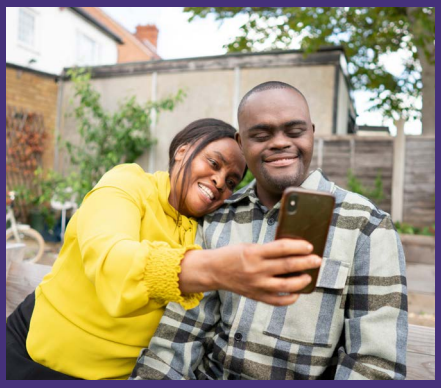
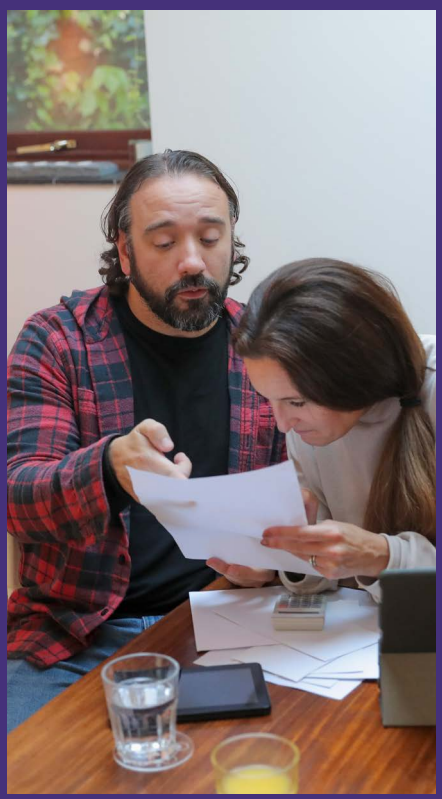


Independent Review of Adult Disability Payment: Final Report Summary



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Foreword

As Chair of the Independent Review of Adult Disability Payment, I am pleased to present the final report and recommendations following over a year of engagement with disabled people in Scotland.

This report marks a significant milestone in ongoing efforts to assess and enhance the effectiveness of Adult Disability Payment in meeting the needs of disabled adults across Scotland. From the outset, my goal has been to ensure that the Adult Disability Payment system is fair, transparent, and supportive, empowering those it serves to live with dignity and independence.

The transition from a reserved system of social security for disabled people to one led and managed by the Scottish Government was an historic milestone. Several welcome and positive changes are evident when the Scottish system is compared to the Personal Independence Payment (PIP) process. However, the devolution of social security is an ongoing process and with a commitment to continuous improvement, the opportunity exists to create a world-leading, human rights-based system of support for disabled people. I sincerely hope that my findings and recommendations will help to:

a) build on great foundations

b) improve the overall client experience

c) improve the systems and processes adopted by Social Security Scotland to, at all times, ensure accessibility, transparency, timely communications, timely decision-making, and ease of use

d) ensure a modern and more realistic approach to determining eligibility based on the principles enshrined in the UN Convention on Human Rights.

This report presents the key evidence I have considered as part of the Independent Review and my recommendations. Readers may wish to also read the full report, which includes further detail on potential financial and delivery implications for the Scottish Government. Further information on the terminology used, can be found in the full report.

In developing my recommendations, I have determined that some elements of change to Social Security Scotland systems or Scottish Government policies may be more readily achieved in the nearer term, than others. Some will come with a one-off cost whereas others will likely involve on-going costs. I have used data that is available to me at the time of writing, but that tells only part of the story. As with any change, there are some gaps or limitations that require a further assessment of cost. I have endeavoured to set out some of the steps that could be used to reach a more complete view. It is worth noting that this exercise considers only the potential costs of making changes to Adult Disability Payment and work hasn't yet been done on the potential wider benefits to the economy of making an investment in the people of Scotland.

At the time of writing this report, I cannot ignore the publication of the UK Government's Green Paper 'Pathways to Work: Reforming Benefits and Support to Get Britain Working'[1] and Sir Stephen Timms' review of the Personal Independence Payment (PIP) assessment that is due to report in Autumn 2026. I am most concerned with how the changes at UK level may impact disabled people in Scotland especially in relation to how people in receipt of certain rates of Adult Disability Payment may be entitled to other benefits.

1 Pathways to Work: Reforming Benefits and Support to Get Britain Working Green Paper (2025) - GOV.UK

Foreword

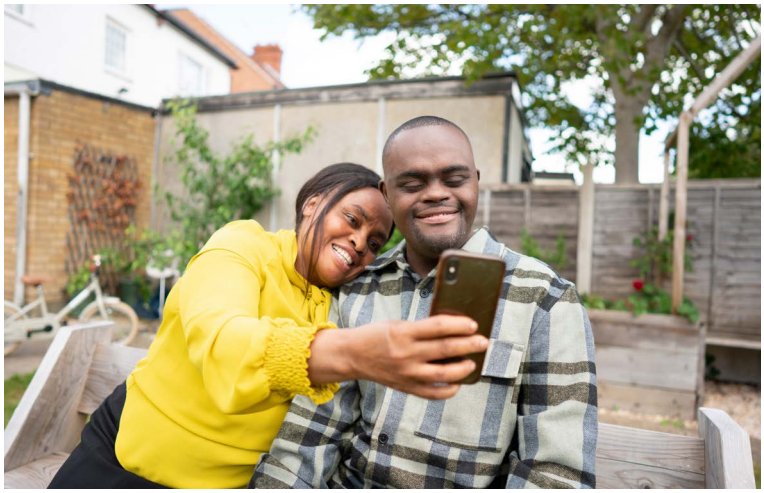
I would like to extend my deepest gratitude to the members of the Advisory Group whose expertise and dedication have been instrumental in shaping this review. Their insights and commitment have been invaluable in ensuring an inclusive and comprehensive process. Similarly, I am immensely grateful to the Secretariat for their support, meticulous research, and organisational skills, which have been essential in conducting such a thorough review.

Furthermore, I wish to acknowledge and thank all the Government, Social Security Scotland and other stakeholders, including individuals and organisations, who have generously given their time to participate in this review. Your contributions, whether through meetings, surveys, or written submissions, have provided a rich tapestry of perspectives and experiences that are critical to understanding the impact of Adult Disability Payment on the lives of disabled people in Scotland. My particular appreciation goes to people who have shared their personal stories and experiences. I acknowledge this is not always an easy thing to do and I am grateful that you felt able to trust me to represent your views.

Edel Harris OBE
Chair, Independent Review of Adult Disability Payment

Chapter 1
A People's Service

A People's Service



The client voice

I have heard throughout the review how both the Scottish Government and Social Security Scotland work to ensure people with lived or living experience of Adult Disability Payment are able to shape both policy and operational decisions.

The Scottish Government stood down the former Disability and Carers Benefits Expert Advisory Group (DACBEAG) in 2023, which provided policy advice to Scottish Ministers. However, I understand that Scottish Government policy officials continue to engage directly with stakeholders through the Ill Health and Disability Benefits Stakeholder Reference Group. Social Security Scotland similarly has an Operational Reference Group covering operational issues that integrates membership from the former Inclusive Communications External Stakeholder Reference Group.

I understand that Social Security Scotland set up its Client Panels in recognition of the need for engaging people with lived experience in ongoing development and improvement of Social Security Scotland. It has recruited Client Panel members from current clients. The Client Panels are a form of social research, involving surveys, interviews and focus groups with participants. Research has informed a range of operational decisions, including letters, SMS updates, and updates to the Charter. I also understand that Social Security Scotland draws insights from the Client Survey and complaints.

I asked disabled people and stakeholders about their ability to influence both policy and operational decisions. I heard frequently that people and organisations are growing tired of repeated conversations with little evident change to the system, which damages trust and results in disengagement. I also heard that some seldom-heard groups had a distrust of the State, and I repeatedly had to emphasise the independence of the Review in meetings.

Recommendation 1:
The reinstatement of an "expert by experience" group to guide the next stage of the evolution of Adult Disability Payment following the publication of this report.

Raising awareness of Adult Disability Payment and encouraging applications

I understand that there are challenges with estimating the number of people who are likely to be eligible for Adult Disability Payment, but do not make an application. I acknowledge that it is not currently possible to estimate take-up rates for disability benefits, or for specific client groups. I heard from stakeholders that there may be several reasons why someone who is potentially eligible for Adult Disability Payment does not make an application:

- people have limited awareness of Adult Disability Payment, and people may not know they are potentially eligible
- there is perceived stigma about applying for disability benefits, which can be a particular issue in some minority ethnic communities
- there is also stigma associated with mental health problems that can function as a barrier

A People's Service

- the application process or fear of rejection may deter some people from applying
- people see the process of applying as complex or challenging and this can negatively impact on people's wellbeing
- some people think Adult Disability Payment is for people with physical health conditions
- people may perceive public resources as scarce and think others are more in need
- a lack of awareness that Adult Disability Payment is not means-tested.

Stakeholders frequently raised the legacy of PIP. Some people describe their experience of engaging with Department for Work and Pensions (DWP) as "traumatic." I also heard that people were not aware of the differences between Adult Disability Payment and PIP. One stakeholder suggested that Social Security Scotland needs to engage more with disabled people to try and improve the awareness of these differences.

I also heard that people's mental health can be a significant reason for not making an application:

> **It impacts my mental health as it focussed on the things I can no longer do. I had to appeal to get the right level of support for the mobility component. It's soul destroying having to relive all the trauma that you go through getting a diagnosis of (Multiple Sclerosis)."**
>
> Quoted in MS Society Scotland response to the Independent Review of Adult Disability Payment Call for Evidence

In response to my call for evidence, one organisational respondent noted that there was not enough available evidence or research detailing the experiences of uptake of social security benefits among Black and Minority Ethnic (BME) communities, noting the Scottish Centre for Social Research had highlighted this in recent research commissioned by the Scottish Government.

> **Unfortunately, there is a significant lack of information on the experiences of Black minority ethnic (BME) people who are applying for (Adult Disability Payment), as well as on BME people with disabilities in Scotland and their access to benefits."**
>
> Coalition for Racial Equality, response to the Independent Review of Adult Disability Payment Call for Evidence

The Scottish Government has a Benefit Take-up Strategy to raise awareness of all its benefits and to support access, but this is not currently benefit-specific. However, the Scottish Government's response to my interim report noted that the findings of the independent review will inform its next Benefit Take-up Strategy. It was positive to hear that further research will be undertaken to undertsand the barriers people from seldom-heard groups may face in accessing social security. It is also positive to see evidence of using the outputs from that research in implementing the Benefit Take-up Strategy to develop approaches to communicate and promote devolved benefits to seldom-heard groups.

A People's Service

Recommendation 2:
To further develop strategies to effectively engage with seldom-heard voices and individuals who may be eligible but do not apply due to stigma. To address the societal and sometimes cultural stigma associated with disability benefits to ensure broader and fairer access.

Recommendation 3:
Social Security Scotland should consider how effective its understanding is of take-up amongst seldom-heard groups and consider ways to maximise its reach.

Trauma-informed approach

For those accessing Adult Disability Payment, the decision-making and consultations can further add to the distress experienced.

A trauma-informed approach to practice aims to minimise the risk of causing trauma and to prevent re-traumatisation. The National Trauma Transformation Programme launched in 2023 includes Government-supported guidelines that reflect the importance of this approach.

However, during the Review, some people described experiences during their Adult Disability Payment journey that did not align with a trauma-informed approach. For example:

> **"a lack of trauma-informed practice was evident in all aspects of the process, including application, assessment, written and verbal communications."**
>
> Premenstrual Dysphoric Disorder and the welfare state: Recommendations for reform

When I met with a group of people who describe themselves as living with pandemic-disability (this includes people with Long Covid, people with vaccine injury, many of whom have Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS), and people at high clinical risk of adverse consequences from re-infection) they stressed how helpful it would be for Social Security Scotland to be aware of the extent of trauma that many of them will have experienced.

Such experiences can have implications for how Social Security Scotland delivers its services and trains case managers and practitioners.

Recommendation 4:
In addition to the pilot underway within Social Security Scotland ensure a trauma-informed approach is embedded in all aspects of its work, by producing a framework where trauma-informed principles are reflected in the practice of Social Security Scotland.

A People's Service

Accessing other relevant services

Beyond the realm of social security, people's lives are interconnected, and they will often receive services from a range of agencies. It is important that these services are complementary and joined up. Most people I spoke to during the Review felt strongly that social security for disabled people and its budget should remain distinct from other services, whilst ensuring that it sits as part of a wider package of support for disabled people.

In a country the size of Scotland it should be possible for the Scottish Government to use its reach to ensure everyone who makes an application for Adult Disability Payment (whether the application is successful or not) is signposted with their consent to the relevant local statutory or voluntary services that may be able to provide additional advice, support, and signposting.

Recommendation 5:

For Social Security Scotland to strengthen its Local Delivery service partnerships to ensure that appropriate links are made to signpost or refer clients seeking assistance in connection with Adult Disability Payment to local services (with the client's consent) so they can ensure they get access to the help and support they may need. This should include identifying areas of best practice in partnership working to continue to enhance the service for Adult Disability Payment clients.

Accessing pre-application advice and support

During the Review I heard that many disabled people recognise, and trust established services like Citizens Advice Bureaux (CABx), because people perceive them to be independent. I also noted that disabled people felt they would not have been able to navigate the application process without support from these services.

> **"When a benefit check with one of our Social Welfare Specialists identifies an individual is eligible to claim (Adult Disability Payment), 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 (Adult Disability Payment) application form, nearly every person has reported they would not have been able to cope with their claim without our expert help and support."**
>
> Multiple System Atrophy Trust response to the Independent Review of Adult Disability Payment Call for Evidence

A People's Service

Unlike advice services, it is important to recognise that the remit of the Local Delivery service is not to provide advice, but to provide pre-application support.

In my engagements, I heard about:

- low awareness of Social Security Scotland's Local Delivery service amongst disabled people
- some people who were aware of it and some other stakeholders expressed concerns about a potential conflict of interest in Government-funded or -delivered services supporting disabled people with applications or re-determinations.

I asked about the Local Delivery and Independent Advocacy Services as part of the consultation.

- A few consultation respondents mentioned long wait times and trouble accessing these services as a barrier to take-up.
- Some people expressed frustrations with having to call a single number in the Social Security Scotland contact centre, rather than having a dedicated route to Local Delivery services.
- A few consultation respondents explained that they needed multiple appointments due to the length of the application form.
- Some people felt that staff require improved training particularly to address a lack of awareness of certain conditions and the impacts they have on daily living.

Some people suggested that if they can get good advice, support, and help to fill in the form all in one place why would they use a limited service.

> **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, response to the Independent Review of Adult Disability Payment Call for Evidence

I acknowledge, however, that the Scottish Government's Service Standards for the Independent Advocacy Service require the separate provision of advice and advocacy.

I also heard positive feedback about these pre-application services:

- people reported positive experiences with their Local Delivery Adviser
- there was appreciation for meeting in a preferred location
- Social Security Scotland staff were helpful on the telephone
- some stakeholders expressed favourable views about home visits and interpretation services working well.

I visited a local service that particularly welcomed the support provided by the Independent Advocacy Service, including the translation services and drop-in appointments.

A People's Service

More widely, I heard from many welfare benefits advisers and support workers in the third sector. In most cases, I heard how their workload is increasing, how there was limited or no statutory funding provided to their organisations to deliver services, with most charities reporting that they rely on fundraising.

I understand that the Scottish Government provides funding through a mixture of a debt advice levy and resource funding to support services which help to maximise incomes, reduce debt and tackle poverty. The debt advice levy is restricted for funding debt advice only, with the resource funding focused on income maximisation, benefits advice and debt advice.

Observation 1:
The user experience of Adult Disability Payment is linked directly to the provision of independent advice and support to clients with the application, re-determination and appeals process and is essential to the realisation of the human rights of the client. There are many advice services across Scotland that clients recognise and trust, as they will be familiar with these services. Ensuring that they are appropriately resourced to support disabled people with Adult Disability Payment is essential to the realisation of a client's human rights. The Scottish Government should consider how it is effectively placed to ensure that these services receive appropriate support in the delivery of vital services.

Recommendation 6:
Social Security Scotland should ensure that it actively promotes and gives due prominence to independent advice services to both potential and current clients, including in materials that clients receive from Social Security Scotland.

Recommendation 7:
Social Security Scotland to increase and improve the promotion of the Local Delivery service and the Independent Advocacy Service.

Recommendation 8:
Introduce a dedicated route to speak to Social Security Scotland about Local Delivery and to book appointments.

Recommendation 9:
Improve Local Delivery staff training to address a lack of awareness of certain conditions and the impacts they have on daily living.

Chapter 2
Processes That Work

Processes that work

Social Security Charter

The Social Security Charter sets out what people can expect from Social Security Scotland, with the objective of treating people with dignity, fairness and respect. It plays a crucial role in implementing the values set out in the Social Security (Scotland) Act 2018 and a Charter Measurement Framework is used to report on measures relating to the commitments in the Charter.

I often heard the word "kindness" in my interactions with disabled people and stakeholders. People felt listened to and valued and in most cases the experiences shared with me were in sharp contrast to experiences with the DWP (specifically the delivery of PIP).

The less than positive issues raised by disabled people and stakeholders relate not to their overall experience, but to their frustrations with some of the processes adopted by Social Security Scotland including: the application process, providing supporting information, processing times, lack of communication, telephone response times, third party mandates, inconsistent decision-making, lack of understanding of particular disabilities or conditions and the fear of losing an award if considering a re-determination request.

Application process

Recurring themes from my engagement with disabled people and stakeholders highlighted the following positives:

- the larger font on the paper form is appreciated, especially for people with a visual disability
- the inclusion of guidance and pictures on the form was thought to be helpful for clients.

Length and complexity of the online form

I also heard that the length and complexity of the application form, with difficulties experienced by some people with the online application form (including setting up an account) can be barriers for disabled people.

There is early evidence that the provision of an online application form for Adult Disability Payment is reducing barriers to take-up among some disabled people. However, digital exclusion, in particular among some seldom-heard groups means it is important that there is provision of a range of application methods. Stakeholders also told me about the risks of digital exclusion, particularly when households may be acutely feeling the impact of the cost-of-living crisis.

Some of the barriers to application include the impact on a person's mental health of filling in the application form. Many people told me that it is highly stressful, and they find completing the application form daunting.

Adjectives used to convey reactions to the form include overwhelming, intimidating, distressing, and exhausting. Clients presenting with mental health problems, Post-Traumatic Stress Disorder (PTSD) related cognitive impairment, and dyslexia were all specifically cited as having powerful reactions.

Processes that work

Stakeholders repeatedly raised the length of the form as an issue. 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.

I heard anecdotal evidence from more than one person that application forms can take at least three hours to complete. The length of time taken to fill in the form also highlights that some people are unable to fully explain the extent that their fluctuating condition impacts on their ability to complete tasks of daily living, without the support of experienced advisers.

Disabled people and stakeholders suggested some improvements to the application form:

- more open questions and space for free text responses throughout
- multiple choice questions for those who struggle with literacy and/or 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 it easier to fit into an envelope to return along with supporting documents
- make it easier to un-staple and copy the forms, as the booklet format means support organisations spend significant amounts of time scanning individual pages.

Answering functional questions

The most prevalent related theme following the consultation and call for evidence was confusion over the fluctuating conditions sections of the application form. While many disabled people acknowledged that there have been changes made to improve how applicants experience the process of completing the application form, these changes seem to have limited or no bearing on how much case managers understand the impact of fluctuating conditions. Some felt that the fluctuating conditions sections are ineffective at capturing the continued impact of bad days on a client's life and wellbeing longer-term, and a few respondents found it difficult to describe the impacts of their fluctuating conditions within the application form.

> **"The questions were impossible to understand, and I wasn't sure how to answer them. For example, did I talk about how my child was that week? That day? Things changed so quickly – I had to list all her medication and chemo drugs, but they would change a few weeks later. It was exhausting and upsetting and then at the end they said it would be six to nine months before I heard."**
>
> Individual response to Young Lives with Cancer

Processes that work

Other reasons for difficulty with completing the application form included:

- people finding the questions vague, contradictory or unclear
- being unable to understand the eligibility criteria in general
- some questions being too similar or repetitive and applicants could easily misinterpret them, especially when using terms such as "sometimes" or "always"
- the binary-seeming questions in some cases so that people sometimes feel that they cannot answer a straight "yes" or "no" to a question
- the application form does not explain the rationale for questions, leaving some people unsure how to answer
- that it is unclear what "reliably and repeatedly" mean in practice.

Technical issues with the online form

Amongst some of the issues identified in relation to technical issues, I frequently heard that:

- some people with certain conditions, for example, hearing impairments or people using assistive technology, find it difficult to access mygov.scot and complete online forms
- a client cannot edit their application form once submitted
- there is not enough file space to upload multiple documents when uploading supporting information online.

I welcomed it when the Scottish Government and Social Security Scotland told me they have attempted to address some aspects of the online application form, addressing some of the recurring issues to improve the client experience. Social Security Scotland continues to review the application form and guidance to try to ensure questions are relevant for all clients and to reduce repetition.

Recommendation 10:
Taking into account the findings in this report, review the application form, including its length and reconsider the way the questions are framed to maximise the opportunity for a client to articulate how their disability or condition impacts on their daily life and to reduce the anxiety and stress associated with the task of applying.

Processing times

The time it takes Social Security Scotland to decide if someone qualifies for Adult Disability Payment was a recurring theme raised by many disabled people. I heard about anxiety and stress associated with this, which can exacerbate the effects of a health condition or disability.

> **"I started needing a wheelchair and was not able to access other supports like a blue badge until my Adult Disability Payment 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 response to the Independent Review of Adult Disability Payment Public Consultation

Processes that work

While it is evident that Social Security Scotland has undertaken a lot of work to reduce the waiting times for a decision, the feedback I have received has highlighted that the time waiting for the decision is an area for improvement.

As well as highlighting the prolonged decision-making process people have told me that there is a lack of information provided to them in terms of how their application is progressing. Many people told me that they had to proactively engage with Social Security Scotland to see what stage their application was at, as they otherwise felt they would not have received any information about their application.

Another person with a similar experience told me that they had "chased a lot" but that the Social Security Scotland could improve the process with an automated system informing people it has received their application and it has been allocated to a case manager for a decision. There was a suggestion that extending opening times for telephone and webchat would assist many applicants as the opening hours clash with people's work or caring commitments.

I heard concerns from stakeholders that introducing an online portal to track progress of an Adult Disability Payment application or re-determination could be challenging for people with certain conditions to use. In particular, people with progressive conditions, such as Huntington's disease, who are at risk of losing the ability to use online systems as the disease progresses.

Recommendation 11:
As indicated in Social Security Scotland's Business Plan 2024- 25, continue to do all possible to improve decision-making times and call wait times.

Recommendation 12:
In addition to providing an estimated processing time when an application is submitted, proactively provide regular updates on likely wait time for processing an application, review or a change of circumstances.

Recommendation 13:
Develop and deliver a "Track Your Application" online portal making it easier for clients to apply for Adult Disability Payment and to improve communication on the status of a client's application.

Implicit consent

Many stakeholders told me that effective communication between Social Security Scotland and third parties such as advocates, welfare benefits advisers, benefit appointees, and others supporting individuals in applying for Adult Disability Payment is crucial.

Many people highlighted that there were more barriers for third parties obtaining consent to deal with Social Security Scotland than they had experienced under the DWP system of "implicit consent". I heard suggestions that the approach was discriminatory given people's communication needs. Several welfare rights advisers also suggested that they could not intervene on a client's behalf to provide reassurance that Social Security Scotland had received an application, despite Social Security Scotland having a process called "unavailable consent" with guidance and staff training available on how to deliver it.

I also heard suggestions that the current absence of a dedicated helpline following the granting of consent to a third party resulted in delays in supporting individuals to provide Social Security Scotland with necessary information, which in turn delays the overall decision-making process.

Processes that work

Social Security Scotland told me it has begun to pilot an escalation process for third party representative organisations for vulnerable Adult Disability Payment clients. An initial pilot ran until 23 May 2025 and Social Security Scotland has extended this to all its benefits. Eleven organisations are now part of the pilot, six local authorities and five third sector organisations.

Recommendation 14:

Improve the service experience for Adult Disability Payment clients and third-party representatives interacting with Social Security Scotland on their behalf by:

(a) developing an understanding of any differences in the implementation of implicit consent (as used by the DWP) and unavailable consent (as used by Social Security Scotland) to ensure third-party representatives can receive equivalent standards of service from both

(b) assessing the consistency of the implementation of the current guidance on unavailable consent to ensure it is aligned with the policy intention and updating it where necessary, and

(c) using learning from the "interacting with third-party representatives" pilot to consider the merits of a third-party escalation route; to update policy and guidance about how declarations and third-party mandates are obtained and to ensure that the way in which mandates are obtained reflect the published policy and guidance

Supporting information

Whilst supporting information is outside the scope of my review, I believe it is important to reflect what I have heard, as the provision of adequate supporting information is a critical part of the initial decision-making process.

When shadowing case managers, I noted how most supporting information came from an applicant's GP. I also saw how the quality and content of supporting information coming from GPs could vary widely. In one case, it contained very little, unhelpful information.

Social Security Scotland told me it has refined its approach to gathering information, recognising a GP is not always the best source of supporting information. It may now contact other professionals involved as part of a refined approach and changes to guidance for contacting GPs reflects this. When contacting GPs, it identified that asking specific questions about the client's application was too onerous and time consuming, so now case managers request universal confirmation of the client's conditions or disability, their needs or symptoms, and what medication, treatment, if any, they are prescribed.

It is too early to see if this revised approach is affecting the quality of decision-making but it reinforces the need and the importance of improving the list of who supporting information can come from so it better reflects the types of professionals the individual will have information from/will be able to easily contact, including that it does not have to be a medical professional (such as GP) but rather a professional involved in the client's treatment or care. Stressing that supporting information from a wider support network can be a useful tool to help case managers understand their needs better is seen by disabled people and stakeholders as a positive step forward.

Processes that work

> **My outcome was better than others but not great. I had my mental health advisor with me as an advocate during my telephone assessment and I think that was vital. They also helped me fill out the forms. They helped give evidence. My GP was not forthcoming or at all helpful in providing supporting evidence. 'Luckily' I had a letter from a retired GP explaining [Premenstrual Dysphoria Disorder] and how it impacts me."**
>
> Individual with Premenstrual Dysphoria Disorder

I understand that Social Security Scotland has sought to make improvements to the external guidance on supporting information for disability benefits. Social Security Scotland has also undertaken work to understand where case managers and practitioners are most likely to need support and to identify where improvements may be helpful in the implementation of the decision-making policy. I understand the process for Social Security Scotland case managers seeking input from Health and Social Care Practitioners continues to flourish, as early input has improved timescales for decision-making.

It is noted that Social Security Scotland has also held stakeholder events for key public sector providers of supporting information.

Observation 2:
Collecting insight/information on whether the changes to the external guidance on supporting information for disability benefits has had any impact on processing times may be a useful approach for Social Security Scotland moving forward.

Decision-making

The Scottish Social Security Charter sets out what the individual can expect in relation to decision-making. It commits to taking decisions in a consistent and accurate way and aiming to get determinations right first time.

I asked about the effectiveness of Social Security Scotland's decision-making process as part of the consultation. The majority of respondents to the consultation said it is "somewhat effective" (35%) with almost 25% suggesting that the process is "not effective at all". 80% of people said they understood the decision they received and 81% declared that they did not need support to understand the decision.

Social Security Scotland told me its case managers are trained to take a person-centred approach to decision-making by:

- considering how the individual's condition affects them
- considering all their circumstances
- listening to the individual
- treating them as an individual
- recognising that the individual understands their own life best

Processes that work

- considering the individual's support network, caring responsibilities and work responsibilities
- making sound judgments about the impact that an individual's condition has on them
- approaching decisions from a position of trust
- only seeking one source of supporting information from a professional where possible.

During the time spent with case managers I saw first-hand the consideration given to the principles of person-centred decision-making and the care and attention applied to the responsibility inferred. What particularly stood out for me was approaching decisions from a position of trust.

Consistency

There is a concern that discrepancies and interpretative variations may lead to inconsistent outcomes, which might undermine the fairness of the process. However comprehensive and thorough the quality assurance process is, there will always be room for a level of inconsistency in a system that allows for case managers' discretion coupled with a degree of subjectivity.

Although some welfare rights advisers felt there was a lack of consistency in decision-making, there was little objective evidence of this provided. Others felt that it was harder to predict the outcome of an application for Adult Disability Payment compared to PIP, with unclear explanations for decisions. I also heard from one person (and observed a case myself) where a decision changed significantly between application, re-determination and appeal.

Quality Assurance

Social Security Scotland took me through its quality assurance process, which appears very thorough and provides an on-going learning opportunity for case managers and other staff.

Although there are regularly reviews of entitlement decisions to identify potential improvements to the decision-making process, I saw or heard of many examples where re-determination decisions varied from the original case manager decision. This may be because of additional supporting information or the existence of new supporting information available to the case manager, or different interpretations of the criteria.

Continuous Improvement

> **Only 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, response to the Independent Review of Adult Disability Payment, Public Consultation

Social Security Scotland has embarked on two major pieces of work aimed at improving decision-making following internal user research to understand where case managers are most likely to need support and where improvements were possible to the implementation of guidance.

Processes that work

One was concerned with providing more detailed guidance and a simplified, quicker way of accessing the tools required. The second was the introduction in 2023 of an intense, targeted training session that covered changes in operational processes to help better gathering of supporting information and covered common areas of the decision-making policy to make improvements to assist case manager's understanding.

Justifications for decisions

I heard anecdotally of a small number of instances where case managers made assumptions about the severity of a client's condition, based on whether they were attending physiotherapy or using prescribed medication. Similarly, I heard of instances of case managers assuming that a lack of input from NHS mental health services (which are under exceptional pressures) meant that the individual's condition was not severe enough to qualify for Adult Disability Payment (this is despite decision-making guidance to the contrary). Welfare Advisers told me about experiences of beginning to receive "cut and paste" decisions.

Recommendation 15:

For Social Security Scotland to continually assess how one can balance the need for fairness and equity with the discretion that is inherent in the determination process.

Recommendation 16:

For the decision-making training and guidance to be reviewed to ensure that undue weight is not given to how a person manages pain or whether they have access to clinical support or therapy.

Recommendation 17:

For each letter from Social Security Scotland to be stand-alone so there is no need to cross reference with other correspondence and put the date of the correspondence on every page when sending letters to clients.

Reliability criteria

I received a great deal of feedback regarding individuals not being able to adequately describe the impact of their fluctuating conditions on their daily life when answering questions determined by the current activities and descriptors.

> **"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 response, to the Independent Review of Adult Disability Payment Public Consultation

Clients are not always aware of the existence of the "reliability criteria", i.e., they do not fully understand that factors such as the time taken to complete an activity, the impact of completing an activity and the ability to undertake an activity as often as required are relevant.

Processes that work

> **"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 response, to the Independent Review of Adult Disability Payment Consultation

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 problem or is neurodiverse.

Another suggestion made was that the exact wording of the reliability criteria (that a person must be able to undertake an activity safely, to an acceptable standard, repeatedly and in a reasonable time) should form part of the activity descriptor itself. Although this would be repetitive, it would highlight the importance of this part of the decision-making process and provide an opportunity for the client to answer the questions on the application form more fully.

I repeatedly heard that confidence in this part of the process is limited because of a "lack of transparency" or because in some determination letters the reasons for not making an award make no reference to the reliability criteria, leaving people to wonder if they were applied fairly or at all.

Recommendation 18:
Ensure rigorous application of the reliability criteria to ensure consistency in the decision-making approach.

Recommendation 19:
The reliability criteria should be explained clearly both in promotional materials, at the start and throughout the application process with more examples, so that clients understand its importance and have a clear understanding of how it is applied in making decisions.

Recommendation 20:
Make clear in decision-making guidance and in training that the inability to complete one activity reliably may be relevant to whether or not a client can complete other activities and should be proactively considered by case managers.

Recommendation 21:
Social Security Scotland should ensure that explicit reference is made to the reliability criteria in all decision correspondence, so that clients and representatives can understand if, and how, the criteria have been applied.

Recommendation 22:
To ensure that the outcomes of case law decisions are reflected in decision-making guidance and training.

Processes that work

Case Discussions

Case Managers can utilise case discussions as part of the decision-making process in order to draw on advice and support from Health and Social Care Practitioners to understand the client's disability or impairment further; to assess the value of the supporting information provided or the types and routes for supporting information that could be further explored.

Eligibility for Adult Disability Payment is based on the impact that a condition or disability has rather than conditions or disabilities themselves. However, I heard that there is sometimes a perceived difference between how case managers manage applications from clients with physical health conditions and clients with mental health problems. There was a perceived lack of transparency and consistency, with people often telling me that they believe this overlooks the psychological symptoms that can have the most detrimental impact on their life.

Whilst it is not possible to ensure that Social Security Scotland trains its case managers and practitioners in relation to every condition or disability, many disabled people told me that there was a need for case managers and practitioners to understand the connections between different conditions, the functional impact these can have and lived experience.

> **"...In some cases, PMDD was not mentioned on the final decision letter despite it being a focus of the application."**
>
> Interim report. Premenstrual Dysphoric Disorder and the welfare state: recommendations for reform

Social Security Scotland do introduce awareness raising sessions when it is apparent that there are several new applications relating to a less common impairment and they may not have the knowledge or expertise within the practitioner team to support case managers to make decisions.

Recommendation 23:

To review the training and guidance available in relation to decision-making to ensure there is no bias in the system when considering mental health problems as opposed to physical conditions and to reinforce the point that an individual's condition is just one of many factors that the case manager needs to take into consideration when deciding upon an award.

Recommendation 24:

For Social Security Scotland to introduce a plan to clarify the approach they take to engage charities and specialist organisations in providing guidance and training to case managers and practitioners on specific disabilities or conditions.

Processes that work

Consultations

Having read the guidance provided to case managers and practitioners and getting the views from Social Security colleagues on the process it is evident that consultations, when they occur, play an important role in the decision-making process.

I heard universal praise from disabled people and stakeholders about the cessation of DWP-style assessments.

When I sought views on consultations, I heard 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 response to the Independent Review of Adult Disability Payment Consultation

Some disabled people who were not asked to attend a consultation, told me that they would have appreciated the opportunity to speak to the case manager. In some cases, this was because writing down all the relevant information in an application form was difficult and in other cases people thought it would speed up the process if they had an opportunity to talk to someone directly. There was also a strong feeling amongst some people that it was their life, their story and as a result case managers should hear their voice, and they should be more involved when someone is taking decisions that will impact on their life.

Another recurring theme from welfare rights advisers, is in relation to how much agency the client has in determining the format of their consultation. Some advisers felt that some people are disadvantaged by having a non-face-to-face consultation. For example, people with learning disabilities may find it easier to engage with someone face-to-face.

Recommendation 25:

For the initial choice of whether or not to have a consultation to be the client's choice, rather than the case managers.

Recommendation 26:

For the initial choice of format for the consultation to be the client's choice to ensure the client understands fully the options available and clients do not feel in any way compelled to default to the telephone route.

Processes that work

Challenging a decision

Re-determinations

It is vital that people who disagree with a decision made by Social Security Scotland have appropriate opportunities to challenge those decisions. Re-determinations provide a first stage of recourse and allow Social Security Scotland to quickly review a decision at an early stage by making a new decision.

The most common reasons cited that prevent people from seeking re-determination include:

- finding the process confusing and therefore did not seek a re-determination in the right time limit or were unable to seek a re-determination without assistance
- concerns that a re-determination may result in fewer points
- concerned about the impact of the process on mental wellbeing
- people do not understand that seeking re-determination is within their rights
- not having a copy of their original application, or having lost documents
- previous negative experiences with PIP.

I sought views about the re-determinations process as part of my consultation and call for evidence. People expressed views that would suggest they feel several things are working well, including the flexibility to provide additional supporting information in multiple formats and offering an online form.

People shared their views about potential barriers to seeking a re-determination. I heard that the trauma of re-telling their story can be a significant challenge for some people. Some people were reluctant to seek a re-determination in case Social Security Scotland reduced their existing entitlement. Others told me they worried that Social Security Scotland may view additional information produced during the re-determination stage suspiciously.

Observation 3:

The re-determination process currently involves a new case manager looking entirely afresh at a disputed decision. This can result in the risk of a client losing entitlement or seeing their entitlement to Adult Disability Payment reduced. However, a client may equally see their entitlement increase, because of the discretionary way in which decisions are made. Communicating the risk of losing an award to clients may result in clients choosing not to ask for a re-determination if they fear that their entitlement may be withdrawn. It is worth considering how to ensure clients are appropriately informed in a way that does not discourage them from exercising their rights.

Recommendation 27:

To consider how to mitigate the risk of removing an award, for example, by empowering case managers only to focus on the areas in dispute raised by the client if a new decision is likely to be disadvantageous and adopting the previous rationale for making a decision in those areas not in dispute.

Processes that work

Appeals

If a person disagrees with their re-determination or Social Security Scotland misses their statutory deadline to make a re-determination, they have the right to appeal to the First-tier Tribunal. Social Security Scotland includes an appeal form with every re-determination outcome letter. People can also lodge an appeal online or by calling Social Security Scotland.

One respondent to my call for evidence said that one of the main reasons for appealing or not is whether a person has support during the appeal process. Welfare rights advisers and advocates may provide clients with the confidence to appeal a decision. People who felt that the original decision did not reflect their circumstances or that Social Security Scotland had not captured supporting information accurately were more likely to ask for an appeal.

Reasons cited that might prevent appeals included:

- the possible impact of the appeal process on mental wellbeing – on occasion driven by bad experiences with appeals under PIP
- clients not understanding their right to do so or how to move forward with an appeal
- lengthy timescales.

I note that the Scottish Government has introduced changes to the appeal process through the Social Security (Amendment) (Scotland) Act 2025. Social Security Scotland can now make a new determination that is advantageous to a client after an appeal has been lodged (with the client's consent) that brings the appeal to an end.

Recommendation 28:
For Social Security Scotland to improve re-determination timescales.

Recommendation 29:
For information about appeals, and re-determinations to be given more prominence on the front page of the determination letter.

Short-term assistance

Short-term assistance is a temporary payment unique to Scotland. A person can access it if they were or are in receipt of Adult Disability Payment and they meet both of the following criteria:

- Social Security Scotland has decided to reduce or stop their long-standing award
- the person has requested a re-determination or appeal against this decision.

The payment tops up the person's award to their long-standing award level for the duration of the re-determination or appeal. A person does not have to repay the money, regardless of the outcome.

I heard that disabled people welcomed the introduction of short-term assistance and saw it as an improvement over the DWP process. However, I also heard some views that suggested Social Security Scotland should automatically award short-term assistance, rather than a person having to apply.

Recommendation 30:
To consider introducing automatic awarding of short-term assistance with an opt-out clause to acknowledge a client's right to choose.

Processes that work

Changes in circumstances

There remains confusion amongst some clients about the purpose of reporting a change of circumstance. Some people I spoke to thought this only applied if something practical happened in your life like moving home or changing your bank account. Others said they would report a change of circumstance if there were changes to how their disability impacted them; if their condition worsened, or if they received any new medical interventions.

As with re-determinations and appeals several people told me that fear of losing existing benefit or ending up with a reduced award can deter people from reporting a change in their circumstances.

Some clients reported feeling disadvantaged because an increased payment did not take effect until a later date (i.e. not from the date they initially reported the change of circumstance).

Two respondents to the consultation liked the online process for submitting a "change of circumstances" form. Two respondents felt Social Security Scotland has not considered updated supporting information and two were confused about what information they could submit alongside their "change of circumstances" form. One individual felt that a practitioner asked irrelevant and intrusive questions during a telephone consultation to review their change of circumstances.

Recommendation 31:
Provide more detailed guidance on what qualifies as a change of circumstances; the reasons why reporting a change of circumstances is important and provide examples to illustrate the types of situations when it might be necessary.

Effect of time in hospitals and care homes

One stakeholder felt that the cessation of payments of Adult Disability Payment in certain circumstances, such as when a client is in hospital for more than 28 days, is unfair. They felt this places a significant administrative burden on young cancer patients to record days spent in hospital across an extended period, since people with cancer can have frequent short-term hospitalisations (due to treatment or sporadic infections). The Scottish Government's position is that a person's care or mobility needs are met out of public funds in the alternative accommodation and therefore the "28-day rule" avoids duplication of public funds.

Recommendation 32:
To re-visit the eligibility rules in respect of cessation of Adult Disability Payment if 28 or more days are spent in hospital.

Qualifying periods

A person must have had a disability or health condition for at least three months, and they expect the condition to last for nine months more to qualify for Adult Disability Payment. This is sometimes known as the "backwards and forwards test" or "qualifying period". There is no qualifying period for individuals who meet the Special Rules for Terminal Illness (SRTI).

Processes that work

The former DACBEAG had recommended the removal of the three-month qualifying period in its advice to the Scottish Government on Assessments in December 2018:

> **We looked at the past period test for PIP, where the condition had to be of at least three months duration before an award is made. We felt that this qualifying period should be abolished, as it discriminates against people who experience sudden onset debilitating conditions (e.g. stroke) who are unable to claim disability benefit for the first three months of their condition."**
>
> DACBEAG Advice on Assessments

An individual who makes a new application for Adult Disability Payment will not always receive arrears of Adult Disability Payment for the three-month qualifying period immediately following a diagnosis. This also precludes access to other types of support, such as a Blue Badge or premiums of Universal Credit (UC). Carers may also not qualify for Carer Support Payment until a person begins receiving Adult Disability Payment. However, the qualifying period is not dependent upon having a diagnosis, but on needs, so it is therefore possible someone may have met the qualifying period by the time they receive a diagnosis.

Due to the immediate nature of the extra costs experienced by young cancer patients and their families, Young Lives vs Cancer believe children and young people with cancer and their families should be entitled to access welfare benefits at once following diagnosis and not be subject to a qualifying period.

Being treated for cancer is not the only time when these issues arise and therefore using supporting information quickly may be worth some further consideration, whilst acknowledging that in terms of fairness and equality, people would need to satisfy explicit criteria. I also acknowledge this would mean a big change that is not only relevant to Adult Disability Payment and may therefore be out of scope of this review.

Automatic entitlement

I am mindful that whilst the eligibility criteria for other forms of assistance such as the Independent Living Fund, Blue Badge or receipt of social care, are different from Adult Disability Payment, one way to improve the client experience would be making an automatic award if a person is in receipt of these types of assistance.

I heard from one stakeholder that the way cancer impacts a person's daily life is not compatible with a points-based system. I also heard from the same stakeholder that they appreciate the interactions between the medical and social model, but in some instances medical supporting information should be sufficient to speedily proceed through the application process in a way similar to the SRTI process.

Work undertaken with the Social Security Experience Panels was supportive of a process of automatic entitlement, with 80% of respondents answering yes to: "Should people with certain conditions be automatically entitled to disability benefits?" (n=241). Only 10% of respondents said "no" and a further 10% said: "don't know/not sure".

Processes that work

The report on the findings noted:

> **Participants were asked if they could think of any ways that Social Security Scotland could identify those who may be automatically entitled before they apply.**
>
> **Responses tended to fall into three groups: enhanced data sharing between the NHS and government, an improved application form and referrals from third parties."**
>
> Report on Social Security Experience Panels: Award Duration and Automatic Entitlement

Keeping in mind that the SRTI and supporting information are outwith the scope of the Review, I am mindful that the Scottish Government will wish to consider on its own terms how to implement the following recommendation (if accepted):

Recommendation 33:
For consideration to be given to granting automatic entitlement to Adult Disability Payment when satisfying certain conditions or being in receipt of other forms of assistance without having to satisfy the qualifying period.

Award periods and reviews

Entitlement to Adult Disability Payment does not have a fixed end date. People who receive Adult Disability Payment will usually have their entitlement reviewed using a "light touch review" to ensure that they are receiving the correct level of payment. Whilst Social Security Scotland conducts a review, the person remains entitled to Adult Disability Payment.

When I visited Social Security Scotland, a case manager told me that two years is usually the minimum award period and ten years is the maximum. Social Security Scotland case managers can also decide that a person does not require a review of their Adult Disability Payment. This is known as an "indefinite award".

Several factors influence whether a case manager sets a review period, or whether they decide to make an indefinite award. These include the likelihood of the impact of a person's needs changing over time, and whether the person's needs are highly unlikely to improve.

I heard in my engagements with stakeholders that the "light touch reviews" are a welcome alternative to DWP-style reassessments. Disabled people told me that they appreciated the ability to submit review paperwork online and most cited effective communication throughout the process. Most also appreciated the lack of face-to-face assessments at the review stage.

Many disabled people told me that they did not always understand the rationale for the review period set by Social Security Scotland.

Processes that work

> **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 response to the Independent Review of Adult Disability Payment Consultation

> **The award of Adult Disability Payment on an indefinite basis offers reassurance and certainty about entitlement which leads to better financial security."**
>
> Alzheimer Scotland response to the Independent Review of Adult Disability Payment Consultation

I also heard in these engagements about some people having shorter review periods for Adult Disability Payment when compared to PIP. Stakeholders told me that this provoked anxiety and created a perception about inconsistencies in the way Social Security Scotland is making decisions about entitlement to Adult Disability Payment.

There were also several people who said Social Security Scotland could improve communication about reviews and review periods. Some disabled people and stakeholders told me they felt they waited too long for a decision and others told me the form was time-consuming to fill out. I do note however that people have the option to say that there have been no changes and in these circumstances filling out a full form is not necessary.

Recommendation 34:
As part of Social Security Scotland's quality assurance process, review a selection of determination letters to assess how effective or otherwise the communication is in relation to the award duration and/or consider using the client survey to gather feedback on decision-making and communication in this regard.

Chapter 3
A Learning System

A Learning System

Throughout the course of my review, I saw that there is genuine intent from Scottish Government and Social Security Scotland colleagues to listen to feedback, embed the learning and adapt policy and practice whilst acknowledging that there is still some way to go to realise all the ambitions set out in the Charter.

I have experienced the Social Security Scotland quality assurance process and have seen evidence of both staff and stakeholder feedback leading to improvements, as well as a "feedback loop" between Social Security Scotland and the Scottish Government.

Some of the most common complaints I heard during the Review related to communications and problems with the systems used by Social Security Scotland.

Communication

Despite the lack of proactive communication being a recurring theme within the consultation, most clients felt that they received the information they needed from Social Security Scotland. Respondents also reported long wait times for decisions and the telephone helpline, as well as staff being unable to provide adequate progress updates. Social Security Scotland have said it is aiming to improve communications with people applying for benefits.

Social Security Scotland has recently stood down its Inclusive Communication External Stakeholder Reference Group, which was created to help provide expert advice and to assist with meeting legal and organisational commitments regarding inclusive communication. The membership of this Group has been incorporated into the Operational Reference Group.

I heard consistently throughout the course of the Review that clear and accessible communication to clients at the outset, with a named point of contact would improve trust and efficiency. I believe that having a more personalised and accessible route to two-way communication throughout the application and re-determination process is worthy of consideration. Consultation responses also highlighted the importance of accessibility, language preferences and a person's preferred method of communication being adhered to, as failure to do this can undermine people's agency and worsen the impact of delays.

I asked disabled people what could be changed about communicating the decision outcome and although nothing specific was suggested, there was a general feeling that more personally tailored communication could help clients clearly understand the decision.

A Learning System

> **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."**
>
> Individual response to the Independent Review of Adult Disability Payment Consultation

I heard from some stakeholders that decision letters were too long and information about appeals and re-determinations should be more prominent. Others felt that the current decision letters make it much easier to form the basis of a re-determination request or appeal. I was also told by stakeholders that "cut and paste" is sometimes being used in shorter and less detailed decision letters, making it harder for clients to understand their decision. Stakeholders welcomed the introduction of translated decision letters but felt that more languages should be added to ensure the needs of minority communities are better met.

Whilst SRTI is outside the scope of my review, individuals with terminal illnesses told me that they do not see themselves reflected in communications. I believe that more inclusive language is needed to ensure these individuals feel adequately represented and I would hope that Social Security Scotland always ensures their communications are considerate. One Advisory Group member suggested that highlighting the relatively low uptake of the SRTI provision in publicity materials and on the Social Security Scotland website might act as an incentive to improve communications and messaging to people with a terminal illness and to professionals involved in their care.

Social Security Scotland said in its response to my interim report:

> **Social Security Scotland will continue to work with stakeholders, including relevant organisations in the third sector, to highlight that Adult Disability Payment is available to terminally ill people and the existence of the special route for applications.**
>
> **Social Security Scotland currently specifies that Adult Disability Payment is for disabled people, people with long-term health conditions and people who are terminally ill in communications where possible and will continue to ensure the use of appropriate language in these communications."**
>
> Social Security Scotland, Response to Interim Report of the Independent Review of Adult Disability Payment

A Learning System

Some of the other communication issues disabled people and stakeholders raised with me during the Review included:

- reasonable adjustments being common in many processes concerned with public services and yet no reasonable adjustments are used or promoted in the application process for Adult Disability Payment
- some suggestions that a "don't panic, it's going to be ok" type of reassurance be noted in correspondence, particularly in relation to the application form
- Social Security Scotland staff not responding to access or communication needs – welfare rights advisers are continuing to highlight the impact of failure to ensure that a person's appropriate communication methods are being used at all points in the journey
- unsolicited telephone calls in an attempt to fill gaps in information continue to cause distress and confusion.

I believe that there is a need for communication methods that do not require engagement in "real-time" to accommodate individuals with fluctuating energy levels, or the use of video calls in situations where real-time communication is essential.

I heard requests from LGBT+ disabled people and stakeholder organisations for all client-facing Social Security Scotland staff to adopt LGBT+ friendly language, for pronouns to be accepted and the use of wording that respects a person's expression of gender identity. This includes developing administration systems that can easily change the name, title and gender on a person's record.

Observation 4:
I recognise that changing communications addressed to clients using a name other than their legal name could have implications for accessing passported benefits or entitlements. However, providing individuals with a service that aligns with values of fairness, dignity and respect should mean that people are addressed in a way that aligns with their expectations and preferences.

I am mindful that there is an option to capture someone's preferred name if they contact Social Security Scotland by telephone.

I am aware that Social Security Scotland currently offers email notifications for some non-statutory client correspondence; however, there are continued client requests for more digital communication options. I understand that a transition to fully digital client communications is not possible due to data protection laws, considering the needs of a variety of audiences, work is ongoing with Social Security Scotland and the Scottish Government, to look at how this might be achieved in the future.

Overall, my findings show that accessible and appropriate communication with individuals applying for Adult Disability Payment should be combined with a consistent approach to providing information to authorised representatives and the provision of escalation routes capable of improving efficient responses to problems that may arise.

A Learning System

Recommendation 35:

Social Security Scotland to consider updating the suite of guidance available to clients to ensure information is always available in Braille, BSL, Easy Read, other commonly used languages and other accessible formats.

Recommendation 36:

Social Security Scotland to review its inclusive communication practices with a view to ensuring there are no barriers to people with communication needs applying for Adult Disability Payment.

Recommendation 37:

To consider providing a point of contact to improve trust and ensure a more personalised and accessible route to two-way communication throughout the application and re-determination process.

Recommendation 38:

For Social Security Scotland to set out whether it intends to highlight and make more prominent the option to request written translations of determination and re-determinations letters to ensure the needs of minority communities are better met.

Recommendation 39:

For Scottish Government and Social Security Scotland to build capacity for policy makers and front-line staff to undertake training on stigma particularly as it relates to for example, poverty, inequality, race, and gender identity.

Chapter 4
A Better Future

A Better Future

Modernisation

Throughout the course of the Review, I heard from many people and stakeholders that various aspects of Adult Disability Payment should be modernised to better reflect the modern-day experiences of disabled people.

> **"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."**
>
> Individual response to the Independent Review of Adult Disability Payment Consultation

The most prevalent theme within the "daily living activities" element of the online consultation was suggestions for new activities as part of the eligibility criteria.

For example, I received views from the online consultation that sleep, the side effects of taking medication, the use of modern kitchen appliances, the use of apps, and managing unplanned events should be included.

I also heard from participants at engagement events that additional areas should be included in the eligibility criteria. For example, IT literacy, quality of life, communication support, filling in forms, and being part of a community. I also heard from several people that household cleaning should be included.

Adopting a human rights social model of disability

I heard from several respondents to the online consultation that there should be a move away from the medical and deficit-based model of disability to help facilitate a more rights-based approach in Scotland.

I heard from several participants at consultation events that the challenges they associate with the deficit-based model include:

- finding it difficult to think about their "worst day" or open up about their difficulties
- not perceiving themselves as disabled
- interpreting the questions differently than others due to ambiguity in the questions
- for people with fluctuating conditions, challenges associated with recognising and conveying their support needs given that their ability to do things might vary at different points in time.

I heard from people living with long term conditions that they try to live their lives "maximising what they can do" but that the application process makes them focus on what they can't do.

> **"Having to take the time to highlight issues and what you can't do is depressing, demoralising and unfair."**
>
> MS Society Scotland response to the Independent Review of Adult Disability Payment Call for Evidence

A Better Future

I received consultation responses that highlighted the devastating impact a deficits-based model can have:

> **It feels like you're having to beg for help."**
>
> MS Society Scotland response to the Independent Review of Adult Disability Payment Call for Evidence

Furthermore, I heard from a few participants from the online consultation that the form or decision-making process were overly focused on people with physical disabilities. For example, I heard from some people in consultation events that the current eligibility criteria are not accurately capturing the needs of neurodivergent individuals or those diagnosed with mental health problems.

Therefore, I believe that a better approach would be one that merges what is relevant in the medical and social models on the basis that disability is always an interaction between features of the person and features of the overall context in which the person lives.

I have attempted in my recommendations to ensure the changes proposed reflect the social model of disability better and capture the rights of disabled people to independent living and equal participation in society. I have tried to consider the aspects of society that disable a person rather than focusing on the medical or functional aspects of a person's impairment.

I believe that the current criteria and decision-making processes should be reviewed to further embrace a social model of disability by adopting an approach that merges what is relevant in both the medical and social models. While not a recommendation of how a decision-making process based on these criteria would look, Annex 1 provides an example of the difference viewing disability through an outcomes-based social model can make when framing questions and determining eligibility.

An individualised decision-making model

I heard from many disabled people throughout the course of the Review that they favour a system where Social Security Scotland looks at a person's overarching need for help, rather than looking at specific activities.

> **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 response to the Independent Review of Adult Disability Payment Consultation

A more individualised decision-making model is likely to lead to more detailed questions, which clients may find onerous and could lead to more subjective outcomes.

Several consultation respondents suggested that some people find it hard to see how the activities relate to their own lives and, most commonly, 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.

A Better Future

The main request that I received from consultation responses was for a more holistic, person-centred and flexible approach to decision-making. Several people said that the current system used to understand disabled people's needs is not fit for purpose for many reasons, e.g., some feeling that the rules or questions were too rigid to allow people to fully articulate how their conditions impacted them.

I brought together stakeholders from the fields of social security and welfare advice for a roundtable session where there was overwhelming sentiment against reintroducing, by another name, DWP-style assessments. No one was in favour of introducing more subjectivity to an already inconsistent decision-making process, which could also make it more difficult to challenge a determination.

> **"We recognised that a more individualised assessment model is likely to lead to more detailed questions, responding to which may feel more onerous for the applicant and that the assessment of responses may lead to outcomes which are potentially subjective and may be inconsistent."**
>
> Law Society of Scotland response to the Independent Review of Adult Disability: Review of the mobility component consultation

There are some overarching principles that Social Security Scotland could adopt to enhance the experience and ensure eligible people receive the right levels of support:

- ensure the application and decision-making process is only as intrusive as it needs to be to establish an accurate picture of the person's needs
- work with others to join up around the individual and avoid multiple assessments taking place
- recognise and seek to draw out the client's knowledge, strengths and capabilities in line with strength-based practice.

An outcomes-based decision-making model

Unlike the deficits-based approach, an outcomes-based eligibility approach would consider what the outcome would be for the client if they had appropriate support in place. For example, if a person with severe depression had support and encouragement to prepare a healthy meal, the outcome is that they would enjoy a good standard of nutrition.

The Review Secretariat commissioned a search of existing literature which found there was no previous work in Scotland that looked specifically at the use of outcomes-based eligibility criteria for non-occupational disability benefits (or indeed any type of welfare benefits). There is an absence of comparative analysis to allow for a clearer understanding of the rationale underpinning such approaches, the impact on those people applying, and funding models. This rapid analysis highlights that it is likely that case managers need an advanced understanding of the conditions of the people they are determining eligibility for. Therefore, this approach could require input from multidisciplinary teams.

A Better Future

Alternatives to a points-based system

The conversations I had throughout the Review highlight that the points-based system used for decision-making is widely disliked, with several respondents making the case for measuring need and/or eligibility to be based on a social model of disability.

> **Overall, we 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 (Adult Disability Payment)."**
>
> Health and Social Care Alliance Scotland (The ALLIANCE) response to the Independent Review of Adult Disability Payment Consultation

Despite this compelling argument for change, I haven't been able to find another suitable and effective way of establishing eligibility that would be:

- more dignified for disabled people
- mirror the social model of disability
- ensure fairness and consistency in decision-making
- make it easy to appeal a decision.

I have considered using percentages, Red, Amber, Green (RAG) ratings, and approaches such as scaling across a range of points rather than a sharp, cliff-edge where people either qualify for a given level of support or don't. These potential alternatives may be more palatable to some and remove the use of arbitrary numerical values; however, I don't believe that their introduction would necessarily improve the system. Ultimately there needs to be some form of transparent measurement applied to clear criteria, to ensure a fair and equitable approach.

I heard calls for greater transparency in how points are allocated at a few events by, for example, including the descriptors and corresponding points on the application form to help people understand the points system and why the form asks the questions it does.

I received several responses through the consultation that suggested people with certain conditions may find it more difficult to gain points. In addition, I heard suggestions that features or symptoms of those conditions that could result in people having a limited understanding or clarity about the daily living activities and how they applied to them, could potentially lead to clients not receiving an award.

In my engagements, I heard calls to address some of the perceived anomalies in the current system, e.g., a person receiving more points for being able to walk up to 20 metres without an aid than someone who can walk the full 20 metres with an aid.

I considered several alternative models for the eligibility criteria, e.g., beginning again, or considering the application of the International Classification of Functioning, Disability and Health as well as considering the way local authorities in England undertake social care assessments.

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However, stakeholders have told me that there is familiarity to the current imperfect system and replacing it wholescale may cause more harm than good.

Recommendation 40:

As recommended in the interim report confirm if Social Security Scotland intends to consider how to make the activities and descriptors and associated points more prominent and accessible for applicants

Recommendation 41:

Taking on board the findings from this Review undertake a thorough review of the eligibility and decision-making criteria to:

(a) move from a deficit-based system based on assessing what people are unable to do to a system that acknowledges a human rights-based social model of disability, places the emphasis on impact and outcome and supports equal participation in society

(b) ensure the activities and descriptors reflect modern life

(c) adopt a more individualised decision-making approach providing an opportunity for a person to describe their whole life and describe in a less restrictive format the ways in which their disability or impairment impacts on their daily life

(d) address the anomalies in the points being awarded per activity and consider the use of weighting to ensure activities are not assessed in isolation.

Fluctuating needs and the 50% rule

Under the current Adult Disability Payment rules, a descriptor applies to a person if it reflects how their condition or disability affects them for more than 50% of the qualifying period.

I heard mixed views from disabled people and stakeholders about people's experiences of the application process in relation to fluctuating conditions. Some felt that there have been positive changes made to improve how applicants experience the process of completing the application, as well as asking about fluctuating conditions. Others felt that the changes have limited to no impact on how much Social Security Scotland understands the impact of fluctuating conditions.

> **"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 response to the Independent Review of Adult Disability Payment Consultation

Many people with MS who took part in the Review welcomed the changes to the application and consultation process but felt that they do not go far enough to recognise the true needs of people living with fluctuating conditions.

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Respondents to the consultation about the criteria for fluctuating conditions suggested problems with using overly complicated language, including using fixed or confusing statements and the lack of examples or sufficiently detailed guidance. I received several suggestions to simplify or further clarify the criteria and to ensure the application form allows sufficient space to adequately describe the impact of the condition or multiple conditions.

One stakeholder stressed the importance of developing a clearer understanding of the consequences of engaging in physical activity, particularly the post-exertion effects.

I also heard several other recurring themes throughout the Review:

- fluctuating conditions can be hard for people to describe
- time limits to complete the application make the activity more challenging
- the importance of asking about the impacts of daily activities on people with fluctuating conditions, rather than just asking if they can achieve certain tasks
- mental health and physical health can fluctuate independently of each other
- when experiencing a flare up, a person may have limited physical and emotional energy, reducing the ability to solve problems, communicate or do activities that they may need to do for an application or consultation
- people often don't feel understood or believed, especially when the condition is not well known, or the symptoms are more generic (such as fatigue and pain)
- the need for case managers to receive more thorough training around specific conditions
- the 50% rule is not a useful measure.

I frequently heard criticisms of the 50% rule (where a person must show they meet a descriptor on or over 50% of days in a 12-month period) which can be challenging for people to understand or even more difficult for them to articulate, as fluctuating conditions have different impacts over time.

> **"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 response to the Independent Review of Adult Disability Payment consultation

I heard from some stakeholders that the problems arise not from the 50% rule itself, but they are due to case managers failing to properly apply the other relevant rules of Adult Disability Payment, such as the reliability criteria.

I believe that a more flexible approach that considers frequency as well as severity of impact, without an arbitrary threshold, may represent an improvement and be more in line with a human-rights based social model of disability.

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Observation 5:
As I have noted, supporting information is out of scope of this Review. However, I would like to take this opportunity to highlight that Social Security Scotland may benefit from considering the merits of a more flexible approach with regards to the timing and format for applicants with fluctuating conditions to provide supporting information about the impact of their disability.

Recommendation 42:
Replace the 50% rule with improved application of the reliability criteria and a more person-centred process that allows people to define how they manage on their worst days and the resulting impact on other days.

Recommendation 43:
Improve the questions asked of applicants within the application process to account for variability, triggers and actions taken to manage conditions.

Recommendation 44:
Case managers and practitioner training (and associated training materials) should be regularly refreshed with a focus on ensuring consistency in the decisions being made and further understanding of the impact of the fluctuating condition on the life and wellbeing of the client.

Substantial risk

Citizens Advice Scotland has advocated for the introduction of a "substantial risk" provision to Adult Disability Payment. This would ensure that where a person may not score enough points to be entitled to Adult Disability Payment through the daily living or mobility activities, a case manager could still make an award if "risk of suicide, self-harm or dangerous levels of social isolation" were determined to be present. The Scottish Government has not to date consulted on introducing a substantial risk provision.

The DWP uses the Work Capability Assessment to decide if someone is unfit for work and therefore eligible to receive Employment and Support Allowance, or the health element of UC. These are not extra-costs disability benefits but are means-tested, earnings-replacement benefits where someone is temporarily or permanently unable to undertake paid work. If someone does not score the minimum number of points, the DWP can still treat them as though they do. This applies where, because of the person's health condition or disability, there would be a substantial risk to the health of the person or others if they were found fit for work. Despite the differences between the purposes of these benefits and Adult Disability Payment, it is reasonable to suggest that the principle of ensuring that a client's health is not put at risk because of a benefit decision could be a meaningful additional measure in the delivery of Adult Disability Payment.

Recommendation 45:
Consider the introduction of a substantial risk provision for people who fail to score points to qualify for an award of the daily living or mobility component of Adult Disability Payment if not making an award would pose a substantial risk to the physical or mental health of the person.

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Eligibility criteria – activities and descriptors

Social Security Scotland case managers use rules to decide if someone qualifies for Adult Disability Payment. These rules are known as the eligibility criteria. Adult Disability Payment has two parts: a daily living component and a mobility component. A person may qualify for one, or both components. Both components have a standard and an enhanced rate. A points-based system determines which component(s) or rate the person qualifies for.

I recognise the strength of feeling to improve the current eligibility criteria to ensure consistency with the aspirations in the Social Security Charter.

> **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 response to the Independent Review of Adult Disability Payment Consultation

Daily living component

I received mixed views on the current daily living component activities, which include the following.

- 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, or mental health problems.
- 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 focused 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.
- 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.
- I received calls for greater transparency about the point allocation.

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Mobility component

I received strong testimonies in relation to the way case managers consider a person's mobility needs as part of Adult Disability Payment. Furthermore, several respondents highlighted that the criteria would benefit from a clearer definition of what moving means and suggested using open ended questions that ask about movement, what people rely on to get around, and how people get around such as the use of public transport and with what aids.

During the Review, I frequently heard calls to include a range of additional impacts reflecting clients lived experiences before, during and after moving around. Participants made various suggestions:

- the planning needed, both physical and mental, to prepare for moving around
- lingering physical and mental impacts, including pain and fatigue associated with moving around or journeys not going as planned, that can last for days, weeks or longer, or have a delayed onset
- that clients may need to pace themselves because the impact of moving could be long-lasting
- people may avoid certain journeys to ensure they do not feel the impacts of those movements in the hours, days or weeks that follow
- consideration should be given to hidden disabilities where moving is possible, but the effect of moving can range from pain and fatigue to dizziness, breathlessness and abdominal pain
- how often the distance can be repeated safely alongside everyday activities.

Daily living component

Activity 1 – Preparing food

Some people suggested that providing more examples on the application form of how the descriptors apply when someone has a mental health problem or is neurodiverse, would be helpful as it can be more difficult to relate the activities to their condition.

Many people with eating disorders reported that the food and nutrition related descriptors do not work for them. More general considerations included the fact that the criteria do not consider the ability of a person to access a diet likely to optimise health. I heard that it is unclear whether all the tasks involved in achieving an activity are considered in the application form or decision-making process and that tasks involved with this activity such as cleaning up and shopping for food should be considered.

Other related issues raised include:

- preparing a "simple meal" could mean beans on toast every day
- specific dietary needs, which due to digestive issues some people have, require a lot of energy-draining chopping even if "simple"
- participants at engagement events added that more points should be awarded if the only food an applicant can prepare is of poor nutritional value

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- there can be significant physical costs after exerting energy needed to prepare and cook a simple meal
- forms do not mention slow cookers which can be safer, as well as air fryers and instant pots, which people felt are also more energy efficient
- people felt that the criteria do not account for memory or cognitive issues; one person who has dementia told me that they can physically chop and prepare food, but they forget they've done it or put the meal into the bin, or they forget to eat what they have prepared – the outcome is the same as it is for someone who cannot prepare food because of a physical impairment (although I appreciate the current reliability criteria should consider this)
- preparing food can be a real problem for people who may have the physical and cognitive ability to prepare food but because of chronic fatigue, or an eating disorder, for example, they may find it very hard to explain why it is so challenging in such a way that would score points under the current criteria – they might be able physically to prepare or cook food, but doing so could put them in danger so it is not safe for them to do so (again I acknowledge the current reliability criteria should consider this)
- aids/adjustments could include frozen chopped vegetables, ready meals, pre-prepared food.

Recommendation 46:
For the 'preparing and cooking a simple meal' activity to be reviewed:

(a) so that it adequately captures that quick simple meal preparation is not always the best approach for people with specific dietary needs, food insensitivities, eating disorders and those experiencing resulting pain or fatigue

(b) so that the ability to shop for food is included.

Activity 2 – Taking nutrition

I frequently heard that diet is a significant part of managing health conditions and specialist diets can contribute to the additional costs of having a disability. Some people suggested re-ordering Activity 1 and 2, because they felt the questions on the application form are repetitive. Others felt the activity overlooks people who can manage to eat when food is put in front of them but would struggle to get the nutrition they needed if left to their own devices.

Many people feel that the current rules are not sufficient as they do not consider the nutritional content of a person's diet, only that the client is able to consume any food. Some people felt that the aim should be to assess if a person is able to prepare food and consume food that is appropriate to their situation and condition to better manage their health, rather than eating what others might say constitutes "a healthy meal".

The key issues I heard regarding people with an eating disorder applying for Adult Disability Payment included:

- a lack of awareness of Adult Disability Payment
- not recognising that an eating disorder is a disability and therefore not seeing themselves as potentially eligible
- not being able to convey the impact of the eating disorder within the questions asked on the application form

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- finding the activities and descriptors irrelevant in particular the "preparing food and taking nutrition" activities
- prompting not taking into account the needs of many people with an eating disorder and the off-putting language that describes the need to be "experiencing severe depression or have a serious eating disorder" (I appreciate that prompting currently forms parts of the eligibility criteria).

I heard a request to include specific mention of eating disorders in the food-related descriptors or to mention eating disorders in the introductory notes at the start of the activity.

Recommendation 47:
For the taking nutrition activity to be reviewed to consider the nutritional content of the food being consumed, being sensitive to the fact that "nutritional value" needs to be appropriate to an individual's situation and help them to better manage their health.

Recommendation 48:
To consider the particular needs of people living with eating disorders especially in relation to the "preparing food" and "taking nutrition" activities.

Activity 3 – Managing therapy or monitoring a health condition

Some stakeholders have questioned why only therapy carried out in the home is considered in Activity 3, noting that therapy outside of the house is still very much a part of a person's ability to manage their conditions and that additional costs may be incurred as a result of needing non-domestic therapeutic interventions or treatment.

One stakeholder told me that some people find it too difficult to go to appointments for several reasons, even though they may physically be able to get there and understand why the appointment is important. They may need prompting or assistance to go. Some stakeholders felt the criteria should consider the cost of paying for therapies outside of the home since the purpose of Adult Disability Payment is to assist with the additional costs of having a disability and many people use private services because they are too difficult to access via the NHS.

Other issues I heard include:

- there are forms of therapy that are helpful but not technically classed as a treatment, for example, homeopathic interventions
- undergoing treatment can also have unintended consequences such as therapy for PTSD, causing a person to feel worse before they feel better
- some people face digital exclusion with certain types of therapy
- it can be costly to get to and from support groups
- the criteria do not account for the side-effects of some medication, including drowsiness, which can compound symptoms and functional limitations.

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Recommendation 49:

For the "managing a therapy or monitoring a health condition" activity to be reviewed so that:

(a) reinforcement of consideration being given to the need for therapy (rather than whether it is in fact provided) being the determining factor, whether inside or outside of the home environment

(b) consideration is given to the inequality of access to diagnosis and forms of therapy

(c) therapy, whether obtained through public (such as the NHS or local authority) or private means (including private healthcare, therapy or community resources), qualify for the purposes of this activity as 'therapy'.

Activity 4 – Washing and bathing

Many people told me that they are confused about the rationale for some of the "washing and bathing" criteria. The wording and eligibility for scoring points is very focused on functional ability and takes no account of other limitations, although the reliability criteria do consider the need for motivation. Some people mentioned the negative impact on personal hygiene is the same regardless of whether the cause is due to a physical impairment or a mental one.

Some stakeholders expressed the view that feeling sticky, dirty and being unable to wash without health consequences is not good for mental health. I received some views that for some people with an eating disorder the psychological impact of washing and bathing can be huge. This can be in relation to observing the naked body and/or the intimate nature of maintaining personal hygiene. A consistent theme around some apparent anomalies included allocating three points for help getting in or out of an unadapted bath or shower, which is a relatively high number of points compared to others in the daily living section.

Many stakeholders would welcome the introduction of reference to intimate hygiene; it is interesting that the current eligibility criteria do not consider this. One person suggested that difficulties around intimate hygiene (for example inserting a tampon or using a sanitary towel) could potentially be worth more points due to being more psychologically difficult to manage.

Event participants also expressed the view that they needed more detail 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 how people complete those tasks and the impact it has on them is more important than whether the person can complete the activity itself or not.

Recommendation 50:

For the "washing and bathing" activity to be reviewed so that

(a) the outcome of not being able to maintain personal hygiene is the determining factor and not the ability to undertake a particular activity

(b) the particular issues related to having an eating disorder are considered

(c) "managing intimate hygiene" is included in the activity descriptor and considered when making an award.

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Activity 5 – Managing toilet needs or incontinence

I heard few comments that relate to this activity and as a result there are no recommendations for review or improvement. However, I did receive some relevant feedback from disabled people that is worthy of noting, including:

- it can use a lot of energy to get to and from the toilet
- while the need to go to the toilet may be harder to avoid or postpone than e.g. making a cup of tea, it is possible that prompting to go in a timely fashion may be needed
- at the more severe end of the scale there have been accounts of people crawling along the floor to get to the toilet
- some people may need assistance to clean up accidents, "poor aim", etc.
- hygiene issues of "imprecise self-care" can have a bad effect on mental health and well-being.

Activity 6 – Dressing and undressing

One stakeholder suggested that this activity should capture circumstances where an individual's difficulty stems from the focus this activity places on their body, such as individuals with eating disorders. Adding a line about psychological constraints could be beneficial. Another person added that individuals who have had a mastectomy can find changing in and out of a bra psychologically challenging.

Other comments I heard include:

- some stakeholders suggested the removal of the distinction between dressing the lower and upper body because from the perspective of an individual they can either fully dress themselves or they cannot
- timelines often pose challenges, particularly when individuals are estimating the time required for tasks like preparing a meal or taking a shower
- the questions in the application form should allow for more detailed, descriptive responses which could better explain how applicants undertake activities such as dressing and undressing and all the steps this would involve
- being clear and explicit as to how the reliability criteria applies to this activity
- the energy cost involved in dressing means that many people with energy-limiting conditions cannot even get out of bed, let alone dress themselves – unless there is an unavoidable need for social interaction, they may well avoid dressing or undressing (even then, they may need support and encouragement).

Recommendation 51:

For the "dressing and undressing" activity to be reviewed so that consideration is given to:

(a) the outcome and/or impact of not being able to dress or undress rather than solely the functional tasks involved

(b) the potential psychological constraints of dressing and undressing

(c) removing the distinction between dressing the lower and upper body.

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Activity 7 – Communicating verbally

I heard few comments in respect of this activity, but some included:

- there is no consideration of the environment in which a person is communicating and for some this is a key factor
- not being able to understand or reliably remember communication could have implications for managing medication
- at a few events I received anecdotal evidence about difficulties for clients in gaining points for "communication skills."

Activity 8 – Reading and understanding signs, symbols and words

Most disabled people I engaged with had little or no comment to make with reference to this activity. However, one organisation raised that a person with a learning disability may score zero points for "reading and understanding questions", as they can read, but this did not capture difficulties comprehending or acting on the information.

Activity 9 – Engaging socially with other people face to face

I had many discussions about the definition of "overwhelming psychological distress" with regards to this activity. One stakeholder felt that there is more flexibility with Adult Disability Payment decisions when compared to PIP decisions, regarding the bar set to reach "overwhelming psychological distress". However other stakeholders suggested that the definition is very strictly applied and open to differing interpretations. I received a suggestion that decision-makers should focus on psychological distress itself, rather than requiring an activity to result in overwhelming psychological distress for it to meet the criteria.

One stakeholder highlighted their view that the guidance in relation to Activity 9(c) for Adult Disability Payment is more restrictive than the equivalent case law for PIP.

Recommendation 52:

Revisit the current narrow definition of "overwhelming psychological distress" to seek clarity on the extent to which anxiety means, for example, that a client cannot follow a route safely or to an acceptable standard; or how the stress of interacting with other people results in social isolation.

Recommendation 53:

For the Decision-Making Guidance on "engaging with other people face to face" activity to be amended to take into account the mental health impacts that engaging with others involves for people who are clinically vulnerable to infection.

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Activity 10 – Making budgeting decisions

I did not receive many comments in relation to this activity but a few things to consider include:

- if someone has a financial guardian, they clearly have difficulty managing money and therefore this could mean an automatic score of the highest number of points
- some disabled people highlighted that accessing in-person banking is becoming increasingly difficult, so not being able to use technology is relevant to this activity
- some welfare advisers noted that they are aware of instances where clients have scored 0 points for this activity because they have a banking app on their phone – however, having a banking app or being able to check your balance is different from being able to manage money.

Recommendation 54:
For clients who have an appointed financial guardian to receive automatic entitlement to the maximum number of points in the "making budgeting decisions" activity.

Mobility component

The Scottish Government's earlier public consultation on the eligibility criteria for the mobility component of Adult Disability Payment found that the main request was for a holistic, person-centred and flexible approach to decision-making, considering each application holistically, including the wider context of clients' lives and circumstances.

Respondents repeatedly raised other suggestions, including:

- clarifying what information Social Security Scotland is seeking in response to the questions posed about someone's mobility needs
- for the Adult Disability Payment criteria to consider, clarify and include additional aspects of mobility beyond simply the ability to move a certain distance or plan and execute a journey
- ensuring case managers consider all aspects of mobility, including a range of additional impacts reflecting clients lived experiences before, during and after moving around
- that the criteria should not judge movement in isolation from the reality of moving around and should consider the complexity of the circumstances people encounter when moving
- broadening the eligibility criteria to consider other conditions, including mental health problems, and a wider range of mobility aids
- that the mobility eligibility criteria are not appropriate for those with fluctuating conditions.

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Activity 1 – Planning and following journeys

> **"The planning and following journeys criteria are overly simplistic. This is again the main reason for them being difficult for applicants to interpret and understand. They lack clarity and detail and use a lot of vague subjective terms to describe the criteria. One person's interpretation of what constitutes a journey may be different from the next persons. What is classed as familiar will vary from person to person adding a great deal of subjectivity into the application process. This subjectivity will then be replicated in the decision-making process as this will add in further level of individual interpretation."**
>
> MS Society Scotland response to the Independent Review of Adult Disability, Review of the mobility component

I heard the following suggestions about the planning and following journeys activity in stakeholder meetings and consultation events:

- inclusion of variable or fluctuating conditions, such as providing space in the application form to allow those with fluctuating conditions to explain their experiences
- suggestions about points-based system changes, such as providing more points to those clients who need assistance from another person to get around
- suggesting that practitioners have specific training, including an understanding of visual impairments and how to speak with clients who have specific conditions
- two individual respondents requesting that practitioners listen and believe the information provided to them
- consideration of environmental factors, public transport routes and difficulties during the journey
- a feeling that the activity does not take into consideration those who are cognitively able to plan and follow a journey but their ability to do so fluctuates due to things like anxiety and psychological distress
- it is not clear that there is a meaningful distinction in practice between planned and unplanned journeys, particularly for people with fluctuating conditions – the same individual may feel quite capable of carrying out an unplanned journey on one day and feel so anxious as to be unable to undertake a planned journey on another
- consideration of clients' experiences during the journey, such as impacts on mental health if the journey does not go to plan or anxiety related to specific types of journeys but not others
- the need to explore frequency/how often people leave their home
- the necessity of better understanding of clinical risk management.

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I heard concerns about the language used in this activity's criteria, including the term "overwhelming psychological distress", which respondents found to be limiting, subjective and unclear. Many people believe there needs to be greater consideration of mental health in relation to this activity. I believe it may be more useful to talk in terms such as anxiety, fear of getting lost and fear of encountering hostility, but to do so in a non-stigmatising way that does not suggest it is unreasonable for people to be anxious or have such fears.

One stakeholder had highlighted in their call for evidence submission that the Adult Disability Payment eligibility criteria may be interpreted more strictly than PIP in relation to descriptors 1(d)[2] and 1(f)[3]. I also heard that many people find the meaning of language within this activity confusing which makes it harder for clients to describe their experiences and the job of decision makers more subjective. Some stakeholders informed me that they feel the definition of "orientation aids" needs to be expanded to include things like mobile phone map applications and support from another person.

Stakeholders raised issues regarding conditions related to fatigue and those at risk of infection if undertaking a journey, including:

- travelling can mean having to go into high-risk environments (crowded, maybe poorly ventilated public transport) – having to make essential journeys can be extremely stressful
- people at high clinical risk may need not just prompting and encouragement to travel but action to mitigate risks
- it can be very hard to plan a journey with severe brain fog – it can mean a person cannot work out how to order a taxi, drive, work out any other way to get there, check train and bus times etc.
- people with energy impairments may need to plan at a very detailed level – for example, "how many steps to the bus-stop", "is there somewhere to rest", "if bus stop is then closed, you're stuck" – they must think of every scenario
- struggling to plan a route that is as risk-free as possible or not being able to contemplate any journey because it would cause psychological distress to the client
- there are many people who remain at high clinical risk following Covid; many have been living in near lockdown, hardly leaving their houses, or having to endure extreme stress of taking risky journeys; the safest ways to travel is in your own car, next safest by taxi (though this is far from risk-free – windows hardly open on some models and not accessible to the passenger)
- because of not being able to travel safely, a wide range of additional costs are incurred (delivery, home visits, heating, etc)
- the stress of having to ask others to put a mask on, not knowing whether you will encounter hostility for wearing one, people angrily refusing to believe in the reality of your situation – wheelchair users may have additional stress of taxi-drivers leaning across you to secure the chair, staff assisting you onto train, etc.

One stakeholder raised specific concerns about how mobility criteria do not currently account for the impacts of bowel or bladder conditions that may cause incontinence. The need to plan for access to toilet facilities may represent an additional further difficulty for many disabled people.

2 Cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid

3 Cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid.

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I also heard positive comments about this activity which include the following.

- The effectiveness of the 'planning and following journeys' section of the application form in that the form was clear, while a few noted it was an improvement on the PIP form.
- The changes made to how planning and following journeys criteria are described and evidenced have had a positive impact.
- Some others suggested the form was more inclusive of those without physical disabilities and clearly spoke to those with mental health problems.
- The examples given of the difference between familiar and unfamiliar journeys are reasonably clear and useful.
- The prompt with a list of mental health problems that may result in anxiety about travelling may help make clear to applicants there are legitimate and understandable reasons they would feel that way.
- Some people welcome the fact that stigmatising behavioural observations have been removed from the process and agree that these perpetuated unhelpful stereotypes.
- The commitment to ensure that where a consultation is necessary in relation to mental health or learning disability, the person conducting it will have relevant experience, and therefore be more capable of understanding the applicant's condition. These changes have helped to create a process that is more dignified and less stigmatising.
- There was also general positive feedback about removing assessments and support for the decision to use professionally trained practitioners instead of assessors.

Recommendation 55:

To review the "planning and following journeys" part of the mobility component to:

(a) clarify the language used

(b) clarify the definition of orientation aids

(c) provide more clarity to clients and case managers on the definition of "overwhelming psychological distress", which respondents found to be limiting, subjective and unclear

(d) ensure the criteria does not remain overly focused on physical ability and takes into account mental health problems and delayed impact (e.g. pain, fatigue, cognition)

(e) better include the impact of variable or fluctuating conditions

(f) consider environmental factors, public transport routes and difficulties that might arise during a journey

(g) take into account the frequency and routine of how often people leave their home

(h) better understand clinical risk management

(i) account for the impacts of bowel and bladder conditions that may cause incontinence.

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Activity 2 – Moving around

Many consultation respondents requested clarification of the language or meaning of the moving around criteria. Several respondents argued that the criteria would benefit from a clearer definition of what moving means and that there is a need for clearer images on the application form.

I believe that the inclusion of impact prompts, such as pain and breathlessness, is likely to help provide more detailed information in support of an individual's application, whilst recognising that the level of impact can vary between individuals. Respondents frequently suggested changing the distance in this activity or not using any distance measures at all. They suggested a better system might be one that focuses on the qualitative aspects of movement, i.e., how people move, captured through open-ended questions and a flexible approach dependent on people's real-life experiences.

In my engagements and through the consultation, participants discussed many issues and proposed changes, including:

- capturing explicitly the reliability criteria – one stakeholder highlighted that welfare advisors do not consider that the "how do you feel after" questions effectively convey and capture the reliability criteria, which advisors feel clients do not understand
- if keeping a scoring system, address the anomalies that mean someone who can walk the same distance as another person without an aid (8 points) scores less than someone who can walk the same distance with an aid (10 points)
- many respondents to the DWP consultation on PIP felt that there was little evidence to show that an individual who could walk a little over 20 metres would face lower costs than an individual who could walk less than 20 metres
- revising the criteria, so it is more in line with the social model of disability
- that criteria should reflect experiences of moving in the built and natural environments
- that criteria should reflect walking in different weather conditions, on a gradient or slope, as well as on stairs and a variety of surfaces
- that criteria should reflect navigable access at destinations, such as ramps, lifts, and Braille signs: the differences between rural and urban environments and road closures or roadworks that complicate familiar journeys
- that criteria should reflect access to necessary community facilities, such as shops, schools and healthcare and navigating environmental hazards like crowds or furniture
- that case managers should consider how people move around their house functionally
- that criteria should reflect the purpose of travel and subsequent difficulties faced at destination
- that criteria should reflect the needs of those with hidden disabilities who may be unable to travel from home due to the availability of specialised supports and resources, such as toilets or resting places
- that case managers should consider the impact of certain medicines on movement.

A Better Future

I am keen to address the rigid nature of the mobility component. I have heard consistent criticisms that strict distances are arbitrary, not a useful measure, and do not adequately cover progressive or fluctuating conditions.

People told me they have difficulty picturing how long 20 metres is and suggested something more relatable (e.g. how many houses could you walk by) might make questions easier to answer more accurately. Some disabled people felt not enough credence was given to how movement affected them. I also heard that the way the criteria are applied fails to consider the full complexities of a client's situation.

I was concerned to hear that some disabled people feel they are effectively discouraged from being active due to the fear they would lose their entitlement to social security, especially given the health benefits that can come with exercise. I believe that disabled people should have the confidence that they will be able to access social security payments necessary to support their additional costs, and that they can do so whilst also engaging in sport, exercise and other physical activity that may both improve their overall health and support their participation in society.

Whilst I recognise there needs to be a way to determine a person's mobility needs, I do not consider that the strict application of arbitrary measurements is the best way to do this. A more flexible approach should be taken which, rather than setting distances, considers a person's ability to move around their own home, local area, and other places they may frequent in daily life. This should account not just for the physical ability to travel within those areas, but also the degree to which doing so results in pain and exhaustion, and whether there is reliable access to facilities such as toilets and comfortable rest stops.

Utilising elements of the way in which local authorities assess people for a Blue Badge could be beneficial. I also feel that formal inclusion of the impacts of pain and exhaustion within the criteria is important, to recognise the serious negative effects that these can have on quality of life and wellbeing, as well as the additional costs of managing those conditions.

I believe these changes would lead to a process that is more supportive and understanding and one that takes account of a person's unique personal circumstances, rather than a perceived tick-box exercise with strict numerical measurements. These changes may also have positive impacts for applicants with mental health problems, as they may feel that the process is more supportive and understanding of them.

> **"It doesn't matter whether it's two metres or 20 metres, if there are changes to an environment or route, then I can't navigate safely – the knock-on effect is social isolation, a reduction in confidence and independence and increased costs – as when I do go out, I call a taxi instead to get me where I need to go."**
>
> Royal National Institute for the Blind Scotland response to the Independent Review of Adult Disability Payment: Review of the mobility component

A Better Future

Recommendation 56:

Review the eligibility criteria for the mobility component to remove reference to a fixed distance and replace it with:

(a) the real-life experience of the client

(b) their living environment inside and outside of the home

(c) availability and accessibility of public transport

(d) whether or not they use aids to assist them in moving around

(e) the impact of moving around and exertion (e.g. fatigue, post-exertional malaise. breathlessness and pain).

Recommendation 57:

Review the guidance and training for case managers and practitioners to ensure improved understanding and accommodation of issues such as delayed impact, exhaustion, pain and anxiety.

Recommendation 58:

To consider any learning and/or good practice from the Blue Badge scheme in relation to establishing a person's mobility needs.

Chapter 5
Final Thoughts

Final thoughts

It is worth highlighting that many people gave positive feedback about Adult Disability Payment and Social Security Scotland, speaking highly of staff interactions, describing feeling respected during the application process and welcoming the lack of medical assessments. I heard the word "kindness" on many occasions. I also witnessed first-hand the culture and values at the heart of the organisation, the willingness to listen to feedback and the genuine desire to improve the client experience.

I recognise that designing a system that captures the whole range of real-world activities, and the barriers and costs that come with them, could potentially result in an unwieldly process and one that becomes more, rather than less, intrusive. There is a balance to be struck to achieve a system that is individualised and curious but not overly burdensome for the individual.

Whatever follows this Review, I would encourage the continuation of the emphasis on client voice and the co-design of any permanent changes. A partnership with Adult Disability Payment clients, others likely to be affected by any changes and those who are currently excluded from the system, would be ideal. I would expect the Scottish Government to deploy a range of participatory methods, with a focus on the most effective ways to include those who face the biggest barriers and seldom-heard voices.

If social security is indeed viewed as an investment in society by the Scottish Government, I hope Ministers will use the findings of the Review to design a truly world-leading, holistic and person-centred disability payment system, that is fair, equitable and supportive of disabled people's needs now, and in the future.

Annex 1: Examples of outcome-based eligibility criteria

Annex 1: Examples of outcome-based eligibility criteria

Introduction

The outcome-based examples keep the separation of daily living and mobility components and assume keeping a points-based system although in this example no points are allocated to any activity.

The example also includes the "reliability" criteria: that a person must be able to undertake an activity safely, to an acceptable standard, repeatedly and in a reasonable time.

Daily living

Making a healthy meal and enjoying a healthy and nutritious diet

The person has access to food and drink to maintain nutrition and are they able to prepare and consume the food and drink without any help.

They can shop for ingredients, can read or understand labels and nutritional values and understand the labelling on food packaging and understand the nutritious value of different foods, and they can prepare and cook a healthy meal without any help or assistance.

Can the person safely use an oven, hob, microwave, air fryer, slow cooker and other kitchen appliances to effectively produce a healthy meal?

Can they safely access food or utensils from cupboards and safely move around the kitchen?

Can they safely clear up, wash up and put away after a meal?

Do they need to use an aid or appliance to be able to eat food safely and effectively; or

- supervision to be able to eat; or
- assistance to be able to cut up food or
- need a therapeutic source such as tube feeding to be able to take nutrition?

Do they need prompting, or support or medical intervention to be able to manage a healthy and nutritious diet, to eat a prepared meal, to shop for ingredients and/or to prepare or cook a healthy meal?

If the person is eating a restricted or unhealthy diet (e.g. only eats toast) it may be because:

- they have difficulty in getting to the shops to buy food
- they do not understand what constitutes a healthy diet for them.

Can they convey food and drink to their mouth, or do they need another person to do so?

Does the person have swallowing problems?

The person has an eating disorder or another cognitive impairment such as dementia which results in them not regularly realising any benefit from eating.

Does their ability to prepare a meal impact on their ability to carry out other tasks due to fatigue, for example?

Annex 1: Examples of outcome-based eligibility criteria

Managing a health condition

The person does not receive medication or therapy to monitor a health condition, or they can manage medication or therapy or monitor a health condition without any help.

The person needs to use an aid or appliance to be able to manage medication or they need supervision, prompting or assistance to be able to manage medication or monitor a health condition.

They need supervision, prompting or assistance to be able to manage medical or related appointments, or homeopathic interventions, or privately funded services, or therapy.

For therapies or medical or related interventions/appointments to be considered even when they are privately funded.

If medical or related appointments, or homeopathic interventions, or privately funded services, or therapy is required to manage a health condition for this to be considered whether the therapy/intervention occurs inside or outside the home.

If the person is on a waiting list for a diagnosis or a medical intervention or therapy, for this to be acknowledged.

Maintaining personal hygiene

Can wash and bathe and launder clothes and bedding and manage personal or intimate hygiene without any help or assistance.

The person needs to use an aid or appliance or may need supervision or assistance to be able to wash or bathe or launder clothes and bedding and manage other personal hygiene or intimate hygiene tasks (such as changing a tampon or sanitary towel). They need assistance, or the use of an aid to be able to get in or out of a bath or shower or to use a washing machine.

The person washes themselves:

- infrequently (resulting in poor hygiene and risk of harm) or
- excessively.

As a result of a disability or health condition the person needs to be motivated or assisted to wash or bathe or launder their clothes and bedding.

If they don't have access to a washing machine and their mobility is poor, clothes and bedding may not be properly clean.

If they cannot buy cleaning products, or cognitively understand how to operate a washing machine, their clothes and bedding may not be properly clean.

As a result of a cognitive impairment or mental health problem, they may not manage their personal hygiene well

Annex 1: Examples of outcome-based eligibility criteria

Managing toilet needs

The person needs to use an aid or appliance or needs supervision or assistance to be able to manage toilet needs or incontinence and/or to clean up after accidents.

Is the person able to access and use the toilet and manage their own toilet needs when outside of the home?

Is their ability to leave the home impeded by their incontinence needs?

If the toilet is no longer accessible due to mobility problems or if the person takes too long to get to the toilet, they may not be managing their toilet needs.

If they are unable to maintain their night-time continence, they may not be managing their toilet needs in a way that promotes their dignity.

Dressing and undressing and being appropriately clothed

The person can get dressed and undressed without any help or assistance.

They need to use an aid or appliance to get dressed or undressed.

Is the person able to dress themselves and be appropriately dressed, for example, in relation to the weather or the activities they are undertaking, which could include work/volunteering?

If they cannot put on or fasten their clothes, they are unlikely to be appropriately dressed. The person may be able to dress themselves in casual clothes unaided but may not be able to dress themselves in more formal clothes e.g. put on a tie, zip up a dress or clean their shoes, and so would not be appropriately dressed for their circumstances.

They need either:

- prompting to be able to dress appropriately, undress or determine appropriate circumstances for remaining clothed; or
- prompting or assistance to be able to shop for and select appropriate clothing or
- to be motivated to get dressed and wash and change clothes regularly.

Due to psychological constraints the person finds the act of dressing and undressing distressing and anxiety inducing.

Because of a disability or health condition they regularly and excessively change their clothes.

If they cannot acquire new clothes when needed, they may not be appropriately dressed e.g. for the change in seasons. This would include where a person needs support to shop for and choose new clothes and shoes.

If they are severely visually impaired, they may be able to dress themselves but not know if clothes are appropriate or clean.

Annex 1: Examples of outcome-based eligibility criteria

Able to make use of their home safely

Is the person able to move around the home safely, including climbing steps, using kitchen facilities and accessing the bathroom/toilet?

If they cannot reach certain rooms, they may not be using the home safely or may be unreasonably confined e.g. having to spend all day in bed.

If they cannot get in or out of the front door (e.g. because they cannot manage the steps), they are unlikely to be using the home safely or have proper access to it.

Can the person use home appliances properly and safely (e.g. cooker, heater)?

Can they maintain a safe home environment without any assistance?

Maintaining a habitable home environment

Is the person's home sufficiently clean and maintained to be safe, including having essential amenities?

Do they require support to sustain the home or maintain amenities such as water, electricity and gas or pay their rent or mortgage?

They cannot clean their kitchen or bathroom without support or assistance.

The impact of hoarding excessively, seriously impacts on the person's safety and wellbeing.

It may not be a habitable home environment if the home is damp or in very poor repair.

Communicating

If the adult is unable to communicate easily and regularly, they may not have, or be able to use, a phone or computer, they may be unable to leave their home safely, they may be unable to communicate successfully or interact with others – this may prevent them from maintaining or developing relationships and lead to social isolation.

They cannot express or understand verbal information at all even with communication support.

The person cannot read or understand signs, symbols or words or is registered blind or has a severe visual impairment.

They need to use an aid or appliance (other than spectacles or contact lenses) to be able to read or understand either basic or complex written information or to be able to speak or hear.

They need communication support to be able to express or understand basic or complex verbal information and act on it.

Because of difficulty with communication the person has problems managing medication.

They may find communicating in certain situations or environments distressing and/or anxiety raising.

The person cannot safely and confidently access and understand how to use modern technology to engage in daily activities such as paying bills, shopping, communicating with professionals and friends and family etc.

Annex 1: Examples of outcome-based eligibility criteria

Engaging and socialising with other people

The person can engage and socialise with other people without any help or assistance.

They need prompting, support or supervision to be able to engage with other people in a contextual and appropriate manner.

They cannot engage with other people due to such engagement causing either

- psychological distress to the individual; or
- the individual to exhibit behaviour which would result in a substantial risk of harm to the individual or another person.

Due to anxiety or a cognitive impairment, the person finds engaging with people difficult.

The person is lonely or socially isolated and may struggle to establish and maintain relationships with family and friends.

The person is at harm if engaging with and socialising with other people online.

Managing a budget, undertaking financial transactions and managing a bank account

Does the person have a formally appointed financial guardian?

The person cannot make any budgeting decisions at all and cannot manage a bank account or be responsible for any financial transactions such as paying bills.

Can they use modern technology such as banking apps to make payments and manage financial transactions?

Are they vulnerable to other people misusing their money?

Can they manage complex budgeting decisions and financial transactions without any help or assistance.

They need prompting or assistance to be able to:

- make simple budgeting decisions
- manage a bank account
- understand financial transactions such as paying bills
- use modern technology safely – such as banking apps.

Mobility

Planning and going on a journey

Can the person get around in the community safely and are they able to use facilities such as public transport, shops and recreational facilities? (This includes the need for support when attending health care appointments and informal appointments e.g. being able to go to the library or to meet a friend in a cafe or pub.)

Can they plan and follow the route of an everyday or more complex journey unaided?

Annex 1: Examples of outcome-based eligibility criteria

The person needs prompting or support to be able to leave the home and undertake any journey to avoid psychological distress to the individual.

Cannot undertake any journey because it would cause significant psychological distress to the individual.

The person leaves the house infrequently because undertaking any journey is challenging physically or emotionally or because the person is clinically vulnerable.

The person leaves the house infrequently due to incontinence or bowel or bladder conditions and the anxiety associated with the availability of public toilets.

If leaving the home unaccompanied can regularly become disorientated or lost.

Cannot go on an everyday journey without another person, assistance dog or orientation aid.

Cannot confidently use public transport.

If the adult is unable to walk, or to use public transport unattended or to organise alternative transport (e.g. someone giving them a lift), or does not have money for a taxi, they may not be able to access services locally.

Where does the person live? For example, a rural area where public transport is limited or where the terrain is not conducive to safe movement. How close are amenities such as shops and GP surgery?

Does the person experience excessive pain when moving around and/or breathlessness and/or chronic fatigue.

Moving around

The person has

- a permanent and substantial disability which means they are unable to walk or virtually unable to walk, or
- has a temporary, but substantial disability, which means unable to walk or virtually unable to walk which is likely to last for a period of at least 12 months, but less than 3 years or
- the effort of walking presents a danger to the individual's life or would be likely to lead to a serious deterioration in their health.

The person's ability to walk is affected to the extent that they are unable to access goods and services unless allowed to park close to shops, public buildings and other facilities.

The person requires help to negotiate the types of pavements or roads normally expected to find while walking outdoors.

The person experiences excessive pain when walking, or because of the effort of walking breathlessness is experienced.

Chronic fatigue is experienced because of walking.

Scottish Government
Riaghaltas na h-Alba

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: 978-1-83691-892-9 (web only)

Published by The Scottish Government, July 2025

Produced for The Scottish Government by APS Group Scotland, 21 Tennant Street, Edinburgh EH6 5NA
PPDAS1615655 (07/25)