a re-determination without assistance.
- Concerns that a re-determination may result in fewer points. Respondents emphasised the importance of ensuring clients were aware of the risks of re-determination before proceeding.
- A small number had evidence that their clients would not seek a re-determination due to the impact of the process on their mental wellbeing. Two organisations suggested that their clients did not want to go through the process of sharing uncomfortable personal details again.
- Clients do not know that seeking a re-determination is within their rights.
- Lengthy timescales for a re-determination can put people off.
- At events it was noted that people not having a copy of their original application, or having lost documents, could put people off.
- One organisation highlighted that there is a language barrier for some in seeking a re-determination.
- One organisation noted that some clients have trouble collecting supporting information for their application and for their re-determination.
- Previous negative experiences with Personal Independence Payment.

“Having to repeat sensitive and on occasion painful information again and again can be overwhelming.” – One Parent Family Scotland

“As a progressive condition, dementia changes and deteriorates over a period of time. Given the length of time to receive a decision, people with dementia’s circumstances inevitably change and this can result in them being unable to pursue a re-determination due to the impact on their health and wellbeing. In these instances, it is only possible to pursue a re-determination where this can be facilitated by a person acting on their behalf, i.e. Attorney, Guardian or Social Security Scotland appointee, and this may not always be possible.” - Alzheimer Scotland

Participants at a few events also noted that the risk of losing points can put people off applying for re-determinations. There were therefore calls for greater transparency about re-determination decision-making processes, for example for this to only focus on the

activity/descriptors that the client disagrees with, rather than the whole application being reassessed, to remove the possibility that re-determinations could result in a lower award.

Q11. Can you provide specific examples of factors that may influence whether a person will appeal an Adult Disability Payment decision?

Just over half answered Q11, providing reasons why a person would appeal as well as reasons that prevent someone seeking an appeal. These are listed below from most to least relevant. Many of the reasons mirrored those influencing whether a person seeks a re-determination.

Reasons preventing appeals

- Some suggested that the impact of the appeal process on the mental wellbeing of their clients was a reason some decided not to appeal. This was particularly related to the tribunal process and included people who had had bad experiences with appeals under Personal Independence Payment.
- Respondents noted some clients they assisted had not appealed as they did not understand their right to do so or how to move forward with an appeal.
- The length of time it takes to undergo an appeal was mentioned by a few.

“To enable an effective appeals process, we believe the following factors could also contribute: knowing you are able to appeal in the first place, knowing that the initial rejection from ADP was not solely based on condition (e.g. that having cancer still makes them eligible to apply/appeal), [and] being aware of the process and steps” - Young Lives vs Cancer

“Lack of understanding of what is involved in the appeal process can be a significant factor in putting people off taking their case to appeal. There is a real lack of information on tribunal attendance and impartiality of the tribunal. We repeatedly have to explain to the parents we support that it is not a “court process” and that they will not be cross examined.” – One Parent Family Scotland

These reasons were also mentioned by participants at engagement events.

Reasons for seeking appeals

- Some mentioned that with the help of third sector welfare advisors and advocates, Adult Disability Payment clients were more likely to seek an appeal.
- A few organisations reiterated that clients would undergo an appeal process if they felt that their decision did not represent their lived experience or had not captured their application supporting information accurately.
- Two organisations mentioned the automatic appeal process as a reason some clients went through appeals.

“One key factor for this will be whether they are supported during the appeal process. This is why it is key for Social Security Scotland and the Third Sector to work closely together to ensure that applicants are supported by organisations who have a full understanding of their condition. People living with epilepsy who have been turned down with regards to their ADP application will see their mental health deteriorate and will require emotional support as well as professional support with regards to the appeal process.” - Epilepsy Scotland

The ability to lapse appeals was requested in a few engagement events. Examples were given of appeals being started but then all parties reach agreement before a tribunal. However, unlike with Personal Independence Payment, the tribunal currently still needs to go ahead, although there are proposals to change this. Participants felt the time and stress involved in this is unnecessary if all parties have come to an agreement.

9. Review periods and indefinite awards

This chapter analyses responses to questions about the review periods for awards. Most reviews of entitlement to Adult Disability Payment are between two and 10 years apart, depending on when a person's needs are likely to have changed. This is to ensure their payment continues at the right level.

Some people may not be asked to take part in a review of their entitlement. This is called an indefinite award and applies to people whose needs are unlikely to change and who already receive the enhanced rate of the daily living and mobility components.

Key findings

- Fewer than one in ten (7%) consultation respondents had received an indefinite award. Those who had described positive improvements to their quality of life as a result. This included improved access to care, financial stability, and reduced stress about future Adult Disability Payment applications. These positive impacts were also reflected in call for evidence responses.
- Calls for improved communication were made by some. Call for evidence respondents requested clearer indefinite award letters, while a few consultation respondents noted the confusion they had experienced due to receiving their first payment before their award letter.
- Two fifths (65%) of consultation respondents had experienced a review of their entitlement to Adult Disability Payment. Respondents were positive about the lack of face-to-face assessments during the review process and felt that communication leading up to the review was clear. However, reducing the waiting time to hear about review outcomes and more communication through text or email were mentioned as areas for improvement.
- Respondents typically favoured using longer review periods, suggesting these would reduce clients' stress and anxiety and provide greater financial stability. A few questioned why permanent or deteriorating conditions were still given review periods or called for greater use of indefinite awards for such conditions.

Indefinite Awards

Consultation

Q17A. Have you ever received an indefinite award for Adult Disability Payment?

Respondents	Yes	No	Don't know	No answer
No. of respondents (n=84)	5	63	7	9
All respondents (%) (n=84)	6	75	8	11
All answering (%) (n=75)	7	84	9	-

Fewer than one in ten (7%) of those answering had received an indefinite award for Adult Disability Payment. The vast majority (84%) had not and one in ten (9%) were unsure.

Q17B. If you said “yes”, how did that make you feel?

In line with the closed question results, only a small number of consultation respondents provided a comment at Q17B. Of those who commented, the most prevalent theme was that an indefinite award provided clients with a greater sense of security. One individual also described a sense of relief.

Q17C. What impact did this have on your quality of life?

Fewer than one in 10 respondents provided a comment at Q17C, covering a range of improvements on the quality of life including:

- Improved access to care as they are now able to plan and decide upon appropriate care knowing their award will not be adjusted in the future.
- Financial security and stability.
- Reduced stress and anxiety around Adult Disability Payment and the possibility of being judged or treated without respect.

Q17D. Was the reason for this decision communicated clearly?

Respondents	Yes	No	Don't know	No answer
No. of respondents (n=84)	2	0	1	81
All respondents (%) (n=84)	2	0	1	96
All answering (%) (n=3)	67	0	33	-

Among the very small number of respondents who had received an indefinite award, two of the three who answered felt the reason for the decision was communicated clearly. The other respondent was unsure.

Q17E. How could your experience of receiving an indefinite award be improved?

Only three individuals provided responses to Q17E. Two had a positive experience and did not think anything could be improved. The other individual recommended better communication as their payment arrived before their award letter.

“The letter should have arrived before, or on the same day, the money went into my bank account. Other than that I don't think it could be improved.” - Individual

Call for Evidence

People may receive an Adult Disability Payment award without a review period (also known as an “indefinite award”) if their needs are highly unlikely to change in the future.

In relation to Adult Disability Payment, do you have any evidence about:

Q13A. How clearly the decision to make an indefinite award was explained?

Q13B. Whether or not people understand why they have or have not been given an indefinite award?

Q13C. What were people’s experiences of having an indefinite award? This could include the impact that having an indefinite award has on people’s quality of life compared to people who have had a review period set.

Just over a quarter of call for evidence respondents provided comments at Q13A, one in six at 13B and just under one fifth answered 13C.

Better communication of indefinite award

At Q13A and 13B the most prevalent theme was a request for better communication when an applicant receives an indefinite award. Respondents suggested that it be written more clearly in all correspondence, on case files and with discussion with individuals and carers. One Parent Family Scotland suggested that the award letter also be provided in an easy read format. One anonymous organisation noted that their clients found the award letters too long and complex to understand that they had been awarded an indefinite award.

Respondents were confused about whether the indefinite award was a lifetime award and whether clients with indefinite awards will still eventually have another review, suggesting that further clarity and explanation is still required. MS Society Scotland noted that in collecting evidence for the call for evidence, they were made aware that some of their members did not know that an indefinite award was available under Adult Disability Payment.

While not directly answering the question, some respondents at both questions reiterated their belief that indefinite awards should be provided to people with permanent, terminal or deteriorating conditions. They explained that the award letters need to be clearer as to why those with permanent conditions do not receive indefinite awards.

“From our engagement with people with dementia and their carers, it appears that there is a lack of clarity around decisions not to award Adult Disability Payment indefinitely for people with conditions, such as dementia, that are progressive, terminal conditions. While some people with dementia who claim Adult Disability Payment are awarded the benefit indefinitely, others are awarded it for a fixed period with the requirement to renew their claim in future. Given that dementia will inevitably see a worsening of symptoms over time with no prospect of improvement, people with dementia and their carers struggle to understand why there would be any need to review a decision in these circumstances.” - Alzheimer Scotland

Impact of an indefinite award

The most prevalent theme in response to Q13C was that indefinite awards improve clients' wellbeing and relieve the stress associated with future applications or reviews. Others noted that they allow clients to feel financially stable and plan their care going forward.

“Claimants have a positive experience and are relieved that they have an indefinite award. It gives re-assurance that their benefit will stop at the point of renewal and that they won't have to go through a cycle of future re-determinations and appeals.” - Glasgow City Council

“The award of Adult Disability Payment on an indefinite basis offers reassurance and certainty about entitlement which leads to better financial security. For example, people with dementia who have an indefinite award of Adult Disability Payment feel more able to source ongoing care and support services since an indefinite award provides them with a secure source of income that enables them to engage services without the risk that this might not be possible in the event that their award ends and is not renewed.” - Alzheimer Scotland

Alzheimer Scotland noted that where it was necessary for clients to provide confirmation of their indefinite award for other purposes, getting duplicate award letters or certificates was a very difficult and lengthy procedure. They recommended making it easier to access this service through Social Security Scotland.

Review periods

Q18A. Thinking about review periods for entitlement to Adult Disability Payment, have you ever received an Adult Disability Payment award that is subject to a review period?

Respondents	Yes	No	Don't know	No answer
No. of respondents (n=84)	44	19	5	16
All respondents (%) (n=84)	52	23	6	19
All answering (%) (n=68)	65	28	7	-

Two thirds (65%) of those who answered Q18A indicated they had received an award that is subject to a review period. Just over one quarter (28%) had not, and 7% were unsure.

Q18B. If you said “yes”, what is the impact of having a longer review period on the quality of life of a disabled person?

Reduced stress or anxiety

Just under half of respondents left an open comment at Q18B. The most prevalent theme, mentioned by many, was that longer review periods would positively reduce clients' stress and anxiety and allow for extended periods of better wellbeing between reviews.

“I have received reward periods of 3 to 5 years. As someone who was born with a condition that impacts my daily life and will never improve, longer review periods give you a sense of relief that you will not continually be subjected to evaluations and reassessments which add to the daily stress and anxiety of living with a condition that daily impacts your life.” - Individual

Some described the stress of review periods and their uncertainty about the process. Several provided details of their experiences with reviews previously, which they described as terrifying, or filled with anxiety and depression. Given the timeframes noted in responses, it is assumed that most of these reviews were conducted by DWP in relation to Personal Independence Payment. At engagement events, it was acknowledged that Adult Disability Payment generally provided longer review periods than Personal Independence Payment, and this was something participants appreciated.

Greater financial security

The security of planning finances and managing the cost of care was mentioned by some. Respondents noted that longer review periods provide clients with long-term certainty. For example, financial security provided one individual with a better quality of life as it provided them access to the Accessible Vehicles and Equipment (AVE) Scheme.

Reviews for permanent conditions

Although not directly related to the question, noting the positive impact of longer review periods, a small number questioned why they needed to undergo reviews when their conditions were permanent and either unchanging or progressively worsening. There was also a suggestion at a few events that those with a lifelong condition should be given indefinite awards or that the review period should be based on the prognosis of people’s conditions.

Q18C. Do you feel the reasons for this decision were communicated clearly?

Q18D. Please give reasons for your answer.

Respondents	Yes	No	Don’t know	No answer
No. of respondents (n=84)	17	20	8	39
All respondents (%) (n=84)	20	24	10	46
All answering (%) (n=45)	38	44	18	-

Among those who had an award subject to a review period and answered Q18C, there were mixed views on whether the reasons for the decision were communicated clearly. Almost two fifths (38%) felt they had been, 44% that they had not and 18% were unsure.

Better communication needed

Just over one third commented at Q18D. Several thought that the reasons for decisions were not communicated clearly. Almost all of these respondents noted that they were never told why they needed to have a review or why their review was set to the time period stated in the award letter.

“The letter didn’t say why my review would be in two years but I kind of understand why as I explained above some of my conditions could improve or worsen in that time frame.” - Individual

An individual felt that they had received regular reminders of their upcoming review, which continued after the review had been completed. They felt that this was very stressful as they were receiving confusing messaging through text, email and by letter.

Enough detail provided

Two respondents said that they had received enough detail in their award letters. Although one did not explain further, the other noted that their award letter provided details about how the points had been allocated but did not mention anything about review periods.

Q18E. Have you ever experienced a review of your Adult Disability Payment award?

Respondents	Yes	No	Don't know	No answer
No. of respondents (n=84)	16	35	3	30
All respondents (%) (n=84)	19	42	4	36
All answering (%) (n=54)	30	65	6	-

Among those who answered Q18E, three in ten (30%) indicated they had experienced a review, while 65% had not and 6% were unsure. Slightly more respondents answered this question than indicated they were subject to a review period, suggesting a few may have misunderstood this question as being about another part of the process.

Q18F. If you said “yes”, what do you think worked well about this process?

Just under a fifth of respondents provided an open comment at Q18F. A few respondents mentioned they appreciated the ability to submit review paperwork online.

“Communication that review would be coming and option to either complete form online or in writing.” - Individual

Two respondents liked the communication they received leading up to the review. They said they were told about the review in advance and provided with a clear understanding of what to expect.

The lack of face-to-face assessments works well according to two respondents, although neither provided further detail. Related to this, an individual thought that the Adult Disability Payment review process shows that Social Security Scotland trust their clients and the information provided in their applications. This compared positively to their experience with Personal Independence Payment.

“Personally, I think the process worked extremely well and is a definite improvement on the DLA and PIP process in terms of reducing the stress and anxiety that those assessment processes caused.” - Individual

Two individuals felt that they would change nothing about the process, with one explaining they thought it worked well as it is.

Q18G. What would you change about this process?

One in six consultation respondents commented at Q18G. The most prevalent theme was that the wait for a decision was too long. One organisation expressed a view that the process of filling out a review form is also too time consuming.

“To make the waiting time less for a person’s review to be assessed currently I’m waiting 8 months this is my first review since changing over from PIP which was more effective.” - Individual

At Q18F, a few respondents, most of whom were either waiting to hear about the outcome of their review or, in one instance had had their award removed, felt that nothing worked well about the review process.

Two respondents recommended changing the process of reviews entirely. One expressed the view that the review process was demeaning and intrusive and made them feel bad about themselves. However, no suggestions for changing the process were given.

The following points were each mentioned by one respondent:

- A request that all communication be done through text or email.
- For “joined-up thinking” and information sharing, though no information was provided about who should be involved in this.
- A request for more empathetic staff members.
- Tech issues were mentioned by one individual who felt they had received irrelevant and stressful communication regarding their review.

Challenges with reviews were raised in a few engagement events. These included examples of instances where Adult Disability Payment review periods had been shorter than Personal Independence Payment review periods and it was unclear why, reviews provoking anxiety in applicants, a perception that there are inconsistencies with Adult Disability Payment decision-making with the nature of decisions changing over time, and confusion over the timescales for review decisions.

A point raised in one event was confusion over the lack of a separate review form. One participant noted that Social Security Scotland send the change of circumstances form, which causes confusion when it is received by clients. They suggested Social Security Scotland creates or clearly label review forms as such. They also suggested communicating the potential benefits of the review process, such as the possibility of a higher award, and to provide a tick box at the start of the review form asking if anything has changed since the last award, removing the need to fill the form in again if not.

10. Processing times

This chapter examines responses to questions about the processing time for Adult Disability Payment applications, which is the time it takes Social Security Scotland to make a decision. The length of processing times can vary and depends on several factors, including:

- The volume of applications being processed.
- Whether applications require supporting information or a consultation.
- The type of application, for example, those made under the Special Rules for Terminal Illness.

This chapter also explores the impact processing times may have on seldom-heard groups or people who face barriers in engaging with others.

In keeping with the format of the rest of this report, the analysis of responses to consultation questions is followed by the analysis of responses to the call for evidence questions. However, it should be noted that both audiences highlighted very similar issues when considering how processing times could be improved.

Key findings

- Three in ten consultation respondents (29%) received a decision about their application within three months, 42% between three and six months and it took six months or more for three in ten (30%).
- While consultation and call for evidence respondents emphasised that shortening processing times would improve applicants' experience, they also noted that better communication could alleviate some anxiety. Respondents suggested email or text updates or a dashboard for applicants to monitor the progress of their application.
- Call for evidence respondents highlighted several groups who they felt were adversely affected by long processing times. These included people needing to access other disability benefits, such as a Blue Badge or a mobility device through the AVE scheme, carers who were struggling financially, those with mental health conditions, those with degenerative cognitive conditions and lone parents.

Consultation

Q19A. If you have ever received a decision on an Adult Disability Payment application, how long after you submitted your application did it take for you to receive this?

Respondents	< 1 month	1-2 mths	2-3 mths	3-4 mths	4-5 mths	5-6 mths	>6 mths	No answer
No. of respondents (n=84)	3	5	10	10	8	8	19	21
All respondents (%) (n=84)	4	6	12	12	10	10	23	25
All answering (%) (n=63)	5	8	16	16	13	13	30	-

When asked how long it had taken between submitting an application and getting a decision, a range of timescales were evident among those who answered. Three in ten (29%) had received a decision within three months, 42% between three months and six months, and for three in ten (30%) it took more than six months.

Q19B. How satisfied were you with this?

Respondents	Very satisfied	Satisfied	Somewhat satisfied	Not very satisfied	Not satisfied at all	No answer
No. of respondents (n=84)	4	8	10	13	26	23
All respondents (%) (n=84)	5	10	12	15	31	27
All answering (%) (n=61)	7	13	16	21	43	-

Those answering Q19B were typically dissatisfied with the time it had taken to receive a decision. Over two fifths (43%) were not satisfied at all, and a further 21% were 'not very satisfied'. At the other end of the scale, fewer than one in ten (7%) were very satisfied.

Q19C. What in your view could have been done to improve your experience of waiting for a decision?

Better communication

Just under two thirds of consultation respondents provided an open comment at Q19C. The most prevalent theme, mentioned by many, was that better communication was needed in the period between submitting an application and receiving a decision. Respondents suggested it would be beneficial to have online portals where they could log on to see the status of their application, or regularly emailed or mailed updates. Others requested easy telephone access to Social Security Scotland staff who could provide status updates.

“The no news during the 7 months while waiting was not helpful.” – Individual

“It helps alleviate concern about waiting if the applicant is kept informed. In the case of people with ME/CFS, as mentioned earlier, there is difficulty in obtaining supporting evidence due to a lack of medical knowledge about the condition. This should be recognised early and the process moved on.” - #MEAction Scotland

Timescales

Several respondents at this question, and also at Q15J (What could have been changed about telling you what the decision was? What do you think the impact of that change might be?) commented more generally that improved timescales would improve the experience of waiting for a decision.

Respondents described the experience of receiving a decision as ‘life-changing’, but the long wait times to hear about outcomes greatly impacted their quality of life over that period. Some described the stress of waiting for a decision and others mentioned

struggling financially. A few respondents noted that increasing Social Security Scotland staff numbers may assist with long processing times.

“The decision-making process took a long time, and I only found out I had been awarded ADP when the money appeared in my bank. Maybe a progress update would help put people’s minds at ease. I had a pretty traumatic experience applying for PIP in the past, which had made me reluctant to apply for ADP. I felt stressed throughout the process and was waiting to hear about a consultation appointment, which thankfully wasn’t required.” - Individual

Participants at engagement events also described long waiting times that they or the people they support had experienced. While it was acknowledged in one event that Social Security Scotland’s waiting time targets are more positive than for Personal Independence Payment, there were frequent reports of these being missed or inconsistent, with some people waiting six, 10 or 18 months. At another event there was a suggestion of introducing a form of triage system, with a participant citing an example of an applicant waiting for nearly a year to be told they did not qualify to apply for Adult Disability Payment.

Other concerns

Event participants also noted the impact of slow decisions. Two main impacts were identified. Financially, people could miss out on money they need to live, or a delay could impact receipt or ability to apply for other benefits, such as carers allowance, or access to mobility aides. This latter point was noted by two consultation respondents. The other impact was emotional, due to the stress and anxiety generated by waiting.

“Having a shorter waiting time. I started needing a wheelchair and was not able to access other supports like a blue badge until my ADP application had been processed. This made every aspect of my life difficult as I could [not] park near places I needed to be like work, the doctor, social things such as parking near a restaurant, etc.” - Individual

There was a suggestion from one individual that being paid while you wait to hear about your decision would assist those dealing with financial uncertainty due to their disability.

Call for Evidence

Q7A. Do you have evidence relating to what could be done to enhance peoples experience of waiting for a decision (if anything)?

Better communication

Just over half of call for evidence respondents answered Q7A. As with the consultation responses to Q19C above, respondents highlighted the need for better communication during the waiting period. Respondents called for updates that confirm an application has been received and is moving through the decision-making process. They suggested updates would reduce stress and provide more certainty.

“Another comment that has been made is that there is not enough communication or updates during the waiting time, and this can increase anxiety for many of the people we support. If this could be improved it would be helpful.” – MECOPP

“Regular but not overwhelming, appropriate communication is key to provide reassurance and reduce anxiety.” - Citizens Advice Scotland Social Policy

From interviews and a survey conducted with stakeholders who have received Adult Disability Payment, RNIB found instances where incorrect communication about decision-making had been sent to clients. One person described confusion and stress after receiving a prompt from Social Security Scotland to submit an application that had already been submitted. In following up, they were notified that Social Security Scotland had received their application, but the systems had not updated before the letter was sent.

An anonymous organisation noted the importance of escalation routes for those assisting people with their application, such as third sector or advocacy organisations. They felt this could provide a way to find out the status of applications and minimise stress.

Timescales

Some emphasised that reducing processing times would be beneficial. Two organisations suggested that better liaison between Social Security Scotland and social care, medical, and third sector services who are asked to provide supporting evidence or assist with clarification could improve processing times. Challenges around chasing professionals to provide supporting information were also noted in one of the engagement events.

Q7. Thinking about the time it takes to decide about whether someone gets Adult Disability Payment, do you have evidence whether this may have a different impact on some people than others, such as those from seldom-heard groups?

Seldom-heard groups affected

Around three quarters of call for evidence respondents provided an answer to Q7. Respondents provided a range of evidence suggesting the decision time affects the following seldom-heard groups, listed below from most to least prevalent:

- Those in need of passported benefits as it can delay the application for access to services such as Blue Badge or mobility vehicles or equipment through the AVE scheme.
- Carers who are already struggling to manage responsibilities and finances may find long wait times challenging as their lives are also impacted. An example was provided by Citizens Advice Scotland from stakeholder consultation where a carer had to give up a job and move house to assist their disabled relative with no financial assistance.
- Those with mental health conditions, with stakeholder engagement conducted by several organisations highlighting the increased stress of long waiting times.
- Those with degenerative cognitive conditions; as Alzheimer Scotland pointed out, the long waiting times for those with dementia can be very difficult to understand.

- Lone parents as the caring responsibilities for disabled children can affect working hours and negatively impact household finances, according to feedback received by both Age Scotland and One Parent Families Scotland.
- Low-income households as waiting for a decision can increase pressure of already tough financial situations, according to staff engagement through Glasgow City Council and SAMH.
- Minority ethnic people as the delay can be due to situations beyond the applicant's control, as highlighted by the experience of one client of MECOPP who had their application delayed due to the lack of availability of interpreters.
- People with terminal illnesses, like some cancers and Motor Neurone Disease, who often need the payments with urgency, according to stakeholder engagement with organisations like MND Scotland and Young Lives vs Cancer.

11. Changes in people’s circumstances

This chapter presents the analysis of responses to questions which sought information about people’s experiences of reporting changes in their circumstances. This can include changes to their banking or contact details, their condition, their care need or level of help, and the support they need with their mobility. If changes do occur, clients or their representatives must report it to Social Security Scotland within four weeks.

Key findings

- One third (32%) of consultation respondents had reported a change of circumstance to Social Security Scotland. While two fifths (39%) of those who answered felt they had been treated with dignity, fairness and respect, fewer than one in ten (8%) felt they had received regular updates.
- Only a few respondents provided further details about their experience. Some spoke highly of the assistance they received, although it was not always clear which organisation had provided them with assistance. Shortening response times and better communication about the status of their change of circumstance were suggested as improvements.
- Call for evidence responses also called for better communication and shorter decision periods. Other suggested improvements included clearer guidance on submitting a change of circumstance, providing more details about what needs to be included in the change of circumstance, and integrating all benefit systems to help those applying get the assistance they need with less paperwork.
- Some call for evidence responses expressed concern about accessibility. This included digital exclusion for online forms and language access issues for those whose first language is not English.

Consultation

Q20A. Have you previously reported a change of circumstances for Adult Disability Payment?

Respondents	Yes	No	Don’t know	No answer
No. of respondents (n=84)	24	48	3	9
All respondents (%) (n=84)	29	57	4	11
All answering (%) (n=75)	32	64	4	-

One third (32%) of those answering indicated that they have reported a change of circumstances. Almost two thirds (64%) have not and 4% were unsure.

Q20B. If “yes”, do you feel that you were treated with dignity, fairness and respect?

Respondents	Yes	No	Don't know	No answer
No. of respondents (n=84)	9	5	9	61
All respondents (%) (n=84)	11	6	11	73
All answering (%) (n=23)	39	22	39	-

Among those who reported a change in circumstances and answered Q20B, two in five (39%) felt they had been treated well, 22% did not and 39% were unsure.

Q20C. Did you receive regular updates about what was happening?

Respondents	Yes	No	Don't know	No answer
No. of respondents (n=84)	2	21	1	60
All respondents (%) (n=84)	2	25	1	71
All answering (%) (n=24)	8	88	4	-

Among those who reported a change in circumstances and answered Q20C, most (88%) felt they had not received regular updates. Fewer than one in ten (8%) felt they had and 4% were unsure.

Q20D. In your view, what worked well?
 Q20E. In your view, worked less well?

Just under a quarter of respondents provided an open comment at Q20D and Q20E.

What worked well with the change of circumstance process

While only a small number of consultation respondents commented, the most prevalent response, mentioned by some, was a positive experience with staff. Not all respondents clarified whether they were referring to Local Delivery Service staff, those contacted by calling a general Social Security Scotland phone number with a question, or Social Security Scotland staff in a consultation. However, they described staff members who were helpful, informative and compassionate. This was also reflected in feedback from participants in engagement events.

Two individuals liked the online process for submitting a change of circumstances.

“The process of submitting a change of circumstances form online is fantastic and by far beats an overload of paperwork and anxiety waiting for phone calls etc.” – Individual

What worked less well with the change of circumstance process

Some respondents were still waiting to hear the outcome of their change of circumstance application and felt the wait was too long. Some mentioned waiting six months while

another waited for over a year. A participant at an engagement event thought that having an online portal to submit and track changes of circumstance updates would be helpful.

As with waiting to hear about decisions (Chapter 7 and 10), the lack of communication about the process or status updates was mentioned by some. As with other questions, respondents suggested Social Security Scotland send messages via text, email or post that provide some clarity about the progress of their change of circumstances.

Other comments included:

- Two respondents felt updated supporting information had not been considered in their change of circumstance decision. One wished that their GP had been approached for further information, and another felt that their supporting information letter had been ignored.
- Two were confused about what they could submit alongside their change of circumstances form. One wished to submit supporting information but was not aware if they could. This was also mentioned by a few participants at engagement events.
- One individual felt that they were asked irrelevant and intrusive questions during a telephone consultation to review their change of circumstance. They did not specify who the call was with, whether they were seeking support, or if it was a call to clarify anything submitted in the change of circumstance form.

Call for Evidence

What evidence exists about people's experiences of notifying Social Security Scotland about a change of circumstances? Can you provide specific examples of:

Q12A. What worked well (if anything)?

Q12B. What could be improved (if anything)?

Two thirds of call for evidence respondents answered each question. Some respondents simply commented that they do not have evidence to support an answer. Because respondents provided positive and negative points at each question, the analysis of responses to both questions has been presented as one below.

Suggested Improvements

Respondents noted that many of the same concerns raised by the stakeholders about getting an initial decision about Adult Disability Payment also applied to the change of circumstances process. This included evidence they had collected from their own stakeholder engagement that showed waiting periods to receive decisions were too long due to delays in processing.

Some again called for better communication during the process. Specific improvements related to change of circumstances included:

- A suggestion to reiterate the need for clients to contact Social Security Scotland in cases where conditions have changed.

- VoiceAbility suggested that older clients be made aware of the “mobility clause” of the change of circumstances form but did not specify why.
- Young Lives vs Cancer recommended integration between benefits systems to ensure that updates to one benefit will update the system for all.
- Alzheimer Scotland recommended providing more details about what needs to be included in the change of circumstances submission.

Multiple System Atrophy Trust, Glasgow City Council, Child Poverty Action Group and Parkinson's UK Scotland all mentioned situations where their clients had been disadvantaged due to confusion during the transition from Personal Independence Payment to Adult Disability Payment. They reported multiple instances where the backdated payments from Social Security Scotland did not match the date of initial contact with DWP. Young Lives vs Cancer suggested better communication between DWP and Social Security Scotland may have minimised the transitional confusion.

“There have been delays and other issues for people whose change of circumstances has triggered the transition from PIP to ADP. In particular, the date of the transition appears to be problematic with the DWP and SSS having some difficulty agreeing on a date. For example, in the case I've previously quoted, the claimant initially contacted the DWP about their change of circumstance in November 2022 and was told the case would be transferred to SSS, who would contact him. Despite numerous phone calls to SSS, nothing progressed until March 2023 when he received a letter advising that his change of circumstance form had not been returned - he'd never received the form. As I stated, once the form was completed and submitted in May 2023, it took until November 2023 for a decision letter to arrive. The claim was increased to the enhanced rates of both daily living and mobility. However, the claim was only backdated to March 2023, despite his initial phone call to notify of a change of circumstance taking place in November 2022. The DWP is adamant they transferred the claim in the correct way and say it's down to SSS, whilst SSS say they can only backdate to March 2023. Neither statutory body will take responsibility for the 4 months in-between.” - Multiple System Atrophy Trust

Accessibility concerns

A few mentioned illiteracy, digital illiteracy, and submissions from those who do not speak English as difficulties with submitting the change of circumstances form.

“Enhanced Support for Non-Digital and Non-English Speakers would be welcome. This would include more accessible, multilingual support services to help individuals who are not proficient in English.” - MECOPP

The Donaldson Trust also noted that the rules and requirements for submitting a change of circumstance form made it difficult for neurodivergent people to self-advocate:

“A neurodivergent person may not be comfortable or willing to disclose information around change in their circumstances, even if it would be advantageous for them to do so, owing to their own interpretation of what ‘change’ means and what the ‘rules’ might mean.” - The Donaldson Trust

Positive experiences

Respondents listed the following stakeholder experiences in describing what worked well about the process of submitting a change of circumstance. These are listed from most to least prevalent:

- Support for online submission, including the main change of circumstances form as well as supporting information.
- Positive experience with telephone assistance, which compared positively to the experience of undergoing an assessment with Personal Independence Payment.
- Good experience with the Local Delivery Service in completing the form.
- Including a “nothing has changed” tick box on the change of circumstances form was suggested as being useful.

12. Other considerations

At the end of the consultation the Independent Review sought respondents' suggestions for actionable changes to Adult Disability Payment that will positively impact those who apply for and receive the payment. While respondents were probed to highlight their priorities and possible unintended consequences, most responded solely with their suggestions. Similarly, the call for evidence asked organisations to provide any other evidence that they deemed relevant for consideration.

Key findings

- Responses to the final section of the consultation covered many of the themes already presented in the report. Most prevalent was the importance of considering the varied impacts that conditions can have on wellbeing and lifestyles, which was also discussed in multiple consultation events.
- Call for evidence responses reiterated the need for better communication throughout the application and decision-making process, including calls for clear escalation routes for applicants, clients, and third-sector support workers.

Consultation

Q21. Are there any other changes you think the Scottish Government could make to Adult Disability Payment? If you proposed changes, what positive impacts could these have, and for who? If you proposed changes, how would you prioritise these?

Consider wellbeing and lifestyle impacts of conditions

Over two thirds of consultation respondents answered Q21. The most prevalent theme was a request for Adult Disability Payment to be more understanding of the wellbeing and lifestyle impacts that disabilities and long-term conditions can have on the people. This was echoed in multiple engagement events.

Respondents emphasised that when creating a social security system, a human rights approach is needed to ensure that benefits consider the complete experiences and impact living with a disability or long-term condition can have on people.

“The ALLIANCE has consistently advocated for a human rights-based approach to social security, including through our membership of the Scottish Campaign on Rights to Social Security (SCoRSS). The 2020 report “Beyond a Safe and Secure Transition” lays out the SCoRSS vision on the future of social security in Scotland, calling for a social security system that follows six core principles: 1) Has a clear purpose; 2) Is human rights based; 3) Supports equal participation in society and independent living; 4) Is adequate; 5) Provides whole-of-life support; 6) Interacts well with future social security developments and is well connected to other services. We would encourage the Scottish Government to embed these principles throughout the devolved social security system.” – The Health and Social Care Alliance Scotland

Other themes already covered in this report

Many of the other points raised by respondents reflected issues and themes addressed in more detail earlier in this report. These are summarised below for reference, alongside where more information can be found.

- **Gathering more information about conditions and their impact on daily living** (see Chapter 5): A few noted the Adult Disability Payment application form should better reflect lived experience and consider a wider range of conditions.
- **Clearer forms** (see Chapter 5): Some noted that the Adult Disability Payment application form could be improved. A few suggested the language should be clarified and questions simplified.
- **Better workforce training** (see Chapter 5): a few again expressed a view that more staff training is required to ensure the Social Security Scotland workforce understand different conditions and the impact they have on people's lives.
- **Improved timescales** (see Chapter 10): Slow timescales were mentioned by some who thought it was important for client wellbeing to improve the time it takes to receive decisions, changes of circumstances and re-determinations.
- **Improve understanding of fluctuating conditions** (see Chapter 6): A few reiterated the importance of considering fluctuating conditions.
- **Better communication**: At this question, a few respondents reiterated the need for better communication throughout the process, particularly around status updates, echoing themes about improved communication noted throughout this report.
- **Consider review award periods**: Longer review periods which could have a positive impact on client wellbeing and stress were advocated by a few at various points.

Other points raised

A few points were mentioned by one or two respondents each. They are listed below from most to least prevalent:

- Although not addressed in this consultation given the evidence available in a previous consultation, a few respondents criticised the mobility component of Adult Disability Payment and asked for changes to be made. For example, some asked for more consideration of non-physical disabilities or for changes to the 20-metre rule.
- Two suggested an increase in the payment amount.
- One individual suggested that the application pack should advise all applicants to seek assistance with the application form.
- Another suggested that applicants should have access to their full application, including supporting information, after the application has been submitted. They felt this could ensure that supporting information had been presented accurately and, if inaccurate, could be changed.

Call for Evidence

Q14. Is there any other evidence you would like to share with us on the delivery of Adult Disability Payment to date?

Over three quarters of call for evidence respondents commented at Q14. While many did not provide evidence, they highlighted potential changes and improvements to Adult Disability Payment based upon their experiences with their clients or stakeholders.

Better communication

As noted throughout the call for evidence, organisations noted that their engagement with their own stakeholders highlighted the need for better communication. This was mentioned by some at this question as well. Some specifically spoke about the need for clear escalation routes. Often this was for third sector or advocacy organisations to assist clients with problems concerning applications or decisions. However, effective means for individuals to contact Social Security Scotland with urgent questions and concerns was also noted as being necessary.

MECOPP and Feniks consulted with their stakeholders and learned that they are not receiving necessary application material and mailed communication in the language of their choice. They felt this could overburden their organisation in assisting the person due to translation time or make the process very difficult for those applying independently.

Supporting information

A few respondents noted that while their stakeholders appreciated the new policy that enables Social Security Scotland to gather medical supporting information, there are often instances where GPs, social care workers, and addiction support workers, to name a few mentioned by respondents, are not responding promptly, which means decisions on applications are being delayed. In some instances, it was suggested that relationships between applicants, these services and Social Security Scotland are strained or do not exist, complicating the requirement for supporting information.

13. Conclusion

Many individuals and organisations with detailed knowledge took part in the consultation, call for evidence and events, sharing their views on how Adult Disability Payment could be delivered more effectively. Reflecting their experience and perspectives, this report provides a high-level summary of the themes evident across the engagement. For more detail, readers are encouraged to look to individual responses where permission was given for publication⁷.

A range of views were expressed in responses. Many gave positive feedback about Adult Disability Payment and Social Security Scotland, speaking highly of some staff interactions, describing feeling respected during the application process and welcoming the lack of medical assessments.

However, respondents also suggested changes they felt would encourage more people to apply for Adult Disability Payment, improve the efficiency of the application process, ensure the breadth of conditions and impacts are considered in decision-making and ensure clients continue to be treated fairly. Improvements highlighted across the engagement included:

- Greater promotion of Adult Disability Payment and pre-application support services, notably via health and social care, while also acknowledging the key role of the third sector in providing individualised support to help people understand their eligibility and apply.
- Reducing the complexity of the application process and considering whether shorter application forms, clearer questions and simpler language can be used, and by providing more examples and case studies of how the rules apply in practice.
- Changes to the activities in the daily living component to ensure they gather relevant information about a wider range of conditions, consider the broader impacts of a condition on daily living, reflect people's lived experience of real-life scenarios, and reduce confusion around fluctuating conditions.
- Training for Social Security Scotland staff to ensure they understand different conditions and accurately capture lived experiences, and to minimise inconsistencies in decision-making.
- Shorter processing times for decisions, re-determinations and change of circumstances to minimise financial harm and ease anxiety.
- Clearer, more personalised communication, including progress updates for applications and making it easier to contact Social Security Scotland.
- Improving accessibility by considering the needs of people with different conditions e.g. neurodiverse or visual impairments, and those in seldom-heard groups who may require translation or interpreter support.
- Longer review periods and the potential for more indefinite awards.

⁷ Responses are published on the [Scottish Government's consultation website](#)

In conclusion, the responses to the consultation and call for evidence, and in particular the lived examples provided by individuals who receive Adult Disability Payment and those who have supported people to apply, will provide valuable and informative evidence for the Independent Review to draw on when considering its recommendations.

Appendix A: Public Consultation Questions

Question 1

How effective do you think the following methods could be at helping people to find out about Adult Disability Payment?

Q1A. Advertisements for Adult Disability Payment (television, social media/online, newspapers etc).

Q1B. Working with organisations like charities to inform those who use their services about Adult Disability Payment.

Q1C. Running events within communities to inform people about Adult Disability Payment.

[Very effective / Effective / Somewhat effective / Not very effective / Not effective at all]

Q1D. Do you think there is anyone who might be left out by these methods? Please give reasons for your answer.

Free Text Box

Q1E. Are there any other methods that might help people find out about Adult Disability Payment? Please give reasons for your answer.

Free Text Box

Q1F. What do you think the Scottish Government could do to help people who know Adult Disability Payment exists but are unsure if they should apply or might be unwilling to apply?

Free Text Box

Q1G. What reasons do you think might mean someone may be unwilling to apply for Adult Disability Payment?

Free Text Box

Question 2

Q2. Do you think there is anything else that could be done to encourage people to apply for Adult Disability Payment?

Free Text Box

Question 3

Q3A. In your view, would it be helpful to have a more detailed eligibility check before filling in the application form?

[Yes / No / Don't know]

Q3B. Please explain your reasons.

Free Text Box

Q3C. If you said "yes", what questions do you think the eligibility checker should ask?

Free Text Box

Q3D. If you said "yes", please consider what the potential advantages/disadvantages would be on people thinking about making an application for Adult Disability Payment.

Free Text Box

Q3E. Would you need help to complete an eligibility check?

[Yes / No / Don't know]

Q3F. If you said "yes", who would you ask to help you?

Free Text Box

Question 4

Q4A. Have you ever used the Local Delivery service provided by Social Security Scotland to help you with something to do with Adult Disability Payment?

[Yes / No / Don't know]

Q4B. If you said "no", are you aware of this service and the support it offers?

[Yes / No / Don't know]

Q4C. If you said "yes", did you feel that you were treated with dignity, fairness and respect?

[Yes / No / Don't know]

Q4D. If you said "yes", how easy was it to access the Local Delivery Service?

[Very easy / Somewhat easy / Neither easy nor difficult / Somewhat difficult /Very difficult]

Q4E. Please provide reasons for your answer. You might want to think about:

- How did you find out about the Local Delivery service?

- What did the service help you with? You might want to think about how that helped you.
- What about this service do you think worked well?
- What would you change about this service?

Free Text Box

Q4F. What do you think would help make people more aware of this service and the help it provides?

Free Text Box

Question 5

Q5A. Have you ever used the Independent Advocacy Service provided by VoiceAbility to help you with something to do with Adult Disability Payment?

[Yes / No / Don't know]

Q5B. If you said "no", are you aware of this service and the support it offers?

[Yes / No / Don't know]

Q5C. If you said "yes", did you feel that you were treated with dignity, fairness and respect?

[Yes / No / Don't know]

Q5D. If you said "yes", how easy was it to access the Independent Advocacy Service?

[Very easy / Somewhat easy / Neither easy nor difficult / Somewhat difficult /Very difficult]

Q5E. Please provide reasons for your answer. You might want to think about:

- How did you find out about the Independent Advocacy Service?
- What did the service help you with? You might want to think about how that helped you.
- What about this service do you think worked well?
- What would you change about this service?

Free Text Box

Q5F. What do you think would help make people more aware of this service and the help it provides?

Free Text Box

Question 6

QA6. Do you agree or disagree that the rules for the daily living part of Adult Disability Payment are easy to understand?

If you need a reminder of what the rules are, you can read them [here](#).

[Agree / Disagree / Don't Know]

Q6B. Please give reasons for your answer, outlining which parts you think are easy or difficult to understand and why.

Free Text Box

Q6C. How could the rules around the daily living part be made easier to understand?

Free Text Box

Question 7

Q7A. If there was an opportunity to change the rules for the daily living part of Adult Disability Payment, what changes would you make (if any)?

Free Text Box

If you suggested changes:

Q7B. Who do you think might be better off?

Free Text Box

Q7C. Who do you think might be worse off?

By 'better off' and 'worse off' we mean either from a financial, wellbeing or any other perspective you think is relevant.

Free Text Box

Question 8

Q8A. Do the current daily living activities adequately allow the impact of fluctuating conditions to be accounted for?

[Yes / No / Don't know]

Q8B. Please give reasons for your answer.

Free Text Box

Q8C. Do you think that people with certain conditions might find it difficult to receive points for any one or more of the daily living activities?

[Yes / No / Don't know]

Q8D. Please give reasons for your answer.

Free Text Box

Question 9

Q9A. Are the rules around an activity needing to be completed safely, to an acceptable standard and within a reasonable time period easy to understand?

[Yes / No / Don't know]

Q9B. If you said "no", what would you change to make them easier to understand?

Free Text Box

Question 10

Q10A. How effective do you think the fluctuating conditions sections of the application form are at helping people to describe their daily living needs?

Please only answer in relation to the fluctuating conditions sections of the application form that are outlined on Page 19 in the consultation paper.

[Very effective / Effective / Somewhat effective / Not very effective / Not effective at all]

Q10B. Please give reasons for your answer.

Free Text Box

Question 11

Q11A. If there was an opportunity to change any specific parts of the rules around fluctuating conditions as part of the daily living activities, what changes would you make (if any)?

Free Text Box

Q11B. If you proposed changes, what positive impacts could these have, and for who?

Free Text Box

Q11C. If you proposed changes, what negative impacts could these have, and for who?

Free Text Box

Question 12

Q12A. How effective do you think the daily living part of the Adult Disability Payment application is at helping Social Security Scotland understand a person's daily living needs?

[Very effective / Effective / Somewhat effective / Not very effective / Not effective at all]

Q12B. Please give reasons for your answer.

Free Text Box

Question 13

Q13A. Are there any other issues with the daily living part of the Adult Disability Payment application that have not been captured above?

[Yes / No / Don't know]

Q13B. If you said "yes", what other issues with the daily living activities do you think need to be considered?

Free Text Box

Q13C. Are there any other things you would like to tell us about the daily living part of Adult Disability Payment?

Free Text Box

Question 14

Q14A. How effective do you think Social Security Scotland's decision-making process is with regards to understanding a person's daily living needs?

[Very effective / Effective / Somewhat effective / Not very effective / Not effective at all]

Q14B. Please give reasons for your answer.

Free Text Box

Question 15

Q15A. Have you received a decision on an application for Adult Disability Payment?

[Yes / No / Don't know]

If you said "yes":

Q15B. Were you invited to take part in a consultation as part of applying for Adult Disability Payment?

[Yes / No / Don't know]

Q15C. How did the consultation take place?

[In person / By telephone / Video call / Other]

Q15D. Did the consultation take place at a convenient date and time for you?

[Yes / No]

Q15E. What worked well about the consultation process?

Free Text Box

Q15F. What worked less well about the consultation process?

Free Text Box

Q15G. Did you understand the decision?

[Yes / No / Don't know]

Q15H. Did you need support to understand the decision?

[Yes / No / Don't know]

Q15I. Please explain your answer.

Free Text Box

Q15J. What could have been changed about telling you what the decision was? What do you think the impact of that change might be?

Free Text Box

Question 16

Q16A. Have you ever asked for a decision on an Adult Disability Payment application to be looked at again through the re-determination process?

[Yes / No / Don't know]

If you said "yes":

Q16B. Do you feel that you were treated with dignity, fairness and respect?

[Yes / No / Don't know]

Q16C. Did you receive regular updates about what was happening?

[Yes / No / Don't know]

Q16D. What do you think worked well about the re-determination process?

Free Text Box

Q16E. What would you change about this process?

Free Text Box

Question 17

Q17A. Have you ever received an indefinite award for Adult Disability Payment?

[Yes / No / Don't know]

If you said "yes":

Q17B. How did that make you feel?

Free Text Box

Q17C. What impact did this have on your quality of life?

Free Text Box

Q17D. Was the reason for this decision communicated clearly?

[Yes / No / Don't know]

Q17E. How could your experience of receiving an indefinite award be improved?

Free Text Box

Question 18

Q18A. Thinking about review periods for entitlement to Adult Disability Payment, have you ever received an Adult Disability Payment award that is subject to a review period?

[Yes / No / Don't know]

Q18B. If you said "yes", what is the impact of having a longer review period on the quality of life of a disabled person?

Q18C. Do you feel the reasons for this decision were communicated clearly?

[Yes / No / Don't know]

Q18D. Please give reasons for your answer.

Q18E. Have you ever experienced a review of your Adult Disability Payment award?

[Yes / No / Don't know]

If you said "yes":

Q18F. What do you think worked well about this process?

Free Text Box

Q18G. What would you change about this process?

Free Text Box

Question 19

Q19A. If you have ever received a decision on an Adult Disability Payment application, how long after you submitted your application did it take for you to receive this?

[Less than 1 month / 1 – 2 months / 2 – 3 months / 3 – 4 months / 4 – 5 months / 5 – 6 months / More than 6 months]

Q19B. How satisfied were you with this?

[Very satisfied / Satisfied / Somewhat satisfied / Not very satisfied / Not satisfied at all]

Q19C. What in your view could have been done to improve your experience of waiting for a decision?

Free Text Box

Question 20

Q20A. Have you previously reported a change of circumstances for Adult Disability Payment?

[Yes / No / Don't know]

If you said "yes":

Q20B. Do you feel that you were treated with dignity, fairness and respect?

[Yes / No / Don't know]

Q20C. Did you receive regular updates about what was happening?

[Yes / No / Don't know]

Q20D. In your view, what worked well?

Free Text Box

Q20E. In your view, worked less well?

Free Text Box

Question 21

Q21. Are there any other changes you think the Scottish Government could make to Adult Disability Payment? If you proposed changes, what positive impacts could these have, and for who? If you proposed changes, how would you prioritise these?

Free Text Box

Appendix B: Call for Evidence Questions

Question 1

The [Social Security Scotland Charter](#) specifically states that the Scottish Government will ensure as many people as possible get the benefits they are entitled to. This includes making a particular effort to reach people who are most likely to be excluded. Thinking about take-up of Adult Disability Payment for seldom-heard groups, what evidence exists about:

Q1A. Levels of awareness and barriers to awareness of Adult Disability Payment amongst seldom-heard groups?

Free Text Box

Q1B. The particular barriers to application facing people in specific seldom-heard groups?

Free Text Box

Question 2

In relation to Adult Disability Payment, can you provide evidence about any initiatives or activities that have measurably increased:

Q2A. Awareness

Free Text Box

Q2B. Take-up?

Free Text Box

You may wish to consider both in the context of seldom-heard groups or more widely.

Question 3

Q3. Can you provide specific examples of the factors that affect whether someone chooses to apply for Adult Disability Payment or chooses not to apply?

Free Text Box

Question 4

Thinking about the pre-application services provided by Social Security Scotland, can you provide specific examples of:

Q4A. Parts of those services that are working well?

Free Text Box

Q4B. Parts of those services that don't work, are confusing or could be further improved?

Free Text Box

Question 5

What evidence exists about the impact of the following pre-application services in supporting people making an application for Adult Disability Payment:

Q5A. Social Security Scotland's Local Delivery Service

Free Text Box

Q5B. The Independent Advocacy Service.

Free Text Box

Question 6

Q6. What evidence exists about what factors influence people approaching third sector or other public sector services for support with Adult Disability Payment?

Free Text Box

Question 7

Q7. Thinking about the time it takes to decide about whether someone gets Adult Disability Payment, do you have evidence whether this may have a different impact on some people than others, such as those from seldom-heard groups?

Free Text Box

Q7A. Do you have evidence relating to what could be done to enhance peoples experience of waiting for a decision (if anything)?

Free Text Box

Question 8

Q8. Thinking about when a decision on an Adult Disability Payment application is made, do you have any evidence about how clearly the reasons for the decision are explained to the person?

Free Text Box

Question 9

Q9. Do you have any evidence about how well-informed people feel during the re-determination process?

Free Text Box

Question 10

Q10. Can you provide specific examples of factors that influence whether a person will request a re-determination of a decision made on an Adult Disability Payment application?

Free Text Box

Question 11

Q11. Can you provide specific examples of factors that may influence whether a person will appeal an Adult Disability Payment decision?

Free Text Box

Question 12

What evidence exists about people's experiences of notifying Social Security Scotland about a change of circumstances? Can you provide specific examples of:

Q12A. What worked well (if anything)?

Free Text Box

Q12B. What could be improved (if anything)?

Free Text Box

Question 13

People may receive an Adult Disability Payment award without a review period (also known as an "indefinite award") if their needs are highly unlikely to change in the future.

In relation to Adult Disability Payment, do you have any evidence about:

Q13A. How clearly the decision to make an indefinite award was explained?

Free Text Box

Q13B. Whether or not people understand why they have or have not been given an indefinite award?

Free Text Box

Q13C. What were people's experience of having an indefinite award? This could include the impact that having an indefinite award has on people's quality of life compared to people who have had a review period set.

Free Text Box

Question 14

Q14. Is there any other evidence you would like to share with us on the delivery of Adult Disability Payment to date?

Free Text Box

Appendix C: Summary of Engagement Events

The Independent Review organised nine engagement events with stakeholders to provide a more accessible opportunity for people to contribute. Following a short introduction by the Review Secretariat, these events were independently facilitated by The Lines Between.

In total 47 people attended across eight in-person events across Scotland and one online event. A summary of the events is provided below.

Event location	Date	Total attendees	Individual attendees	Organisation attendees
Edinburgh	1 August 2024	8	2	6
Stirling	5 August 2024	6	2	4
Dundee	8 August 2024	2	1	1
Cowdenbeath	12 August 2024	4	0	4
Online	13 August 2024	3	2	1
Perth	14 August 2024	2	2	0
Glasgow	19 August 2024	14	6	8 ⁸
Inverness	21 August 2024	2	0	2
Aberdeen	22 August 2024	6	4	2
Total		47	19	28

⁸ Two attendees represented VoiceAbility, who provide the Independent Advocacy Service.

Appendix D: Daily Living Activities

Ten activities are considered for the daily living component:

- Preparing food.
- Taking nutrition.
- Managing therapy and monitoring a health condition.
- Washing and bathing.
- Managing toilet needs or incontinence.
- Dressing and undressing.
- Communicating verbally.
- Reading and understanding signs, symbols and words.
- Engaging socially with other people face-to-face.
- Making budgeting decisions.

A Social Security Scotland case manager looks at a person's ability to complete the ten activities based on the information they give in their application form. Each activity has an associated series of statements called descriptors, and the case manager decides which descriptor applies to the person, with each activity given a score between zero to 12.

Which descriptor the case manager selects depends on several factors, but the case manager must only choose one descriptor. This applies to both fluctuating conditions and stable conditions. To decide which descriptor applies for those with fluctuating conditions, a '50% rule' is applied, as set out in the consultation paper. Case managers must also consider whether a person can reliably complete an activity. Reliably means whether a person can carry out activity safely, to an acceptable standard and repeatedly.



© Crown copyright 2024



This publication is licensed under the terms of the Open Government Licence v3.0 except where otherwise stated. To view this licence, visit nationalarchives.gov.uk/doc/open-government-licence/version/3 or write to the Information Policy Team, The National Archives, Kew, London TW9 4DU, or email: psi@nationalarchives.gsi.gov.uk.

Where we have identified any third party copyright information you will need to obtain permission from the copyright holders concerned.

This publication is available at www.gov.scot

Any enquiries regarding this publication should be sent to us at

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

ISBN: 978-1-83691-001-5 (web only)

Published by The Scottish Government, November 2024

Produced for The Scottish Government by APS Group Scotland, 21 Tennant Street, Edinburgh EH6 5NA
PPDAS1526370 (11/24)

W W W . g o v . s c o t