Independent Review of Adult Disability Payment

Final Report

July 2025

Scottish Government
Riaghaltas na h-Alba

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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 ensure (at all times) 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.

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 ongoing 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 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.

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

Note on Terminology

In this report I use the terms ‘disabled people’ and ‘disabled people and people with long-term conditions’ to refer to people who have lived or living experience of Adult Disability Payment. I acknowledge that to be eligible for Adult Disability Payment a person may not necessarily see themselves as a disabled person. They may have a terminal illness, a mental health condition or problem, a condition such as Autism or ADHD.

I welcome consideration of a social rather than a medical model of disability (more on this later in the report) recognising that people are disabled by barriers that arise because society is not designed to accommodate them.

I recognise that not everyone who applies for Adult Disability Payment will see themselves as disabled. For example, wherever possible within my report I have sought to use terminology that people use to refer to themselves, specifically with reference to people who have a mental health problem, rather than condition. This also applies to people who have lived or living experience of a terminal illness. I am grateful to the Advisory Group members for their expertise and representations in ensuring that the terminology used in my report reflects the preferences of people who may apply for or receive Adult Disability Payment.

For the purposes of this report, I use the Equality Act 2010 definition which defines a disabled person as someone who has a physical or mental impairment which has a substantial and long-term adverse effect on your ability to carry out normal day-to-day activities[2].

I am aware that there are ongoing debates about identity and terminology. Whilst the Review recognises these debates and the importance of language in making people feel included or excluded, it is not for me as Chair of the independent Review to impose any terms or definitions. In the interests of inclusivity, I have opted for the broadest definitions of all equality and diversity-related terms.

What is Adult Disability Payment?

Adult Disability Payment launched nationally on 29 August 2022 to new applicants and is one of fifteen payments that Social Security Scotland delivers.

Adult Disability Payment has replaced PIP for disabled people of working age in Scotland, which is administered by the UK Government's Department for Work and Pensions (DWP).

Adult Disability Payment is a form of social security benefit provided by Social Security Scotland to support disabled adults. It is designed to help cover the extra costs that disabled people may incur due to their condition.

As of 30 April 2025, 476,295 people are receiving Adult Disability Payment, just under 8.7% of Scotland's population.[3] Most of the people receiving the payment have had their payments transferred across from PIP or Disability Living Allowance (DLA) (318,600 people or 67%) and the remainder are new applicants (157,700 people, or 33%).[4]

At the same time, 340,655 people had submitted the first part of the application for Adult Disability Payment and 287,780 people had submitted the second part of the application. Social Security Scotland has processed 313,430 applications with 47% being approved, 49% being denied and 4% withdrawn.

The total value of all Adult Disability Payments made to 30 April 2025 is £3.6 billion.

The number of people receiving Adult Disability Payment is forecast to grow from 379,000 in 2024-25 to 703,000 in 2030-31.[5]

Purpose and Remit of the Independent Review

The Cabinet Secretary for Social Justice, Shirley-Anne Somerville MSP, appointed me to Chair an Independent Review of Adult Disability Payment in January 2024.

Work began on the Independent Review in February 2024, and I published my Interim Report[6] on 5 November 2024.

I have considered people's experiences of the delivery of Adult Disability Payment, as well as the eligibility criteria. The Review took into account the analysis[7] of the consultation on the eligibility criteria for the mobility component of Adult Disability Payment, published in August 2023, and the analysis of the consultation and call for evidence[8] for the daily living component of Adult Disability Payment, published in June 2024.

The Scottish Government asked me to look at:

- the activities and descriptors that determine entitlement to Adult Disability Payment, including how these apply to disabled people with fluctuating conditions
- people's experiences of applying for, receiving or challenging a decision about Adult Disability Payment or undergoing a review (including unsuccessful applicants)
- the consultations process, Adult Disability Payment-specific guidance for practitioners and decision-making guidance to ensure that a rights-based model of social security is being applied
- considering initial priorities capable of early action that do not require changes to the application, decision-making or service delivery, where those changes offer value, are deliverable and useful regardless of any longer-term changes. These initial priorities are included in the recommendations outlined in the Independent Review of Adult Disability Payment Interim Report,[9] published November 2024.

The following were beyond the scope of my Review:

- the purposes of Adult Disability Payment or the adequacy of payments
- wider aspects of disability assistance which have implications for other forms of disability assistance, such as supporting information, Special Rules for Terminal Illness (SRTI), duration of awards and reviews
- alternative forms of mobility support, such as grants, reductions in the cost of mobility equipment and vehicles and associated costs
- alternative bodies to Social Security Scotland for delivering Adult Disability Payment.

Executive Summary

My findings suggest that improving access to Adult Disability Payment could enhance the lives of all those who need support and who currently either face barriers to getting it or are not eligible under the current system. This builds on existing evidence that underscores the need for a review of the eligibility process and decision-making framework.[10]

Disabled people have told me that the application process, although much kinder in nature, is still at times inaccessible, complex and burdensome, causing some clients significant stress and anxiety. Building on great foundations and continuing to focus on a good client experience, simplifying and improving systems and processes and refreshing the eligibility criteria could make a substantial positive difference on the lives of all those who need this additional support.

The understandable argument to control public spending and to ensure fairness of allocation suggests that governments should look to limit eligibility and reduce or certainly not increase the numbers of people receiving disability payments. The Scottish Fiscal Commission forecasts in December 2024 noted that applications in the UK are expected to continue to rise in the near future[11]. The May 2025 forecasts noted changes that are anticipated to impact on benefits expenditure spending in England and Wales:

> “The UK Government announced several policy measures, in March 2025, to reform elements of the UK welfare system with the aim of reducing spending and helping disabled people and people with long-term health conditions into employment. These measures include changes that are expected to reduce spending on Personal Independence Payment (PIP) and Carer’s Allowance in England and Wales.” – Scotland’s Economic and Fiscal Forecasts, May 2025[12]

However, my recommendations suggest that the Scottish Government should not restrict eligibility or introduce further barriers to application. Anything in practice, that opposes the human rights approach currently adopted by the Scottish Government and Social Security Scotland could potentially harm the quality of life of many disabled people.

If viewed as an investment in the people of Scotland there is evidence of the economic value of the wellbeing impacts of disability benefits and these significantly outweigh the financial costs associated with administering them.[13] This means not only should we continue to encourage people to apply for Adult Disability Payment, but we also need to make the application process as accessible and anxiety-reducing as possible.

In determining my recommendations, I used the questions from the Charter Measurement Framework[14] to determine if Social Security Scotland, in the context of delivering Adult Disability Payment, is realising its ambitions or if there is still work to be done. As a result, this report and the resulting recommendations are set out under the following four headings:

A People's Service – recommendations include continuing to place the client voice at the heart of continuous improvement and enhancing the client experience to ensure it is truly person-centred; to further develop strategies to effectively engage with seldom-heard voices and individuals who may be eligible but do not apply due to stigma and to address the societal and sometimes cultural stigma associated with disability benefits to ensure broader and fairer access; ensuring the funding available to third sector advocacy and welfare advice organisations to support disabled people is sustainable and actively promote and share information on the range and location of advice, advocacy and support services available to potential clients; to ensure that taking a trauma informed-approach to practice is embedded in all aspects of Social Security Scotland's work and ensure people are always treated with dignity, fairness and respect. Everyone who is eligible for Adult Disability Payment should have an adequate level and type of support, offered in a timely manner, to maximise the chances of the right decision being made first time.

Processes That Work – recommendations include improved systems that allow people to track and follow the progress of their application; reduced phone waiting times and faster, more transparent decision-making; reviewing 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; consideration of the feasibility of introducing 'implicit consent' and introducing a process that meets the needs of third-party representatives and their clients; for Social Security Scotland to continually assess how it can balance the need for fairness and equity with the discretion that is inherent in the determination process and ensure rigorous application of the reliability criteria; for consideration to be given to automatic entitlement to Adult Disability Payment when satisfying certain conditions.

A Learning System – recommendations include further training and guidance for case managers on certain conditions and the impact they can have on a person's daily life; specific guidance on fluctuating conditions, and; the reinstatement of an 'expert by experience' group to guide the next stage of the evolution of Adult Disability Payment. It is also recommended that Social Security Scotland should consider updating the suite of guidance available to clients and review its inclusive communication practices and set out whether it intends to highlight and make more prominent the option to request written translations of letters.

A Better Future – recommendations include suggested changes to the points-based scoring system to ensure fairness; undertaking a thorough review of the decision-making criteria; providing further training and guidance for case managers to aid good decision-making; replacing the 50% rule with improved application of the reliability criteria; removing reference to a fixed distance in the mobility component, and; improving the questions asked of applicants within the application process, to account for variability, triggers and actions taken to manage conditions.

Methodology

Considering the views and experiences of people with lived or living experience of a long-term health condition, disability or terminal illness, and the organisations who support them, has been a key priority for me throughout this Review. Their input is at the heart of this report. To gather their views and experiences, I conducted a comprehensive programme of engagement:

- I recruited and regularly met with an Advisory Group, consisting of ten members representing individuals with lived or living experience of a long-term health condition, disability or terminal illness.
- I invited people to share their experiences of Adult Disability Payment by responding to a public consultation and call for evidence between 28 June and 30 August 2024.
- As part of the public consultation, I hosted a series of eight in-person events across Scotland and one online event, to provide an alternative method for people to contribute to the consultation.
- Since the beginning of the Review in February 2024, I have met with a broad range of stakeholder groups and organisations who work with disabled people, including people with lived or living experience of Adult Disability Payment, to discuss their experience and gather their views.
- Throughout the course of the Review, I met on multiple occasions with Scottish Government and Social Security Scotland officials to gain a better understanding of the policy landscape and internal processes which shape people’s experience of the Adult Disability Payment client journey.

Advisory Group

One of the first actions I undertook as Chair was to appoint members to an Advisory Group. The purpose of the Advisory Group was to provide me with their guidance, expertise and scrutiny to ensure that the Review was being conducted effectively, fairly and with integrity.

I met quarterly with the Advisory Group and minutes of these meetings were published online.[15]

Topics which were discussed during these meetings included:

- what the main priorities of the Review should be
- the consultation and call for evidence
- the interim report
- stakeholder engagement
- engagement with seldom-heard groups
- the eligibility criteria.

In addition to these regular meetings, I met with members on an ad hoc basis to draw from their knowledge of specific areas over the course of the Review. I issued fortnightly updates to members to keep them informed on the progress of the Review.

Scottish Government mobility component consultation

Prior to my appointment as Chair, the Scottish Government ran a public consultation on the mobility component[16] between 31 January and 25 April 2023. The consultation aimed to gather a wide range of views on alternative approaches to the mobility component and identify any gaps, issues or unintended consequences of any suggested changes.

This consultation covered the following areas:

- the moving around activity
- the planning and following journeys activity
- support for people with fluctuating conditions
- other considerations for the independent review.

The Scottish Government also organised six engagement events. The Lines Between facilitated these events on behalf of the Scottish Government. In total, 22 individuals and 12 representatives from stakeholder organisations attended the events.

A total of 173 individuals and 37 organisations provided responses to the consultation. Responses to the consultation were independently analysed by The Lines Between and the analysis report[17] was published on 14 August 2023.

Public consultation

Between 28 June and 30 August 2024, I invited people to share their experiences of Adult Disability Payment by responding to a public consultation[18]. Whilst responses were open to all, my intention was that the consultation was primarily for responses from people with lived and living experience of accessing (or trying to access) Adult Disability Payment.

The consultation covered the following areas:

- take-up of Adult Disability Payment
- eligibility check
- pre-application support for Adult Disability Payment applications
- rules about who can get Adult Disability Payment
- the fluctuating conditions section of the Adult Disability Payment application
- asking about a person's daily living activities
- decision-making
- re-determinations
- review periods and indefinite awards
- processing times
- changes in people's circumstances
- other considerations.

The Scottish Government's consultation on the mobility component and Supporting Information Evaluation provided relevant evidence about the mobility component and supporting information. Therefore, this consultation focused primarily on the daily living component of Adult Disability Payment.

I received a total of 84 responses to this consultation, with 80 responses from individuals and four from organisations. Responses to the consultation were independently analysed by The Lines Between and the analysis report[19] was published on 29 November 2024.

Call for evidence

Between 28 June and 30 August 2024, I also invited people to share any available data and evidence relevant to key elements of the Adult Disability Payment process.[20] Whilst responses were open to all, my intention was that the call for evidence was for responses from stakeholder organisations.

The call for evidence covered the following areas:

- factors affecting take-up of Adult Disability Payment
- pre-application support for Adult Disability Payment applications
- processing times for Adult Disability Payment applications
- decisions, re-determinations and appeals

- informing Social Security Scotland about a change of circumstances
- review periods
- other considerations.

The call for evidence did not ask questions about the eligibility criteria or fluctuating conditions. However, I asked questions about these in the consultation and at events. I received a range of evidence regarding the stages of the Adult Disability Payment process. These items of evidence often contained feedback from the responding organisation's own stakeholders; with case studies tending to account for people's lived experience.

I received a total of 36 responses to the call for evidence, with 7 responses from individuals and 29 from organisations. Responses to the call for evidence were independently analysed by The Lines Between, and the analysis report[21] was published on 29 November 2024.

Consultation events

To provide an alternative method of responding to the consultation, I held a series of eight in-person engagement events across Scotland, and one online event. The Lines Between independently facilitated these on my behalf.

Whilst I welcomed views on any aspect of Adult Disability Payment, the events focused on the following key stages of applying for Adult Disability Payment:

- awareness of Adult Disability Payment and pre-application support
- the eligibility criteria
- asking about daily living needs
- getting a decision.

A total of 47 people attended these events, with 19 individuals and 28 organisational representatives.

Stakeholder engagement

Over the course of the Review, I met with over 70 different stakeholder organisations through both roundtable events and meetings with individual organisations, attended by over 160 individuals. Each meeting gave me the opportunity to hear about the areas that impact specific groups of disabled people as well as hearing many stories and experiences of individual Adult Disability Payment journeys.

Whilst I have endeavoured to capture a range of views as part of my report, I acknowledge that not all views expressed are representative of disabled people's experiences, or the organisations who support disabled people.

Scottish Government and Social Security Scotland

I also met on multiple occasions with Scottish Government and Social Security Scotland officials, who provided valuable insights into the design and delivery of Adult Disability Payment. Their input helped me to better understand the Adult Disability Payment process, as well as the research which forms the basis of decisions taken with regards to the delivery of the benefit. This understanding has been an invaluable asset when considering the practicalities and implications of my recommendations.

The Legislative Context

The legislative context for social security in Scotland is primarily governed by the Social Security (Scotland) Act 2018.[22] This landmark legislation established a new framework for the delivery of social security benefits devolved to the Scottish Government. The Act signifies a significant shift in the administration of social security from the UK Government to the Scottish Government, encompassing benefits such as Adult Disability Payment and others.

The Act is underpinned by principles of dignity, fairness, and respect, ensuring that social security is viewed as a human right and an essential public service.

The Social Security (Scotland) Act explicitly recognises social security as 'an investment in the people of Scotland'. Making it clear who the payment is intended for and what the intended social effects are.

The United Nations Convention on the Rights of Persons with Disabilities[23] (UNCRPD) recognises the right of disabled people to an adequate standard of living and social protection, in particular adequate food, clothing and housing, and a continuous improvement of living conditions. The Convention on the Rights of Persons with Disabilities also commits governments to equality and non-discrimination in social protection, ensuring access to appropriate services and assistance for disability related needs, and assistance from the state with disability-related expenses including financial assistance.

It also contains explicit recognition of the equal right of all disabled people to live independently in the community, with choices equal to others and commits governments to take steps to ensure disabled people can enjoy the right to full inclusion and participation in the community.[24]

The Scottish Government has set out its commitments to delivering the Convention on the Rights of Persons with Disabilities – including some provisions for social security – in 'A Fairer Scotland for Disabled People: delivery plan'.[25]

Fiscal and Economic Context

Historical context

Previous reforms to disability social security, in particular the introduction of PIP by the UK Government in 2013 expressly aimed to reduce the costs of social security[26]. However, the introduction of PIP had the effect of increasing the costs of social security[27]. Scottish Campaign on Rights to Social Security (SCoRSS) members believe that this approach is incompatible with the human-rights approach, and longer-term changes to disability assistance in Scotland should not be motivated by cost reduction.

The funding of social security in Scotland

One of the Scottish social security principles states that 'the Scottish social security system is to be efficient and deliver value for money'.[28] The policy intent is that this value for money will be achieved not just through an efficient system but also through the value it brings to society, by reducing poverty and by enabling people to live more independent lives. It will, however, be important in an increasingly pressurised economy to maintain a balance and ensure that value for money and/or cost is not disproportionately prioritised over other principles.

The 2025-26 Scottish Budget was approved by the Scottish Parliament in February 2025.[29] The Budget invests £6.9 billion in social security, expected to support around two million people in 2025-26.

The Scottish Government is now responsible for devolved social security payments in Scotland, such as Adult Disability Payment. Because the UK Government is no longer responsible for this spending, it gives the Scottish Government funding for this known as Block Grant Adjustments (BGAs). This reflects what the UK Government would have spent in Scotland had benefits not been devolved. The Scottish Government must fund from the Scottish budget, any extra costs over the BGA funding as a result of any policy choices or delivery changes it makes.

When the UK Government introduces a policy in England and Wales for a payment with an associated BGA, and that policy leads to a change in the level of spending, then there is a proportional effect on the level of BGA funding the Scottish Government receives.

Forecasts for Adult Disability Payment

Application rates

In December 2023, the Scottish Fiscal Commission noted that quarterly applications rates as a percentage of the working age population for PIP in England and Wales and for Adult Disability Payment in Scotland started to diverge at the beginning of the Adult Disability Payment pilot in March 2022, and widened further when Adult Disability Payment was launched nationally in August 2022.[30]

Potential drivers in demand

The drivers for the increase in demand for disability payments are complex. The Scottish Fiscal Commission has revised its assumptions about potential drivers in demand for disability benefits over time. This has included a move away from including NHS waiting lists as a potential reason for the increase in the number of applications:

> "In December 2022, we increased our forecasts for disability payments to reflect months of record high applications and inflows for disability benefits across the UK. We attributed the increase in demand to a combination of factors, including a long-term increase in mental health-related cases, NHS waiting lists, and the cost-of-living crisis, which together could exacerbate existing health conditions or increase the likelihood of people applying for disability payments.
>
> The high volume of applications has continued, and we have revised our assumptions further increasing our Adult Disability Payment (ADP) forecast. Our assessment of the explanation for the increase has also developed and we now place more weight on the role of the cost-of-living crisis. Therefore, in the future, as the cost-of-living pressures ease and real household income levels return to pre-pandemic levels, some of the additional demand for disability payments is expected to ease." – Scotland's Economic and Fiscal Forecasts (December 2023), Scottish Fiscal Commission[31]

The assessment of the number of applications for Adult Disability Payment was revised further by the Scottish Fiscal Commission in December 2024, noting that its assumption was that number would progressively decrease as the elevated cost-of-living pressures ease:

> "We assume that the number of applications for ADP will progressively decrease from the current elevated level as cost-of-living pressures ease. We have adjusted our new application forecast to allow for a more progressive decrease in the application rate as the recent number of applications has remained at a slightly higher level than previously forecast" – Scotland's Economic and Fiscal Forecasts (December 2024)[32]

The Scottish Fiscal Commission also recognises the impact of changes made by the Scottish Government in its forecasts, including maximising take-up and the approach to reviews of entitlement.

> "The effect of delivery and operational changes introduced with Adult Disability Payment is now evident in the published statistics. There are now a higher number of applications, reflecting the Scottish Government's policy to maximise take-up, and a decrease in the number of people exiting the caseload at award review because of the light-touch review policy implemented" – Scotland's Economic and Fiscal Forecasts (December 2024)[33]

Approval rates

In its December 2023 forecast, the Scottish Fiscal Commission noted that the available data had indicated that the success rate for new applications for PIP in England and Wales was lower than the comparable success rate for Adult Disability Payment in Scotland. However, its December 2024 forecast noted that the reverse was true:

> "One of the reasons for the decrease in the ADP success rate could be because applications for more severe conditions, or for which more detailed supporting information was provided, were processed more quickly when ADP was introduced, skewing the initial success rate. In 2024, the ADP success rate in Scotland has been lower than the comparable success rate for PIP in England and Wales." – Scotland's Economic and Fiscal Forecasts (December 2024)[34]

Average payments

In contrast to the increase in applications, a decrease in the average payment award received by new applications to Adult Disability Payment has been noted in comparison to PIP in England and Wales.[35] This is attributed to a shift in the distribution with an increase in the percentage of applications receiving a higher-value award, and the percentage of applications receiving a lower-value award.

Budget implications

The Fraser of Allander Institute published its Economic Commentary Q1 2025.[36] In the report it acknowledges that while the caseload for disability benefits is growing across the UK, it is rising more rapidly in Scotland. The reasons behind this trend are complex, and there is no single explanation. Some possible contributing factors are that while eligibility criteria remain broadly similar to the UK system, Scotland's system is seen as more accessible, with a simpler application and review process. In Scotland, the three disability benefits are driving most of the recent growth including Adult Disability Payment.

Overall social security spending in Scotland is forecast to increase from £6.9 billion in 2025-26 to £9.4 billion in 2030-31. By 2029-30, the Scottish Fiscal Commission forecasts that the Scottish Government will spend £2.1 billion more on social security than block grant funding received from the UK Government.[37] In the Scottish Fiscal Commission's assessment, the largest contributor to this difference is Scottish Government policy changes. For example, Scottish Child Payment spending (on itself) accounts for 25% of the funding gap.

The Scottish Fiscal Commission forecasted in May 2025 that, by 2029-30, the Scottish Government would be spending around £770 million more on Adult Disability Payment than it receives in funding through the BGA for PIP. Although that shortfall is significant it is only 9% of the total spend.[38] The £770 million figure factors the proposed changes to PIP, as outlined in the UK Government's 2025 Spending Review.[39] However, it does not reflect the potential impact of the removal of Work Capability Assessments for Universal Credit and the linking of the Universal Credit health element to the PIP assessment.

If as a result of changes to PIP, spending is forecast to fall in real terms, and if Adult Disability Payment spend in Scotland stays the same, then the gap between the Block Grant and actual spend gets bigger. Quite how much bigger will become clearer once the scale of forecast savings from the UK welfare reforms are set out in more detail.

The Institute for Fiscal Studies (IFS) view is that the Scottish Government's overall short-term funding position (beyond social security) has improved substantially compared to what was expected a year ago. However, the IFS's view is also that the longer-term outlook presented is less positive, stating 'it seems likely that a range of services and capital investment will face cuts from 2026–27 onwards in order to meet NHS and social care spending pressures.'[40]

Whilst this is the IFS view of the Scottish Fiscal Commission's forecasts and budget, that only covers the funding position. The Scottish Fiscal Commission's Chair, Professor Graeme Roy said:

> "The Scottish Government has benefited from significant extra funding from Rachel Reeves' Autumn Budget. However, the consequences of much stronger income tax revenues elsewhere in the UK affecting the net tax position, combined with ongoing pressures from a rising pay bill and increased commitments on social security, continue to act as a binding constraint on the Scottish Government's broader spending decisions." – Scottish Fiscal Commission, December 2024[41]

The IFS also notes that the Scottish Government's intention to mitigate the impact of the Universal Credit two-child limit, noting that it is particularly well-targeted to reduce child poverty, but the forecast cost (averages around £180 million per year between 2026-27 and 2030-31) may have a significant impact upon funding available elsewhere.

The IFS notes in its report the widening gap between BGA and spending on disability benefits in Scotland:

> "In 2025–26, lower-than-previously-expected inflation in September 2024 (the inflation rate typically used to index most social security benefits) will also reduce benefit spending (in cash terms) in the rest of the UK and hence the social security BGA, further offsetting the impact of higher caseloads for disability benefits." – IFS

Passporting

Passported benefits are benefits, entitlements or concessions that people receiving a specific rate of the daily living and mobility components of Adult Disability Payment may be entitled to.[42] Examples of passported benefits in relation to Adult Disability Payment include some benefits administered by the DWP, such as specific additional premiums in Universal Credit and Employment and Support Allowance.

The UK Government has agreed that whilst the eligibility criteria for Adult Disability Payment and PIP remain broadly aligned, people receiving Adult Disability Payment can automatically access the same passported benefits that someone getting PIP would receive from the DWP.

There is already a risk of divergence considering the UK Government's announcement to introduce changes to the eligibility criteria for PIP in 2026 as part of its Pathways to Work Green Paper.[43] This includes the requirement that in addition to scoring a minimum of eight points to be eligible for the daily living component, the person must also qualify for a minimum of four points from a single descriptor (although at the time of publication the UK Government has signalled that this will now only apply to new applicants of PIP).

The significance of protecting clients who need to access passported benefits cannot be overstated.

> "Several argued that changes should not disrupt or adversely affect clients i.e., clients should retain their existing entitlements regardless of any changes made to ADP, and none should become worse off."– Consultation on the Mobility Component: Analysis[44]

My engagements with disabled people and stakeholders during the course of the Review have highlighted the concerns that many people have with regards to accessing passporting benefits, as highlighted in the consultation and call for evidence analysis.[45] During engagement events, disabled people and third sector organisations spoke of their concerns about the qualifying periods for Adult Disability Payment (which are identical to PIP) which had resulted in delays to receiving passported benefits. Furthermore, participants highlighted the stress and anxiety caused by processing time delays for decisions on an Adult Disability Payment application. This has meant that that they have been unable, in some cases, to access passported benefits.

Equally, people have expressed views that passporting arrangements should not constrain future ambitions for Adult Disability Payment in Scotland.

However, should the Scottish Government consider making any changes to the eligibility criteria because of my Review, passporting remains a crucial issue for the people it affects. There are both fiscal and practical challenges to any potential changes to passported benefits, for example:

- the way that the UK Government might respond to any changes is rightly a matter for it, although it has said if it cannot use Adult Disability Payment to identify people entitled to a passported benefit, it would identify another way;[46] the practical extent to which it might do so might mean that arrangements could look very different for disabled people
- if changes to the eligibility criteria result in more people qualifying for UK Government passported benefits, resulting in increased costs for the UK Government, the Scottish Government would be required to cover these expenses under the Fiscal Framework agreement.[47]

Whilst it is outside the scope of this Review to recommend how the UK Government should respond to any potential changes to Adult Disability Payment; I would urge both Governments to engage at an early stage on this matter. This would benefit disabled people by providing certainty and putting them at the heart of any considerations.

In terms of costing the impact of potential changes to the eligibility criteria on passported benefits, this would first require an understanding of the changes in the number of people who would qualify for Adult Disability Payment. That work is a far larger undertaking than is possible within the scope of this review, as it would require a comparison between how many people would qualify under the old rules and then comparing that to the new rules. The Scottish Government may be able to undertake this, for example by:

- reviewing the activities and descriptors
- taking a sample of applicants, and then undertaking qualitative research to explore whether the suggested changes would have caused them to make any changes in what they put in the application
- taking a sample of decision makers to then look at that data along with the new activities and descriptors, to see how they would interpret and score those
- undertaking a comparison of the points awarded in the first instance and the second.

A People's Service

The client voice

Throughout the Review I saw how both the Scottish Government and Social Security Scotland are working hard to ensure that people with lived experience of Adult Disability Payment are involved in all matters from policy setting to accessible communications. There is evidence of the learning from the Client Panels and Client Surveys being incorporated to improve customer service and during the early years of the establishment of Social Security Scotland there is evidence that demonstrates a commitment to listening to the experiences of disabled people. However, for Adult Disability Payment applicant respondents to the Client Survey, overall ratings of experience with Social Security Scotland decreased from 85% in 2022-23 to 75% in 2023-24 (the number of these respondents increased from 4,790 to 11,808). For Adult Disability Payment case transfer respondents overall ratings of experience increased from 82% to 85% (again, the number of respondents increased from 2,704 to 9,231).[48]

During the establishment of devolved social security powers in Scotland, many of the decisions taken in relation to the policy and delivery of disability benefits were informed by external input, in particular the Disability and Carers Benefits Expert Advisory Group (DACBEAG).

DACBEAG operated from 2017 to 2023 to provide recommendations and advice to Scottish Ministers, by request and proactively, on the policy and practice options under development by officials on disability benefits. The Group's membership consisted of individuals working for significant stakeholders across the Scottish landscape, including The ALLIANCE, Child Poverty Action Group in Scotland, Inclusion Scotland and Glasgow Disability Alliance.

The Scottish Government established the Ill Health and Disability Benefits Stakeholder Reference Group (IHDBSRG) in 2016, and it is still active. Scottish Government officials chair the Group, and the Group provides advice directly to them (unlike DACBEAG). Membership of the Group includes representatives from across the stakeholder landscape and the remit of the Group is to provide advice on:

- the evidence-base for policy decisions
- potential impact of policy decisions
- user and stakeholder engagement
- fit with the wider public sector landscape
- interaction with wider Scottish and UK social security benefits.

In addition, the Social Security Experience Panels operated from 2017 to 2024. Members of the Panels had experience of at least one of the benefits delivered by the DWP that transferred to Scotland. Over 2,400 people registered to take part in the Experience Panels[49]. As Social Security Scotland is now operational and most benefits are live, the Experience Panels closed in March 2024. Client Panels are a significant legacy of the Experience Panels and will ensure people with lived experience remain at the heart of the delivery of social security in Scotland. Social Security Scotland launched Client Panels in 2020 in recognition of the need for engaging people with lived experience for ongoing development and improvement of Social Security Scotland. Client Panel members are recruited from current clients of Social Security Scotland.

Social Security Scotland Client Panels include Social Security Scotland clients from across Scotland. Social and user researchers invite Client Panel members to take part in research to inform improvements to Social Security Scotland's service, 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. There is also a programme of Scottish Government evaluation of the devolved benefits,[50]which includes the Scottish Government's supporting information evaluation.[51]

Client panels are not the only route for client input. Social Security Scotland also have the Client Survey and other client feedback, including complaints, on which official statistics are published annually. Social Security Scotland also undertakes user research on specific topics, to understand client's experiences and to test new ideas and designs.

Social Security Scotland has integrated the membership of the Inclusive Communication External Stakeholder Reference Group into its Operational Reference Group.

The Operational Reference Group brings together a range of experts and practitioners to provide advice to Social Security Scotland on how it delivers its services. The remit of the Group is to:

- provide advice on the design and delivery of Social Security Scotland's service
- support Social Security Scotland's continuous improvement by providing stakeholder insight on what is going well and areas for improvement
- provide advice and support for Social Security Scotland's communication and engagement with clients and stakeholders - this will include operational updates and information about new benefits
- advise Social Security Scotland on the development of effective partnership arrangements that will enable it to increase the level of support it can provide its clients.

And yet, despite all this engagement and consultation some disabled people and stakeholder organisations either don't feel heard or they fear that little or no change will come about because of their engagement. I was frequently told that people and organisations are growing tired of repeated conversations with little evident change to the system which damages trust and results in disengagement. We need to continue to be conscious of the consultation fatigue experienced by some people with lived experience and those from third sector organisations. Some seldom-heard groups have a distrust of the state and in some meetings, it was necessary for me to stress repeatedly the independence of the Review.

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

Disability benefits are an essential source of income for many disabled people in Scotland. They provide vital financial support to cover the extra living costs that arise from living with a disability or long-term condition. Disabled people in the UK tend to have lower incomes and lower wellbeing than the average person/household.[52] Not only are disabled people facing more financial difficulty overall, but they report a lower quality of life.[53]

Receiving disability benefits significantly enhances the life satisfaction of recipients, potentially reducing their anxiety levels and improving their wellbeing overall. The observed increase in life satisfaction among disability benefit recipients suggests that these benefits mean more than a simple cash transfer to those who receive them.[54]

Given the significant potential boost in wellbeing after receiving disability benefits, it is necessary to explore why someone who is eligible might not be receiving them. While the specific reasons why some individuals may not be applying for Adult Disability Payment can be difficult to pinpoint from my findings, it is evident that more could be done to address the most common reasons cited.

Discussions with stakeholders suggested that there may be many factors that influence the take-up of disability benefits. Some factors suggested are:

- the awareness of Adult Disability Payment itself is limited, and individuals may be unaware of their eligibility and the process to make an application
- the perceived stigma associated with applying for disability benefits; this included stigma from within close social and familial circles to the perceived national discourse about benefit recipients being viewed as ‘work-shy’ and ‘scroungers’; it can be a particular issue in some minority ethnic communities
- the application process itself or fear of rejection deters some people from applying; existing evidence (which includes PIP cases as well as Adult Disability Payment applications) on how difficult people find the process, and the number of rejected applications, suggests these are common barriers to people receiving benefits that they are eligible for.[55] Social Security Scotland data shows that 42,855 re-determinations have been requested by new applicants for Adult Disability Payment; of the re-determinations that have been completed by 30 April 2025, 51% resulted in a change to the decision in favour of the client[56]
- while I generally have had positive feedback on the differences between Adult Disability Payment and Personal Independent Payment, there is still difficulty in believing that the systems are materially different

- the process of obtaining Adult Disability Payment is often complex and challenging, potentially exacerbating the already heightened anxiety levels experienced by disabled people; this difficulty can negatively impact people's mental health and overall wellbeing, creating a vicious cycle as mental health problems are increasingly becoming the primary reason in the UK for applying for disability benefits in the first place.[57]
- stigma associated with mental health problems also acts as a barrier for some people which can be a particular issue for some minority ethnic communities where stigmatising language and harmful stereotypes of mental health problems can be prevalent
- eligible people believing that Adult Disability Payment is only for people with a physical health condition
- people not applying because they view public resources as scarce in supply and other people as 'more eligible' for support
- people who are eligible not applying because they are unaware that the benefit is not means tested.

There are studies which have corroborated these stakeholder insights. A Joseph Rowntree Foundation study exploring how social security can deliver for disabled people in Scotland concluded that a benefits system 'littered with add-ons and extras' was experienced by disabled people as 'confusing, exhausting and inefficient'.[58]

Another study, a systematic review carried out by Public Health Scotland, looked at the impact of UK welfare reform in 2024,[59] also found that UK welfare reform was associated with a worsening in mental health outcomes for those affected, with no evidence of an improvement in physical health.

Stakeholders frequently raised the legacy of PIP. Some people describe their experience of engaging with 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.

In the case of devolved benefits, there are concerns from stakeholders that the requirement to interact with two systems (Social Security Scotland and the DWP) creates further complexity and additional barriers to take-up among some groups. In evidence given to the Scottish Parliament's former Social Security Committee in 2021, the Council for Ethnic Minority Voluntary Organisations Scotland noted the concern that 'people will lose out on benefit entitlements due to the increasingly confused welfare benefits landscape' created by the parallel reserved and devolved system.[60]

> "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 MS. Nothing is ever going to improve as it's a progressive illness. Having to fill in the lengthy paperwork is mentally challenging and difficult to do." – Quoted in MS Society Scotland response to the Independent Review of Adult Disability Payment Call for Evidence[61]

> "It was a very long and stressful process that I would not rush into again. I believe I should be entitled to a higher rate but the fear or having to go through it again has stopped me from applying for it." – MS Society Scotland, response to the Independent Review of Adult Disability Payment Call for Evidence[62]

A robust estimate of the eligible population for Adult Disability Payment cannot currently be made. This is because disability-related questions that are currently asked in surveys may not capture all of the eligibility criteria for disability benefits, and disability is self-reported in surveys which means perceptions of disability may vary person to person.

A further complication is that Social Security Scotland make person-centred decisions based on the specific circumstances of the application/review and detailed information provided. Therefore, it is not possible to match those identified as disabled through surveys with those determined to be eligible for disability benefits.

The Scottish Government has a take-up strategy which focuses on raising awareness of benefits and supporting access but does not currently focus on benefit-specific areas.[63]

Robustly estimating eligibility and take-up for disability-related benefits is a significant challenge.

Revised estimates for general take-up, produced by Scottish Government analysts, were published in November 2024[64] although there are no results for Adult Disability Payment.

It is not currently possible to estimate the take-up rate of Adult Disability Payment; this includes take-up estimates for Adult Disability Payment in seldom-heard groups.

Data on seldom-heard groups is not routinely collected by Social Security Scotland. Collecting this data would only provide an indication of the numbers of people from seldom-heard backgrounds who have engaged with Social Security Scotland, rather than providing the size of the eligible population.

Understanding the eligibility for Adult Disability Payment amongst seldom-heard groups at a population level would be additionally challenging, as the population of those who were seldom heard would need to be calculated from the overall eligible population.

Maximising benefit take-up among seldom-heard and vulnerable people is central to the Scottish Government's take-up strategy.[65] A stated aim of the Scottish Government is to increase inclusivity within the benefits system. This inclusivity incorporates a commitment to engage with seldom-heard groups and people with protected characteristics.

To further improve benefit take-up, the Scottish Government commissioned the Scottish Centre for Social Research (ScotCen) in 2023 to better its understanding of those groups furthest removed from the social security system and the particular barriers they face in accessing entitlements.[66] The insights highlighted align with Scottish Government understanding of barriers and enablers to take-up, as reflected in the current Benefit Take-Up Strategy and Benefit Take-Up Principles.[67]

In addition, there was one evidence review, commissioned in 2023, conducted by ScotCen and published in May 2024, and one follow-on market research piece conducted by Social Security Scotland (to inform communications and marketing approaches), that were not published.

The Scottish Government, together with Social Security Scotland, is currently focused on responding to the research recommendations contained in the Seldom Heard Groups Evidence Review.[68] This also includes responding to the recommendations from separate activity conducted in Spring 2024, via a Citizens Panel, to understand the impacts of stigma on benefit take-up.[69]

The findings from the research will support the Scottish Government in the implementation of its Benefit Take-up Strategy by providing information that will help develop new approaches to support people to access social security benefits. Social Security Scotland commissioned further research with a range of seldom-heard groups (including Gypsy Travellers, recently released prisoners, care experienced people and ethnic minority community members) to explore barriers, communication needs and effective messaging with the findings informing communication and engagement approaches.

Throughout the 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 this was also highlighted in the ScotCen research commissioned by the Scottish Government. While they cite Social Security Scotland's client equality and diversity data release for June 2021 - March 2023, which would suggest Adult Disability Payment uptake for BME communities is lower than average, that data is complicated by the transfer of the payment from the DWP to Social Security Scotland during that period.

> "Unfortunately, there is a significant lack of information on the experiences of Black minority ethnic (BME) people who are applying for [Adult Disability Payment], as well as on BME people with disabilities in Scotland and their access to benefits. We continue to highlight the issues with evidence in Scotland and advocate for better data collection by ethnicity, higher standards for public sector data, and proactive plans to fill these gaps in data and evidence. The lack of data severely limits the ability to implement effective policy and accurately evaluate its impact." – Coalition for Racial Equality, response to the Independent Review of Adult Disability Payment Call for Evidence[70]

There may be specific reasons why applications from people who identify as belonging to a minority community appear to be less successful in terms of receiving an award. Whilst these could stem from take-up barriers, I recognise the need for caution in equating refusal rates with take-up, because it is not currently possible to estimate take-up rates for disability benefits or for specific client groups.

> "Those in seldom-heard groups have likely overcome many barriers in their lives already, so it is unlikely to be one particular barrier that prevents them from applying, but 'barrier exhaustion'. They may have found it difficult to get information about benefits in the past; not known how to apply; needed support to apply but none was available; felt embarrassed or stigmatised; and are additionally already dealing with so much that they just don't have the energy to fight for something they are entitled to." – Age Scotland, response to the Independent Review of Adult Disability Payment Call for Evidence[71]

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 importance of this approach is reflected in government supported guidelines such as the roadmap launched by the National Trauma Transformation Programme in 2023.[72]

During the Review people described experiences during their Adult Disability Payment journey that did not align with 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[73]

> "When you are emotionally drained from what's happening, filling out a booklet wanting to know how poorly your child is, it just adds to the emotional trauma you feel as a parent." – Individual, The Cost of Waiting Report[74]

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 set expectations for engaging with any official body. It is no exaggeration to say that for some people an appointment could re-traumatise them or cause trauma or Post-Traumatic Stress Disorder (PTSD) symptoms.

> "Now I think the PTSD [post-traumatic stress disorder] is quite important, because I feel traumatised as a person going through what I go through every month and gone through it for so many years as well." – Individual, quoted in Premenstrual Dysphoric Disorder and the welfare state: Recommendations for reform[75]

For Social Security Scotland, this clearly has implications for how it delivers its services and trains case managers and practitioners[76].

> **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.

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 complement each other and are 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,[77] 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.

In Australia, the National Disability Insurance Agency works formally in partnership with other government services that provide support to disabled people such as health, social care, education, justice and transport.[78]

All areas work together so disabled people receive support to meet their individual needs. Access to mainstream services, community-based activities and other statutory services is a shared responsibility with the Agency and governments work together to resolve any issues where their services interact. Local area coordinators support communities and multiple levels of government to create a more inclusive society and deliver improved outcomes for all people with a disability. A person can ask their local area coordinator about the support available in the local community, even if they are not eligible for the Australian equivalent of Adult Disability Payment. Local area coordinators have strong connections in the community and can help connect with supports in a local area including community groups, recreational activities such as sporting clubs, performing arts groups and other social networks.[79] The local area coordinator can also help a person to understand how a social security payment works with other government services and can connect to statutory agencies like education, health and transport.

Although it is unrealistic to replicate the Australian model in Scotland – indeed there are aspects of the model that I wouldn't recommend, there are some aspects of it that, if introduced, would significantly enhance the quality of life of disabled people in Scotland and address some of the recurring themes concerning access and eligibility for complementary services.

There is an established model in Scotland for people with a learning disability. One example of this is ENABLE's local area coordination (LAC) service[80] which aims to support every person who has a learning disability, as well as their families and carers - wherever and however they are needed.

LAC is a globally recognised approach to supporting people of all ages in local communities, and their families, in pursuit of their vision of a good life. LAC aims to be there for everyone regardless of their circumstances. You don't need a budget or a referral to access this service.

Coordinators do different things depending on what people want. Coordinators might:

- work with individuals, families and communities to make local activities and services more inclusive
- work with people who want them in their lives, go at a pace that suits them and stay involved for as long as they want their support
- focus on what people can do, rather than what they can't do – empowering them to live the life they choose.

Scotland has an established network of Third Sector Interfaces (TSIs). The TSIs are part of a wider network called TSI Scotland Network which is made up of 32 partnerships and 'single door' TSIs who work across communities of Scotland to support the third sector on the ground. Together they aim to support Scottish Government and influence critical thinking and future policy development for the third sector including charities, development trusts, community and voluntary groups, social enterprises and volunteering. Although the TSIs themselves do not provide a 'one-stop shop' type service they will have members in each local authority area who provide services, advice and other forms of support to disabled people.

Research undertaken by the Scottish Government[81] exploring barriers to collaborations between third sector, local government, and national government. found that although TSIs have the potential to strengthen third sector capability and capacity, there were challenges which included:

- the short-term funding model acted as a barrier against collaborative working as did the general reduction in funding
- funding that is received by third sector organisations and local government is often inflexible, rigidly structured, and/or ring-fenced; this poses challenges for organisations to respond flexibly to meet the needs of service users
- third sector organisations, which felt that public sector-funded organisations did not trust them, which had an impact on funding for specified projects.

ALISS,[82] ‘a local information service for Scotland’, created by The ALLIANCE is a website that can be used to find services, groups and activities for health and wellbeing across Scotland. ALISS contains information on more than 5,000 services from almost 3,000 organisations across Scotland.

The information is determined by postcode so it provides a comprehensive local hub of knowledge, services and support and can be accessed by disabled people and their families. A person can find food banks, addiction services, mental health support services, youth groups, money advice, social security advice, employability support and much more.

Getting it right for everyone (GIRFE) is a Scottish multi-agency approach to health, social work, and social care support and services from young adulthood to end of life care. GIRFE intends to shape the design and delivery of health and social care services, ensuring that people’s needs are met. It is about providing a more personalised way to access help and support when it is needed. The ambition of GIRFE is to place the person at the centre of all the decision-making that affects them, with a joined-up consistent approach regardless of the support needed at any stage of life.[83]

During the GIRFE co-design process, people with lived experience expressed their sense that they often felt overwhelmed with the number of different people involved in their care and the number of different uncoordinated appointments that they were required to attend. People found the health and social care system very complex to navigate and it was often difficult to understand what services were available to them and how to access them. As a result, the pathfinder and partner teams co-designed the ‘co-ordinator’ role, which aims to provide people with a single point of contact from their multi-disciplinary team, who will provide a co-ordination role to ensure that their health and social care needs are understood and met.[84] I appreciate that the focus for GIRFE is to assist people to navigate the health and social care system; however, the intent behind the co-ordinator role is similar to that of the local co-ordination role in the Australian insurance system, and as it is already being promoted in Scotland, it may be worthy of further consideration in relation to social security and joining up services for disabled people.

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

Accessing support to make an application appears to be a vital and effective way of improving benefit take-up among seldom-heard groups. However, a lack of knowledge of where to go for support can present a barrier to applying.[85]

I heard from stakeholders that many disabled people recognise brands such as Citizens Advice Bureaux because they are well-established and perceived to be independent and they choose to seek advice from them rather than the Local Delivery service. In addition, people who are already part of a community where advice and support are provided often feel that their needs are better met there. It is important to note, however, that the remit of the Local Delivery service is to provide pre-application support, rather than advice to clients.

> "When a benefit check with one of our Social Welfare Specialists identifies an individual is eligible to claim ADP, we have a 100% take up record of them going on to make a claim - with the guidance and support of one of our specialists. After completing and submitting the ADP application form, nearly every person has reported they would not have been able to cope with their claim without our expert help and support. In our experience, contact with our service and subsequent discussion about possible entitlement then provides the person with confidence and assurance that a claim is justified and appropriate. Without this, the claim might not be made at all. This is because we have expert awareness of how their condition affects people and how this dovetails with ADP entitlement." – Multiple System Atrophy Trust response to the Independent Review of Adult Disability Payment Call for Evidence[86]

Responses to the consultation highlighted that there is a notable lack of awareness about the support available pre-application, such as the Independent Advocacy Service provided by VoiceAbility, and what is available via Local Delivery teams. In a recent Social Security Scotland Client Panels survey, the majority of respondents (57%) had not heard of the Local Delivery service.[87] Where people are aware, there is a level of suspicion about independence and a lack of clarity over what precisely the services offer. Some other stakeholders have expressed concerns about the potential for actual or perceived conflict of interest inherent in benefit application support being delivered by the same agency that will determine eligibility. This concern is especially acute in the context of re-determination requests.

Consultation respondents who used the Local Delivery Service reported a positive experience with their adviser and appreciated that the meeting could be held in a preferred location.

Similarly, those who had used the Independent Advocacy Service felt that they had been fairly treated. A few consultation respondents mentioned long wait times and trouble accessing these services as barriers to uptake.

> “The local delivery team were described as helpful in mitigating the distress caused by completing the ADP application, particularly where the applicant has a history of trauma. For example, link worker staff stated that people that use our services had told them that the volume and detail of information required in an application for ADP can be triggering, especially those who are writing down the symptoms they experience as a result of trauma. One person we support felt unable to have the physical copy of their evidence and application form within their house as seeing their experience in written form was triggering for them. This has been mitigated with support from the local delivery service, as the service can visit applicants and take evidence for the application orally.” – SAMH response to the Independent Review of Adult Disability Payment Call for Evidence[88]

The parts of Social Security Scotland’s pre-application services that are working well include some respondents emphasising that Social Security Scotland staff were helpful when they called with questions. The Minority Ethnic Carers of People Project (MECOPP) and Citizens Advice Scotland emphasised that home visits are a very useful aspect of the services provided, and Feniks and Age Scotland noted the success of the language support and interpretation services offered by VoiceAbility and Social Security Scotland respectively.

Some clients reported that when they are being supported by a third party, they can feel like a burden on the person supporting them due to the long wait times for the third party to get through to speak to someone at Social Security Scotland about their case. One Parent Families Scotland and SAMH have both heard from key stakeholders that timely access to the Local Delivery service could be difficult, although they noted that experiences varied across the country.

Respondents also gave suggestions on what else could improve the service including:

- improved communication
- reduced waiting times on the phone lines
- more information prior to the appointment with the adviser
- more clarity over next steps after the appointment
- more choice around the location, timing and length of appointments.

While generally happy with their experience with the Local Delivery service, a few respondents to the consultation highlighted that because their Adult Disability Payment application was very long, they required multiple appointments with the service. Some people felt that improved staff training is required, particularly to address a lack of awareness of certain conditions and the impacts they have on daily living.[89]

I have received generally positive feedback about the support people have received from the Local Delivery team, to help them complete the application form. One person told me that the support they received was invaluable as:

> "they teased out aspects of how my condition impacts on my ability to do things that I would have never considered" – Individual, MS Society Scotland response to the Independent Review of Adult Disability Payment Call for Evidence[90]

Another person explained how the support they were given helped:

> "it was like they were translating what I said into language that would make it easier to get an award, I am not sure I would have been able to explain my condition as clearly without this support." Individual, MS Society Scotland response to the Independent Review of Adult Disability Payment Call for Evidence[91]

However, when compared to a more holistic welfare advice service, although the service is appreciated by those who use it, Local Delivery is still perceived as limited. 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.

In the three years from its launch in January 2022 until the end of 2024, the Independent Advocacy Service provided by VoiceAbility has received 11,385 referrals, leading to over 9,878 advocacy cases and supported 8,704 people in Scotland, of whom 7,884 were people going through the Adult Disability Payment process.[92] The results of the VoiceAbility client survey for the period July 2023-April 2024 show that the vast majority of people who used the service were satisfied with the support they received with 90% rating their overall experience as 'very good'.[93]

One response to the call for evidence suggested than an automatic referral 'opt-out' provision be built into the system going forward.[94] The respondent believed that there are several advantages to this model in relation to streamlining service delivery, better client experience, increasing uptake, and building up robust data to support service modelling. The client keeps the right to opt out of the advocacy service at any time, but it means that the client isn't required to go through their own self-referral process, nor do they have to rely on others being aware of the service to refer them.

I spent a day shadowing an Independent Advocacy Service advocate in Aberdeen. It is evident from the conversations I had with some local community members, and the team at the Tillydrone Community Flat, how valued the service is. The advocate I met can provide support to people whose first language is not English, and this part of the service was particularly welcomed. The team at the community flat really welcomed an advocate being based a few days a week on their premises. The fact that people can just drop in for a chat and that there is no rigid appointment system as there is with the Local Delivery service, was also seen as a positive.

> "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[95]

However, I do note that the Service Standards for the Independent Advocacy Service[96] (as required under the Social Security (Scotland) Act 2018)[97] state that advocacy and advice must be provided separately. The Independent Advocacy Service therefore cannot provide advice. The Scottish Government's position is that it developed the current Service Standards with input from organisations delivering advocacy.

I enquired about the training and development available to advocates and although there is obviously very thorough and comprehensive training (including accreditation) in relation to being an advocate, I was surprised that in this case, there wasn't more training available in relation to Social Security Scotland processes, and training relating to specific benefits such as Adult Disability Payment. It may be that because of the importance of the independence of the advocacy service it is felt that this would not be appropriate. Social Security Scotland has confirmed that it does provide introductory e-learning materials about the benefits it delivers, including Adult Disability Payment. It has also fed into the development of the original learning and development materials used by the Independent Advocacy Service.

The most recent Social Security Scotland Client Survey showed that almost half of respondents (46%) received help to complete their Adult Disability Payment application with one-in-four (26%) of those who received help with their application getting help from a friend or family member and around one-in-five (18%) getting help from Social Security Scotland. 45% received help from welfare benefits advisers, housing support workers, money advice organisations and other welfare rights services.[98]

I heard anecdotally from some of the welfare advice organisations who have been involved in the Review that the success rate is higher when a person has received independent advice and support to fill in the application form, although I have no evidence to support this theory. Increasingly, support to apply is lacking and there is evidence that reduction, fragmentation and withdrawal of services providing support with benefit applications are creating significant barriers to improve take-up especially among seldom-head communities.[99]

A report by Get Heard Scotland Citizens Panel published in 2024[100] found that many panel members identified that having support and encouragement was a turning point in feeling able to apply for their entitlements, for example from a healthcare professional or welfare rights advisor. This was important for people to demystify the system, understand their rights and entitlements, and how to go about applying for them, often at times of trauma and crisis.

> “If we are saying access to benefits is a human right - we need to know what those rights are. If we don't know, we can’t use them and hold government to account.” – Participant, quoted in the Get Heard report[101]

I met many welfare benefits advisers and support workers from third sector organisations who collectively support thousands of people to apply for Adult Disability Payment in any given year. In most cases there is no statutory funding provided to organisations to provide this service with most charities relying on fundraising income. The Scottish Government’s approach to the funding of advice services is stated as ‘intending to maximise household incomes, tackle problem debt and reduce poverty’.[102]

Most government funding is allocated via grants to third sector organisations which have a national reach. However, they also invest funding in initiatives that target priority groups or that explore innovative approaches which may support the advice sector as a whole and those that work within it. The Scottish Government invested over £4.6 million to specifically support the delivery of welfare advice and income maximisation services in 2024-25.[103]

For most independent welfare advice services, the funding is a mixture of debt advice levy and Scottish Government resource funding. The debt levy represents a significant proportion of the overall advice services budget with the remaining proportion coming mainly from Scottish Government resource budgets. As the debt advice levy is restricted in its’ use, i.e., for debt advice services only, the Scottish Government supplements the levy with resource funding, in order to fund wider, holistic income maximisation and welfare advice alongside debt advice provision.

This is in addition to the support made available to fund Local Delivery and the Independent Advocacy Service and the continuation in some areas of Welfare Advice and Health Partnerships. The Welfare Advice and Health Partnerships pilot ran in urban areas from 2021 to March 2024 following provision of additional continuity funding, and in remote/rural areas between 2022 and 2025.[104]

It is clear that advice and support has proven invaluable to those that have had access to it, however, more needs to be done to promote benefits advice, the Independent Advocacy Service and Local Delivery service so that more people can access the right level of support in a timely manner. If help is not accessible to everyone then there is a chance that a two-tier application process may develop, with the risk that people who apply without support are not receiving the level of award they would qualify for if they were given more advice and guidance.

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.

Processes That Work

The Charter

Adult Disability Payment is delivered by an Executive Agency of the Scottish Government, Social Security Scotland that has been created with the explicit objective of treating disabled people with dignity, fairness and respect, guided by a Charter against which the public can measure its performance.

The original Social Security Charter[105] was created and approved in 2019 and sets out the service that people should expect from the whole social security system in Scotland. The Charter, developed through extensive consultation with users of the system and other disabled people, articulates commitments aligned to the principles, delivering high-quality services, and involving people in the design, development, and delivery of social security policies and services. It is a document of legal status that both empowers individuals and holds the Scottish Government and Social Security Scotland accountable for their actions. The Charter plays a crucial role in implementing the values enshrined in the Act, ensuring that the social security system in Scotland not only meets legislative requirements but also aligns with the principles of fairness, dignity, social justice and human rights. The Charter also plays a crucial role in guiding this Independent Review.

The revised Charter was unanimously approved by Parliament on 26 June 2024, and the Scottish Government continues to work with Social Security Scotland to implement the revisions – an updated Charter Measurement Framework[106] was published on 12 November 2024.

In the revised Charter there are several new outcomes related to the question 'do processes work'?

- clients are supported when they make an application
- clients are kept updated and given information about what will happen and why
- clients receive clear and accurate decisions and receive the right amount, on time
- clients feel able to challenge decisions and are supported to do so.

There is evidence that this commitment is inspiring hope of meaningful culture change in Social Security Scotland among disabled people and disability support organisations.[107][108]

The Social Security Scotland Client Survey 2023-24[109] results show that three-quarters (75%) of respondents with experience of applying for Adult Disability Payment (n = 11,808) rated their overall experience with Social Security Scotland as very good or good, while only 8% described their experience as poor/very poor. Also, the majority of respondents with experience of applying for Adult Disability Payment believed that they had been treated with dignity (76%), fairness (70%) and respect (76%). Written comments left by respondents also highlighted the humanising treatment they received from staff, as well as Social Security Scotland processes.

I often heard the word 'kindness' and that people felt listened to and valued and in most cases the experiences shared with me were in a sharp contrast to experiences with the DWP.

The less than positive issues raised by disabled people and stakeholders relate not to their overall experience, which as noted above is generally good, but rather to their frustrations with some of the processes adopted by Social Security Scotland namely 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.

Eligibility checker

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

The Independent Review sought views on whether a more detailed eligibility checker should be introduced to ask questions about a person's daily living and mobility needs to help them know, before applying if they are likely to be eligible for Adult Disability Payment or not. This was proposed as a potential way of addressing the stress and anxiety associated with the length of the application form, the time it takes to make an application and the waiting time for a decision to be made, particularly by people who go through all this and then find that they are 'not eligible' when receiving their determination letter.

These were the key findings:

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

Some of the advantages of such an approach included:

- it would help people understand if they qualify
- it would help to reduce stress and anxiety
- it would ensure the application is worthwhile
- it would save time and effort if people do not meet the criteria.

Some of the disadvantages were expressed as technical problems which could result in an incorrect result, putting people off applying. It was felt by some people that introducing something like this at this stage could cause confusion and most respondents said they thought the current approach is preferable.

Therefore although 45% of consultation respondents thought it would be helpful to have a more detailed eligibility check before filling in the application form, for the reasons set out above I am not recommending this as an action. It may be something worth keeping under review.

Application

Pain points across four key areas in the application journey include:

- eligibility criteria
- uploading supporting information
- answering functional questions
- technical issues with the on-line form.

The length and complexity of the application form, coupled with difficulties in the online application process, including setting up an account, present significant barriers.

There is evidence that the simplification of benefit application processes would improve take-up of benefits[110]. The introduction of automatic enrolment for Scotland's Five Family Payments is an example of a streamlined application process that is likely to positively impact benefit take-up among families. Following the introduction of automated payments for Best Start Grant School Age Payment, the estimated take-up rate of the payment increased by 20 percentage points.[111] [112] [113] Offering a range of application modes may also improve take-up.[114] [115] [116] [117]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.[118] However, digital exclusion in particular among some seldom-heard groups, means it is important that there continues to be provision of a range of application methods.

Disability benefit applications are experienced as particularly burdensome by people with terminal illness, mental health problems, fluctuating or less visible conditions, and learning disabilities/difficulties.[119] [120] [121] [122] [123] However, people who are terminally ill do not need to complete the application form and the process for applying is more streamlined. Therefore, a distinction should be made in understanding the lived experience of people who are terminally ill applying for Adult Disability under SRTI, and people with mental health problems, fluctuating or less visible conditions, and learning difficulties/disabilities who are not applying via the SRTI route. A survey conducted by the National Autism Society found that people with autism frequently experienced severe challenges when applying for benefits.[124]

For people with energy impairment, chronic fatigue and/or neurological dysfunction, the process is extraordinarily stressful and draining. Completing a lengthy form, providing supporting information (including from professionals who often do not understand their conditions), uploading it when current systems are very cumbersome and time-consuming, waiting on the phone and long phone calls add to stress and exhaustion. There is a genuine risk that the demands of applying for a much-needed benefit cause a deterioration in health.[125]

Research undertaken by Young Lives vs Cancer[126] shows that just one-in-three young people with cancer and their families (35%) report being satisfied with the application forms in place throughout the disability benefits process. Many find the forms incredibly complicated. One parent/carer in Scotland commented:

> “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 vs Cancer[127]

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.

However, I also heard in my engagements some negative experiences:

- access to the internet is not universal, especially with the current cost of living crisis
- people continue to have issues with log-in and passwords
- some people with certain conditions, for example hearing impairment or those using assistive technology, find it difficult to access mygov.scot online systems and complete online forms
- once submitted the application form cannot be edited
- document upload is causing issues and delays
- when uploading supporting information online, there is not enough file space to upload multiple documents
- it was highlighted by the Royal National Institute of Blind People (RNIB) that the colour contrast on the form is poor for people with severe visual impairments

- people with low levels of literacy or people whose first language is not English find the language used in the application form particularly difficult to understand
- it is difficult to get an overview of the entire application form online, making it challenging for applicants to see which sections have been completed, what questions are coming up and the answers they have already provided.

Other reasons given by some consultation respondents for difficulty understanding the application form included:

- questions being vague, contradictory or unclear
- being unable to understand the rules generally
- questions being too similar or repetitive and can be easily misinterpreted, especially terms such as ‘sometimes’ and ‘always’ which can lead to confusion
- the questions seeming to be binary in some cases and people sometimes feel that they cannot answer a straight ‘yes’ or ‘no’ to a question
- the thinking behind questions not being given, so unsure how to answer
- that it is unclear what ‘reliably and repeatedly’ mean in practice
- that illustrative examples were needed.

> “The questions are very repetitive, and I sometimes feel that they are this way to try and catch a person out, because you can ask two different questions, but they amount to the same answer. This confuses me.” – Individual response to The Independent Review of Adult Disability Payment Public Consultation[128]

Clarifying the language used in questions and enabling people to put into their own words, the impact of living with their condition, by adding more free text boxes would allow for a better understanding of their lived experience.

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, PTSD-related cognitive impairment, and dyslexia, were all specifically cited as having powerful reactions. However, evidence was also present of a more generalised response by applicants of feeling overwhelmed.[129]

In a meeting with the Young Lives vs Cancer charity, I was told how their service users have repeatedly underlined the complexity of the application form as a key reason for them seeking help when applying for financial assistance. Many families also found it difficult to manage both cancer treatment and the application process at the same time.

The length of the form has been raised repeatedly 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.

One benefit adviser told me that it can sometimes take two separate three-hour long appointments with a client to complete the form. When I personally shadowed a Local Delivery adviser the appointment lasted almost three hours, and I was told this is typical.

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.

The most prevalent related theme following the online consultation and call for evidence was confusion over the fluctuating conditions section 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 section was 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.

Feedback from the MS Society included comments such as:

> "There wasn't space on the form for me to explain how my condition changes day to day." – Individual, MS Society Scotland response to the Independent Review of Adult Disability Payment Call for Evidence [130]

The strengths of the form, such as the value of free text questions and space for elaboration at the end, the straightforward layout and sensible grouping of questions were noted at a few of the consultation events.

> "Provide a section to enable a free text/narrative to allow the applicant to describe how their disability affects them from a very personal perspective. We are all individual, how a person's disability affects one differs to another. Therefore; a section where the applicant can present their disability in their own words can be empowering." – Client Survey – Child Disability Payment and Adult Disability Payment January – March 2023[131]

Improvements to the application form were suggested including:

- more open questions and space for free text responses throughout
- multiple choice questions for those who struggle with handwriting
- improvements to colour contrasts on the paper version to increase accessibility for those with visual impairments

- reviewing the use of language through a neurodiversity lens to support understanding of the questions
- providing different versions of the form, for instance a condensed version without photos (specifically for support organisations) so that it is easier to navigate
- less high-quality paper and binding to make 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.

The Scottish Government and Social Security Scotland have attempted to address some aspects of the online application form, including:

- resolving some of the difficulties some people have expressed with uploading attachments
- introducing the ability for clients to download a copy of their submitted application
- ensuring clients receive confirmation that their online application has been received
- providing an estimated processing time when an application is submitted
- signposting clients and representatives to existing guidance about the type and level of information to include with their Adult Disability Payment application
- continuing to review the guidance
- continuing to review the application form to ensure the questions are relevant for all clients and to minimise any repetition
- improving awareness about the fact that clients will not have to complete the full application again when their award is due for review.

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

Processing times were a recurring theme with many disabled people describing the stress and anxiety associated with waiting to hear the outcome of their application alongside the fact that this stress and anxiety could exacerbate people’s existing health conditions or disability.

Feedback from the online consultation and call for evidence included:

- 29% had received a decision within three months
- 42% waited between three and six months
- 30% waited more than six months
- 43% were not satisfied at all with wait times[132].

Recent research from Young Lives vs Cancer cited that for those applying for Child Disability Payment and Adult Disability Payment, the average time from diagnosis to decision was six months[133] [134] which resulted in their social 'workers referring several households to food banks, in addition to providing the maximum amount of grants we can'.

> "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[135]

Social Security Scotland commissioned a programme of work in 2023 to review end-to-end processes for disability benefits, with a view to understanding how transformation and automation could release capacity and reduce the time it takes to make decisions on applications.

Social Security Scotland states it has been working towards reducing processing times for making decisions. The median average processing time from Part 2 of the application being received for non-SRTI applications has decreased from 42 days in January 2025 to 37 days in April 2025.[136]

While it is evident that a lot of work has been undertaken by Social Security Scotland 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 that could be improved further.

> "It has taken 9 months for the assessment to be completed, and decision given." - Individual, MS Society Scotland, response to the Independent Review of Adult Disability Payment Call for Evidence[137]

> "Waiting to hear about my application will take at least 6 months for a decision. It is impacting my mental health, and I am worried about keeping my mobility car." - Individual, MS Society Scotland, response to the Independent Review of Adult Disability Payment Call for Evidence[138]

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.

> "I regularly went on to the online chat to see if there had been any progress. But if I hadn't instigated this, and I am quite IT literate, I wouldn't have been given any information about my application." – Individual, MS Society Scotland, response to the Independent Review of Adult Disability Payment Call for Evidence[139]

Another person with a similar experience told me that they had ‘chased a lot’ but that the process could be improved if there was an automated system in place that informed people when their application has been received and when it had been allocated to a case manager for a decision. There was a suggestion that extending opening times (telephone and webchat) would assist many applicants as currently the opening hours clash with people's work or caring commitments.

Almost half (47%) of respondents to the Social Security Scotland Client Survey 2023-24[140] said they received enough updates on the progress of their application for a Social Security Scotland benefit. This proportion was smaller for recipients of Adult Disability Payment (36%). Within written comments, some respondents suggested that more updates were needed between application and decision. Some expressed that this would ease anxiety during the application processing time.[141]

The Social Security Scotland Business Plan 2024-2025[142] states:

> “We know that our clients want to hear updates from us about their applications. Improving how we communicate with people applying for Scottish benefits will improve their experience while making us more efficient. We have introduced new application progress updates by text or email for Child Disability Payment and Adult Disability Payment clients. Next, we will develop and deliver a new online portal making it easier for clients to apply for Adult Disability Payment.”

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

It was felt by many stakeholders 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 the fact that there were more barriers to obtaining consent to act on behalf of a third party with Social Security Scotland than they had experienced under the DWP system. One Parent Families Scotland and one anonymous organisation emphasised the importance of providing implicit consent to advocacy organisations, in the same way as it is used for PIP.

Some people stressed that the way that Social Security Scotland required consent to be given was a challenge and potentially discriminatory given their communication needs, despite Social Security Scotland having a process called 'unavailable consent' which operates in a similar manner to implicit consent. Interview participants in recent SCoSS research[143] with people with communication needs, highlighted their concerns about waiting for, getting and using a 'mandate' (a form authorising third party representatives to have discussions with Social Security Scotland directly). Such delays could result in welfare rights advisers using the complaints process as a way to obtain a mandate, though this could further delay the process.

However, Social Security Scotland has explained that a mandate does not have to be a Social Security Scotland mandate for it to be accepted. Social Security Scotland can accept a letter from the client; authorisation on the application form; verbal authorisation from the client; and an organisation's own mandate.[144]

Several welfare rights officers told me that they are frequently contacted by clients because the client has not received a decision. Clients are anxious that something may have gone wrong and are looking for welfare rights workers to intervene to confirm all is in order and to speed up the decision.

The current absence of a dedicated helpline following the granting of consent to a third party, is suggested to have resulted in delays in supporting individuals to provide Social Security Scotland with necessary information, which in turn delays the overall decision-making process. This was raised several times during our engagement sessions, as obviously timely communication is vital for the smooth functioning of the application and decision-making process.

> "We experience long delays getting through on the phone and are not always able to do so while in the presence of the service user." – Glasgow City Council, response to the Independent Review of Adult Disability Payment Call for Evidence[145]

Since the publication of my interim report Social Security Scotland has begun to pilot an escalation process for third party representative organisations. The pilot was set up initially with Glasgow City Council for vulnerable Adult Disability Payment clients who were experiencing issues with the service. The pilot has now been extended to cover all Social Security Scotland benefits. Eleven organisations are 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

Providing 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 factor in the initial decision-making process.

In the most recent Disability Payments Client Survey[146] most respondents who applied for Adult Disability Payment provided supporting information with their application (67%), whilst 25% asked Social Security Scotland to gather it on their behalf. The remaining 9% submitted evidence after they were contacted by Social Security Scotland. The most common forms of supporting information provided were: 'confirmation of diagnosis' (44%) 'medical or social work reports' (33%), and 'test results' (17%). Respondents most often got their supporting information from: 'a GP' (44%), 'a hospital (including from doctors, consultants or nurses)' (16%), and 'a family member' (14%).

When shadowing case managers and experiencing first-hand how they reach a decision about an award I saw many examples of the supporting information provided directly by an applicant and the supporting information requested by the case manager usually from a GP or other professional whose contact details had been noted on the application form. The quality and the content of the supporting information varies widely and in one example I saw supporting information from a GP that contained very little information and, in this case, none of it was helpful in assisting the case manager to make a decision.

In my interim report, I recommended that Social Security Scotland consider ways of working with GPs and other medical professionals in order to promote better longer-term health outcomes for clients. Social Security Scotland said in response:

> "Social Security Scotland recognises the importance of this action, and that more evidence and research is required to demonstrate the relationship between receipt of award and long-term health outcomes.

> Social Security Scotland is developing a communications plan to improve engagement with Health Boards and practice managers and would be supportive of participating in any research aimed at demonstrating the impact of awards on longer-term health outcomes for clients."

In its response to my interim report, Social Security Scotland said of the guidance for GPs in relation to supporting information:

> "The Scottish Government and Social Security Scotland recognise the importance of clear guidance for GPs. Further assessment will be required to determine feasibility of delivery against current commitments; however Social Security Scotland has established regular engagement sessions with Health Boards to provide support and guidance to improve the timeliness and usefulness of the information provided. These sessions are used to gather feedback and inform updates to guidance."

One young person with cancer applying through the SRTI route expressed concern over how supporting information held up the granting of their award when Social Security Scotland repeatedly tried to contact their GP for details, despite the contact information for other specialists being on the application form.[147] In addition, I have been told of difficulties in obtaining supporting information from medical practitioners by people who are clinically vulnerable. People in these situations often avoid engaging with professionals due to the perceived clinical risk.

Social Security Scotland has refined its approach to gathering supporting information by recognising a GP is not always the best source of information on how disability impacts clients and, for example, may instead look to contact other professionals involved with the client. Social Security Scotland has also changed its guidance in relation to contacting GPs for supporting information. It was felt that the previous approach of asking specific questions relating to the client's application was too onerous and time-consuming a task for many GPs. So, a new approach has been introduced where universal, basic information is requested, by asking GPs to 'confirm the client's conditions or disability, if they do not have a diagnosis, please confirm their needs or symptoms, and tell us 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 documents 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 person's treatment or care. Stressing that supporting information from a wider support network can be a useful tool to help decision makers understand their needs better, is recognised as a positive step forward.

> "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 PMDD and how it impacts me." – Individual with PMDD

When applicants say on the application form that they need help in accessing supporting information several factors are considered by a case manager in terms of next steps. In a recent case that I observed the case manager tried to contact the client directly using the telephone number provided but was unable to reach them. On the application form the person had articulated problems with anxiety and depression and the case manager was concerned that an approach from the Local Delivery team to offer assistance may not be the best course of action. The case manager had approached the person's GP and received limited information. A case discussion, with the input of a Health and Social Care Practitioner was requested in order to assist with the decision-making in the absence of adequate supporting information being available.

Since the publication of the evaluation of supporting information[148] in addition to the steps taken as outlined above the application form has been reviewed to improve structure and layout of the guidance in the downloadable Portable Document Format (PDF) and physical application form i.e. the hints/helpful information provided in the margins of the form. This focuses on giving better examples of supporting information and what it should contain.

Core messages within public facing communications have been reviewed, updated and strengthened including fact sheets, social media posts, articles, leaflets to specific organisations, stakeholder engagement events, and media enquiries to, where possible stress the following key messages:

- the requirement of one piece of supporting information from a professional, where possible, and what this should include (broadly confirming condition/needs, and should stress that it does not have to include a medical diagnosis)
- that Social Security Scotland can gather the information on behalf of the client but that this can lead to longer processing times
- if they do not have supporting information to hand, they should still apply
- improving the list of who supporting information can come from
- signposting individuals to relevant support i.e. Phone lines and Local Delivery if they need further information/help applying.

Since the evaluation of supporting information was published there have been two other major internal initiatives within Social Security Scotland aimed at improving staff knowledge of both supporting information and its relevance to decision making. Both pieces of work were completed following internal user research to understand where case managers and practitioners are most likely to need support and to identify where implementation of the decision-making policy could be improved.

Some key messages were reinforced including:

- the importance of the approach to social security being trust-based and person-centred
- ensuring case managers understand the principle of equal consideration and what this means in practice i.e. That there is not an intrinsic hierarchy of supporting information and that each piece should be considered on its own value rather than on what the source is
- how supporting information should and shouldn't be used i.e. A broad confirmation rather than confirming every aspect of the application/every condition listed
- the purpose of the different types of supporting information and what they are likely to be useful for
- when supporting information needs to be gathered and encouraging case managers to think critically about who the best person would be to get this information from, rather than defaulting to GPs
- stressing the importance of other decision-making tools, such as case discussion, or using guidance rather than relying on gathering supporting information Empowering case managers to make decisions on the balance of probabilities.

Social Security Scotland also held stakeholder events for key public sector providers of supporting information.

Improvements have also been made to the Decision-Making Guidance[149] on supporting information. Clearly 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.

Social Security Scotland do not currently hold any insights/information on whether the changes to the external guidance on supporting information for disability benefits introduced last year has had an impact on processing times. Anecdotally I was told that supporting information improvements have helped to improve processing timescales, although this alone is not the only reason. There are other contributing factors including case managers being more experienced; their confidence, capability and output levels have naturally increased as part of their development. The interaction with Health and Social Care Practitioners continues to flourish via increased case discussions at the earliest opportunity to support decision-making and improve timescales and there have been improvements to the service design of Adult Disability Payment including straight through processing which speeds up the application process.[150] Straight through processing allows the case management system to automatically process certain applications through to a decision without the need for client advisor intervention.

While conducting the Review, I was introduced to a method of measuring functional capacity called the FUNCAP55 Functional Capacity Questionnaire[151] which could be a useful tool for case managers if submitted as a piece of supporting information. It uses a self-scoring system across a range of daily activities and considers the impact that carrying out an activity has on carrying out further activities. FUNCAP27 is a patient-informed and validated questionnaire that uses 27 questions to measure Functional Capacity.

As I have noted, supporting information is outside of the scope of the review, but Social Security Scotland may benefit from considering the merits of a FunCap55 assessment being recognised as supporting information and if adopted train case managers and practitioners to understand it.

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

Decision-making at the first stage of the application and award process is probably the most important and critical element in a client's journey. The initial determination will always include a decision about whether or not the individual satisfies the eligibility rules and also what components of Adult Disability Payment (and at what rates) the individual is entitled to.

The Scottish Social Security Charter[152] 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.

From 21 March 2022 to 30 April 2025, there were 340,655 Part 1 applications and 278,780 Part 2 applications received.[153] There were 313,430 applications processed with a decision made by 30 April 2025, of which 47% were authorised, 49% were denied and 4% were withdrawn.

As of 30 April 2025, 171,875 reviews had been completed[154] of which 5,090 resulted in a decrease in award, 32,645 resulted in an increase in award and 134,140 resulted in no change in award.

In the consultation to support the work of the Independent Review I asked 'how effective do you think Social Security Scotland's decision-making process is with regards to understanding a person's daily living needs?' and received 72 responses to this question. There were mixed views amongst respondents to this question. While three-fifths (60%) felt the decision-making process is effective in understanding a person's daily living needs, 35% felt the process is 'somewhat effective', with 7% indicating they find it 'very effective'. Conversely, 17% found it 'not very effective' and 24% 'not at all effective'.[155]

The analysis of the qualitative responses is available online.[156] As part of the consultation, I also asked 'did you need support to understand the decision?':

I received 43 responses to this question. Reflecting levels of understanding, four-fifths (81%) of those who answered did not need support understanding the decision. However, one-in-ten (12%) did. A small percentage of respondents said, ‘don’t know’ (7%).

I spent time shadowing case managers and Health and Social Care Practitioners in addition to reading all the decision-making guidance and exploring the training available. It is evident that careful and thorough consideration has been given to the framework and context within which case managers make their initial decision. The importance placed on supporting information is evident as is the role played by the case discussion process, when and if a case manager deems it to be useful or necessary. Consultations also play an important role. I understand from engaging with Social Security Scotland that the number of consultations undertaken each year represents a small proportion of applications received (see the Consultations part of my report).

Case managers are trained to take a person-centred approach to decision-making by:

- considering how the individual’s condition affects them
- taking into account all of their circumstances
- listening to the individual
- treating them as an individual
- recognising that the individual understands their own life best
- 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.

Case managers must make findings of fact on the balance of probabilities. This means that a factual circumstance must be accepted as true if the information available shows that it is more likely than not that it occurred. The very process of applying the balance of probabilities involves the use of judgement and although case managers need to be able to explain why they have made a certain decision; this results in an additional degree of subjectivity and personal judgement being introduced to the process.

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. As one case manager told me:

> “Weighing different pieces of supporting information can prove subjective despite case managers always aiming to be objective in their decision making. If it can be demonstrated that sound judgement and rationale has been used to make a decision, it is rare that managerial team leaders will push back against this decision beyond asking the case manager to justify the rationale for making their decision.” – Case manager, Social Security Scotland

Some welfare rights advisers who, since the launch of Adult Disability Payment have amassed an ever-growing client base, stressed a lack of consistency in how Social Security Scotland made decisions but there was little evidence provided, to substantiate this. Welfare rights advisers from Citizens Advice Scotland told me that there is a greater level of unpredictability in the Adult Disability Payment process when compared to PIP. They are finding it difficult to clearly see rationale in some of the determination letters. Attendees at one of the consultation events discussed the issue of entirely different decisions being reached between application, re-determination and appeal stages.

> “The reasons for the decision are usually clear, however, they are also inconsistent. We are aware of decisions made with regard to some claimants with similar circumstances which can vary. With the inconsistent decision-making it leads to further additional workload through appeal processes.” – Epilepsy Scotland, response to the Independent Review of Adult Disability Payment Call for Evidence[157]

As part of the Review, I was taken through Social Security Scotland’s quality assurance process which appears to be very thorough and provides an ongoing learning opportunity for case managers and other staff. Although entitlement decisions are regularly and independently reviewed and analysed to determine where improvements to the decision-making process can be made, I saw or heard of examples where re-determination decisions varied considerably from the original case manager decision. This may be because of additional supporting or other information being made available or due to a different interpretation of the criteria, the second time around.

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

The first 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 where understanding could be improved.

Social Security Scotland has a thorough process for ensuring guidance is updated whenever there is a legislative change. The process demonstrates how multiple layers of Scottish Government sign-off are embedded to mitigate risk when any changes are being made.

> “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[158]

In the context of a system that allows ‘discretion’ it is likely that decision-making will continue, at times, to be inconsistent. The ongoing challenge for Social Security Scotland in this regard, is to continually assess how one can balance the need for fairness and equity with the discretion that is currently applied.

An interesting point was raised with me several times and it relates to an interpretation of the use of over-the-counter pain relief when case managers are making a decision. Determination letters cite the reason for not scoring a higher number of points is because the applicant is not on any prescribed pain relief. It appears that a case manager is determining that the pain cannot be as severe as articulated in the application. This is contrary to the Adult Disability Payment Decision-Making Guidance which explains reasons why a lack of particular medication, treatment or reliance on services is not necessarily an indication of the impact of a condition.[159] One welfare rights adviser told me that they know of a client who, just to satisfy Social Security Scotland, asked for a prescription for pain relief from their GP even though they had been managing their pain effectively with over-the-counter paracetamol. A similar argument being cited in the decision-making process relates to physiotherapy, where a case manager supposedly made a decision on the severity or otherwise of the person’s condition based on whether or not they were receiving physiotherapy. Similarly with some mental health problems where the absence of any medical intervention has been used as a reason not to give an award with no account taken of the fact that it can be extremely difficult to access NHS mental health support.

When shadowing an Independent Advocacy Service advocate, I saw a determination letter that stated that the decision not to award higher points for mobility was because the client had ‘cancelled a physiotherapy appointment’. The client was visibly distressed telling the advocate that there was good reason for cancelling the appointment and that subsequently they have been back to the physiotherapist for help. Interestingly there was reference in the re-determination letter to the ‘use of pads to manage irritable bowel syndrome (IBS)’. The client was adamant that they do not use pads and had never told Social Security Scotland that they do. They were concerned that their case had been mixed up with someone else’s and this might be why the case manager had reduced the number of points from those awarded in the original determination. The other consideration was that the author of the letter was making assumptions about people with IBS and potentially using 'cut and paste' instead of making an individualised decision.

Interestingly, at the same advocacy appointment the client suggested that correspondence from Social Security Scotland be dated on every page. The client was having trouble determining which pages referred to the original determination letter and which belonged with further communication, as all the correspondence was held loosely in a paper folder and had become muddled. At a time of stress this was an additional complication.

Other considerations include:

- the source of the supporting information adding weight to informing a case manager's decision
- under-reporting, which experienced case managers come to recognise
- applying the reliability criteria to ensure consistency in the decision-making approach
- case managers using practitioners as a sounding board to confirm their thinking ahead of making a decision noting that some case managers would feel less confident going against the advice of a practitioner
- stressing the importance of other decision-making tools, such as case discussion, rather than relying solely on gathering supporting information
- the value to some case managers of drawing on peer support
- the importance of explaining in the determination letter why a decision has been made but in such a way as to not discredit a person's experience.

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[160]

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.

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

> "It should clearly state can you reliably and repeatedly perform a task. It should ask can you undertake certain tasks. Simple 'yes' or 'no' or 'do you need assistance?' Ask how long it takes to walk a certain distance, undertake a task such as dressing, make a meal etc. Include things like being incontinent as you can't get to the toilet in time, not washing because it's too difficult, eating ready meals. How long does it take to put your shopping away? Can you hang your washing up or hoover? – 'How long does it take?' is a very good indication on general ability." – Individual response, to the Independent Review of Adult Disability Payment Consultation[161]

> "Reliability is a really important criterion for people with energy impairment conditions (ELCI), but it's problematic because the energy required to perform any of the activities draws upon the same limited supply of energy, and doing one activity means there is less energy for another activity. Reliability refers to someone who is so exhausted after preparing breakfast that they can't eat it, or they cannot prepare lunch too. Or someone with ELCI might be so exhausted after preparing breakfast that they can't get dressed or have a shower. The cumulative impact of activities needs to be recognised, and the need to take into account the full spectrum of activities (e.g. preparing food + washing + dressing). The impact should take into account a range of factors including fatigue as well as delayed fatigue (one symptom of post-exertion symptom exacerbation) as, with people with ME/CFS, the onset may be 48-72 hours or more later." – #ME Action Scotland response to the Independent Review of Adult Disability Payment Consultation[162]

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

One third (33%) felt the reliability criteria are easy to understand, just under half (45%) felt they were not, and one quarter (23%) were unsure. Those who felt they could be clarified recommended that a ‘reasonable time period’ be better defined and proposed using more examples to improve applicants’ understanding.

Participants at the consultation events shared similar views but also suggested other changes to enhance understanding of the reliability criteria. This included referencing the reliability criteria in or at the start of the Adult Disability Payment application form and explaining reliability on any initial communication.

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

- reference the reliability criteria on promotional material
- explain reliability in the initial letter to applicants and during any initial phone call with a Social Security Scotland advisor, to help people determine if they should apply
- explain at the start of the application form how the reliability criteria is being used to understand people’s condition and the impact it has
- restate the reliability criteria more often throughout the application form
- have boxes next to each activity to describe what is ‘reasonable’ to expect e.g. To not be in more pain
- change the wording to ‘reasonable’ to reflect that it is not always possible to be ‘reliable’ due to environmental factors such as the weather.

It appears that one way to partly address this problem would be better transparency of and improved applicability of the existing reliability criteria to ensure that the reliability criteria are at the forefront of all decisions.

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. Comments included that examples should be specific or given for each daily living activity. #MEAction Scotland called for ‘the use of an example of someone with an energy limiting condition’.[163]

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

It has been a perennial problem that there is no clarity about what a ‘normal’ baseline comparator is understood to be.

> “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[164]

One welfare rights adviser highlighted the fact that the ‘reasonable time period’ to carry out each activity is not clearly defined although the Adult Disability Payment regulations state that ‘to carry out an activity ‘within a reasonable time period’ means no more than twice as long as the maximum period that an individual without a physical or mental condition or conditions which limits that individual’s ability to carry out the activity in question would normally take to complete that activity.[165]

Despite this definition I was informed of instances where a tribunal judge has asked the client/their welfare rights advisor to find out the national average of the time people take in the shower. One suggestion could be (where applicable) to compare what a person does now with what they did before i.e. to establish what is normal for that individual rather than what might be deemed normal for a non-disabled person.

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.

In the guidance provided to case managers it is made clear that ‘where an individual’s ability to carry out an activity is being determined, the case manager should apply the descriptor which they are satisfied applies for the individual to be able to undertake the activity reliably’.[166] However 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.

PIP guidance includes some wording to say that assessors should consider the impact of an activity on the ability to carry out other activities.[167] Specific mention of that point is not within the case manager guidance for Adult Disability Payment although it does say: ‘It is important to consider the impact completing the activity has on the individual. This requires consideration to be given to how a person feels both during and after carrying an activity out’.[168] I think this doesn’t go quite far enough.

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

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 caselaw decisions are reflected in decision-making guidance and training.

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.

As part of the Review, I observed a case discussion. In this example the case manager was utilising the discussion as a way of confirming their approach to and rationale for making a particular decision. The practitioner's knowledge of the disability being discussed was used as affirmation of the facts as set out in the application and within the supporting information.

Although it was acknowledged that people determining applications could not be trained in all disabilities and long-term health conditions, there is concern that if the person making the decision does not understand a client's disability and how it typically impacts a person's life the client is somehow disadvantaged in their application. In addition, there is sometimes a perceived lack of transparency and consistency between decisions made about mental health problems and decisions relating to people with physical disabilities. People often told me that they believe there is a difference in how their physical versus mental health symptoms are assessed, despite the psychological symptoms having the most detrimental impact on their life.

> "...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.[169]

In the most recent Social Security Scotland Client Survey[170] issues were raised about practitioners' knowledge of individual health conditions, as well as issues with the format of consultation questions. When suggestions for improvement were made, these included the need for practitioners to have a good understanding of the individual health condition(s) that impact a client so as to better understand a client's lived experiences.

Respondents to the Social Security Scotland 2023/2024 Client Survey[171] described discrimination against particular health conditions, especially those that relate to mental health or 'invisible' disabilities. Some respondents described how biases in the application process, as well as errors in the decision-making process, led to unfair decisions on benefit applications. Several respondents commented that they were made to feel 'not disabled enough', as though their ability to cope with their health condition was misconstrued as them not needing support.

Many disabled people I engaged with felt strongly that Social Security Scotland staff need to be well trained and supported to understand the complexity and inter-connections between various conditions, functional limitations and lived experiences. Inclusive New Normal (INN) stressed that as a minimum, a basic understanding of 'spoon theory', chronic fatigue, post exertional malaise, cognitive dysfunction and clinical risk are needed.[172]

Following a meeting with people impacted by Long Covid, ME and CFS, I enquired about training and awareness raising related to certain conditions. Social Security Scotland does not deliver specific training on every disability, condition or impairment.

Following a public Freedom of Information request by a third party in relation to ME and CFS,[173] Social Security Scotland confirmed this position by stating:

> "We do not deliver specific learning around Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. Learning is primarily designed around guiding decision makers to use a range of decision-making tools to aid them such as medical guidance tools, case discussions and consultations. The emphasis for training is always on the impact to daily living and mobility for clients and to use these avenues of support in particular around health conditions and disabilities. Advice can also be provided by a health and social care practitioner with relevant experience and/or specialism based on the case manager's request. Practitioners do not diagnose conditions or advise on treatment and are all Social Security Scotland staff members."

There is no formal policy regarding condition-specific awareness or training although it is noted that organisations can deliver information sharing sessions with staff on an ad hoc basis. In the last eighteen months, sixteen such sessions have taken place.

However, 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 a decision. A recent example concerns an increasing number of Adult Disability Payment applications relating to issues arising from transvaginal mesh implants. It was acknowledged that additional knowledge on this subject matter would be beneficial and as a result a specialist was invited to speak to case managers and practitioners.

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.

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.

There is universal praise for the cessation of DWP-style assessments and that consultations do not appear to be used on the same scale. I understand from engaging with Social Security Scotland that the number of consultations undertaken each year only represents a small proportion of applications received (5% reported having had a consultation as part of the Disability Payments Client Survey).[174] This is reflected both in the responses to my own consultation and call for evidence. Most people I spoke to said that in their experience, most consultations took place by telephone.

A client is asked to attend a consultation when it is the only feasible way for Social Security Scotland to obtain the information needed for making a decision. From the online consultation of those receiving a decision only 10% of respondents[175] said they had been invited to a consultation as part of applying for Adult Disability Payment.[176] This will usually be because the application itself doesn't contain all the information required to make a decision or there is insufficient supporting information and/or a case discussion hasn't been helpful. A consultation only covers the areas of the application that Social Security Scotland need more information about.

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

> "The lady was very polite, explained fully why she was calling and didn't keep me for too long. She only asked one question, and it wasn't intimidating or anxiety inducing." - Individual response, to the Independent Review of Adult Disability Payment Consultation[177]

Most comments about the quality of service provided by Social Security Scotland's practitioners were positive. Some respondents mentioned that they felt vulnerable or upset explaining their circumstances, but for most the practitioner put them at ease. Qualitative responses to the survey said:

> "My (consultation) was amazing, very patient and understanding. It was very easy and stress free." – Client Survey: Disability Payments (October 2024 – March 2025)[178]

> "It is upsetting but I understand why it's needed and the lady I had was polite and professional." – Client Survey: Disability Payments (October 2024 – March 2025)[179]

As part of the Review, I engaged with disabled people's organisations to acquire more information on their and their client's experience of the consultation process. One person described their experience as 'excellent' and explained that Social Security Scotland took the use of assistive technology into consideration, ensuring that everything was accessible. They recalled that the consultation invitation arrived via email, and they simply had to respond to it to confirm the details. They highlighted that they felt they were given sufficient time to respond and described the experience as 'barrier-free', saying that "I struggle to think of any negatives with regards to the consultation process".

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 has helped to create a process that is more dignified and less stigmatising.

The other common themes raised included:

- disabled people potentially being disadvantaged by not having the opportunity to have a consultation and to speak to someone about their application
- people not understanding what a consultation is
- people thinking they have had consultation when they have had a clarification or update phone call from a client advisor or case manager

- not having enough information about a consultation in advance, including what will be discussed during the consultation
- greater clarity being required to inform clients that consultations should be held in the way best suited for the client.

Social Security Scotland colleagues stressed that the client should receive adequate information in advance of the consultation.

Some disabled people who were not invited to take part in a consultation by Social Security Scotland 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, that their voice should be heard, and they should be more involved when decisions are being taken 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. It is 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. Feedback from the online consultation showed that 88% of consultations took place over the telephone.[180]

It was highlighted that when a decision goes to consultation, case managers and practitioners will decide the method of communication in the first instance and the letter that is issued to the client will outline how to change the method of communication if required or requested. Social Security Scotland explained that unless something has been stated in the application which indicates a specific preference or a practitioner feels that a specific format would best suit the client, a consultation by telephone is routinely offered. It was suggested that this approach can potentially disadvantage individuals with communication challenges or anxiety and some stakeholders felt that a person's health condition or disability can't always be captured fully on the application form.

It appears that more can be done to balance the benefits of in-person interactions with the fears associated with previous DWP practices to get the process right for the individual in a way that gives them the best opportunity to convey vital information.

During a visit to Social Security Scotland, I asked about trauma and how this is considered when colleagues are determining the need or otherwise for a consultation. I was told that a client does not need to say the word 'trauma' for this to be considered and that practitioners have the relevant experience needed to carefully explore the impact of trauma on a person's quality of life. It is unlikely that a consultation would be requested if a client has indicated a high-level of trauma in their application. Social Security Scotland should take into account the emotional and physical toll a consultation may have on a client, for whom the consultation may include the disclosure of upsetting and/or traumatic life experiences.[181]

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.

Re-determinations and appeals

The re-determination step offers recourse for those that do not agree with the outcome of their determination who may otherwise not pursue a challenge if they were forced to go straight to appeal.

Re-determinations also allow Social Security Scotland to correct mistakes at an early stage, as well as strengthening decision-making as advisors engage with clients, gather any further supporting information and coordinate referrals to Health and Social Care Practitioners for clinical views if relevant.

Social Security Scotland publishes regular statistics on the number of re-determinations and appeals received by Social Security Scotland and the number of Tribunal decisions made. They monitor Tribunal outcomes to continuously inform and enhance learning through regular reviews of the appeal process.

There were 52,790 re-determinations received by 30 April 2025.[182] Of these, 42,855 were requested by new applicants, while 9,935 were by people who had their award transferred from the DWP. By 30 April 2025, 49,355 re-determinations had been completed. Of these 22,655 (46%) were disallowed, 25,025 (51%) were allowed and 1,365 (3%) were invalid.

There were 9,140 appeals received by 30 April 2025.[183] Of those, 3,510 have had an appeal decision made. Of those 1,835 (52%) were upheld and 1,670 (48%) were not upheld. Of the appeals received by 30 April 2025, 79% were for clients who applied as new applicants, and 21% were for clients who had their award transferred from the DWP.

When considering the feedback from the online consultation and call for evidence it is evident that clients feel several things are working well about the re-determination process. Two individuals noted that they liked having the flexibility to provide additional supporting information in multiple formats and one individual reflected positively about their treatment during the re-determination process. Offering an online form reportedly makes the process more accessible. Other feedback from the online consultation included a request to improve the re-determination timescales.

The most common reasons cited for seeking re-determination included case managers incorrectly interpreting application information and support from outside agencies being available, enabling clients to feel confident in asking for a re-determination.[184]

Although people can call Social Security Scotland if they would like further support to request a re-determination or appeal, Social Security Scotland also encourage people to seek support from independent advice services to discuss all their options. Re-determinations and appeals advice for Adult Disability Payment is the fastest growing area for independent welfare advisers:

> "For the second consecutive quarter, redeterminations and appeals together represent 19% of Adult Disability Payment advice being delivered and are the fastest growing areas of Adult Disability Payment advice"– Citizens Advice Scotland[185]

More recent data from Citizens Advice Scotland (at the time of publishing) indicates that assistance with re-determinations and appeals has grown to 21% of advice work related to Adult Disability Payment delivered by Bureaux.[186]

The most common reasons cited within the call for evidence responses that prevent people from seeking re-determination include:

- finding the process confusing and therefore did not seek a re-determination in the right timeframe or 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.

The administrative complexity and duration of the re-determination and appeal process can be a significant determinant of whether a person proceeds to challenge a decision.[187] The necessity of repeating sensitive information and continually confronting limitations, which has been described to me as the trauma of 're-telling' and by one welfare adviser as 'the pressure of intense scrutiny', can be a formidable barrier. People considering requesting a re-determination are often weighing up the extent to which they feel able to re-tell their story to progress a re-determination, knowing that they may have to go through the same process a third time if the re-determination is unsuccessful and an appeal is required.

Some clients are hesitant to provide new information during the re-determination stage in case it may be viewed suspiciously by Social Security Scotland which could then risk their award.

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. An appeal form is included with every re-determination outcome letter and is also available online through the Social Security Scotland website or can be requested by phone.

The main reason cited in the online consultation for seeking appeals included having help from third sector welfare advisors and advocates which gave the appellants additional confidence to appeal.

> "One key factor for this will be whether they are supported during the appeal process. This is why it is key for Social Security Scotland and the Third Sector to work closely together to ensure that applicants are supported by organisations who have a full understanding of their condition. People living with epilepsy who have been turned down with regards to their ADP application will see their mental health deteriorate and will require emotional support as well as professional support with regards to the appeal process." – Epilepsy Scotland, response to the Independent Review of Adult Disability Payment Call for Evidence[188]

Also, if clients felt that the original decision did not represent their lived experience or had not captured their supporting information accurately, they were more likely to 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 heard some evidence from stakeholders that going straight to appeal could put some clients off challenging a determination altogether. Many people reiterated the high levels of stress and worry they had experienced when going through appeal processes in the past with PIP and DLA.

The First-tier Tribunal is independent of Social Security Scotland and can uphold Social Security Scotland's determination or make its own determination. This may result in a different level of entitlement (including removal of entitlement) for the client.

> "We have noted on occasions that at the appeal stage, points that were awarded on the initial claim have been removed in the re-determination process without a full explanation. This is confusing for appellants and undermines their trust in the process." – Glasgow City Council, response to the Independent Review of Adult Disability Payment Call for Evidence[189]

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.

During the Review, the comparison with the DWP process was raised where a person can lodge an appeal directly upon receipt of a decision. Meanwhile if an automatically triggered re-determination resulted in an acceptable award decision, the appeal would not be required to go ahead. The Scottish Government response is that the DWP introduced a mandatory reconsideration process[190] for clients in 2013. Whilst the Scottish Government cannot speak further to the Department's past and present policies, they were able to provide factual background on the policy decision of implementing a two-stage process for challenging a decision in Scotland. Some respondents to the Social Security in Scotland Consultation in 2016 felt it was important to have a clear, consistent and impartial internal review process, with clear timescales, and they recognised that an internal review could provide an opportunity to correct mistakes at an early stage. This consultation helped to inform the development and design of the re-determination and appeal processes for Social Security Scotland. Challenging a decision has been designed to be accessible for clients, with clear timelines and accountability if these are not met, making it easier for people to engage with the process.

I met with Scottish Government officials, who provided me with factual information during the passage of the Social Security (Amendment) (Scotland) Bill[191] about its provisions. I note that the policy memorandum to the Bill explains the changes are intended 'to empower clients and give them choice and flexibility.' Provisions via the Social Security (Amendment) (Scotland) Act 2025 allow Social Security Scotland to make a new, more advantageous determination after a client has lodged an appeal. A new determination will only be made with the client's consent and would end their appeal. This means that should a client wish to challenge re-determination outcome further and opt for an appeal, Social Security Scotland can make another advantageous determination should the client agree, thereby preventing unnecessary appeals.

These new provisions were designed to embed client choice and ensure that clients can engage with the challenge process on their own terms, thereby helping to promote continued accessibility to challenging a Social Security Scotland decision.

Social Security Scotland seems keen to change the perception of the challenge process and reduce anxiety and stigma. However, there are a few further areas of improvement to the process that could be considered.

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 that is unique to Scotland. A person can access short-term assistance if they were or are in receipt of Adult Disability Payment and a decision has been made to reduce or stop their longstanding award (e.g. via a review or re-determination) and the client has requested a re-determination or an appeal against this decision. The payment tops up a person's current award to their longstanding award level for the duration of the re-determination and/or appeal process. People will not have to repay any money they were entitled to, regardless of the outcome of their challenge. Short-term assistance was introduced to protect a person's right to challenge decisions and so they don't have to try to manage for a period on a reduced income.

Without any doubt it is evident that the introduction of short-term assistance is welcomed by disabled people and is viewed as an improvement on the DWP process. There were some suggestions that the process should be automatic without the need for clients to apply but other than that, the issue of short-term assistance was rarely mentioned.

Keeping in mind that short-term assistance is out of scope of the Independent 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 30: To consider introducing automatic awarding of short-term assistance with an opt-out clause to acknowledge a client's right to choose.

Changes in circumstances

Some people commented on the length of the change of circumstances form; with many people saying it is too long.

There remains some confusion amongst 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.

Young Lives vs Cancer suggest that further guidance could be provided by Social Security Scotland on what changes of circumstances need to be reported and when in the patient journey, e.g. when is the change in circumstance of a young person finishing cancer treatment considered to apply, because despite treatment ending, the young person is still impacted by their condition for a significant period of time post-treatment.[192]

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 that they had been left disadvantaged because their Adult Disability Payment change of circumstances 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 updated supporting information had not been considered in their change of circumstance decision and two were confused about what information they could submit alongside their change of circumstances form. One individual felt that they were asked irrelevant and intrusive questions during a telephone consultation to review their change of circumstance.

Many people suggested improvements including shortening wait times, improving communication by providing updates during processing, and offering clearer guidance on submitting a change of circumstance and what needs to be included on the form.

Specific improvements related to change of circumstances included:

- a suggestion to reiterate the need for clients to contact Social Security Scotland in cases where conditions have changed
- a suggestion from VoiceAbility that older clients be made aware of the ‘mobility clause’ of the change of circumstances form
- a recommendation from Young Lives vs Cancer to create integration between benefits systems to ensure that updates to one benefit would update the system for all
- a recommendation from Alzheimer Scotland to provide more details about what needs to be included in the change of circumstances submission.

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

Effect of time in hospitals or care homes

People in receipt of Adult Disability Payment must tell Social Security Scotland when they go into hospital or a care home as soon as reasonably practicable. Subject to some exceptions, if a person is in hospital or a care home for more than 28 days (either as one single period, or multiple periods no more than 28 days apart), payment of their daily living component stops.[193]

For hospital stays, someone who is aged over 18 and receiving in-patient treatment where the costs are met out of public funds, will have their payments of both the daily living and mobility component stop after 28 days.

The Scottish Government says that in most cases, people in alternative accommodation will have the costs of their care met out of public funds, so non-payment of the daily living component ensures that a person does not receive the support for the costs of their care twice. Furthermore, the mobility component of a person's award is not paid either, as the Scottish Government's position is that disabled people will not have the same mobility costs to meet while receiving in-patient care.

According to Young Lives vs Cancer the condition that an individual will stop receiving their payment if they spend more than 28 days in hospital (across a series of short stays separated by no more than 28 days) places a significant administrative burden on young cancer patients to record days spent in hospital across a large period. Considering the frequent short-term hospitalisations that a person with cancer experiences (due to their treatment or sporadic infections), as well as the lasting impact that their treatment can have on their finances and mobility, they have requested that cancer patients are exempt from this aspect of eligibility for Adult Disability Payment.

Keeping in mind that consideration of payment when a person is spending time in hospital or a care home, is out of scope of the Independent 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 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

To qualify for Adult Disability Payment, a person must have a disability/health condition that has lasted at least three months and is expected to last at least nine months more. This is sometimes referred to as 'the backwards and forwards test' or 'qualifying period'. There is no backwards test or forwards test for individuals qualifying under the SRTI route.

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[194]

Research published by Young Lives vs Cancer[195] shines a light on the experiences of, and challenges faced by, children and young people with cancer and their families as they navigate the disability benefits system to help manage the additional costs of living with cancer. On top of the significant financial costs, a prolonged wait for Adult Disability Payment of an average of six months following a cancer diagnosis is resulting in young people and their families in Scotland being forced into impossible financial positions, having to find and pay out nearly £3,000 in extra costs before their disability benefits are awarded.

Almost one-in-two young people with cancer have to use their savings and three-in-five must borrow money following a diagnosis[196]. Almost half the patients in Scotland finish active treatment before receiving a decision on their application for Adult Disability Payment.[197]

There is no option to receive backdated payments to cover the wait during the qualifying period, meaning support is not always provided immediately following diagnosis. However, a diagnosis is not required in order to satisfy the qualifying period if a person has been impacted for three months before diagnosis. Being entitled to Adult Disability Payment allows people to access other forms of support such as a Blue Badge for parking and additional Universal Credit premiums, which cannot be accessed until Adult Disability Payment is awarded. A carer will similarly not qualify for Carer Support Payment until the person receives the daily living component of Adult Disability Payment. 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 immediately 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 utilising 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

Automatic entitlement to Adult Disability Payment could potentially be introduced for people who have already been assessed for and awarded other forms of support such as for example, a social care package, Independent Living Fund and Blue Badge for mobility. This would significantly decrease the administrative burden on clients and on Social Security Scotland by simplifying the application process and reducing the amount of supporting information needed to make a decision. It could also help reduce the volume of case discussions and consultations carried out and go some way to reduce the trauma, anxiety and stress associated with having to repeatedly tell one's story and prove one's eligibility.

Automatic entitlement could also potentially be used in cases where people with particular conditions are entitled to an award without having to provide any further information beyond confirmation of their diagnosis with an eligible condition.

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.'

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[198]

Young Lives vs Cancer believe that given the medical supporting information available, young cancer patients should be able to bypass the application process in a similar way to SRTI clients. They understand the medical vs social models of disability, but for cancer they believe they are intertwined. More than seven-in-ten young people with cancer and their families (72%) believe introducing automatic entitlement would be most helpful to them and other children and young people diagnosed with cancer. To help achieve this, many of them felt that supporting information from a medical professional could be better utilised in the process.[199]

There are obvious challenges with this approach including the emphasis on a medical model of disability however it is worthy of further consideration when coupled with the current approach taken to identifying particular disabilities and conditions when deciding upon indefinite awards.

Keeping in mind that SRTI and supporting information are out of scope of the Independent 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

Awards of disability assistance do not have a fixed end date after which clients have to re-apply for disability assistance. As Adult Disability Payment is ongoing, most awards are reviewed periodically to ensure that the individual continues to receive the right amount of assistance.

'Light touch' reviews which don't require a DWP-style assessment were broadly welcomed as is the use of a diagnosis, in some cases, to determine award periods.

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

As part of the consultation,[200] I asked 'Have you ever received an indefinite award for Adult Disability Payment?' and received 75 responses to this question. The responses show that only 7% of respondents to the consultation said they had received an indefinite award whilst the majority (84%) said they had not. A small number of respondents said they did not know (9%).

I also asked, 'Was the reason for this decision communicated clearly?' and received three responses. The majority of respondents felt that Social Security Scotland communicated its decision clearly (67%), whilst the remainder said they did not know (33%).

Disabled people told me that they appreciated the ability to submit review paperwork online and most cited good communication throughout the process. Most also appreciated the lack of face-to-face assessments. Two respondents liked the communication they received leading up to the review. There were also several people who said communication about reviews and review periods could be improved. Decision waiting time is felt to be too long and the review form was cited as being too time-consuming to fill out.

Many disabled people told me that they do not always understand the logic behind the decision to determine the period of time before a review is deemed necessary. This is most pronounced if a person views their condition as progressive or if they are living with a life-long condition. People reported feeling intimidated by the prospect of a review, even when there had been no changes. There have been some very particular issues arising from an apparent lack of consistency in award length with one person left perplexed when their case was transferred, and with them being given their award for two years even though their previous DWP award had been for four years.

The most prevalent theme, mentioned by many, was that longer review periods would positively reduce clients' stress and anxiety and allow for extended periods of better wellbeing between reviews. The security of planning finances and managing the cost of care was mentioned by some and a small number questioned why they needed to undergo reviews when their conditions were permanent and either unchanging or progressively worsening.

> "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[201]

> "The award of Adult Disability Payment on an indefinite basis offers reassurance and certainty about entitlement which leads to better financial security. For example, people with dementia who have an indefinite award of Adult Disability Payment feel more able to source ongoing care

> and support services since an indefinite award provides them with a secure source of income that enables them to engage services without the risk that this might not be possible in the event that their award ends and is not renewed." - Alzheimer Scotland, response to the Independent Review of Adult Disability Payment Consultation[202].

On a visit to Social Security Scotland a case manager talked me through how they make a decision regarding the award period. I was informed that two years is usually the minimum review period with ten years being the maximum. Case managers can also award clients an 'indefinite award'. This is where a client remains entitled to Adult Disability Payment without the need for a scheduled review in the future and can be awarded to clients who are entitled to the enhanced rate of both components and whose needs are highly unlikely to change. Furthermore, case managers must request a case discussion in all cases before making an indefinite award. This is because decisions on indefinite awards can be highly complex.[203] The case discussion must focus on whether or not setting a review date is appropriate. This is a mandatory step and practitioners must approve an indefinite award.

An award of less than two years can be selected in some instances, for example, where a person is scheduled to receive surgery that is likely to improve their condition, and the healing time is considered to be less than two years. In cases where a person's condition is likely to be degenerative a shorter review period may also be determined.

Some conditions or their impact on the individual are likely to change over time, so a review may be appropriate to see whether the individual might be entitled to a different rate of Adult Disability Payment in the future. Small changes in the individual's condition might make a significant difference to their overall level of entitlement for Adult Disability Payment, depending on the score for each activity awarded by the case manager for the daily living and mobility components. This should not prevent a case manager from setting a longer review period, as the individual can still ask for an unscheduled review by reporting a change of circumstances.

Several things are taken into account including the awareness that some conditions are degenerative and it may be that a shorter review period will benefit the client as it provides an opportunity to update Social Security Scotland on any changes that are affecting their daily life. This would apply in cases where the highest rates for daily living and mobility have not been determined.

The guidance for case managers[204] has a list of conditions that is used in cases where the individual is entitled to the enhanced rate of both Adult Disability Payment components and where, based on the balance of probability the client's condition is unlikely to improve. The first list refers to 25 conditions that are likely to mean the individual has a stable level of needs and it is highly unlikely that the individual's condition will improve. The second much longer list refers to a number of conditions that potentially mean the individual has a stable level of needs, but it is possible that the individual's condition may improve. If the individual has a condition or multiple conditions that do not appear on the list, the case manager should nevertheless go on to consider whether the individual's needs are highly unlikely to improve.

It is important to note that there is no specific guidance on review periods for individual conditions. This is because an individual's condition is just one of many factors that the case manager needs to take into consideration when setting a review period.

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.

A Learning System

It was evident throughout the course of my review 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.

The Chief Executive Officer of Social Security Scotland, David Wallace said in in the Annual Report 2023-24:

> "As the number of people we serve grows, we continue to listen, learn, and act on the feedback we receive from our clients and stakeholders. Their feedback helps us ensure we are delivering the best possible service to the people of Scotland while also delivering value for money" – Social Security Scotland Annual Report 2023-24[205]

In this report I have already recorded examples of where Social Security Scotland uses feedback to improve performance and how they demonstrate that learning from experience is embedded into practice particularly in the case management space. In addition, I have experienced the Social Security Scotland quality assurance process and seen evidence of the 'feedback loop' operating between Social Security Scotland and policy colleagues at the Scottish Government.

Some of my conversations with Social Security Scotland staff provided clear instances of times when staff feedback led to an improvement. A common theme was improvements to internal processes which were put in place to manage workloads. There were also examples about improvements to communications within and between teams.

Although several stakeholders expressed not being listened to or engaged with effectively, several also gave examples of where they had provided feedback that led to improvements. One gave an example related to issues of accessibility for clients who use British Sign Language, and another told me that they had seen improvements to the application form as a result of their input.

Communication

Although the lack of proactive communication or progress updates on applications after submission were themes within the consultation, in the most recent Social Security Scotland Client Survey[206] most respondents agreed with the statement 'I got the support (information or advice) I needed' (69%). The survey covers all benefit recipients, so it is worth noting that respondents with experience of applying for Adult Disability Payment were less likely to agree with each of the statements regarding communication choices and support received.[207] Other areas highlighted in the online consultation included the long waiting times for a decision and the long waiting times for someone at Social Security Scotland to answer the telephone helpline, as well as staff not being able to provide adequate progress updates on a person's application over the phone.

As mentioned earlier in the report, within the Social Security Scotland Business Plan 2024-25, it states:

> "we know that our clients want to hear updates from us about their applications. Improving how we communicate with people applying for Scottish benefits will improve their experience while making us more efficient."[208]

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 Social Security Scotland to meet legal and organisational commitments regarding inclusive communication.

Members of the group provided expert opinion and insight across a number of areas, including the use of visual imagery in the Adult Disability Payment application form; the approach to consultations and decision-making; and the design of Social Security Scotland buildings.

The Group members worked collaboratively with Social Security Scotland to progress various recommendations in the inclusive communication action plan. The plan has now been incorporated into a wider Inclusive Communication and Equality Strategy as ongoing work is mainstreamed into day-to-day activity.

The Social Security Scotland Client Survey 2023-24[209] highlighted lower satisfaction rates overall among people with specific communication needs.[i] The survey highlighted that:

- the overall experience rating for people with communication needs (78%) was lower than that for those without (81%)
- respondents with communication needs were less likely than those without to agree that they had a choice of how to communicate with Social Security Scotland (74% and 80% respectively)
- 9% of those with communication needs said they had experienced discrimination, compared with 5% of those with no communication needs.

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. The determination and re-determination letters currently have the name of a manager on them and in discussion with Social Security Scotland I have heard that there are plans to change that for 'safety reasons'. It is evident why having a named point of contact may

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[i] I note that the Client Survey reflects all respondent's views to the Client Survey and is not disaggregated by the individual benefits Social Security Scotland delivers.

be operationally challenging; however, the point of having a more personalised and accessible route to two-way communication throughout the application and re-determination process is worthy of consideration. Interestingly when the name of a person along with their signature was removed in a testing environment most people didn't notice the change. A small number who did notice didn't like the idea that the name had been removed with their main concern being who to get into contact with if they had questions about their application.

Accessibility and language considerations came up frequently in the consultation, as did noting a person's preferred method of communication and this not always being adhered to. The evidence reveals the vital role of ensuring that the person's appropriate communication method is recorded at the outset of an application and acted upon consistently through the application journey.[210] Failure to do so can undermine people's agency and their ability to provide all relevant information in support of an application. Failure to use the most suitable communication tool can also worsen the impact of delays.

SCoSS undertook some research on the experiences of people with communication needs and their interactions with Social Security Scotland.[211] This research was not specific to Adult Disability Payment clients, but the findings are relevant to this Review. These include:

- enhancing understanding of the process among clients and representatives, including continued review of communication by Social Security Scotland to ensure information is as clear, accessible and understandable as possible
- more regular communication, which would be expected to have a positive impact on people especially people with mental health problems or who are neurodiverse, who are frequently also dealing with delays accessing other services while often juggling work or caring responsibilities.

When asked about the reasons for understanding or not understanding the award decision the most prevalent theme in response to this question was confusion about why the client received the points they were awarded, often reflecting disagreement with the decision. Some respondents on the other hand provided positive comments about the clarity of communication around their award.

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.

> "The award letter explained perfectly why I received points for each section and although it was really upsetting and quite shocking to read that back about myself and realise the seriousness of my conditions, I felt that they did it with understanding, compassion and most importantly respect. Something I never received from PIP. I actually cried reading my PIP letter and felt sick to my stomach. My ADP letter, although hard to read those things about myself, they said

> nothing derogatory or discriminatory about me." – Individual, response to the Independent Review of Adult Disability Payment Consultation[212]

Stakeholders provided a mixed response to the issue of decision letters. Some felt determination letters were too long and information about appeals, and redetermination should be given more prominence on the front page so applicants can quickly access the decision and its implications. Others felt that the current decision letters make it much easier to form the basis of a re-determination request or appeal.

I was told by stakeholders that 'cut and paste' is sometimes being used in determination letters with welfare advisers in particular noting word for word similarities in different client determination and re-determination letters. They also noted that determination letters are much shorter and less detailed than they used to be which makes it difficult for the client to understand the reasons why a certain decision has been made.

The introduction of written translations of Adult Disability Payment determination letters was welcomed but it was felt that more languages should be added to ensure the needs of minority communities were better met.

Whilst SRTI is outside of the scope of the review, Social Security Scotland has explained that if a client does not want to know that they are terminally ill, an indicator will be placed on a case reference note highlighting that a person is not aware of their prognosis and communications will reflect this. Individuals with terminal illnesses told me that they do not see themselves reflected in communications, which impacts their engagement with the Adult Disability Payment system. Clearer, more inclusive language is needed to ensure these individuals feel adequately represented.

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."

One member of the Advisory Group suggested that if Social Security Scotland data about the relatively low uptake of SRTI provision (which makes up 2% of the overall (not just Adult Disability Payment) case load) was highlighted in promotional materials and on the Social Security Scotland website it might act as an incentive to improve communication and messaging to people with a terminal illness and to professionals involved in their care.

Some other communication issues that were raised during the course of 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 for Adult Disability Payment process
- 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 appropriate communication methods are being used at all points in the journey
- unsolicited telephone calls in an attempt to fill gaps in information that continue to cause distress and confusion.

> “Some participants said they had been in contact with multiple advisers and had to either repeat the same information they had already given, or were given information which appeared to them to be inconsistent with what another adviser had said” - People with communication needs and the Scottish social security system: fulfilling the expectations of ‘Our Charter’ (2025), Scottish Commission on Social Security[213]

There are several ways in which communication processes could be improved for people with energy impairment. Ideally there is a need for methods that do not require engagement in ‘real-time’ to accommodate fluctuating energy levels. For example, email correspondence means people can provide information when energy levels permit, in short bursts or on good days. Alternatively, if real-time communication is key, it can require less energy to process information on video calls than phone calls.[214]

In meetings with LGBT+ disabled people and stakeholder organisations, accessible communication and appropriate terminology were frequently raised. There was a request for all staff involved in the process (local delivery, advocacy, call handlers, case managers) to adopt LGBT+ friendly language, for preferred pronouns to be accepted and wording that respects a person’s expression of gender identity to be adopted. They asked that individual needs are provided for so that equal access to services is achieved with no discrimination and that actions publicly demonstrate a commitment to open and inclusive approaches, including developing administration systems that can easily change 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.

Social Security Scotland has a communication needs indicator that is included on a client record and clients are invited to share any communications needs or preferences during the application process. SCoSS found in recent inclusive communications research conducted, that there is often some reluctance to ask for help among participants, often as a result of a desire to maintain independence and autonomy.[215] Participants in this research indicated that proactively being offered support might be more readily accepted.

Since Adult Disability Payment launched, Social Security Scotland has offered emails for some non-statutory client correspondence. This included contact to notify clients that it had received their application. In 2024, in response to continued client requests for more digital communication options, Social Security Scotland launched a pilot to assess feasibility and benefits of email-based communication. Currently, it only sends non-statutory correspondence about the annual uprating (the uplift in benefits) via email, with a process to monitor failures in receipt, with a follow-up letter, if needed. It is obviously important that Social Security Scotland complies with data protection laws and considers the needs of a variety of audiences as part of this work, including people whose first language is not English. I understand that whilst a transition to fully digital client communications is not currently possible, work remains 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.

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.

Learning from other pieces of work

Audit Scotland

During the Review, I met with the team from Audit Scotland who are conducting an audit into Adult Disability Payment. Although the independent review and Audit Scotland's work are different in scope and approach, there are obvious overlaps, and we agreed to keep each other updated as our respective pieces of work progress.

The Audit Scotland audit will look at how well Adult Disability Payment is being managed and assessed, how well the financial and non-financial consequences of this approach are being managed, and if Adult Disability Payment is contributing towards wider efforts to improve outcomes for people with disabilities.

The Audit Scotland audit will provide assurance on how well Adult Disability Payment has been implemented and the added value of the approach taken in Scotland. It will deliver findings and recommendations on the delivery of social security and the future affordability of benefits payments. The overall aim is to assess how much value the Scottish Government is adding through its approach. The audit questions to support this aim are:

- how well are the Scottish Government and Social Security Scotland managing and assessing Adult Disability Payment?
- how well are the Scottish Government and Social Security Scotland managing the financial and non-financial consequences of its approach?
- to what extent is the Scottish Government considering how Adult Disability Payment is contributing towards overall efforts to improve outcomes for people with disabilities?

The findings and recommendations from the audit will provide lessons on the delivery of social security in Scotland and the future affordability of benefits payments. It will also assess the impact Adult Disability Payment has had on overall efforts to improve outcomes for people with disabilities. The Audit Scotland work will be carried out throughout 2025 with a plan to publish the audit report in Autumn 2025.

Minimum Income Guarantee

The Scottish Government funded an independent Steering Group to research the feasibility of piloting a Citizens' Basic Income in Scotland. In June 2020, the Steering Group published a report concluding that piloting would be desirable, but the Scottish Parliament does not have the necessary range of social security and tax powers to do so. Any pilot scheme would require further devolution or close cooperation from the UK Government, which was not forthcoming.

> “The Scottish Government has committed to start work in this parliamentary term to deliver a Minimum Income Guarantee (MIG) in Scotland, incorporating the idea of Universal Basic Services as part of this work. A MIG can be described as a guarantee that everyone will receive a minimum level of income, and can be delivered through a combination of employment, social security and other policies. A Scottish MIG may contribute to reducing poverty over the next parliament so that everyone in Scotland has enough support to live a dignified life.” – Letter from former Minister for Social Security and Local Government to Social Justice and Social Security Committee[216]

A MIG is an assurance that no one will fall below a set income level. This could be delivered through a combination of fair and accessible paid work, high-quality services that reduce household costs and adequate social security.

During the Review I met with Russell Gunson, Chair of the MIG Expert Group. There are obvious connections between the MIG work and the Independent Review as they both directly or indirectly relate to poverty and wider Scottish Government policy on accessing work, reducing household bills and providing adequate social security.

A Steering Group was appointed in 2021 and includes a Strategy Group of cross-party MSPs and an independent Expert Group with membership drawn from across the third sector and academia.

The 2023 Programme for Government included a commitment to continue to work with the MIG Expert Group, to consider feasible steps towards delivering a MIG in Scotland.

The MIG Expert Group considered the potential impacts and delivery options for both households and the wider economy and society. Its recommendations considered costs, legislative powers and delivery mechanisms – to ensure that they are deliverable. The Expert Group published an interim report in March 2023[217] which highlights the need for a robust safety net and long-term action to tackle poverty, financial insecurity and broader inequalities across Scotland. The report sets out early considerations for the Scottish Government which could prepare the ground for a MIG. The roadmap includes calls to reform social security policies, address inequalities, improve employment conditions and opportunities, pilot MIG, improve services and reduce household costs. The Expert Group appointed an Experts by Experience Panel to ensure that a MIG is developed with the voices and experiences of financial insecurity at its core. The Panel were tasked with deliberating key elements of a MIG from the level at which it is set, the role of work, what services should be included, and much more. The final report from the Experts by Experience panel was published in July 2024.[218]

While there was no universal consensus, members reflected throughout on the potential societal and economic benefits of introducing a MIG.

The MIG Expert Group published its final report on 18 June 2025.[219] The Group said:

> "Our vision from 2036 is that we work to progress implementation, balancing the role of work, services, costs and social security to successfully manage our social needs with our economic needs. Through fuller powers and flexibilities or through action from the UK Government we are now able to regulate the costs of essentials more fully, and to shape the world of work. Everyone has access to the essentials of life either for free, or at an affordable cost, with income from fair work and/or social security making this possible."

To this end they have adopted a Roadmap approach, outlining how Scotland can deliver a full MIG, step by step. They combine long-term vision with near-term steps that mean significant progress can be made straight away, even if full implementation will take time, investment and action.

Research

During the Review, I have engaged with many stakeholders and organisations, several of whom have been happy to share relevant pieces of research with me. I have quoted from said research on a number of occasions throughout this report and I would like to take this opportunity to express my gratitude. All relevant research has been passed on to colleagues working in Scottish Government or Social Security Scotland to enhance their awareness and learning.

A Better Future

The Scottish Government priority to date has been the safe and secure transition to a devolved system of disability assistance. It is now therefore, when almost all PIP recipients have had their cases transferred to Adult Disability Payment, that attention is focused on addressing some of the anomalies and challenges inherent in the current system.

Modernisation

The current activities and descriptors for Adult Disability Payment are identical to those used for PIP, with some changes having been made to reflect case law or to make their meaning clearer. The PIP activities and descriptors were designed and formalised in 2012 but have not been the focus of a review since.

> “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[220]

Modern-day living, in particular the advancement of technology has reshaped almost every aspect of human life. From setting alarms on smart devices to the everyday use of assistive technology, our daily routines now intertwine seamlessly with digital innovations. These transformations extend far beyond mere convenience and for many disabled people they have fundamentally altered how they communicate, work, and live. For example, the closure of so many local bank branches and the move to an online banking experience. For some disabled people this is a huge advantage and for others who cannot manage a bank account or be responsible for financial transactions such as paying bills, the move to everything being done in an App can further disable them in society.

Consideration is required with regards to both the ‘digital divide’ and how a disability or condition may make the use of everyday technology progressively more difficult. For example, when discussing the potential benefits of an online portal to track progress of an Adult Disability Payment application or re-determination, a person from the Huntington’s Disease Association suggested that trackers being online would be challenging for people with Huntington’s disease. As the disease progresses they may no longer be able to use online systems. Some members of the Neurological Alliance stated that ‘increasing use of the internet by authorities can be challenging for people with neurological and mental health conditions and this needs to be recognised’.[221]

One RNIB Scotland client suggested that the use of technology to assist blind and partially sighted people must be considered carefully. Whilst some visually impaired people might readily use mobile phone technology and navigation software to plan and follow a route, the level of use will vary considerably among people with sight loss. The availability of technology and other aids for personal use to plan and follow journeys may not be useful for every visually impaired individual.

Technology is an obvious consideration in terms of modernisation and relevance. However, the most prevalent theme within the 'daily living activities' element of the online consultation was suggestions for other activities to be included in the activities and descriptors and become part of the decision-making process. Respondents to the online consultation suggested 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. Calls were also made at engagement events for the eligibility criteria to be more aspirational and modernised. Participants suggested additional areas to include could be housekeeping, IT literacy, quality of life, communication support, filling in forms, and being part of a community. Several people asked that 'household cleaning' be included. They were concerned that even though people may be at risk if not cleaning their house, it is not currently considered in the eligibility criteria.

> “This is something that is assessed for social care and having a clean and tidy house is deemed to be a basic necessity. 'In our experience, people often use the benefit to pay for cleaners. This can be a key issue for people with mental health conditions and can also be a good indication of the severity of a condition. Hoarding can have an impact on people’s ability to access their kitchen, bathroom etc. but there is no scope for that within the criteria.” – The Action Group & VOCAL & Grapevine at Lothian Centre for Inclusive Living, response to the Independent Review of Adult Disability Payment, review of the mobility component[222]

There appears to be a general desire for changes to be made to the activities in the daily living component to ensure they gather relevant information about a wider range of conditions, consider the broader impacts of a condition on modern daily living, reflect people’s lived experience of real-life scenarios, and reduce confusion around fluctuating conditions.

Adopting a human rights social model of disability

Scotland has an opportunity to create a world-leading, rights-based system of social security for disabled people and this Review plays an important role in outlining ways in which the current eligibility criteria can be more reflective of a social model to better reflect the real-life experiences of disabled people in Scotland today. According to the human rights model of disability, disability is a social construct. It is the barriers within society, rather than personal impairments, that exclude disabled people.[223] This model does not allow the exclusion of persons with disabilities from the community or from any area of life for any reason. The UNCRPD has noted that the failure to understand and implement the human rights model of disability is a major cause of discrimination and exclusion of persons with disabilities in society.

When considering alternative approaches to the current system, several respondents to the consultation advocated a move away from the medical model of disability. It was argued that moving away from this medicalised and deficit-based approach is necessary to help facilitate a more rights-based approach in Scotland.

The Scottish Government has committed to a human rights-based approach to social security which includes adopting this approach in the evolution of Adult Disability Payment and ensuring a system that focuses on removing the barriers to people's rights to equal participation in society and independent living. As part of this shift to a human rights-based approach, it is important that social security for disabled people supports a person's right to independent living.[224]

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

The eligibility and decision-making criteria have been reviewed by me, and 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. The Independent Living movement in Scotland defines independent living as:

> "all disabled people having the same freedom, choice, dignity and control as other citizens at home, at work and in the community. It does not necessarily mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life."[225]

However, on their own, neither the medical or the social model is adequate, although both are valid. Disability is always an interaction between features of the person and features of the overall context in which the person lives. In other words, both medical and social responses are appropriate to the problems associated with disability; we cannot wholly reject either kind of intervention.[226]

A better approach would be one that merges what is relevant in the medical and social models without making the mistake of reducing the holistic, personal life experience and real-life impact of a person's condition or impairment on their daily life, to a set of inflexible deficit-based criteria.

For example, following the online consultation a perception was expressed by a few that the form or decision-making process was overly focused on those with physical disabilities.[227] Respondents felt this made it harder for others to be awarded points, as the questions were not aligned to their situation. It was felt those with mental health problems would experience this, and a view raised in a few events was that the current eligibility criteria are not accurately capturing the needs of neurodivergent individuals or those diagnosed with mental health problems such as anorexia or bulimia. It was suggested during one engagement event that a mental health question should be included alongside each activity.

The deficit-based approach to determining eligibility for Adult Disability Payment is an issue that many people consider when deciding whether to apply. People living with long-term conditions told me 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. This can have a devastating impact on their sense of self and mental wellbeing,

> "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[228]

> "It feels like you're having to beg for help." – Individual, MS Society Scotland response to the Independent Review of Adult Disability Payment Call for Evidence[229]

At a few consultation events, participants highlighted the need to avoid using a deficit-based model in the questions on the application form, and instead introduce more questions grounded in a social model.

Parkinson's UK Scotland, for example, would welcome a move away from the reductive task orientated system towards one that provides a much more person-centred approach to capturing how an individual's condition affects them and the way that they are able to live their life in light of their conditions or impairments.[230]

Without any doubt the current criteria and decision-making processes should be reviewed to further embrace a social model of disability, acknowledging that disability is a socially created problem and not an attribute of an individual. The existing eligibility criteria descriptors for Adult Disability Payment are more closely associated with the medical model of disability. For instance, descriptors that refer to people who 'can stand and then move unaided more than 20 metres but no more than 50 metres either aided or unaided' or 'who need assistance to be able to wash either their hair or body below the waist' are not consistent with a social model approach. 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 a social model can make when framing questions.

An individualised decision-making model

Many disabled people are keen on a system where someone's overarching need for help is looked at, rather than looking at specific activities. This is because some things don't get captured by the current system or the current activities that are considered by case managers. There was a strong call for a system that assesses the support that people need to achieve the best possible quality of life across a range of parameters that are determined by them.

I recognise that a more individualised decision-making model is likely to lead to more detailed questions, responding to which may feel more onerous for the applicant and that the consideration of responses may lead to outcomes which are potentially subjective and may be inconsistent. Steps would be required to ensure consistency and fairness across the system.

> "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[231]

People finding it hard to see how the activities relate to their own lives, was an issue raised by several consultation respondents.[232] Most commonly, it was noted that support was needed to help people describe their situation or the impact of their condition effectively within the context of the activities, or that relevant daily activities were not included.

The main request arising from the online consultation was for a more holistic, person-centred and flexible approach to decision-making, considering each application holistically, including the wider context of clients' lives and circumstances. Several people feel that the current system used to understand disabled people's needs is not fit for purpose. The use of arbitrary measures with little or no flexibility do not fully consider the frequency or the impact that symptoms have on a person, and as a result should not be used as a means of deciding what level of support they should receive. The only way to achieve this is to adopt a more person-centred, holistic decision-making process.[233]

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

Taking a holistic approach is important when considering fluctuating needs to ensure that the decision is not simply a 'snapshot' of a person's needs but considers those needs over a suitable period of time to gain a complete picture and full understanding of the implications of their condition and circumstances.

The need for holistic, wellbeing and quality of life-based criteria that reduces the need for people to envisage hypotheticals that they do not fully understand was the prevalent theme in discussion with CAS advisers working on the frontline.[234] A more holistic decision-making framework would put more weight on the depth of the information gathered, rather than the breadth of it.

When considering how social security is awarded in other countries, I looked at Sweden's welfare system which is known for its universalistic approach, where everyone has access to similar levels of benefits and support. For disability benefits, Sweden uses a needs-based approach with universal criteria for all citizens. Decisions are made through a series of assessments focusing on medical, social, and economic factors to ensure that decisions are holistic.[235]

A potential model for how such a decision-making process might be framed is provided by the legislative framework governing assessments of social care needs in England under the Care Act 2014.[236] Although the provisions in the Care Act have no legal effect in Scotland, as health and social care is devolved, it is a model worth exploring in relation to the way assessments are carried out and decisions made.

Woven through the tapestry of the Care Act, are eight fundamental principles to consider when undertaking an assessment and determining eligibility:

- strengths-based approach
- transparency
- whole family/holistic
- maximise person’s involvement
- recognise fluctuating needs
- promote individual choice and control
- appropriateness
- proportionality.

Adhering to these principles ensures that the decision is person-centred and promotes individual wellbeing. In the guidance for decision makers, it states that: ‘Your assessment style should therefore not be one size fits all, but adapted to the individual’s circumstances, needs (communication needs, levels of complexity etc) and preferences.’[237]

In a roundtable session where I brought together stakeholders from the fields of social security and welfare advice, we looked at the benefits and drawbacks of adopting a more holistic and all-encompassing decision-making process based on a conversational assessment, with the decision, in relation to an award being made, determined by a health care professional. Although there are definitely some benefits to be gained from providing an opportunity for a person to talk about their whole life and describe in a less restrictive format the ways in which their disability or impairment impacts on their daily life, the overwhelming sentiment was that this would involve a backwards step by reintroducing, by another name, DWP-style assessments. It would also introduce more subjectivity to an already inconsistent decision-making process and make it far more difficult to challenge a determination. No-one was in favour of this.

> "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[238]

However, there are some overarching principles that could be adopted by the Adult Disability Payment system in Scotland that would enhance the experience and increase the probability of all those who are eligible for support getting what they are entitled to:

- 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

As already noted, disability benefits in the UK and Scottish social security systems currently use an impairment (or deficits-based) approach to establishing eligibility. When the UK Government introduced PIP, assessments to determine eligibility were explicitly defined as 'a functional assessment of a capability'.[239]

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.

As identified in a search of existing literature commissioned by the Review Secretariat, it appears that work hasn't been conducted 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). While different approaches to decision-making and criteria/eligibility were considered, either as part of formal government reviews or as suggested 'good practice' approaches, the use of outcomes-based eligibility criteria did not tend to be considered.

Conversations around an outcome-based model tend to focus on trying to attract more disabled people into the workforce, rather than being a feature of any eligibility criteria for non-occupational disability benefits. For example, Re:State have highlighted that:

> “[The separation of benefit eligibility and capability for work] would enable the work capability assessment to be a more positive and personalised conversation about what a claimant could do with support. It facilitates a more open, constructive dialogue between claimant and an appropriately trained adviser in which together they can devise a support package tailored to that individual claimant’s particular needs and circumstances. This, it has been argued, is key to enhancing the relationship between the claimant and adviser to advance the former’s return to work.”[240]

The Scottish Government published a report[241] in 2018 which compares aspects of financial support models for people receiving disability benefits in five countries: Denmark, France, New Zealand, Norway, and Sweden. These countries were chosen on the basis of the comparability of their disability benefits to those being devolved to Scotland at the time of publication. When considering the available literature, two French and Australian disability benefits do take outcomes into consideration as part of the assessment process. However, it is difficult to consider either of these models as successfully delivering a service based on an ‘outcomes-based eligibility criteria’, as outlined below.

Whilst not explicitly an ‘outcome-based’ model, the French ‘Prestation de compensation du handicap’ model does consider the outcome of the decision as part of the assessment. The client is still required to demonstrate they have an:

> “absolute difficulty’ in carrying out one activity from a list including elements of mobility, personal conversation, communication, tasks and general requirements and relationships with others, or a ‘serious difficulty’ (requiring assistance) in carrying out at least 2 of those activities.”[242]

> “[A multidisciplinary] team is responsible for assessing the disability of the disabled person by means of a scoring guide for the assessment of disability and impairment of persons with disabilities. They also assess the claimant’s compensation needs on the basis of their projet de vie, or ‘life plan’. The Life Plan is a fundamental element of the assessment process and gives claimants an opportunity to outline their aspirations and the kinds of activities which would increase their quality of life, but which they cannot currently undertake as a result of their disability. The team may have to meet with the disabled person, their parents if the claimant is a child, or their legal representative. They may also visit the claimant’s home or place of work. However, face-to-face forms of assessment are not always necessary, and the team often meets without the claimant present.”[243]

The Australian model is intended to be outcome-based. However, Dr Kate Anderson (Senior Research Fellow at RMIT University, Melbourne) argues that this principle is rarely applied in practice and notes that there is a gap in available knowledge required to definitively state why this is:

> "The voice of [National Disability Insurance Scheme] planners is rarely heard in research, so it's hard to know why the strengths-based approach isn't taken more often. However, suggested reasons include a lack of disability expertise and unclear eligibility criteria. Planners may also be safeguarding against potential sympathy bias in providers' recommendations, although there is little evidence to show this bias exists in practice." [244]

This does highlight the importance of ensuring case managers have sufficient training and clear guidance, in order to be able to apply an outcomes-based approach, if adopted.

Upon completing a search for existing literature which addresses outcomes-based eligibility criteria for non-occupational disability benefits for adults, knowledge gaps (particularly with regards to international approaches) are evident. 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 would be required to have an advanced understanding of the conditions of the people they are determining eligibility for. Therefore, this approach would likely require input from multidisciplinary teams.

While not a recommendation of how an outcome-based decision-making process would look in practice, Annex 1 provides an example of the types of questions and considerations that could potentially be applied to the current activities and descriptors to enable a more outcomes-focused approach.

Alternatives to a points-based system

The points-based system used for decision-making is widely disliked. When considering alternative approaches to a points-based system, several respondents advocated a way of measuring need and/or eligibility to be based on a social model of disability. It was argued that moving away from the current approach was necessary to help facilitate a more rights-based approach in Scotland, which could benefit disabled people's wellbeing through increased trust in the system.

> "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 ADP." – Health and Social Care Alliance Scotland (The ALLIANCE), response to the Independent Review of Adult Disability Payment Consultation[245]

At present Adult Disability Payment mirrors PIP eligibility criteria. When the UK Government introduced PIP, it noted that a key purpose of the eligibility criteria was to target support to those most in need and to be ‘financially sustainable’.[246] It noted that in introducing PIP, it expected that the number of people previously in receipt of DLA would reduce as a result.

The 2020 SCoRSS report states:

> “We should not be confined to what has been done before. Scotland should take a more flexible approach than continuing to utilise a points-based deficit system. Measuring a disabled person’s need for support by their ability to complete simple tasks does not align with the Scottish Governments stated position that social security is an investment in society.” – Scottish Campaign on Rights to Social Security[247]

Many organisations in Scotland who responded to the consultation including The ALLIANCE have consistently advocated for the removal of a points-based system. They state that:

> “…whilst a points-based system may be easy to administer, it does not necessarily sit well with a human rights-based approach to social security or with the provision of adequate support. Whether fairly or not, people may perceive a points-based system to be rooted primarily in controlling costs for the government, rather than ensuring the right support is given to disabled people. In particular, there is potential for serious psychological distress where individuals fall only marginally short of a required number of points, risking giving the sense that they are ‘disabled, but not disabled enough’ to justify support.” – Health and Social Care Alliance Scotland (The ALLIANCE), response to the Independent Review of Adult Disability Payment Consultation[248]

Despite this strong argument for change, I haven’t been able to find another suitable and effective way of measuring eligibility that would:

- be more dignified for disabled people
- mirror a human rights 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.

One comparator is how benefits are awarded to people with industrial injuries. Industrial Injuries Disablement Benefit (IIDB) is a payment for people who are disabled as a result of an accident, disease or event that happened at work, in connection with work, or whilst on an approved employment training scheme or course. IIDB's percentage system enables a calculation in order to work out the level of disablement resulting from occupation taking into account loss of function due to other factors. It also allows multiple occupational diseases/injuries to be aggregated together to work out overall entitlement. There's not a lot of information publicly available on rationale behind the percentage system beyond this but, interestingly, a 2014 external review of assessing disablement under the Scheme found:

> "It is not clear if the commonly assigned percentages as a measure of disablement suggest a level of linearity and interval spacing in the disablement scales that is not, or cannot be, reflected reliably in other measures of functional ability… a review on the scientific base of functional disability assessments might shed more light on this." – Industrial Injuries Advisory Council[249]

As far as I can tell, no further review on this specific question has been undertaken. Some other countries' equivalent systems use a points-based system rather than a percentage-based system to calculate entitlement. However, they also assign certain conditions and injuries a value which corresponds, in most cases, to value of payment as it is the case for IIDB.

If we accept that some form of awarding points to aid decision-making, is to remain then there are some issues to be addressed that could potentially improve the client experience and ensure further transparency.

Calls for greater transparency in how points are allocated were made at a few events. It was noted that the descriptors used to allocate points, are not currently included anywhere in the Adult Disability Payment application form. It was suggested that the descriptors and corresponding points should be included on the application form to help people understand the points system and why they are being asked the questions. In turn, this may enable them to understand what information about their condition and daily needs is relevant or helpful to include in their application. One of my recommendations in the Interim Report[250] states 'although available online if searched for, consider how to make the activities and descriptors and associated points more prominent and accessible for applicants.' This will be reinforced in my final recommendations.

Several people who responded to the online consultation suggested that people with certain conditions may find it more difficult to gain points. These included those with mental health problems, learning disabilities, neurological conditions such as ME/CFS, neurodivergent individuals and those with ADHD or Long Covid. In addition, it was suggested that features or symptoms of those conditions could result in people having a limited understanding or clarity about the daily living activities and how they applied to them, potentially leading to points not being awarded.[251]

There have been calls to address some of the perceived anomalies in the current system.

For example, in the moving around activity the focus of the scoring system is on the distance someone can walk, aided or unaided. This means more points are awarded for someone being able to walk up to 20 metres without an aid (10 points) than someone who can walk the full 20 metres with an aid (8 points). People are therefore awarded more points if they can walk further, but with help, than a lesser distance without an aid.

> "In reality, if someone needs an aid in order to walk, whether that's a walking stick, a crutch or an ankle foot orthosis, they have less mobility than someone who does not need an aid to walk." – Neurological Alliance of Scotland response, to the Independent Review of Adult Disability, review of the mobility component[252]

Another anomaly relates to the awarding of two points to all activities that require the use of an aid or appliance except in one case which 'requires the use of an aid to be able to manage medication', and which is awarded only one point.

Some other apparent anomalies were pointed out to me including:

- the allocating of three points for help getting in or out of an un-adapted bath or shower - as this is a relatively high number of points allocated to a task some people I spoke to question the logic
- why there is only one assessed activity in the full suite that awards one point and three points respectively - one welfare adviser told me that they view the one-point descriptor as just as serious as the equivalent descriptors in other activities which are worth two points, stressing that 'it can be very frustrating when people receive seven points and are only one point short of an award'
- if a person needs to sit down to prepare a meal, this counts as an 'aid' for preparing food but not for dressing and undressing.

It was also noted that points are not awarded for nuance. One participant told me that:

> "they ask if you can catch the bus, yes but how do you do this? If the bus doesn't stop where my (...) thinks it should, then (they) completely freak out. (They) can manage if we can rehearse it, practice it. But that doesn't get you any points."

I considered several possible alternatives to a points-based system to address the argument that the current PIP eligibility criteria are out of date and not fit for a human rights-based system. This included starting from scratch with a blank sheet of paper; considering the application of the International Classification of Functioning, Disability and Health[253] (as is used in other countries as a way of assessing eligibility for social security amongst other things) and considering the way social care assessments and decisions are made in England.[254] None of these options, on their own, address the challenges inherent in the current system and so I have concluded that it is in the best interests of disabled people to balance the improvements any proposed changes will bring, with the potential issues that such changes may cause. Significant changes could create further anxiety and result in some clients being further disadvantaged. I have been told by many stakeholders that although we have an imperfect system, it is a system that a lot of people are familiar with, and welfare advisers are nervous about significant change unless there is a very clear and substantial benefit to clients as a result. Change for change's sake is not desirable. This is not to say that changes to the system should not be made, and the following recommendations confirm this view. However, the impact of any such changes should be carefully considered.

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 current Adult Disability Payment rules, an activity descriptor is deemed to apply to a person with a condition if it reflects how their condition affects them for more than 50% of the required period (one year). For some clients with fluctuating conditions for a wide range of reasons it can be difficult to quantify how your condition affects you in such a set way. People with unpredictable conditions, for example ME, multiple sclerosis (MS), or epilepsy, may not always have acute symptoms that fit neatly within this rule. Nevertheless, they require support when symptoms do occur and/or because they manage their condition or disability in a way that results in them needing support irrespective of the amount of time they are experiencing an issue.

The term 'fluctuating condition' covers a wide variety of symptoms, impacts and outcomes. Within any single condition there is significant variation in people's experiences of fluctuations and the impacts on their lives. Individual experiences of fluctuating conditions are shaped by the frequency, duration and extent of change on what they can do and achieve on any given day, and what happens in the context of their lives when this occurs. What is consistent across the experiences described to me, is that the impact on day-to-day life is unpredictable and variable and therefore subject to uncertainty.

While many stakeholders acknowledge that there have been changes made to improve how applicants experience the process of completing the application, these changes have limited or no bearing on how much Social Security Scotland understands the impact of fluctuating conditions. Several respondents gave positive feedback about the fluctuating conditions section of the application form, stating they welcomed the broader range of conditions, found the contextual information helpful or felt it improved the previous application form.[255]

Many people with MS who took part in the Review have also welcomed the changes to the application and consultation process but the overwhelming feedback the MS Society has had is that while there has been some changes to how fluctuating conditions are considered, when compared to PIP, these will have minimal or no impact as they do not go far enough to recognise the true needs of people living with fluctuating conditions.

People with MS and other fluctuating conditions may incur additional costs as a result of their health condition and some of these costs will be incurred to mitigate the impact of their symptoms on their worst day, regardless of how often these days happen. A 2022 MS Society survey found that nearly a third of people with MS sometimes could not afford to eat balanced meals while others have had to reduce or give up altogether treatments or therapies.[256] These treatments and therapies play a vital role in managing an individual's MS and keeping them as well as possible.

Based on feedback, it is evident that many people with fluctuating conditions find the current application form challenging when trying to describe the changing levels of impairment that they experience. Some stakeholders told me this results in frustration, and a sense of unfairness and inequality for clients with such conditions.

Many people commented on the difficulty of understanding the criteria for fluctuating conditions, which they felt were unclear and overly complex. Respondents to the online consultation highlighted the formal, overly complicated language, including using fixed or confusing statements and the lack of examples or sufficiently detailed guidance. A common suggestion was to simplify or further clarify the criteria.[257]

Respondents also called for a more open-ended approach to allow clients to express themselves in their own way. A key concern was for the application form to allow sufficient space to adequately describe the impact of the condition or multiple conditions.

The DWP wanted to develop an improved evidence base and understanding of applicant experiences of fluctuating conditions. Its research, published in October 2024,[258] set out to understand the best way, within the disability application and assessment process, to capture the impact of conditions which fluctuate.

The research highlighted:

- the complexity of living with conditions that fluctuate over time and the impact this has on an individual’s life
- the difficulty in describing fluctuations – their physical, emotional, and cognitive outcomes, and impacts of these on daily life.

Through the research the DWP identified four potential areas in which the application and assessment process for disability benefits could be strengthened. These included:

- improving the questions asked of applicants within the application and assessment process accounting for variability, triggers and actions taken to manage conditions
- providing greater flexibility in the application and assessment process including the timing and format for applicants to provide evidence of the impact of their conditions
- ensuring health disability assessors receive training on predictability, manageability, and varying fluctuation cycles experienced by many applicants
- providing support and guidance to help clients describe the impact of fluctuating conditions through the process.

An ongoing cycle of fluctuation with five constituent elements was identified. This framework for understanding fluctuation may be helpful in staging conversations with clients going through the Adult Disability Payment process to support a better understanding of the nature and impacts of life with a fluctuating condition.

Those five elements are:

- underlying condition(s) – the foundation that causes differing degrees of predictability and manageability of a condition
- trigger – a trigger can bring on, worsen, or change a condition at a certain point in time
- manage – actions that are taken to both prevent fluctuations or flare-ups and/or reduce outcomes
- outcome – the level and duration of a variance in physical, cognitive, and emotional ability
- impacts – how the variance in physical, cognitive, and emotional ability influence an individual’s current and future ability to undertake daily living tasks and responsibilities such as work commitments or social activities.

Many people I spoke with have described how living with a fluctuating condition is complex, requiring them to monitor and manage changes in capability so they can undertake routine daily living tasks in a way that causes them no further harm. Which activities an individual undertakes can have implications for themselves and those around them for example, using energy for one activity can reduce or rule out someone's capacity to undertake another activity.

In a meeting with Inclusive New Normal[259] I was told how essential it is to develop a clearer understanding of the consequences of engaging in physical activity, particularly the post-exertion effects. These effects, when combined with cognitive impairment, brain fog, and energy depletion, can lead to post-exercise malaise. This condition may leave individuals unable to function for several days and there is a risk that the impact of the activity causes permanent harm.

> "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[260]

Other recurring themes include:

- describing fluctuating conditions can be hard for many, especially when the condition itself makes engaging in complex communication more difficult
- time limits to complete the application make the activity more challenging; one person said that the application was hard to complete due to intermittent fatigue, so they had to spread the completion of it over a period of time – the deadline then became stressful
- the importance of asking about the impacts of daily activities on people with fluctuating conditions, rather than just asking whether certain tasks can be accomplished
- mental health and physical health can fluctuate independently of each other, in differing directions or one being more stable while the other varies
- when experiencing a flare-up, physical and emotional energy can be significantly limited, reducing the ability to solve problems, communicate or do activities that may be required 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, including fluctuating conditions, to help them understand the impact on the life and wellbeing of the client
- the belief that the 50% rule is not a useful measure and should no longer be used.

The 50% rule remains controversial, as one participant told me:

> "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."

Clients must show they meet a descriptor on over 50% of days in a 12-month period. This can be quite challenging for people to understand and even more difficult for them to articulate, as fluctuating conditions have different impacts over time. Welfare advisers suggest that it may be helpful to adjust the ways in which questions are asked to help people express the amount of good and bad days they experience, what effects this and what effect this has on what they can and cannot do. For many people activities can be achieved on some days and not others. They may be achieved without triggering further symptoms (such as pain, stress or significant energy decline) on some days and not others. Fitting this complex life experience into a 50% rule to many people, just doesn't make sense. As one person put it:

> "the current system only achieves a pigeon-holing of people into holes that don't always fit." – Individual, response to the Independent Review of Adult Disability, review of the mobility component[261]

Some stakeholders feel very strongly that using the 50% rule does not provide an accurate picture of how a person's condition is impacting on them, and it has the potential to deprive them of the financial means to effectively manage their condition.

CAS has identified that certain impairment types, such as unpredictably fluctuating conditions, are at greater risk of being refused what is often a lifeline award or being awarded benefit at a level that does not reflect actual need.[262] Emerging patterns in Adult Disability Payment application data supports some degree of consistency of award refusals across less visible, fluctuating conditions, with an additional likelihood of refusal for characteristically unpredictably fluctuating conditions such as the various forms of inflammatory bowel disease.[263]

Some stakeholders suggested 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.

The MS Society would endorse a more person-centred holistic approach. Rather than trying to measure the presence of a fluctuating condition 50% of the time, the eligibility criteria should focus on how the fluctuating condition impacts the applicant on their worst days.

> "The current system does not adequately measure the support needed for people with fluctuating conditions like MS, post-polio syndrome, epilepsy and ME. Therefore, by taking on a more person-centred approach, looking at what can be achieved on a 'worst day', would allow many more people with a fluctuating condition to access higher rates of financial support." – Neurological Alliance of Scotland Response to the Consultation on the Mobility Component[264]

Another good example of this comes from people living with PMDD. Symptoms are not present all the time and the prescriptive nature of the application process makes it difficult for people with PMDD to evidence the impact of their condition. Although the symptoms of PMDD are present for one-to-two weeks per month (every month), it is known to have a debilitating impact on all aspects of life, even when symptoms are not present. This, however, can be challenging to demonstrate.[265]

However, even when describing 'worst days', there appear to be differing views amongst people affected by PMDD and those supporting them:

> "The top tip that I was told is to write it from the perspective of your worst days." – Participant with PMDD, quoted in Premenstrual Dysphoric Disorder and the welfare state: recommendations for reform[266]

> "People do always say you should take your worst day. But actually you shouldn't. I've been in so many tribunals where people have come across like they've exaggerated." – Professional stakeholder, quoted in Premenstrual Dysphoric Disorder and the welfare state: recommendations for reform[267]

SAMH[268] and other stakeholders recognise that replacing the 50% rule is a significant challenge, with competing demands to design a social security system that balances fairness and objectivity, with the complexities of individual circumstance. However, if it is to be done then now is the time – replacing the 50% rule as part of a wider reform of Adult Disability Payment.

My overriding sense when considering people with fluctuating conditions is that each person will experience similar situations differently. This applies to everyone, not just those living with fluctuating conditions and further supports the suggestion that a more holistic and personalised approach to eligibility might be better than the current narrow way of doing things. What is clear is that the additional costs incurred to mitigate a person's worst symptoms have to be met on the vast majority of days as people don't know when or to what extent these symptoms will be impacting on their ability to complete tasks of daily living. A more flexible approach that considers frequency as well as severity of impact, without an arbitrary threshold, may represent an improvement. In line with a human rights social model of disability it may be more appropriate to explore the wider causes of fluctuating need as needs may fluctuate not just because of a condition but also because of changing circumstances such as changes in home environment, relationships, employment or wider societal things such as the Covid-19 pandemic.

> **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[269] has advocated for introducing a substantial risk provision to Adult Disability Payment, much like there is a substantial risk provision for the Work Capability Assessment (see below). 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 Universal Credit. 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. However, the only similarity between the Work Capability Assessment and the decision-making process for Adult Disability Payment is that both use a points-based system with a series of functional activities and descriptors to establish eligibility.[270]

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.[271]

CAS advocate introducing a substantial risk provision to Adult Disability Payment would be beneficial for several reasons. These include providing an additional level of safeguarding for potentially vulnerable clients.

Whilst the UK Government's substantial risk provision for the Work Capability Assessment operates within the context of means-tested benefits, entitlement to Adult Disability Payment is intended to meet the extra costs of having a disability or health condition and does not depend on being in or out of employment.

Despite the differences between the purposes of these benefits, 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. However, this does depend upon the extent to which the Scottish Government keeps a purely functional assessment model for 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.

Eligibility criteria – activities and descriptors

Rules that decide whether someone is entitled to Adult Disability Payment are called the eligibility criteria. Adult Disability Payment is made up of two parts, a daily living component and a mobility component.

During the Review consideration was given to the benefits or otherwise of combining the two parts. However, there was no call for changes to be made and no evidence to suggest a merger of the two components would improve the client experience.

As outlined previously, consideration was also given to creating a totally new framework for the eligibility criteria. This was ruled out on the basis that the negative impact from the disruption and confusion that would inevitably result would outweigh the benefits of such an approach. In addition, any newly devised system would still ultimately require some form of measuring and scoring against a set of criteria and therefore stakeholders could not see any merit in simply replacing one system with another.

What is clear however is that there is an overwhelming expectation because of this Review, for the inherited PIP criteria to be improved to sit more comfortably with the aspirations set out in the Charter and to ensure that Adult Disability Payment is fair, transparent and supportive, empowering those it serves to live with dignity and independence. As already recommended, the eligibility criteria should be reviewed to address the anomalies and to ensure a modern, outcomes-focused and more realistic approach to determining eligibility based on a social model of disability and the principles enshrined in the UN Convention on Human Rights.

Daily living component

Following the consultation and call for evidence, many respondents considered the rules, the nature and wording of the daily activities, and how these are asked about in the Adult Disability Payment application form, as one and the same.

Key findings on the Daily Living activities include:

- views on the clarity of the rules for the daily living part of Adult Disability Payment were mixed – one third (35%) of consultation respondents agreed that the rules for the daily living part of Adult Disability Payment are easy to understand, just under half (48%) disagreed and 17% were unsure

- reasons for disagreeing included vague terminology, difficulties relating the activities to real life, and difficulty applying them to fluctuating conditions or other specific conditions like Long Covid, ME/CFS, autism spectrum disorder, or mental health 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
- consultation respondents suggested making the activities more inclusive of all conditions, including fluctuating conditions, and ensuring that the criteria reflect the needs of those who currently feel underrepresented by the application process.
- There were also calls for greater transparency about the point allocation.[272]

> "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[273]

Mobility component

While it was acknowledged in the consultation on the mobility component that the Scottish Government has sought to make the application form guidance clearer the strength of feeling in relation to the way mobility is determined is the prevailing theme.

The second most prevalent theme, raised by several, was that the criteria would benefit from a clearer definition of what moving means. A few respondents specifically requested clarity on the difference between 'aided' and 'unaided' movement. Respondents suggested using open questions that ask about movement, what people rely on to get around, and how people get around such as speed and with what aids.

A common overarching theme was a call to include a range of additional impacts reflecting clients' lived experiences before, during and after moving around. Respondents suggested considering:

- 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
- as others mentioned, 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.

The final section of the report is concerned with specific issues with reference to the activities and descriptors.

Daily living component activities

Activity 1 – Preparing food

This activity considers an individual's ability to prepare and cook a simple meal from fresh ingredients. Case managers will consider whether the individual uses aids or appliances such as a perching stool, or impaired sight utensils and whether they use a cooker or a microwave, and whether they require any help. 'Cook' in this section means to heat food at or above waist height on a standard height cooker hob or using a microwave, and 'prepare' means to make food ready for cooking or eating. It does not consider an individual's ability to bend, access food or utensils from cupboards, move around the kitchen, hear (if visual kitchen indicators such as a flashing light instead of sound could be used on a kitchen appliance), food presentation, shopping for food or use of an oven to cook food.

As with other criteria the factors considered here are very focused on physical ability. For example, 'in this section 'cook' means to heat food at or above waist height on a standard height cooker hob.' The criteria are not concerned with the outcome, only the activity itself.

Despite prompting being captured in the reliability criteria, some people felt that there is no consideration given to the relevance of mental health barriers to preparing food, things like motivation and psychological fatigue. 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.[274] For example, someone who is experiencing a serious mental health problem may not be motivated to eat or to get out of bed. The descriptors could be re-worded to include mental health and neurodiversity.

Many people with eating disorders reported that the food and nutrition related descriptors do not work for them. I met with a clinician from an eating disorders clinic who illustrated the ways in which people can fall through the gaps of the current criteria and find themselves without the financial support that they need. More general considerations include the fact that the criteria do not consider the ability of a person to access a diet likely to optimise health.

In certain activities such as food preparation, the effort required to complete these activities often outweighs the benefits. For example, consuming a prepared meal. For such situations, support from other people can be the deciding factor in determining whether a person chooses to expend the energy on an activity.

Two organisations raised issues with the preparing food activity, with #MEAction Scotland reflecting it was unclear if all the tasks involved in achieving an activity are considered in the application form or decision-making process. They highlighted that tasks involved with this activity should also include preparation and clearing up of equipment, utensils, work surfaces, washing up, drying and putting away after each meal, washing, cleaning the area and paying for food items in a shop, with all that entails, including getting there and back and waiting to pay.[275]

Shopping for food is not currently considered in the ‘preparing food’ activity. Many respondents to the consultation raised the point that if a person is not able to shop for food, they cannot prepare it or eat well.[276] Online shopping has made this easier, but there is a cost attached and not everyone has the digital or cognitive skills to be able to do this.

One disabled person felt that although someone may be physically able to make a meal, they may need emotional support to ensure that the meal is healthy and currently this isn’t considered.[277] They highlighted that if you cannot cook a simple meal using a conventional cooker, but can do so with a microwave, you score two points. However, if the microwave meal is overly processed and lacking in nutritional value it is not a balanced, healthy meal.

Without prompting, some people may avoid eating, etc., to the point where that becomes detrimental to health. Cognitive dysfunction can be present, and prompting may be required to follow preparation and eating processes. This is particularly relevant for people with an eating disorder. Taken together, these circumstances should currently score points, but some people applying for Adult Disability Payment may not realise this.

Other related issues raised include:

- preparing a ‘simple meal’ could mean beans on toast every day
- specific digestive needs 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[278]
- there can be significant physical costs after exerting energy needed to prepare and cook a simple meal –

> "assistance may be required for an individual who is unable to cook due to lack of energy, or the risk of fatigue or delayed fatigue. It would therefore be unsafe for them to do so." – #MEAction response to the Independent Review of Adult Disability Payment Consultation[279]

- slow cookers which are not mentioned can be safer, as can air fryers, instant pots, etc., which are also more energy efficient
- memory or cognitive issues are not always accounted for; 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 (I note that the under the current reliability criteria, a person presenting this case should be considered as unable to prepare food to an acceptable standard)
- 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 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
- aids/adjustments could include frozen chopped vegetables, ready meals, pre-prepared food.

> "Again, it is the 1-size-fits-all approach. I can make a cup of tea. I cannot remember when or where I put it. But that does not matter. The box is ticked." – Individual, response to the Independent Review of Adult Disability Payment Consultation [280]

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

This activity considers an individual's ability to be nourished either by cutting food into pieces, conveying food and drink to the mouth, then chewing and/or swallowing, or through the use of therapeutic sources. The defined term 'taking nutrition' refers solely to the act of eating and drinking. The quality of what is being consumed is not currently relevant, as long as it is capable of providing nourishment. The guidance says 'this should be distinguished from a client choosing to eat an unhealthy or restricted diet, to eat to excess, or to avoid certain foods due to dietary requirements'.[281]

There was a fair bit of discussion about the ‘taking nutrition’ activity in my meetings with stakeholders and at some of the consultation events including the point raised a few times 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 that the two food-related activities should be flipped because the questions on the application form are repetitive, cover the same ground and clients report that they often are saying the same thing in response to both questions.

Some people felt that this activity does not take into account 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 (this may particularly be the case for people with mental health problems). I note, however, that people who need prompting to eat the food in front of them would currently score points under the current eligibility criteria.

One person who shared their story with me lives in a supported living facility with a communal dinner hall. These facilities do not give people the choice to be able to prepare food for themselves, so it makes the preparing food activity/descriptor-related questions difficult to answer.

Many people feel that the ‘taking nutrition’ descriptor is too narrow. For example, if someone is eating unprompted but only eating crisps and biscuits, they do not get points. We heard during the consultation that if someone has diabetes and cannot afford appropriate food, such as good quality carbohydrates, this can result in poorer health outcomes.

The current rules do not consider the nutritional content of the food being consumed, only that the client is able to consume any food, which many people feel is not sufficient. However, defining a ‘healthy’ meal is a contentious issue. 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 in order to better manage their health, rather than eating what others might say constitutes ‘a healthy meal’.

The benefits of healthy eating, active living and maintenance of a healthy weight are widely recognised and directly associated with a wide range of health benefits.[282]

> “The impacts of poor diet and overweight are profound. They affect not only our health, but also our ability to lead happy, fulfilling lives. They have also led to increased, unsustainable demand on the NHS and other public services.” – A healthier future: Scotland's diet and healthy weight delivery plan[283]

The Scottish diet remains stubbornly unhealthy, and we are far from meeting our dietary goals.[284] This has a direct impact on levels of overweight and obesity – and therefore health harm – in the population.

Progress towards the Scottish Dietary Goals has been slow. Around two-thirds of all adults in Scotland (66%) are living with overweight (including obesity), with around one-third (30%) of children being at risk of overweight (including obesity).[285]

Affordability can be a barrier to being able to eat a healthy balanced diet. Research has shown that those with the lowest income currently must spend around 50% of their disposable income to eat a healthy diet compared to only 11% for those with the highest income.[286]

The Good Food Nation Act presents an opportunity to adopt a 'Whole of Government' approach to the development of food and drink policy, that prioritises actions to address the social, commercial, economic, and environmental factors that influence health inequalities.[287] There may be a role for Adult Disability Payment here.

In addition, I met with a member of the Faculty of Eating Disorders. The Faculty states that it works to secure the best outcome for people with eating disorders.[288]

The main issues raised during the meeting for people with an eating disorder when 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
- 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'.

There was 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

This activity is concerned with the need for medication or therapy to monitor a health condition in a domestic setting. In the guidance for this descriptor 'therapy' is defined as a non-pharmaceutical treatment which does not involve the use of medicinal drugs.[289]

The following are examples of therapy which includes but is not limited to:

- physiotherapy
- home dialysis
- special diets where both attention to the nature and timing of food is integral in the management of the diet and where failing to adhere to the diet would result in an immediate deterioration in an individual's condition
- psychotherapy.

Therapy does not include either of the following:

- taking or applying, or otherwise receiving or administering, medication (whether orally, topically or by any other means)
- any action which, in the individual's case, falls within the definition of 'monitor a health condition'.

Reflecting on the point made earlier that the outcome of the activity is what is important to many people, some stakeholders have questioned why only therapy carried out in the home is considered in Activity 3.[290] One person speculated that when the PIP criteria was established, the DWP determined that someone requiring a professional to come to their house indicated a higher level of impairment than someone who can travel to receive treatment.

Some would argue that therapy outside of the home 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 noted that some people find it too difficult to go to appointments for a number of 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.

There is also a built-in assumption within this activity descriptor that everyone has equal access to forms of therapy and support. CAS supports many people who have had negative experiences of seeking support, such as clients with mental health problems. Some conditions are difficult to diagnose, and this can leave people without the therapy or support they need. These scenarios are difficult to account for under the current system.[291]

As the purpose of Adult Disability Payment is to assist with the additional costs of having a disability some stakeholders thought that paying for private physiotherapy and other therapies, outside of their home, should be included. Some stakeholders highlighted that people use private services because they are too difficult to access on the NHS. It is technically an additional cost, but the pushback comes from these treatments being available on the NHS.[292]

Other issues raised 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 are excluded from forms of therapy due to being digitally excluded
- it can be costly to get to and from support groups
- the side-effects of some medication, including drowsiness, can compound symptoms and functional limitations which isn't currently taken into account.

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

Activity 4 considers an individual's ability to wash and bathe. The guidance from Social Security Scotland states that 'washing means cleaning one's body and hair, including removing dirt and sweat and bathing includes getting into and out of both an un-adapted bath and an un-adapted shower'.[293]

Many people I spoke to are confused as to why the 'washing and bathing' criteria are written in the way that they are. They highlighted their views that the wording and eligibility for scoring points is very focused on functional ability and takes no account of other limitations, despite the current reliability criteria taking this into account, which the need for prompting reflects. One participant with a mental health problem told me that they go days without washing or bathing even though they have the functional capability to do so. Their argument is that the outcome is the same (a negative impact on personal hygiene) and therefore it shouldn't matter whether the cause is due to a physical impairment or a mental one. It is common among people with energy limiting conditions, for example, that people won't have a shower unless they have to go out/interact with other people. In other cases, whilst maintaining personal hygiene might not be a strong enough motivator on its own, the prospect of showering to prepare for meeting someone could provide the necessary encouragement.

There can be hygiene issues associated with having to spend so much time in bed. Some stakeholders expressed the view that feeling sticky, dirty and being unable to wash is not good for mental health. Both the act of doing things and the consequences of not doing them may have adverse consequences for health.

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.[294]

Some apparent anomalies were pointed out to me including the allocating of three points for help getting in or out of an un-adapted bath or shower. As this is a relatively high number of allocated points compared to others in the daily living section, some people I spoke to questioned the logic.

Event participants also expressed the view that more detail was needed to help understand aspects of daily living activities that are already in the application, including managing washing and bathing, managing toilet needs, and preparing food. They felt greater emphasis should be placed on how people complete those tasks and the impact it has on them, rather than whether they can be completed.[295]

Many stakeholders would welcome the introduction of reference to intimate hygiene; it is interesting that it is not currently included. One person suggested that difficulties around intimate hygiene could potentially be worth more points due to being more psychologically difficult to manage.

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.

Activity 5 – Managing toilet needs or incontinence

This activity considers an individual’s ability to get on and off an un-adapted toilet, to manage evacuation of the bladder and/or bowel and incontinence, and to clean afterwards. It does not currently consider the ability to manage clothing, climb stairs or move to the toilet. Managing incontinence means the ability to manage involuntary evacuation of the bladder and/or bowel, including the use of a collecting device or self-catheterisation, and cleaning oneself afterwards.[296]

There were very few comments made 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

Daily living component Activity 6 considers an individual's ability to put on and take off un-adapted clothing, including socks and shoes, that is suitable for the situation. The clothing must also be of an acceptable standard in terms of suitability for the weather and cleanliness. The type of clothing to be considered should be within the range that people would usually be expected to wear, including fastenings such as buttons, zips, laces etc.

A client's preference to wear clothing which is particularly challenging to put on, for example, a full kilt outfit or ball gown, should not be taken into account if they could manage other types of clothing. The only exception to this is if the client is required to wear a particular type of clothing for cultural or religious reasons, in which case their inability to dress in those specific items would be relevant.

How often a client changes their clothes should be taken into account if their disability or health condition impacts the regularity with which they can do so. It is reasonable to expect an individual to put on one outfit each day and take their clothes off or change their clothes at the end of the day. If a client is unable to do so because of their disability or health condition, then they will score under this activity. However, if a client has a personal preference to change their clothes three times a day, an inability to do so would not be taken into account. The only situation in which this would be relevant would be if their disability or health condition was the reason for them needing to do so. For example, if a client has obsessive compulsive disorder (OCD) which means they become extremely anxious and distressed if they perceive their clothes to be dirty, it is reasonable that they need assistance to change their clothes numerous times a day.

This activity, like many of the others is very focused on the physical activity, the functions and functional ability required to put on and take off clothes and not on the outcome or impact of not being able to dress appropriately. The guidance for case managers states that 'a case manager should evaluate an individual by their level of functional ability to select appropriate clothing, dress and undress. The key consideration should be the functions that are involved in doing so and the individual's condition that may impact their ability to perform those functions'.[297]

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.[298]

Other related comments include the following:

- 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[299]
- when assisting clients with application forms, timelines often pose challenges, particularly when individuals are estimating the time required for tasks like dressing and undressing
- the questions in the application form should allow for more detailed, descriptive responses which could better explain how applicants undertake activities such as bathing and all the steps this would involve
- the application form and accompanying guidance should be clear and explicit as to how the reliability criteria applies to this activity
- the energy cost of getting dressed mean that many people with energy impairments cannot even get out of bed, let alone get dressed. Unless there is an unavoidable need for social interaction, they may well not waste precious energy on getting dressed. 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.

Activity 7 – Communicating verbally

This activity is concerned with people’s ability to express and understand basic and complex verbal information unaided. It considers an individual’s functional ability to communicate verbally (using words) with regard to both:

- receptive (receiving, hearing and understanding) communication
- expressive (conveying, talking) communication in one’s language of preference.

Few comments were made in respect of this activity, but some included:

- that there is no consideration for the environment in which a person is communicating, and for some people this is an important factor

- not being able to understand or reliably remember communication could have implications for managing medication
- at a few events it was reported to be hard to gain points for 'communication skills'.[300]

Activity 8 – Reading and understanding signs, symbols and words

It is most likely that individuals will have difficulty with this activity for one or more of the following reasons. (This list is not exhaustive.) It may be because they:

- are blind or have a visual impairment
- have a cognitive or learning disability.

Illiteracy is not taken into consideration for this activity, unless it is a consequence of a disability or health condition.

Most disabled people I engaged with had little or no comment to make with reference to this activity. However, some of the comments made included the following:

- one organisation raised that a person with learning disabilities can score zero points for 'reading and understanding questions', as they can read, but this did not capture difficulties comprehending or acting on the information
- an organisational representative raised the issue that people with a learning disability may be disadvantaged in terms of reading and understanding questions as it is easy for them to score nothing. They may be able to read but may struggle with comprehension, and with acting on what they have read.[301]

Activity 9 – Engaging socially with other people face to face

Daily living component Activity 9 considers all aspects of an individual's ability to engage socially with other people face-to face which include:

- interacting face-to-face in a contextually and socially appropriate manner
- understanding body language
- maintaining their own and others' safety
- establishing relationships.

The environment in which the face-to-face interaction is taking place is a significant factor for some people. If one is immunocompromised, social interaction with people can put a person at risk.

It was in relation to this activity that we had the most discussion about the definition of 'overwhelming psychological distress'. 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. There was a suggestion made that decision-makers should focus on psychological distress itself, rather than requiring an activity to result in overwhelming psychological distress.

One stakeholder highlighted their view that the guidance in relation to Activity 9(c) for Adult Disability Payment[302] is more restrictive than the equivalent case law for PIP. They noted a decision by the UK Supreme Court[303] in relation to PIP exploring the difference between Activity 9(b) and 9(c):

> “The key case exploring Activity 9, descriptor c was decided by the Supreme Court. The main finding was that ‘Responding to the greater degree of disability [envisaged] requires the attention not just of another person, but of a person trained or experienced in assisting people to engage in social situations. That is what differentiates prompting for the purposes of 9b from prompting which is social support for the purposes of 9c. And where the support takes a form other than prompting, it will similarly only qualify for 9c if the claimant needs it to come from a person so trained or experience’.
>
> In contrast, the [Social Security Scotland] guidance states: ‘The threshold for awarding daily living component activity 9 descriptor C for mental health conditions is much higher’, which is not suggested by the Supreme Court case. The guidance has a clear clinical focus in the summary it provides of what might be ‘expected’ to be available to establish that the descriptor applies. This might lead a case manager to conclude that the social support must be provided by a professional, which is explicitly not the case.” – Citizens Advice Scotland, response to the Independent Review of Adult Disability Payment Call for Evidence[304]

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.

Activity 10 – Making budgeting decisions

Daily living component Activity 10 considers an individual’s cognitive ability to complete a budgeting task. It does not consider their ability to leave the house to pay bills, the handling of money or where the individual is unable to pay bills due to a lack of money. Simple budgeting decisions are those that are involved in calculating the cost of goods and working out how much change should be given following purchases. Complex budgeting decisions include decisions, such as calculating household and personal budgets, managing and paying bills, and planning future purchases.

Few comments were made in relation to this activity but some things to consider include the following:

- if someone has a financial guardian, it is clear that they have difficulty managing money and therefore this should mean an automatic application of the highest points
- some disabled people highlighted the point 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 not been awarded 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 not the same as being able to manage money.[305]

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 activities

A public consultation[306] on the eligibility criteria for the mobility component of Adult Disability Payment ran between 31 January and 25 April 2023. The consultation aimed to gather a broad range of views on alternative approaches to the mobility component and identify any gaps, issues or unintended consequences of changes suggested by respondents.

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, which is covered earlier in the report. Some other suggestions were raised repeatedly, including:

- 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
- to clarify what information is being sought in response to the questions posed about someone’s mobility needs
- ensuring all aspects of mobility are considered, 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.

Activity 1 – Planning and following journeys

An individual is entitled to the mobility component if the individual's ability to carry out mobility activities is limited or severely limited by their physical or mental health problem(s) and the individual meets the required period condition i.e. 50% of the time.

This activity considers an individual's ability to plan and follow the route of a journey which means to navigate and make their way along a planned route to a planned destination.[307]

This activity is relevant for people whose mobility is affected by mental health, cognitive and sensory impairments, and physical problems. Cognitive impairment includes orientation (understanding where, when and who the person is), attention (including awareness of risk and danger), concentration and memory.

> "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 person's. 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[308]

CAS's ongoing research highlights concerns that the application form does not make clear that sensory and mental health-based impacts are both included and of equal relevance in this activity. Advisers have observed that clients don't necessarily grasp that 'needing company to go out' is as relevant as 'someone needing a white stick'.[309]

When asked if there was an opportunity to change any specific aspects of the planning and following journeys activity the following themes were each mentioned by a few respondents and were also raised in consultation events and at some stakeholder meetings:

- 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
- as two individual respondents requested, ensuring that practitioners listen and believe the information provided to them
- consideration of environmental factors, public transport routes and difficulties during the journey

- a sense 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
- whether 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 for vulnerable people.

Section 2 of the consultation asked respondents to consider the clarity of the planning and following journeys activity, to comment on feedback received about the criteria through previous research, and to explain any suggested changes to the planning and following journeys activity. Two further themes were raised. These were the language used, and expanding the definition of orientation aids.[310]

Many respondents shared concerns about the language used in the planning and following journeys criteria and suggested changes. Research conducted by CAS has also highlighted the impact of the use of definitive language throughout the application. The words 'at all', and 'never' caused particular concern, and the related prevalence of what are being experienced as binary questions. The research also identified that clients have limited understanding of the interaction between mental and physical health impacts and mobility needs, and frequently artificially separate mobility and daily living needs.[311]

Comments included criticism of the term 'overwhelming psychological distress', which respondents found to be limiting, subjective and unclear, and suggested it should be defined, amended or removed. The descriptors can be interpreted in a restrictive manner, construing PIP case law as meaning that only if a client is experiencing 'overwhelming psychological distress' would anxiety be a cause of being unable to follow the route of a journey.

> "In general terms, the following journeys criteria are easier to understand than the moving around criteria, as they are not reliant on arbitrary numerical distances that may be difficult to relate to daily life. However, we are concerned that the phrase 'overwhelming psychological distress' is poorly defined, and it may not be clear to applicants what this means in practical terms" – Health and Social Care Alliance Scotland (The ALLIANCE), response to the Independent Review of Adult Disability, review of the mobility component[312]

> " 'Overwhelming psychological distress' is a very broad definition that might not be clear to applicants. It would be particularly useful to incorporate explicit examples. This could be

> approached in a way that acknowledges feelings and difficulties, such as anxiety, fear of getting lost or missing taxis/buses or fear of encountering unanticipated difficulties." – Scottish Association of Social Work, response to the Independent Review of Adult Disability, review of the mobility component[313]

'Overwhelming' indicates a very high bar for distress, when lower levels may still significantly impact a person's ability to plan and follow a journey. 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 doesn't suggest it's unreasonable for people to be anxious or have such fears.

The impact is primarily on those living with mental health problems, neurodiverse people, and people who have learning disabilities or difficulties. Some descriptors within this activity appear to apply to those who are visually impaired and so have difficulty navigating, whereas other descriptors apply to those liable to experience overwhelming psychological distress if they go outside unaccompanied or at all. A liability to get lost due to a physical or mental health problem is relevant to whether a client can follow the route of a journey or not.

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) and 1(f):

> "The argument presented in the landmark case MH v Secretary of State for Work and Pensions[314] was that where claimants have anxiety, descriptors 1(d) and 1(f) are applied in the light of descriptors 1(b) and 1(e), with due regard being had to the term 'overwhelming psychological distress'. However, it is acknowledged that this is only one scenario in which these descriptors apply.
>
> Claimants can potentially score in several descriptors in the activity if they cannot commence journeys because of their condition or need prompting or another person to accompany them to make a journey. The points variation across the descriptors reflects the difference between someone who requires prompting to leave the house and someone who is unable to follow a journey unless accompanied by another person.
>
> The (Social Security Scotland) Decision Makers Guidance, through the illustrations used, gives the impression that these descriptors 1(d) and 1(f) only apply on mental health grounds where restrictions constitute overwhelming psychological distress. People who do not meet the reliability criteria, or who are experiencing a complex interaction of symptoms affecting their ability to navigate and make their way along a route, would be inappropriately potentially excluded by such an interpretation." – Citizens Advice Scotland response to the Independent Review of Adult Disability Payment Call for Evidence[315]

Similarly, several people noted confusion about the meanings of ‘orientation aids’, ‘planned’, ‘unplanned’, ‘familiar’ and unfamiliar’, while a few suggested ‘journey’ could be confusing. Respondents explained that unclearly defined or overly simplified language makes it difficult for those responding to describe their experiences accurately and makes the job of the case managers and practitioners more subjective.

Some respondents requested that the definition of orientation aids include technology like satellite navigation tools and mobile phone map applications that respondents noted are crucial to their ability to move around. This was also raised in stakeholder events, where discussion included the importance of aids in getting around. A few others also suggested that a family member or carer travelling with a person to provide support should also be included as an aid regardless of whether they are acting in a supervisory role or providing another type of support.[316]

For some the planning and journeys section seems overly focused on physical ability.

A need for greater consideration of mental health in relation to this activity was mentioned on several occasions. These comments often focused on clients’ experiences during the journey, such as the impacts on mental health if the journey does not go to plan, or anxiety related to specific types of journeys but not others.

The Neurological Alliance state that neurological conditions cause a variety of physical issues, but they also often impact on mental health. Their ‘Together for the 1 in 6’ report, which was published in 2022, revealed that 80% of adults with a neurological condition said their condition negatively impacts their mental health. 59% said their condition caused moderate to severe pain. Eligibility criteria do not take into account pain, fatigue or mental health problems like anxiety, all of which can disrupt the intention to undertake a journey or might disrupt the journey itself.[317]

> “For people with dementia, particularly those at the early stages of the condition or who experience variability in their symptoms and who may be unwilling to acknowledge the changes in their cognition, may struggle to identify or describe the unpredictability of their condition. For example, they may manage to plan a journey but not follow it and may mask their difficulties by assuming that they can manage one element of this task so indicate that they can do all of it.” – Neurological Alliance of Scotland response to the Independent Review of Adult Disability Payment, review of the mobility component[318]

For fluctuating conditions like epilepsy, post-polio syndrome and MS, both physical and cognitive fatigue are directly impacted by the symptoms someone is having. Despite safety currently being one of the reliability criteria, this does not appear to be fully realised in practice, e.g., when someone becomes overly fatigued and falls whilst out on a journey due to symptoms flaring up, or experiences from a seizure, and needs help to get home.

For conditions and impairments related to fatigue and those where people may be at risk of infection if going on a journey, certain issues were raised by stakeholders (such as Inclusive New Normal[319]), including:

- that 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
- that people at high clinical risk may need not just prompting and encouragement to travel but action to mitigate risks
- that 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.
- that 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 which is as risk-free as possible or not being able to contemplate any journey because it would cause overwhelming psychological distress to the client
- that 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 are in your own car, and (next safest) by taxi (though that is far from risk-free – windows hardly open on some models and not accessible to the passenger)
- that as a result 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'll 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.

Crohn's & Colitis UK raised specific concerns about how mobility criteria do not currently account for the impacts of bowel conditions that may cause incontinence. The need to plan for access to toilet facilities may represent an additional further difficulty for many disabled people, with uncertainty around whether facilities will be open, accessible, free to use, and of good quality, all liable to contribute significantly to feelings of anxiety about planning journeys. Especially in the context of many public toilets being closed, having limited opening hours, or charging for access, some people living with bowel conditions find their mobility limited not by their own physical capability to walk, but because they cannot be assured they will have access to the facilities they need. A sudden need to use a toilet mid-journey might lead to heightened anxiety about leaving the house in the future.[320]

Positive comments received in relation to this activity include:

- 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 traveling may help make clear to applicants there are legitimate and understood reasons they would feel that way
- some people welcome that stigmatising behavioural observations have been removed from the process and agree that these perpetuated unhelpful stereotypes.

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.

Activity 2 – Moving around

The moving around activity considers a person’s ability to stand and move specific distances without severe discomfort. While this considers movement on flat and outdoor surfaces, such as pavements and kerbs, it does not consider walking up slopes or stairs. The criteria consider how easily a person can stand and then move up to 20 metres, up to 50 metres, up to 200 metres and above 200 metres. Application guidance asks clients to consider factors that affect their experience of moving around. These include how quickly a person can move; the risks of falling or injury; breathlessness, pain or fatigue; the way a person moves; and symptoms or side effects from moving around.

The reliability criteria apply so when making a decision in relation to a client's mobility a case manager must consider the person's ability to be able to move around 'safely', 'to an acceptable standard', 'repeatedly' and 'within a reasonable time period'.

> "The determination of how these factors affect a claimant's ability to move around provides significant discretion in how a Social Security Scotland assessor understands and assesses a claimant's individual ability to walk around which sets the conditions for disparity in decision-making assessments." – Alzheimer Scotland, response to the Independent Review of Adult Disability Payment, review of the mobility component[321]

> "People who are new to the benefits system do not realise - and the form doesn't tell you - that the issue is not just how far you can walk, but whether you can do it 'reliably' i.e. safely, to an acceptable standard, repeatedly and in a reasonable time. While the form highlights pain, fatigue and breathlessness, it does not mention speed, issues with gait or uncontrolled movement which may mean that people are not moving to 'an acceptable standard', or the need to be able to repeat the distance - all of which are common for people with Parkinson's." – Parkinson's UK Scotland response to the Independent Review of Adult Disability Payment, review of the mobility component[322]

> "Many of our members and people with lived experience are calling for the 20-metre rule and 50% rule to be removed from the criteria. We understand these are in place to measure the applicant's mobility, however, this is a numerical criteria that does not consider a person's daily life and take different environments into account. Instead of this criteria, the application should measure how a person is able to move within their local and wider area and their home and the degree said movement results in pain and exhaustion. This would allow the application and assessment to move away from a strict measurement and measure capability more effectively." – Scottish Association of Social Work response to the Independent Review of Adult Disability Payment, review of the mobility component[323]

Formal inclusion of pain and exhaustion and other physical effects allows one to measure a person's capabilities beyond just the distance they might be able to travel and recognises the true effects of their condition on their quality of life and wellbeing.

Clarifying the language or meaning of the moving around activity criteria was requested by many respondents to the consultation, for example, by using examples and real-life scenarios. Several respondents also argued that the criteria would benefit from a clearer definition of what moving means. While there was appreciation of, and support for the visual examples now included in the application form, the need for clearer images was mentioned by several respondents.

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. However, it is not entirely clear whether a person's responses to these prompts are taken into consideration within the points system, even though there may be significant differences between two people who can walk the same distance unaided. If someone can walk 50 metres but is in pain or exhausted for a significant period afterwards, that should potentially be given more weight than someone who can walk 50 metres with only mild or brief impacts.

Changing the distance measure in the moving around activity was frequently suggested as another opportunity for improvement. These responses ranged from changing the 20-metre measurement in the criteria – the '20-metre rule' – back to 50 metres, to not using any distance measures at all. Respondents argued that 20 metres is an unrealistic and limiting distance. 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. Several suggested that these changes would improve disabled people's circumstances and independence and positively impact those with fluctuating conditions as the decision-making process would be more inclusive, holistic and nuanced.

The SCoRSS coalition is calling for the removal of the 20-metre descriptor; this descriptor means that clients who are assessed as being able to walk over 20 metres are not entitled to receive the enhanced rate of mobility support and are therefore ineligible for the Motability scheme, a lifeline for many. SCoRSS believe that the descriptor is arbitrary, devastating in its impact, and not consistent with the purpose of Adult Disability Payment to support clients to meet the additional costs associated with their health profile. The use of this descriptor is also incompatible with a commitment to a system of social security that puts respect for the dignity of clients at its heart, recognises the role of social security in the realisation of other human rights, and that is evidence-based.[324]

A survey of 300 potential Adult Disability Payment clients, conducted by Inclusion Scotland during February and March 2021, found that an overwhelming majority (81%) expressed the view that '20 metre' criteria should not be retained in Scotland.[325]

> "A shift from the fixation on numerical distance walked, to a more person-centred approach of how someone moves (whether aided / assisted or independently and what the impact of moving around is on each individual) would yield a more accurate representation of someone's level of disability." – Neurological Alliance of Scotland response to the Independent Review of Adult Disability Payment, review of the mobility component[326]

> "Mobility isn't just how far you can walk; it's about the freedom to do things independently... A more holistic approach is needed remembering not every person is the same. Mobility should be based on the individual person and their overall disability challenges." – Organisation[327]

> "The restrictive element of the '20-metre rule' has caused unnecessary stress and in most cases, has exacerbated their PPS symptoms… The recommendation is to increase the distance to a more realistic 100-200 metres, or indeed to take away the requirement altogether." – Scottish Post Polio Network, response to the Independent Review of Adult Disability Payment, review of the mobility component [328]

> "In our clinical experience of treating individuals with cerebral palsy, we believe that focus must be given to the quality of an individual's mobility, rather than a simple emphasis on how far an individual may be able to walk. A more nuanced approach will give a clearer picture of the reality of the cost to the individual of achieving mobility. An individual's attitude to mobility is also important: some want to continue to stay mobile (walking) with/out a mobility aid so they don't 'look' disabled. They often use compensatory strategies to keep on their feet (e.g. shifting weight away from a painful area) which can cause deterioration and further asymmetry in their posture, requiring more effort of movement, causing more pain, and premature wear and tear to joints and muscle tightening. Longer-term health and support consequences for them should be considered, as the consequences of not being able to access help for their mobility are severe." – Cerebral Palsy Scotland, response to the Independent Review of Adult Disability Payment, review of the mobility component[329]

Other issues raised and changes proposed included:

- capturing explicitly the reliability criteria (Research conducted by CAS has highlighted that advisors do not consider that the 'how do you feel after' questions (in this context 'after you have walked this far, does this change how you feel?') effectively convey and capture the reliability criteria, which advisors feel are not understood by clients)[330]
- 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)
- the feeling among many respondents to the DWP consultation on PIP was 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[331]
- revising the criteria, so it is more in line with the social model of disability
- criteria that reflects experiences of moving in the built and natural environments
- 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
- consideration should be given to how people move around their house functionally

- the purpose of travel and subsequent difficulties faced at destination
- 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 consideration should be given to the impact of certain medicines on movement.

> "The distance doesn't matter as much as the environment. Things that should be considered more are ability to walk uphill or downhill, taking stairs and other issues with moving around." – Individual response to the Independent Review of Adult Disability Payment, review of the mobility component[332]

The rigid nature of the mobility component is something I am keen to address. The sense that strict distances are arbitrary, not a useful measure, and do not adequately cover progressive or fluctuating conditions, has been a consistent criticism.

People explained they find it hard to meaningfully appreciate distance set out in terms of metres. 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. For example, someone may be able to walk 200 metres at one time, but that would mean they could not do any other activities that day. I also heard that the way mobility is currently considered fails to take into account the full complexities of a client's situation. That is, the Adult Disability Payment distance test seems to take place in a hypothetical world of flat surfaces devoid of obstacles. The difficulties people with chronic fatigue face are that they may be able to walk but don't because they have to stay within their energy limits, or they risk a major setback. This looks like choice but is, in fact, necessity.[333]

In 2013 when DLA was replaced by PIP for people of working age, many of the criteria that meant a person was eligible for the higher rate of the mobility component for DLA changed. One criterion of the higher rate of the mobility component (of 'being virtually unable to walk without severe discomfort'[334]) was removed. PIP introduced the concept of looking at whether the person could stand and move a fixed distance. The original descriptors included in the UK Government's consultation set this distance at 50 metres. However, when the UK Government responded to the consultation, the threshold was subsequently replaced with 20 metres.[335] The 20-metre rule was replicated by the Scottish Government when determining the criteria for Adult Disability Payment on the basis that this approach would avoid a two-tier system, whilst case transfer was ongoing.[336]

> "The continued application of mobility criteria, including the 20 metre and 50% rules have been disappointing, and the ALLIANCE have repeatedly joined with partners across the third sector and people with lived experience to call for these to be reformed, if not abolished

> entirely." – Health and Social Care Alliance Scotland (The ALLIANCE), response to the review of the mobility component[337]

For people with a degenerative neurological or inflammatory condition such as Parkinson's or MS, the issue is not about the ability to manage a set distance, but the summative effect of functional or recreational use of that distance.

It was particularly concerning within the consultation document to see that two-fifths of respondents to a survey[338] highlighted that they were effectively discouraged from being active due to the fear they would lose their entitlement to social security. The health benefits, both physical and mental, arising from exercise or otherwise being active are well established. Disabled people already face higher barriers to accessing sport and physical activity. Therefore, further discouraging individuals from being physically active may have negative effects on their health and wellbeing in the longer term, potentially including the worsening of their condition(s).

Human rights are interrelated and interdependent, and the realisation of one right should not have any negative impact on the realisation of other rights. 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.

Many stakeholders welcome the approach of supporting information to confirm mobility issues, operating on a balance of probabilities basis, rather than an automatic requirement for a consultation. In addition, many disabled people feel it is a significant improvement that where a consultation does take place, any informal observations must be shared with clients, and they must be given an opportunity to respond. By trusting supporting information to be accurate and disallowing secretive informal observations, these changes have created a more dignified approach.

However, it was suggested that these positive changes relate less to the ability of Social Security Scotland to understand a person's mobility needs, and instead to how individuals experience the application process.

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 – such as their place of education or employment, shopping and leisure facilities, and healthcare services. 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.

One example that could be adopted is the way in which people are currently assessed by the local authority for a Blue Badge.[339] Under this scheme, a person is automatically entitled if they have a Certification of Blindness or Defective Vision BP1 (3R) or Certificate of Vision Impairment (CVI) or a previous equivalent, signed by a Consultant Ophthalmologist.

In March 2020, Transport Scotland launched a 12-month trial (later extended to 24 months) to test a fast-tracked prescription model for applicants with Motor Neurone Disease (MND). The trial involved MND nurse specialists assessing their patients against the blue badge eligibility criteria and completing, and submitting, a streamlined application form on their behalf. Individuals with MND are not required to submit a blue badge application form or go through a formal assessment with local authorities. Additionally, these applications do not require local authorities to request proof of ID and address. The MND nurse specialist's declaration is sufficient evidence that these individuals have had their identify confirmed via NHS systems. The fast-tracked prescription model was formalised as a permanent process for blue badge applications for applicants with MND in Spring 2022. Transport Scotland will aspire to explore and expand the scope of the fast-track model, beyond MND, for other conditions that will improve the overall experience of applicants.

To qualify for a Blue Badge an applicant must have a permanent and substantial disability that means that they are unable to walk, or means they are virtually unable to walk and/or have no awareness of traffic and are likely to compromise their safety, or the safety of others as a result of a diagnosed mental disorder or cognitive impairment.

Rather than answer questions on how many metres a person can walk aided or unaided, applicants for a Blue Badge will need to demonstrate that their ability to walk is affected to the extent that they would be unable to access goods and services unless allowed to park close to shops, public buildings and other facilities. Consideration is given in the Blue Badge Scheme Local Authority Guidance (England) 2014[340] to the applicant's ability to negotiate the types of pavements or roads they would normally expect to find in the course of walking outdoors. 'No pavement or road is absolutely flat therefore slopes and or uneven surfaces should be considered in the course of a mobility assessment.'

Excessive pain reported by the applicant when walking, or as a consequence of the effort of walking is considered as is breathlessness reported by the applicant when walking, or as a consequence of the effort of walking. 'It does not matter whether excessive pain or breathlessness occurs at the time of walking, or later - what counts is that it is a direct result of their attempt to walk, and that physical activity is considered detrimental to the applicants diagnosed medical condition.'[341]

How far a person can walk without experiencing severe difficulty is also taken into account. Rather than limiting decision-making to 'activity' and numerically defined distances, each factor is considered as part of a holistic assessment which contains all factors that are impacting on an applicant's ability to walk.

An independent mobility assessment is required to assess eligibility under the 'unable to walk or virtually unable to walk' criteria, particularly if there is a lack of clarity or understanding in the information provided by the applicant. If this approach was adopted for Adult Disability Payment, it runs the risk of re-introducing PIP type assessments which are universally disliked.

However, this type of approach may allow for better reflection of individual circumstances. For example, for people living in urban versus rural areas, where it should be recognised that it is not simply individual physical capability that is relevant to how an individual's mobility is affected, but additionally the infrastructure and services around them. 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. Clients living with chronic pain may benefit from explicit recognition of pain as a barrier to mobility. Similarly, for applicants with fluctuating conditions, less strict criteria may result in them being eligible for a higher rate of payment, which is likely to improve quality of life and ultimately reduce poverty. 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[342]

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.

Final Thoughts

Many individuals and organisations with lived experience and detailed knowledge took part in the consultation, call for evidence and engagement events, sharing their views on how Adult Disability Payment could be delivered more effectively. I have done my very best to reflect their experiences and perspectives.

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.

Scotland’s social security system aspires to be human rights based, providing adequate support that helps to reduce poverty and ensure participation in society, in line with the principles set out by the Scottish Campaign on Rights to Social Security.[343] I have kept these principles in the forefront of my mind throughout the whole process of Chairing this Independent Review, and hope I have done them justice.

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.

In an ideal world, decisions about eligibility for Adult Disability Payment would always be made on a human rights basis, rather than being led by cost considerations. However, I recognise the financial limitations facing the Scottish Government, and that these have grown significantly in recent years.

If implemented, some of the recommendations included in this report may have the effect of reducing delays and reducing the number of challenges to decisions which, in turn, is likely to reduce some of the costs associated with delivering Adult Disability Payment.

It is also worth noting that changes to the eligibility criteria may result in more people receiving Adult Disability Payment. However, some people would argue that disabled people who are currently being denied financial support by a system that doesn’t adequately capture their needs would, as a result of any changes, receive what they are entitled to.

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

Introduction

The outcome-based examples keep the separation of daily living and mobility components and assumes 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?

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 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.

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.

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.

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
- to 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 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?

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 they are 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.

Annex 2: Impact of Making Changes

It is important to recognise that should the Scottish Government decide to accept the recommendations in my report, there may be costs involved. These can be thought of in two terms:

- **Benefit expenditure costs:** these are the value of payments made to individual clients, so are likely to continue into future years
- **Benefit delivery costs:** these are the costs associated with implementing changes to systems, processes and procedures.

Benefit Expenditure

Estimating the change in benefit expenditure as a result of implementing individual or combined recommendations can be challenging. Alongside data requirements and assumptions that are needed to make robust calculations, there may also be behavioural changes from clients, particularly in the way in which they respond to questions, or activities and descriptors. Given the scope for this behavioural change, it may take a period of time for any change in trends to become established enough for costing analysis to be completed.

The specific nature of how recommendations would be implemented or appear in practice as part of Adult Disability Payment processes, would likely depend on further evaluation or design by Social Security Scotland. Data that directly captures, or can be used to estimate, how these changes might influence the number of applications received or the outcome of determinations, would be required to make a comparison to how Adult Disability Payment was delivered before these recommendations were implemented.

Total Adult Disability Payment benefit expenditure broadly depends on the number of people receiving Adult Disability Payment, in combination with the award level each of those people receive. For example, benefit expenditure for Adult Disability Payment may change where recommendations:

- influence a change in the volume of applications received by Social Security Scotland
- influence a change to the authorisation rate for new applications
- influence a change to the outcome of award reviews
- influence a change to the amount of time people receive an award
- lead to more people applying for redeterminations or appeals
- lead to a difference in the outcome of redeterminations or appeals.

Statistics capturing many of the above are published by Social Security Scotland, which can give an indication of how these may influence benefit expenditure.

Adult Disability Payment remains a relatively new benefit and some of the longer-term trends are still becoming established. Given the influence of the different factors above in determining benefit expenditure, new trends may take time to present in the data and for the effect of recommendations to become clear.

The Scottish Fiscal Commission, in their earlier Scotland's Economic and Fiscal Forecasts series, had anticipated an initial spike in applications for Adult Disability Payment and a longer-term uplift in applications compared to before Adult Disability Payment was launched. While determining the true scale of any behavioural change and differentiating that from other factors driving applications is difficult, this may demonstrate the influence that behavioural change and delivery choices could have.

Using factual information provided by Scottish Government officials, I have considered the information provided by those officials whilst forming an independent view as to having appropriate assurance that the potential costs of any changes to benefit expenditure have been considered, in reaching my recommendations.

Review of Recommendations for Benefit Expenditure Estimates

Of the 58 recommendations outlined in my report, producing estimates of the potential scale of the impact on expenditure, can be more straightforward where these relate to specific cohorts of people and where data is more readily available.

Illustrative estimates of the scale of benefit expenditure, for recommendations where particular cohorts of people or data have been identified, have been outlined below to give an indication of the impact these might have.

Where it has not been possible to source the information to carry out these calculations, a potential approach to carrying these out, if the recommendations are implemented, is outlined below. Further commentary is provided where recommendations may require more extensive investigation, citing the challenges associated with estimating these at this time.

For recommendations that are more straightforward to estimate, forecasts of the average award rates for Adult Disability Payment alongside the value of daily living and mobility component awards for 2025/26, can be used as a starting point for calculations. Using illustrative scenarios of the number of people that could be brought into eligibility by the recommendations, an approximation can be derived based on the number of people and these different award rates.

In the latest Scottish Fiscal Commission forecasts (May 2025), the average award for Adult Disability Payment in 2025/26 is estimated to be £130.19 per week. The value of an enhanced daily living and enhanced mobility award in 2025/26 is £187.45 per week.

As an example, to give a sense of the scale and a resultant cost estimate, for 1,000 people to receive the average award level for 2025/26, for 52 weeks, it would cost around £6.8 million.

For 1000 people to receive the enhanced daily living and mobility award level for 52 weeks, it would cost around £9.7 million.

These estimates can be applied to the scenarios outlined for the recommendations below, to give an indication of the potential scale of additional expenditure that might result.

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

According to the most recent Social Security Scotland statistics for Adult Disability Payment, 2,245 cases of Short-term Assistance have been paid by Social Security Scotland. This compares to around 3,630 planned award reviews where the outcome of the award was a reduction or stopping of the award.

If it is assumed that only planned award reviews are considered, rather than people reporting an improvement in their condition through a change of circumstances, then out of the 3,630 planned review outcomes that resulted in a decrease or stopping of the award, 2,245 would have requested Short-term Assistance.

In a scenario where the remaining 1,385 were reduced from enhanced to standard awards, a reduction of £84.35 at 2025/26 levels, based on an 8-week redetermination processing time it would have cost Social Security Scotland around £900,000 to pay them Short-term Assistance over this time if they requested a redetermination and Short-term Assistance payments.

The scenarios are outlined below –

- Paying the 1,385 cases Short-term Assistance based on a reduction from enhanced daily living and mobility to standard award levels (a reduction of £84.35) for 8 weeks, would have cost around £900,000.
- If based on Social Security Scotland's statistics 19% of redeterminations are assumed to go on to appeal, then paying this portion of the 1,385 cases would have cost around £90,000 for every further month that passed.
- If the 1,385 cases were paid Short-term Assistance based on a reduction from the average award level for 2025/26 (£130.19) to no award, this would cost around £1.4 million if paid for 8 weeks.
- If 19% of these went on to appeal, then paying this portion of the 1,385 cases in this scenario would have cost around £140,000 for every month that passed.

It is important to note that while these costs are based on published statistics, the number of award reviews and the outcome of these may be different in future. It is also worth noting that the recommendation in relation to Short-term Assistance would not necessarily result in more people being eligible for Short-term Assistance but rather all, or the majority, of those currently eligible to apply for Short-term Assistance, do so.

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.

To estimate the cost of this recommendation, a starting point could be to see if the number of people affected by this rule historically can be identified. Alongside this, if it were possible to identify how long these awards were stopped for on average and what the average award level was, certain assumptions and simplifications could be made to help produce an estimate of the scale of the impact.

As an illustration below:

- Using the number of people who have been affected by the rule, in combination with the award amount and duration where they did not receive an award, the total potential cost if they had received payment could be estimated as a starting point.
- Depending on the number of people affected and the award amount, averages or assumptions about the cohorts of people affected may be needed to simplify the calculations.
- While these provide an illustrative example, any estimates would be dependent on the data available and the caveat that these numbers may change based on future caseload or demand for Adult Disability Payment.

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.

It is likely that many of the people below who relate to this recommendation are already aware of, or receive Adult Disability Payment, but the calculations below can demonstrate the potential impact. These have been identified based on the Independent Living Fund as well as Blue Badges, as outlined in the main report. As many people may already receive Adult Disability Payment, a scenario where an assumed 10% of each cohort do not already receive Adult Disability Payment, is illustrated below.

This approach has been taken as it has not been possible to identify the overlap between the different support outlined above and receipt of Adult Disability Payment. As a result it is important to note that the true figures could differ, but these calculations can give an indication of the scale:

- The Scottish Government outlined that around 2,000 people were receiving support through the Independent Living Fund in March 2024. A further 1000 people are due to be supported through 2024/25. If it is assumed that 10% of these people don’t already receive Adult Disability Payment, then supporting an estimated 300 people with an enhanced daily living and enhanced mobility award for 52 weeks, at 2025/26 award levels, would lead to an expenditure impact of around £2.9 million.

- Blue Badges are provided on an automated or discretionary basis. If it is assumed that those who receive an automated Blue Badge already receive Adult Disability Payment and calculations involve the discretionary cohort, this amounted to around 159,000 people in March 2024. If in this scenario, 10% of the cohort did not receive Adult Disability Payment already, then this group receiving the average award level for 2025/26 for 52 weeks would cost an estimated £108 million.

Expenditure for the recommendations noted below may be more feasible to produce should further investigation establish a source for the data required to do so. It has not been possible to source the data between these recommendations being confirmed and finalisation of the report, however a possible approach to deriving benefit expenditure estimates has been described to outline how it could proceed if the information were available.

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.

To produce an estimate for this recommendation, a starting point could be to explore whether information on the number of people who may have fallen into this category when applying for Adult Disability Payment could be identified.

If it could be determined how many of the cohort identified above were successful at application or not, then for those who were not successful but would have potentially qualified under a substantial risk provision, the cost of paying a given award level could be estimated.

For instance:

- Based on current and forecast award levels, what would it have cost to pay the cohort who were not successful in addition to the existing caseload.
- This could provide an illustrative estimate but it would be important to recognise any simplifying assumptions, the impact of behavioural changes, or changes in the number of applications in future.

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.

Estimates for this recommendation would likely begin with exploring whether information is available on the number of people who had an appointed financial guardian when making an application for Adult Disability Payment.

It would also likely be necessary to explore whether this could be linked to the number of points that clients scored on the making budgeting decisions activity, if not the maximum number already. While it may be challenging to source this information, as with other recommendations, assumptions or simplifications could possibly be made, such as grouping clients by points scored.

If the number of people who had a financial guardian and the number of points scored on this activity could be identified, this could be compared to a scenario where these clients received the maximum number of points in this activity.

If more people are entitled to an enhanced daily living award as a result, then this would increase benefit expenditure compared to the current proportion of enhanced awards on the Adult Disability Payment caseload.

As with other illustrative estimates, it would be important to recognise the assumptions and simplifications made in any calculations, alongside the difficulty in determining any future behavioural changes.

The recommendations not included above are likely to require further investigation, definition, and agreement from Social Security Scotland before expenditure estimates can be produced. Given the different interconnecting factors that are likely to influence application numbers to Adult Disability Payment and the challenges associated with predicting behavioural changes, it may be difficult to assign precise numbers to many of these recommendations before further discussion and understanding can be sought. Some recommendations also relate to more broad themes that may not have any measurable impact on expenditure.

While it hasn’t been possible to attribute expenditure estimates to the remaining recommendations, some further discussion is provided below for each section of the report, on the main challenges and a potential way forward in future.

A People’s Service (Recommendations 1 to 9)

The recommendations in this section relate primarily to ways to address take-up and improve access. There are also recommendations related to better signposting and accessibility of Local Delivery services.

Some of the recommendations relate to broader suggestions to improve take-up through the implementation of strategies to do so, rather than being specific changes to Adult Disability Payment, which would have a more readily quantifiable impact on benefit expenditure. The Scottish Government has published estimates of take-up for certain benefits, however accurately estimating take-up rates for disability benefits remains challenging owing to the absence of reliable data to determine how many people in the population are eligible for the benefit. While any strategy to improve take up would have the potential to increase the Adult Disability Payment caseload and hence expenditure, it would not be possible to quantify the impact of Adult Disability Payment take-up currently.

Similarly with improvements to signposting and training, it is possible that this could influence the number of people coming forward to apply for Adult Disability Payment, however without understanding client behaviour around these improvements it would be difficult to determine any impact on expenditure without some further investigation. For instance, a possible alternative is that the demand could remain similar but the recommendations would make these services more accessible and helpful to those already making an application and their application may have an improved chance of a successful award being made.

As a result, it would likely be necessary for further work to take place before the expenditure implications can be determined fully.

Processes That Work (Recommendations 10 to 34)

Within this section, a number of the recommendations relate to steps to improve the experience and accessibility of Social Security Scotland's processes to those making an application. They relate to processing times, application tracking, and other steps to improve the journey itself. Steps to implement these recommendations may incur operational costs to Social Security Scotland but it is not clear if any material impact on benefit expenditure would be realised by improving these aspects.

One influence could be that clients find the application process more straightforward, though it is difficult to say whether this would lead to higher demand in the form of more new applications overall.

Where recommendations relate to reliability criteria and decision making by case managers, further investigation would likely be required to explore any measurable change this may bring about to the outcome of people's applications as a result of these revisions. While the potential impact on application numbers and authorisation rates may be difficult to determine until these changes are investigated and monitored, any estimated change in the overall outcomes for clients could be compared to outcomes prior to the recommendations being introduced.

The above would likely also apply to any change to the communication of, or processes associated with, clients applying for redeterminations or appeals.

As previously outlined, recommendations where a more specific and measurable cohort of clients are affected, whose circumstances are already captured in readily available data, are more likely to have illustrative cost estimates that can be associated with them (including recommendations 30, 33 and 32 covered above). Though subject to the availability of any underlying data, the Scottish Government and Social Security Scotland could look to identify what data exists on these cohorts.

A Learning System (Recommendations 35-39)

Many of the recommendations in this section relate to the way Social Security Scotland communicates with clients to ensure inclusivity and accessibility. Many of these suggestions impact those already making an application. As a result, it would be difficult to comment on how many people either would not have applied without these recommendations, or how it would impact on the approval rate of clients who would have already applied. It is feasible that these changes have little to no impact on overall benefit expenditure as a result.

A Better Future (Recommendations 40-58)

Many of the recommendations made in this section relate to potential changes to the activities and descriptors used by clients and case managers, as well as revised guidance and application of items such as the reliability criteria. Alongside this are recommendations around improved interpretation and definition of how different conditions may affect clients.

In order to anticipate the potential benefit expenditure associated with changes to the activities, descriptors, and decision making, further detail would first likely be required on how any revisions to the activities and descriptors would look in practice. It might be that these and the accompanying guidance require further investigation by Social Security Scotland. In the first instance involving due process to design and consult on the changes before a decision can be reached.

Costing the impact of potential changes to the activities, descriptors, and case manager guidance is therefore a far larger undertaking than what is possible within the scope of this review. The specific methodological approach would need to be explored by the Scottish Government in detail, dependent on what specific changes were identified. The potential research question that would need to be addressed could be:

- How do any potential changes to activities, descriptors, and/or case manager guidance impact:
  - Caseload
  - Award levels

This question could potentially be addressed through a series of more specific questions, such as:

- How do current clients understand any changes?
- For current clients, would the changes have meant they approached their application differently? If yes, how?
- Is the wording of activities or descriptors prior to the changes a reason why potential clients (e.g., those who are eligible but have not applied to Adult Disability Payment) have not applied?
- Would potential clients be more likely to apply after the changes?
- How many people may apply who would not have applied prior to the changes?
- How do decision makers understand any changes?

- How do any changes affect how decision makers make decisions?
- Are more people eligible for Adult Disability Payment as a result of changes to the activities and descriptors?

If it could be established through further research how a sample of clients and case managers respond to these changes, it may then be possible to compare if the number of people with successful applications under existing criteria, differs to those eligible under the recommendations. It may not be until these are implemented and data starts accumulating, that any new trends can be identified.

The Scottish Government may be able to undertake exploratory work around the feasibility of these questions, however due to the complexity of this work it is not possible to undertake as part of this review.

This is similar with recommendations such as revisiting the mobility criteria. If this is updated to account for specific individual circumstances rather than categorising by distance, costings would require an understanding of how a more qualitative approach would then map to existing mobility award levels.

As with the Processes That Work section, there are recommendations which relate to particular cohorts of people where further investigation of the data could be undertaken. For instance the number of people with a financial guardian or those who have a specific condition, recommendations 47 and 56. If these cohorts can be identified then it is more likely that illustrative cost estimates could be derived.

The Scottish Government may wish to consider a more in-depth analysis of the extent to which changes which result in automatic entitlement for individual components, activities or descriptors would have on administration costs and client satisfaction, for example, does it reduce the time required to process an application, improve client satisfaction with the outcome of decisions, or encourage better take up amongst eligible client groups etc.

Using factual information provided by Scottish Government officials, I have considered the most appropriate way to set out the cost and potential complexities involved in making those changes.

Benefit Delivery Impacts

The Scottish Government established the Social Security Programme to develop the systems that Social Security Scotland needs to deliver its benefits. The Programme sits within the Social Security Directorate in the Scottish Government, but the Programme will close in the current financial year (2025-26). Some of the Programme’s functions will be absorbed into Social Security Scotland, so that future changes to benefit delivery systems and processes will therefore be for Social Security Scotland to take forward.

For example, having spent time with colleagues from the Social Security Programme and Social Security Scotland, I appreciate that what may appear simple in relation to changing questions on an application form can involve a number of unseen changes to the systems, training, guidance and decision-making tools used by Social Security Scotland. That takes time and it also involves a cost, in addition to managing several other devolved benefits.

Social Security Scotland's case management system (SPM) is a key component of how it delivers its benefits. SPM holds information about which benefits a client is entitled to, including the rates of payment a client is entitled to receive. SPM also interacts with other systems that receive digital applications from clients, produce letters to clients, or give Social Security Scotland management information (MI).

Given that my recommendations, if accepted, would be subject to a detailed technical assessment by the Scottish Government, I have sought to consider whether the recommendations in my report are technically feasible where they involve an element of change to SPM only, as well as illustrative costings for the technical development of those changes.

The following recommendations would involve an element of change to SPM:

- **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
- **Recommendation 13:** Develop and deliver a 'Track Your Application' on-line portal making it easier for clients to apply for Adult Disability Payment and to improve communication on the status of a client's application
- **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
- **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 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 29:** For information about appeals, and re-determinations to be given more prominence on the front page of the determination letter
- **Recommendation 30:** Consider introducing automatic awarding of short-term assistance with an opt-out clause

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

General points and assumptions

The assessment of feasibility is focused on the technical changes required to SPM only. Although I have made recommendations relating to changing the eligibility criteria the following assessment of feasibility has been based on the assumption that there would be no changes to the eligibility criteria for Adult Disability Payment made by the Scottish Government that might otherwise impact on this.

All of these recommendations, if accepted, would be subject to prioritisation within Social Security Scotland, the availability of appropriately skilled staff with knowledge of the existing software and a more detailed assessment of the programme/project management costs. Therefore, I have been told that they might not be capable of being delivered immediately and some of these changes may be capable of delivery sooner than others.

There are variables that also cannot be accounted for, because it depends exactly how the Scottish Government and Social Security Scotland may choose to implement individual recommendations.

Both the cost and the timing of the work exclude:

- changes to paper forms
- project/programme management
- changes to guidance or training
- contingency costs, which may or may not therefore materially affect that assessment of feasibility.

If the Scottish Government accepted each recommendation involving an element of change to SPM, it may be more cost-effective to undertake all of the activity at the same time, rather than commissioning individual projects. The illustrative development costs involved could range from £1.27 to £2.09 million to implement all of the recommendations as a single package of work.

The following illustrative costs have been provided based on the factual information provided by Scottish Government officials:

Recommendation	Low Cost £	High Cost £
10	161,700	254,100
13	495,880	779,240
17	64,680	101,640
19	58,212	91,476
21	43,120	67,760
29	43,120	67,760

30	120,736	189,728
43	291,060	457,380

Table 1 Illustrative SPM development costs for individual recommendations

These costs are purely indicative, and it would require a more comprehensive, technical assessment of all of the requirements involved. Some of the recommendations also involve a higher degree of confidence than others.

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

As I have noted in the body of my report, a particular recurring theme has been anxiety amongst disabled people about the state of progress with their application for Adult Disability Payment. The provision of an online portal provides an element of self-service for clients who might otherwise have to call Social Security Scotland or use the web chat functionality to receive updates.

I understand that this recommendation could potentially take longer than the others to implement, because of the technical aspects to it and is not (strictly speaking) an SPM-related recommendation. Social Security Scotland may wish to consider whether it is necessary to develop an entirely new system from the ground up, or whether there is an existing system that could be procured, customised and used to deliver this portal. Social Security Scotland would also need to consider how familiar its teams might be with an existing system that could be brought in to deliver the portal.

Recommendation 30: Consider introducing automatic awarding of short-term assistance with an opt-out clause

Currently, Social Security Scotland administers the handling of applications for Short-term Assistance manually. Social Security Scotland staff enter key contextual details to SPM, including detailed information such as previous decision dates and award values. This helps to ensure that the client receives the right payment, at the right time. Once that process is completed, payments are then issued to clients.

From the factual information provided by Scottish Government officials, developing SPM to work with this recommendation could involve illustrative costs between £120,736 and £189,728. However, there is low confidence both in terms of the potential time and costs involved in implementing this recommendation.

I would therefore encourage the Scottish Government to carefully consider undertaking a more detailed technical and operational assessment of the feasibility of this recommendation, with the aim of reducing the administrative burden on clients, the anxiety of waiting and ensuring clients continue to receive the right payment, at the right time.

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

The approach to designing the application process for Adult Disability Payment has involved disabled people and drawn input from stakeholders, to improve the process compared to PIP. It has involved user testing to ensure equity of provision to clients applying for Adult Disability Payment. The significance of that undertaking cannot be underestimated in terms of the time and thought that was given to the format of the current questions on the application form.

I understand that a similar process would be required to inform this recommendation, if it is accepted by the Scottish Government. My understanding is that this recommendation would need a detailed specification of requirements from the Scottish Government: what scenarios should be captured, what questions need to be asked and how they should be asked. It would potentially involve a significant update to SPM as well as other systems and is potentially a significant change.

An illustrative costing of changing SPM would be between £291,060 and £457,380, although this is a low confidence estimate. Whilst I appreciate the element of uncertainty involved, this recommendation (if accepted) would help clients, especially those with fluctuating conditions, to better describe the impact of a disability or health condition, whilst also providing case managers with a better understanding also.

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