

Interim Report – Independent Review of Adult Disability Payment

November 2024

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Foreword



As Chair of the Independent Review into Adult Disability Payment, I am pleased to present this interim report.

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. This interim report reflects the work that has been undertaken so far and highlights the initial findings and recurring themes that will guide our work as I move forward into the second stage of the Review.

The transition from a reserved system of social security for disabled people to one led and managed by the Scottish Government was a historic milestone. Several welcome and positive changes are evident. 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 when the Review is complete in July 2025, that I have helped set the stage for Adult Disability Payment to meet the needs of all people living with a disability in Scotland.

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 ongoing support, meticulous research, and organisational skills, which have been essential in producing this report.

Furthermore, I wish to acknowledge and thank all the internal and external stakeholders, including individuals and organisations, who have generously given their time to participate in this review to date. 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.

This interim report is not the conclusion of my work but rather a significant step along the journey. It encapsulates our current understanding and provides a foundation upon which we will continue to build. As I move into the next phase of this review, I will continue to engage with all stakeholders and refine my approach based on the feedback and evidence I gather.

Over the coming months I remain committed to the overall aim of the review, to ensure that Adult Disability Payment truly serves the needs of disabled adults in Scotland, fostering a society where everyone has the opportunity to thrive.

Edel Harris OBE
Chair, Independent Review into 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 a condition such as Autism or Attention Deficit Hyperactivity Disorder (ADHD).

A medical diagnosis is not what is important when decisions are made about a person's eligibility. It is the impact of that disability or long-term condition on daily life that is important.

I also 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.

There are many people who are disabled by societal barriers who do not regard themselves as disabled or identify as a disabled person. Others choose to identify in a different way, for example people may identify as a member of the hearing loss community, or as having a mental health condition.

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 activities¹.

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 Personal Independence Payment (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 31 July 2024, 315,495 people are receiving Adult Disability Payment², just under 6% of Scotland's population³. Most of the people receiving the payment have had their payments transferred across from Personal Independence Payment or Disability Living Allowance (199,460 people or 63%) and the remainder are new applicants (115,035 people or 37%).

At the same time, 251,815 people had submitted the first part of the application for Adult Disability Payment and 213,265 people had submitted the second part of the application. Social Security Scotland has processed 216,960 applications with 50% being approved, 45% being denied and 5% withdrawn.

The total value of all Adult Disability Payments made to 31 July 2024 is £1.6 billion. The monthly value of payments issued has been increasing since the benefit launched, rising from £12,390 in April 2022 to a peak of £182.4 million in July 2024. The key features of Adult Disability Payment include:

Eligibility: Adult Disability Payment is available to adults between 16 and state pension age applying for the first time who have a long-term physical or mental health condition or disability. The condition must have lasted, or be expected to last, at least 12 months. People who have been awarded Adult Disability Payment before state pension age can continue to be entitled to it after reaching state pension age.

Components: Like Personal Independence Payment, Adult Disability Payment has two components:

- **Daily Living Component:** This helps with extra costs associated with everyday activities such as dressing, eating, and personal care.
- **Mobility Component:** This helps with extra costs associated with moving around and getting out and about.

Decision-making Process: The decision-making process for Adult Disability Payment focuses on understanding the impact of a person's condition on their daily life and mobility. The Scottish Government aims to make the decision-making process more person-centred, reducing stress and ensuring that individuals are treated with dignity and respect.

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Rates: Both the daily living and mobility components have two rates – a standard rate and an enhanced rate, depending on the severity of the impact of the disability or condition.

Application Process: The application process for Adult Disability Payment is designed to be straightforward, with support available to applicants through various channels and at different points on the client journey. Supporting Information can be obtained on behalf of the client by Social Security Scotland.

The Purpose and Remit of the Review

The Cabinet Secretary for Social Justice, Shirley-Anne Somerville 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 will issue my final report to Ministers in July 2025.

The Independent Review will consider people's experiences of the first year of delivery of Adult Disability Payment, as well as the eligibility criteria. This builds upon the [analysis of the consultation](#) on the eligibility criteria for the mobility component of Adult Disability Payment, published in August 2023.

Remit and Terms of Reference

The Independent Review will look at:

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

The Independent Review will not look at:

- 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, 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.

The Legislative Context

The legislative context for social security in Scotland is primarily governed by the Social Security (Scotland) Act 2018⁴. 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 Disabilities⁵ (CRPD) 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 community⁶.

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’⁷.

Executive Summary

The Review is seen by many stakeholders as an opportunity to do more than ‘tinker around the edges’ resulting in potential recommendations for minor changes to wording and/or processes. There was a desire exhibited in many stakeholder meetings that the Review should result in strong recommendations about how to shift the system from the ‘safe and secure transition’ stage to one that is truly rights-based in practice as well as on paper, and one that reflects the social and human rights model of disability as opposed to a medical and beneficiary/charitable model.

In the interim report I have captured the recurring themes from stage one of the Review. This has been done following extensive internal and external stakeholder engagement, a consultation and call for evidence, consultation events and a comprehensive literature review.



Whilst there are many evident, positive aspects to the current system, the Review has uncovered recurring themes that may be addressed by the implementation of a revised system and we will explore what this might mean in practice, in the second stage of the Review.

Whilst it is clear that the Scottish Government has introduced many improvements during the transition from Personal Independence Payment and shown a willingness to embrace feedback, there are many aspects that remain unchanged, potentially unfair and problematic for some clients.

There are several priorities that I feel should be capable of early action, and these are captured in full later in the report. The actions include improving communication between Social Security Scotland and clients, and third party representatives; making some small adjustments to the application form; improving the consultation process; improving decision making timescales and ensuring more consistency in decision making; improving the way supporting information is provided; promoting further take up of the benefit and ensuring people know about the support available to assist them in making an application; ensuring all information is as accessible as it can be and suggestions for further research to be conducted.

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I have not addressed the eligibility criteria or the merits or otherwise of a points-based system, as further work is required on these areas during phase two of the Review.

At the end of July 2025 a full report will be produced with recommendations that I hope the Scottish Government will welcome.

With the support of the Advisory Group and continued stakeholder engagement, I am committed to ensuring that our review process is thorough, inclusive, and reflective of the needs and experiences of those it aims to serve. The feedback gathered from the consultation and call for evidence will be invaluable as we continue to evaluate and ultimately enhance the Adult Disability Payment system in Scotland.

Progress to date

Appointment of Chair and Inception of the Review

In January 2024, I was appointed as the Chair of the Independent Review of Adult Disability Payment. This marked the official commencement of a comprehensive review process dedicated to evaluating the effectiveness and impact of Adult Disability Payment in Scotland. In February 2024, the review officially began with the support of a dedicated secretariat, initiating a detailed and structured project plan.

Project Planning and Framework Establishment

The initial stages of the review involved extensive project planning, which included defining the principles and values guiding my approach. Central to my way of working is a commitment to transparency, accessibility, inclusivity, and fairness. I established a robust methodology to ensure that the review process is thorough and reflective of the diverse experiences and needs of Adult Disability Payment applicants and recipients.

Chair's Preparatory Work

I dedicated several weeks to essential reading and research to gain a comprehensive understanding of the history of devolved social security benefits in Scotland. This included an in-depth review of the legislative and fiscal context, as well as the Scottish Government's vision for social security. This foundational knowledge was crucial for conducting an informed and insightful review.

Literature Review and Identification of Focus Areas

A comprehensive literature review was undertaken to identify existing gaps and areas requiring further focus. This process included examining the existing report from the consultation on the mobility component of Adult Disability Payment⁸ and evaluating previous work on the use of Supporting Information⁹ and the evaluation of Case Transfer¹⁰ published as part of the [Disability Benefits Evaluation Strategy](#).

The insights gained from the literature review have been instrumental in shaping the consultation and call for evidence.

Establishment of the Advisory Group

To ensure that the Review is guided by a diverse range of perspectives, I established an Advisory Group. This group comprises ten members, many of whom have a disability or mental health condition and have lived experience of applying for Adult Disability Payment. The group also includes representatives from third-sector organisations.



The Advisory Group plays a pivotal role in providing guidance, expertise, and scrutiny to ensure the effectiveness, fairness, and integrity of the review. They offer advice to the Chair on the approach, methodology, and engagement strategies, and help facilitate access to a wide range of audiences.

Stakeholder Engagement

For the purposes of this report, I use the term stakeholders in its widest sense, to include disabled people and third sector stakeholders that I have met with so far.

Effective stakeholder engagement is a cornerstone of my review process. I have conducted comprehensive stakeholder mapping and held numerous meetings with a wider audience including the Scottish Government, Social Security Scotland and the UK Government.

Intersectionality plays a crucial role in understanding and addressing the diverse needs of individuals who apply for Adult Disability Payment in Scotland. The concept of intersectionality recognises that people's experiences of disability are influenced by multiple overlapping factors such as race, gender, socioeconomic status, and other identities. I have aimed to engage with a diverse range of seldom-heard groups and will continue to do so as part of the next stage of the Review to ensure intersectionality is properly considered as part of the client experience.

Consultation Fatigue

We need 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 engagement meetings it was necessary to stress repeatedly the independence of the Review.

Many third sector organisations told me that they are operating in difficult financial circumstances and as a result, they must make careful decisions about where to dedicate resources.

In choosing to dedicate time, resource and attention to this review they wanted to be assured that any outcome would ultimately make a positive difference. People want to know what changes will come about because of the Review. I was told frequently that people and organisations are growing tired of repeated consultations with little evident change to the system which damages trust and results in disengagement.

Consultation and Call for Evidence

The call for evidence and consultation, ran between 28 June 2024 and 30 August 2024 and provided an opportunity to conduct a 'deep dive' into people's experiences of Adult Disability Payment. This research forms only one part of on-going engagement with me and provided an opportunity to explore in-depth experiences of seldom heard voices and seldom heard communities in addition to allowing stakeholder organisations to contribute to the Review and discuss possible ways forward.

All materials produced for the public consultation were designed to be as accessible as possible, including formats such as easy read, translations into languages other than English, and British Sign Language (BSL) versions.

I received an encouraging number of responses - 84 to the consultation and 33 to the call for evidence. These responses are currently being collated and analysed.

In addition, we held in-person consultation events across the country facilitated by The Lines Between who have been appointed to carry out the collation and analysis of the findings. On-line consultation events were available for those who found travelling to a venue too difficult. Overall, the events attracted 46 attendees, and I am very grateful to them for contributing to this Review.

Emerging themes

Social Security Charter

The Social Security Charter¹¹ was created and approved in 2019 and sets out the service that people should expect from the whole social security system in Scotland (including Social Security Scotland), built on the principles of dignity, fairness and respect.

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.

In 2023, a review of the Charter was undertaken in accordance with section 18 of the Social Security (Scotland) Act 2018. The review¹² found that the Charter is held in very high regard by clients and partner stakeholders and following the conclusion of the review, Scottish Ministers laid a proposed revised Charter in the Scottish Parliament on 16 May 2024. Parliament approved the revised Charter on 26 June 2024.

New commitments in the revised Charter include providing clients with more information on what they can expect from Scotland's social security system and increased accountability for delivering the Charter commitments. The revised commitments reflect the priorities identified by clients, staff and partner organisations, whilst adopting a more inclusive use of language. The revisions also reflect experience gained since Scotland's social security system became operational.

Findings from the research show that the Charter continues to reflect values which align with the priorities of clients, staff, and partner organisations. As such, all original commitments have been retained in some form in the new version and a small number of new commitments have been made.

For example, a new commitment has been made to give clients more information about receiving support with their interactions with Social Security Scotland, which will help address some of the views expressed during the first phase of this Review relating to lack of communication sometimes leading to anxiety and stress.

There is also a new commitment about providing information about social security at community locations. We hope this will go some way to addressing the needs of all

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communities in Scotland both in terms of communities of place and communities of interest.

The Social Security Charter measurement framework¹³ is a list of measures relating to the commitments set out in the Charter. It exists to ensure that the commitments in the Charter are being implemented and having a positive impact on the people of Scotland.

The findings from the evaluation of the 2022-23 measurement framework showed that:

- 93% of Client Survey respondents who had been in contact with Social Security Scotland believed that they were treated with kindness
- 81% of Client Survey respondents believe that Social Security Scotland is an honest organisation, and
- 97% of People Survey respondents said that Social Security Scotland understood their needs¹⁴.

Principles set out in the Charter

While the principles of dignity, fairness, and respect are evident in the standards of service provided by Social Security Scotland, the current mirroring of the Personal Independence Payment process potentially undermines these principles, rendering them 'empty words' by some recipients.

In my meeting with Scottish Government policy colleagues, it is clear how much work has gone into and continues to go into developing the Charter. It was their view that while we go through the safe and secure transition, the principles of the Charter are relevant and important to uphold. The ways of working and the values underpinning this work are critical, irrespective of the legacy system (referring to Personal Independence Payment) we are operating within. Colleagues in Scottish Government and other stakeholders shared thoughts about their journey from prior to the introduction of the Social Security (Scotland) Act, to implementation. It seems that some people feel disappointed with where we are today, the sense being that the closer Scotland got to implementation the more aspirations had to be abandoned.

The Additional Costs of Living with a Disability

Adequacy of payment is out of scope for the Review. However, one of the most pressing themes that has emerged during the Independent Review to date is the significant additional costs associated with living with a disability. These costs often encompass a wide range of areas, including healthcare, social care, mobility aids, home modifications, and additional daily living expenses such as taxis.

As the issue was raised several times in our stakeholder meetings, I feel the sentiment should be captured here. In the opinion of several disabled people and their advocates, the support provided through the social security system needs to adequately reflect additional financial burdens to ensure that disabled people can have a reasonable standard of living.

I have looked at the findings of several pieces of research^{15, 16, 17, 18, 19} in the early stages of the review, including a small-scale study commissioned by the Social

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Justice and Social Security Committee into the additional costs of living with a disability in Scotland²⁰. However, to my knowledge, there is no Scotland-specific baseline of the scale of the additional costs faced by disabled people.

Approaches in other countries

I considered an earlier report commissioned by the Scottish Government in 2019²¹ which was shared with me during the initial stages of the Review. The report provided comparisons with other countries with broadly similar systems for providing financial support to disabled people, although none were directly comparable. It is notable that the UK social security system is the only one that adopts a functional or deficits-based approach to financial support for disabled people.

Medical v Social Model of Disability

Studies show that diagnosis alone does not predict financial needs, level of care or functional outcomes. Nor is the presence of a disease or long-term health condition an accurate predictor of receipt of disability benefits.

The social model of disability was developed by disabled people and other advocates who were involved in the 'Independent Living Movement'.²² Unlike the medical model, where an individual is understood to be disabled by an impairment, the social model views disability as the barriers created by society, such as negative attitudes towards disabled people, and inaccessible buildings, transport and communication, as the cause of disadvantage and exclusion, rather than the impairment or disability itself.

A truly rights-based system of financial disability assistance would focus on removing the barriers to people's rights to equal participation in society and independent living. Many people with lived experience and their advocates told us that taking a more social model and human rights-based approach, would help challenge and overcome the culture of stigma and prejudice that often surrounds Adult Disability Payment.

There is a strong perception that decisions continue to be made through a medical model rather than a social model of disability, despite Scotland's stated aim to adopt a different approach from the Department for Work and Pensions. There has also been a suggestion that standardised text is beginning to creep in when relating to the general manifestations associated with some conditions or disabilities. There is a risk of a perceived reinforcement of a medical model if general medical information is being used instead of considering the actual experiences of the individual.

In my meeting with Glasgow Disability Alliance²³, I was told of several instances where applications were not successful based on the absence of a medical diagnosis and/or the absence of prescribed medication despite there being descriptions of how the person's non-diagnosed disability was impacting their mobility and daily living. This appears to be a particular issue for people with learning difficulties and learning disabilities and other conditions such as those that result in fatigue and exhaustion.

I will look further into this during the second stage of the Review considering what it might take to replace the current perceived medical and deficit-based model that is predominantly focused on impairments.

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Legacy of Fear and Anxiety

The legacy of fear and anxiety stemming from experiences with the Department for Work and Pensions, and the Personal Independence Payment process continues to impact individuals' willingness to engage with Adult Disability Payment. This has come up in every meeting I have had to date. Many still carry the emotional and psychological burden from previous negative experiences, which hinders their willingness to engage.

It seems that people are not always aware of the differences between Social Security Scotland/Adult Disability Payment and the Department for Work and Pensions/Personal Independence Payment respectively. Occasionally when I probed it was evident that the experience being shared related to Personal Independence Payment despite me asking about Adult Disability Payment.

I don't think we can underestimate the trauma experienced by some Personal Independence Payment recipients and how this continues to affect them. One person's sibling told us that they will never answer their phone for fear that it is the Department for Work and Pensions 'trying to catch (them) out', even though this person's case has already been transferred to Adult Disability Payment and they were supported positively by colleagues at Social Security Scotland.

Fiscal and Economic Context

Previous reforms to disability social security, in particular the introduction of Personal Independence Payment by the UK Government in 2013 expressly aimed to reduce the costs of social security²⁴. The Scottish Campaign for 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.

One of the Scottish social security principles states that 'the Scottish social security system is to be efficient and deliver value for money.'²⁵ 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 isn't disproportionately prioritised over other principles.

Social Security spending is rising. In 2024-25 it is forecast to be nearly £1 billion higher than in 2023-24²⁶. The Scottish Government has made changes to payments which replace previously UK-wide payments, including Adult Disability Payment. There has been UK wide increases in successful new applications for both Personal Independence Payment in England and Wales and Adult Disability Payment in Scotland. This rate in Scotland has been higher since the Scottish Government introduced Adult Disability Payment to replace Personal Independence Payment in March 2022, however more recently it has been decreasing and becoming more in line with Personal Independence Payment²⁷.

In contrast to this increase in applications, a decrease in the average payment award received by new applications to Adult Disability Payment has been noted in comparison to Personal Independence Payment in England and Wales²⁸.

Quarterly applications rates to Personal Independence Payment in England and Wales and to Adult Disability Payment in Scotland started to diverge at the beginning of the Adult Disability Payment pilot in March 2022, and further widened when Adult Disability Payment was launched nationally in August 2022²⁹.

Overall social security spending in Scotland is forecast to increase from £5.3 billion in 2023/24 to £8.0 billion in 2028-29. By 2028-29, the Scottish Fiscal Commission (SFC) expect the Scottish Government to spend £1.5 bn more on social security than block grant funding received from the UK Government³⁰. This has been attributed by the Scottish Fiscal Commission in part because of a UK-wide increase in the number of people receiving disability payments and in part because of the policy and operational changes to disability payments introduced by the Scottish Government³¹.

Block Grant Adjustments (BGA) are added to the Scottish Block Grant (SBG) as they represent expenditure which the UK Government is no longer required to make when social security powers are devolved to Scotland. If overall spending on Personal Independence Payment is reduced, then the Social Security Block Grant Adjustments will be reduced accordingly.

Link with wider forms of state support

As part of the initial stage of the Review, I explored and compared the purposes and eligibility criteria for adult social care and disability assistance in Scotland, as one example of links with wider forms of state support. Although both fall within the same broad category of state support, the purposes of each are different. Social care involves supporting people to live independently for as long as possible, by providing practical assistance with daily personal care and living tasks. The purpose of disability assistance such as Adult Disability Payment is to support working age people who have a disability or long-term condition to mitigate some of the extra costs associated with their condition.

There are markedly significant demographic differences between disability assistance and social care, age being the most notable. People who receive social care are generally over the age of 65³², whilst a more substantial proportion of people paid Adult Disability Payment are under 65. As noted earlier in this report, a person applying for Adult Disability Payment for the first time must be under State Pension Age. However, a person who does qualify for Adult Disability Payment before State Pension Age will continue to receive it (subject to meeting the eligibility criteria).

I will return to the topic of state support in the second phase of the Review as there may be some merit in looking at the potential to align eligibility and decision making across some other areas of publicly funded provision to improve the client experience.

Differences between Personal Independence Payment and Adult Disability Payment.

The Scottish law on social security states that the receipt of social security is a human right. The Scottish Government says it has developed a system that is rooted in trust to make sure people can access the support that they are entitled to³³.

There are no UK Government-style assessments and Social Security Scotland do not use the private sector to carry out health assessments. According to Social Security Scotland, it will only invite people to take part in a consultation if a decision cannot be made without one. On occasions when a consultation is required, Social Security Scotland says this will be a compassionate conversation with a health and social care professional which starts from a position of trust. There aren't any functional examinations.

The Scottish Government has also made changes to the review process. Reviews are intended to be light-touch and some reviews may take place less frequently than in the UK Government system. The Scottish Government has introduced indefinite awards for some severely disabled people whose needs are highly unlikely to change. It says this will help to avoid the stress and anxiety that can be associated with reviews, while providing long-term financial security to people.

Interpretation of Personal Independence Payment Legislation

Some issues have been raised in relation to potentially diverging interpretations of Personal Independence Payment legislation and the need to treat Personal Independence Payment case law as informative rather than binding for Adult Disability Payment. There is a fine balance between not disturbing existing rights and ensuring decisions are made based on current and relevant legal frameworks. I will investigate this further during the second stage of the Review.

Passporting

Passporting or 'access to related social security benefits' is a mechanism where eligibility for certain benefits automatically qualifies an individual for additional assistance or benefits. In Scotland, this system plays a crucial role in simplifying access to a variety of supports, including housing benefit, free school meals, and other welfare provision.

The principle behind passporting is to reduce the administrative burden and to ensure that people who are already identified as needing support receive it without having to navigate unnecessary, complex and repetitive application processes.

The implications of passporting for Scotland's devolved social security system are significant. With the devolution of certain social security powers, Scotland can tailor social security to better meet the needs of its residents. This includes designing passporting systems that are more responsive and integrated with other devolved services such as health, education, and housing. However, this also presents challenges, particularly in ensuring alignment with UK-wide benefits.

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Both ad hoc and formal data sharing arrangements have allowed disabled people to access these further supports to date. Now that some benefits are paid by Social Security Scotland (including Adult Disability Payment) this has added an additional layer of complexity to 'passporting' entitlements which can create difficulties for clients.

As part of my final report, I will consider any potential impacts of making changes to Adult Disability Payment, on passported benefits. This will be particularly relevant if I recommend making any changes to the eligibility criteria.

It is recognised that it is important that clients in Scotland can continue to access these supports and any resultant impact on reserved benefits is fully understood³⁴. In choosing whether to accept any recommendations from my final report, it will be for the Scottish Government to decide how to address this issue.

Many stakeholders stressed the importance of making it as easy as possible for clients to get the additional support that they are entitled to. Currently a person must make many different and separate applications to get access to these different supports, which is administratively ineffective and can create a barrier to take-up.

I understand the complexities inherent in using multiple systems and the problems that are evident in data sharing between the Department for Work and Pensions and Social Security Scotland and also within the different benefit systems within the Department for Work and Pensions. In the future it would be ideal if applications could be automated to reduce the burden on the individual of informing different organisations and departments of their transfer or award.

I will look in more depth at passporting during the second stage of the Review where it relates to a client's experience and where any potential recommendations may impact on passported benefits.

The UK Government Green Paper and potential implications for Personal Independence Payment and Adult Disability Payment

Effective coordination between the Scottish Government and the UK Government is essential to maintain coherence in the social security system, ensuring that passported benefits operate smoothly and efficiently across different jurisdictions.

The pressure the Department for Work and Pensions is under to support devolution as well as its own programmes, is recognised.

The complexity of systems and levels of governance it works within means any suggested or needed changes could take longer than ideal. It is imperative to have a clear understanding of where issues are likely to occur and anticipate this by ensuring that any required legislation is in place and by giving plenty of time to minimise the impact to the Department for Work and Pensions.

In my meetings to date with senior officials and Ministers from the Department for Work and Pensions and the UK Government respectively, it appears that

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relationships across the two administrations are good and there is evidence of effective co-operation in relation to the safe and secure transition from Personal Independence Payment to Adult Disability Payment.

It appears that the working relationship with the Department for Work and Pensions is generally strong, especially in the case transfer space although it is noted that the proposed reforms to social security benefits, including Personal Independence Payment were announced by the last UK Government without any prior notice to the Scottish Government.

Following the then Prime Minister's speech on 19 April 2024, the UK Government published "Modernising support for independent living: the health and disability green paper³⁵", setting out a number of proposed reforms to social security benefits, including Personal Independence Payment. The previous UK Government said that reforms are necessitated by the increasing cost of providing Personal Independence Payment in its current form. Particular attention is paid to the increase in support for mental health conditions, specifically anxiety and depression, noting a doubling since 2019 of Personal Independence Payment applications that cite these conditions as the primary health condition.

The paper explores potential changes to the Personal Independence Payment eligibility criteria and assessment model which if introduced in England and Wales would potentially impact on Adult Disability Payment. The suggested changes include changes to the activities and descriptors contained within the Personal Independence Payment eligibility criteria. For example, the paper discusses the option of removing functional questions which focus on someone's needs and replacing them with condition-based requirements. Further changes have been suggested to the time someone is required to demonstrate additional needs relating to their disability before becoming eligible. The suggested changes reflect a more medical model of disability which is a different view to that of the Scottish Government which says it is committed to working towards a social model of disability³⁶.

The Green Paper also explores alternatives to cash payments such as vouchers and one-off grants for equipment and proposes options that would potentially better align Personal Independence Payment with National Health Service and social care services.

The consultation does not contain specific policy proposals and at the time of publication, no definitive proposals for reform have been put forward by the UK Government. Timescales for implementation of any such proposals also remain unclear, particularly considering the formation of a new UK Government.

If the measures announced in the Green Paper are designed to reduce costs on social security spending across the UK, this will ultimately reduce the funding available to the Scottish Government and therefore may have implications for Adult Disability Payment.

The UK Government's consultation analysis and any potential recommendations will likely not be published for some time but as things move forward, I will, of course, keep an eye on anything that has implications for this Independent Review.

Social Security Scotland - Values, Culture, and Capacity

The establishment of Social Security Scotland brought about the usual challenges associated with setting up a completely new organisation. Whilst I recognise that Social Security Scotland continues to mature as an organisation, I didn't shy away from asking questions relating to people's experiences.

While the values of dignity, fairness, and respect are central to its mission, concerns have been raised about the organisation's capacity to meet these ideals consistently. Prioritisation of resources and effective training for staff are areas identified as potentially needing improvement to uphold these values effectively.

Some colleagues at Social Security Scotland expressed concern that performance management and targets (referred to as outputs) are placing an emphasis on quantity over quality, and the organisation is potentially in danger of eroding client's and worker's trust in the values of the organisation. Social Security Scotland are clear in their operational delivery that performance is measured in terms of client satisfaction and getting decisions right first time, while also reducing processing times for applications.

I met with colleagues involved in the induction and training of staff at Social Security Scotland and studied training plans and materials. It is evident that alongside the functional requirements of the role a proportionate emphasis is placed on values, the principles enshrined in the Charter and providing a good standard of service to clients.

Everyone I have met at Social Security Scotland has been accommodating, responsive and helpful in answering questions and providing me with information. The days I have spent in Social Security Scotland's Dundee office have been enlightening; with an evident commitment to the organisation's values sometimes, as one staff member said, 'to the detriment of efficiency and productivity'.

Safe and Secure Transition and Case Transfer

The initial priority for Social Security Scotland is ensuring that responsibility for client's payments transition safely and securely from the Department for Work and Pensions to Social Security Scotland. The other key principle for Social Security Scotland is that people must continue to get the right payments at the right time until everyone's payments have transferred.

Principles

Case transfer involves the transfer of a person's payments from the Department for Work and Pensions to Social Security Scotland, with entitlement to Personal Independence Payment stopping one day and to Adult Disability Payment the next. This process has been designed to be automated, without the need for a person having to re-apply for their benefits.

Those principles³⁷ underpinning the case transfer process are ensuring correct payment at the correct time, no re-applications, no face-to-face Department for Work and Pensions re-assessments, complete as soon as possible and clear communication with clients.

The case transfer process is being conducted in-line with these principles to avoid replicating the negative experiences associated with the transition from Disability Living Allowance to Personal Independence Payment to build trust through a positive first experience of the transition from the Department for Work and Pensions to Social Security Scotland administered benefits.

Furthermore, the reason for transferring Personal Independence Payment and Disability Living Allowance clients before considering their change of circumstances is because the alternative would be for their change in circumstances to be considered by the Department for Work and Pensions through the standard Personal Independence Payment review process, potentially involving a face-to-face assessment which would not align with the case transfer principles.

Committing to this 'safe and secure transition' as the starting point for Adult Disability Payment has meant that many aspects of the new system have been lifted from the Personal Independence Payment process which evidence has repeatedly shown doesn't work for many disabled people. While the experience with Social Security Scotland appears to be kinder in nature when compared to people's experiences of the Department for Work and Pensions, it seems that for many people the new system and process don't yet achieve the lofty and ambitious principles and aims of the Social Security (Scotland) Act.

The prioritisation of a 'safe and secure transition' to the devolved system of disability assistance leaves some unanswered questions and results in several parts of the legacy system intact, which repeatedly came up as an issue in our stakeholder meetings.

The Scottish Campaign for Rights to Social Security members (and others) believe longer-term reforms are needed to disability assistance to create a world-leading rights-based system of support for disabled people³⁸.

The Process

Case transfer has been regarded as a complex and substantial undertaking which has carried risks at certain points. This has occurred within the context of complex legislative, regulatory and communication considerations.

Once a person's payments are selected for transfer, there is a 13 to 17-week transfer window to allow for alignment with the client's normal payment cycle. The old award would end, and a new award begin at a specific point in the payment cycle, so the client does not have a break in payment. The 13 to 17-week window is needed to ensure Social Security Scotland's systems have all the information (including client details) that are required to ensure the client's transfer is as smooth as possible. This required a great deal of consideration as part of the legislative and system design process planning to avoid disruption to client payments.

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There is evidence at times of inconsistent communication from the Department for Work and Pensions and Social Security Scotland.

The complex IT systems sometimes make it difficult for automatic notifications of a case transfer to other benefits. Therefore, the onus is on the client to inform other benefits that their payments have transferred so areas like Universal Credit can be aware.

It is evident that a lot of effort has been put into establishing processes to ensure client's wider support is protected, although it is not possible to guarantee in all circumstances that there would be no impact on payments and therefore, clients are asked to inform local authorities, His Majesty's Revenue and Customs (HMRC) and the Department for Work and Pensions of the new award. This is clearly set out in determination letters along with the contact details/ signposting to the contact details for those organisations.

Progress so far

The transition from Personal Independence Payment to Adult Disability Payment appears to be going well when one considers the volume of people's payments to be transferred. As of 31 July 2024, 275,780 people's payments have been selected for transfer from the Department for Work and Pensions to Social Security Scotland from Personal Independence Payment or (in some cases) Disability Living Allowance (DLA) for adults. This means that 83% of Personal Independence Payment clients in Scotland have started the transfer process, with the remainder due to transition before the end of December 2025.

Social Security Scotland has completed the transfer process for 207,295 people. The total number of people receiving Adult Disability Payment as of 31 July 2024 is lower than this, as some clients with transferred awards are beginning to leave the Adult Disability Payment system.

Since the process of transferring people's payments began the most recent high-level statistics for case transfer clients show³⁹:

- 4,725 clients asked for re-determinations, with 3,730 completed and:
- 345 resulted in a change and 85% of these were undertaken within the 56-day time limit.
- 59,985 planned award reviews have taken place for case transfer clients, with:
 - 83% resulting in no change in entitlement,
 - 16% resulting in an increase in entitlement, and
 - 1% resulting in a decrease (or end of) entitlement.
- 16,595 reviews because of change of circumstances being reported, with:
 - 40% resulted in no change in entitlement,
 - 59% resulting in an increase in entitlement,
 - 1% resulting in a decrease (or end of) entitlement.

Experience of case transfer

The Scottish Government published [an evaluation report](#) of the Personal Independence Payment to Adult Disability Payment, Disability Living Allowance to Child Disability Payment and Disability Living Allowance to Adult Disability Payment

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case transfer process on 11 July 2024. The report presents findings from an evaluation of the first benefits that were part of the transfer process and includes the experiences of people whose cases had transferred to Adult Disability Payment from either Personal Independence Payment or Disability Living Allowance.

The evaluation includes the period between April 2022 and July 2023 and covers clients' experiences of case transfer and, where one has taken place, the first review of their award by Social Security Scotland.

Overall, what I am hearing as part of this Review is that case transfer is going relatively well, and most client experiences are seamless and positive.

This is reinforced by the most recent client survey⁴⁰ which found that 89% agreed or strongly agreed that they had 'felt informed about the process' of their case transfer and 82% agreed or strongly agreed that they had 'felt reassured about the process' of their case transfer.

Other findings from the client survey include:

- 88% agreed or strongly agreed that the communication they received from Social Security Scotland about their case transfer was 'clear and easy to understand'. 3% disagreed or strongly disagreed with this.
- 83% agreed or strongly agreed that 'the tone was friendly'. 1% disagreed or strongly disagreed with this.
- 84% agreed or strongly agreed that the communication they received 'helped them to understand what was happening and why'. 4% disagreed or strongly disagreed with this.
- 79% agreed or strongly agreed that the communication they received 'made them feel confident that they could approach Social Security Scotland if they had a query'. 4% disagreed or strongly disagreed with this.

During a consultation event, one participant expressed confusion about when the level of their payment might change if they notify the Department for Work and Pensions of a change in their circumstances before moving from Personal Independence Payment to Adult Disability Payment. Scottish Government Policy colleagues explained that they have aimed to improve both guidance and communications about this to improve clarity to people.

An issue, raised by practitioners in Social Security Scotland relates to the volume, quality and relevance of information supplied at case transfer stage. The format of information which comes from the Department for Work and Pensions is often a problem. Information can be unnamed and non-dated and often more than 20 pages with each page including a link to a larger document. Everything must be read because a practitioner or case manager wouldn't know what parts of the documentation are relevant until it has been read, which takes up a significant amount of time. One practitioner told me that 'there could be as many as 500 documents and you have no idea what they are or if they are relevant, so you are required to read them all'.

In my conversations with Scottish Government colleagues involved in the case transfer process it was evident the amount of preparation, planning, thought and sheer hard work that has gone into what can only be described as a momentous data migration and technological project.

Some areas that I will explore further include:

- Mixed understandings and expectations of the Adult Disability Payment review process.
- Areas of confusion such as the process for backdating payments and the process and timescales for the review element.
- The length of time the whole process takes contributing to increased anxiety.
- Issues with the length and online functionality of the review form when notifying of a change in circumstance.
- Difficulties in contacting Social Security Scotland which impacted on clients' understanding and anxiety about the process.
- Inconsistent communication from the Department for Work and Pensions and Social Security Scotland.

During the second stage of this Review, I will continue to reflect on people's experiences of the case transfer process for Adult Disability Payment.

Potential longer-term reforms to Adult Disability Payment, post-completion of the safe and secure transfer, will be considered during the second stage of the Review.

Adult Disability Payment awareness and Benefit Take-up

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. Awareness of Adult Disability Payment itself appears to be limited, leading potentially to ineffective take-up. This potentially suggests the need for a specific Adult Disability Payment benefit take-up strategy to ensure eligible individuals are informed and encouraged to apply.

Discussions with stakeholders suggest that there may be many factors that influence the take-up of Adult Disability Payment. Some factors suggested were:

- The name of the benefit resulting in people who don't see themselves as disabled not thinking they are eligible and/or not applying.
- 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 'scroungers'. This can be a particular issue in some minority ethnic communities.
- People not applying for Adult Disability Payment because they view public resources as scarce in supply and other people as 'more eligible' for support.
- People who are eligible for Adult Disability Payment not applying because they are unaware that the benefit is non-means tested.
- Eligible people believing that Adult Disability Payment is only for people with a physical health condition.

- Stigma associated with mental health conditions also acts as a barrier to some people applying for Adult Disability Payment which can be a particular issue for some minority ethnic communities where stigmatising language and harmful stereotypes of mental ill-health can be prevalent.
- The legacy of applying for Personal Independence Payment and Disability Living Allowance which has left some people feeling too traumatised to consider applying for Adult Disability Payment.

Some stakeholders suggested that the stress and exhaustion associated with the application process itself has resulted in some people not applying for Adult Disability Payment despite being eligible. This was a point made several times during my meetings with Long Covid, Myalgic Encephalomyelitis (ME) and clinically vulnerable representatives.

Reaching seldom heard voices and individuals who may be eligible but do not apply due to stigma is a critical challenge. Strategies need to be developed to proactively reach out to and engage these groups effectively to try to address the societal and sometimes cultural stigma associated with disability benefits to ensure broader and fairer access. I will consider this further in the second stage of the Review.

Pre-application support

There is a notable lack of awareness about the support available pre-application, such as advocacy services provided by VoiceAbility, and what is available via Local Delivery Teams. Where people are aware, there is a level of suspicion about independence and a lack of clarity over what precisely the services offer.

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. This is in addition to the support funded by Social Security Scotland.

The most recent client survey⁴¹ showed that almost half of respondents (48%) received help to complete their Adult Disability Payment application with over a third (35%) of those who received help with their application getting help from a friend or family member and around a quarter (23%) getting help from Social Security Scotland. 51% received help from welfare benefits advisers, housing support workers, money advice organisations and other welfare rights and advocacy services.

Local Delivery

Local Delivery Teams operated by Social Security Scotland are present in all 32 local authority areas of Scotland. The Scottish Government has set up the Local Delivery service across Scotland to help support people applying for social security benefits.

Social Security Scotland state that it continues to be committed to giving people a choice in how they apply for benefits. Local Delivery teams work in communities, people's homes, prisons and healthcare settings across Scotland. They offer face-to-face support, give information about Scottish benefits and assist people to make applications.

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A Local Delivery appointment is intended to give people the opportunity to access private and confidential support with their Adult Disability Payment application from a trained client support adviser or ask questions about the application process more generally. Appointments are arranged at accessible locations or in people's homes, wherever suits the client best.

The most recent Client Survey statistics⁴² report on how much people agreed or disagreed it was easy to get support from Social Security Scotland with their application. Of the people who responded:

- 371 strongly agreed or agreed (93%)
- 16 neither agreed nor disagreed (4%)
- 11 disagreed or strongly disagreed (3%).

Most people attending our consultation meetings had no awareness of Local Delivery. In stakeholder meetings there were suggestions that there is a lack of awareness of the service amongst potential Adult Disability Payment applicants, and the routes to making an appointment are not clear.

A Local Delivery Adviser told me that initially an important part of their role had been to make local connections, but they had been asked to stop doing this to allow for more centralised communication about the service.

Social Security Scotland has told me that it has created a centralised stakeholder engagement plan and restructured to support the delivery of this. As such, it still undertakes engagement and outreach at a local and national level but all from within a single business area so that this is better aligned, recorded and reported and they are ensuring engagement is in line with strategy.

Social Security Scotland has also told me that the Local Delivery services will continue to support clients in communities - and community spaces. They will continue to have delivery relationships and attend things like financial inclusion meetings.

Other emerging themes included:

- People being unaware of the Local Delivery service with one person saying it is Social Security Scotland's 'best kept secret'.
- A desire for Local Delivery services to be more proactive and to reach out to local communities more frequently, explaining the service they provide and giving opportunities to engage with the service.
- A mixed experience for clients depending on where they live. In more remote locations Local Delivery teams are not always located within a reasonable travel distance of their area due to the size and diverse geography of the local authority area covered by them.
- Confusion for some people regarding the most appropriate place to access the support provided by the service.

- Seeking assistance in completing an already started online application from Local Delivery advisers was problematic, as advisers cannot edit an already started online application and therefore need to start over again with a new form.
- Language barriers meaning people cannot always access the service as I have been told that not all languages are catered for in materials and interpretation services (Social Security Scotland have noted translations and interpretations are available in over 200 languages and if there is a request for a language outside the current offerings, additional options would be explored).
- 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. Coupled with 'lack of trust in the state' and hesitancy in some cases on the part of clients, this can lead to poorer outcomes.
- People recognising brands such as Citizens Advice Scotland (and many others) because they are well-established and perceived to be independent and then choosing to seek advice from them rather than the Local Delivery service.
- People already part of a community where advice and support are provided (Wise Group, Enable, The Action Group, Glasgow Disability Alliance, for example) and therefore, as strong relationships have already been established people often feel that their needs are better met there.
- Local Delivery Client Support Advisers acting only as note takers and not providing detailed guidance on how to complete the form. Some people suggested that if they can get advocacy, good advice, support and help to fill in the form all in one place why would they use a limited service?
- Client advisers not being experts in social security case law and therefore unable to offer good and comprehensive advice⁴³.
- Reluctance on behalf of welfare benefits advisers to refer people to Local Delivery as they can only help with Social Security Scotland benefits. Action Group, for example are more likely to help people themselves or to refer to Voice of Carers Across Lothian (VOCAL) as they able to help with devolved and reserved benefits too.

Some stakeholders identified instances of difficulties for appointees and welfare benefits advisers accessing the service, stating that they were aware of appointees being missed out of communications. This was reported to have resulted in delays in providing information or progressing applications.

Appointments with Local Delivery teams are only accessible via the main Social Security Scotland contact centre. No referral pathways exist between third party support organisations and Local Delivery teams, even when they are co-located, and this is seen as inefficient and counterproductive. One person told us that they received a standard text/email from Social Security Scotland when the individual failed to complete part two of their application in time. It offered help to fill in the form from a Local Delivery adviser and provided the contact centre number if they wanted to make an appointment. The phone waiting time exceeded an hour so they gave up but asked us why, if Social Security Scotland has this person's postcode, Social

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Security Scotland couldn't provide more personalised and local information for them to receive help.

One Local Delivery adviser I met told me that people wanting assistance to fill in an application or a change of circumstances form for Adult Disability Payment (and other benefits) are often waiting for more than 2 months for an appointment because of the volume of appointee assessments the advisers are expected to undertake. An average appointee assessment meeting takes 2 hours minimum and there is a lengthy form to fill in afterwards, leaving very little time for appointments with Adult Disability Payment clients.

Despite these challenges there were some positive comments about the Local Delivery service. Where contact between clients and Local Delivery teams is known about, there are frequent reports of very positive interactions with staff, including that the advisers were generally kind and understanding, and helpful in explaining how to complete the application form, especially around the eligibility criteria for clients. The value of the home visit service is frequently highlighted although some stakeholders suggested there is a default to offering a phone call and not making it easy for people to feel they can request an in-person meeting.

Social Security Scotland's Business Plan for 2024-25⁴⁴ has committed the organisation to reviewing how local services are meeting clients' expectations in communities across Scotland.

In addition to the Local Delivery service, the Scottish Government funded a two year 'test and learn' programme for Welfare Advice and Health Partnerships (WAHP) which started in October 2021 and ended in December 2023.

Welfare Advice and Health Partnerships integrate local authority, or third sector, welfare rights and money advice services into primary care settings. This is done by the inclusion of a dedicated Welfare Rights Adviser (WRA) who has consensual access to medical records, as a member of a GP Practice Team. By providing regulated and accredited advice services in a non-stigmatised setting, which usually involves referral by a trusted member of the medical, or an allied, profession Welfare Advice and Health Partnerships are able to offer a delivery model which supports earlier intervention and engages individuals who would be unlikely to use 'traditional' advice services. There is supporting evidence that demonstrates the multiple benefits this approach to service delivery offers to funders, providers of both health and advice services and individual patients/ service users.

23% of the total financial gain because of the pilot was because of awards of Adult Disability Payment.

The evaluation of the pilot showed that Advice providers, GPs and patients have positive experiences of being able to access welfare rights advice in GP surgeries. Whilst recognising the benefits of this approach to service delivery there have also been challenges⁴⁵. This marks the first stage of evaluation into the initiative and covers the original participating GP Practices. Welfare Advice and Health Partnerships have also been made available in 30 GP Practices across remote/rural

locations and a further evaluation report on the impacts in these areas will be published later this financial year.

Following conclusion of the 'test-and-learn' period in March 2024, Welfare Advice and Health Partnerships continue to be funded in 2024/205 through contributions from the Scottish Government and participating local authorities.

Advocacy

The Scottish Government also funds an independent advocacy service (VoiceAbility). This service is intended to support people to better engage with Social Security Scotland in terms of access, information, and assistance.

VoiceAbility was commissioned by the Scottish Government in September 2021 and most recent data from VoiceAbility (2 May 2024) shows that the Independent Advocacy Service (VoiceAbility) has handled 5,772 cases, of which 4,858 relate to Adult Disability Payment. The majority of advocacy is provided to support clients with applications (3,526 cases), followed by re-determinations (878 cases) determinations (270 cases) and appeals (180 cases).

Early themes emerging include:

- A lack of awareness of the service, including amongst some third sector providers.
- Some welfare benefits advisers expressing no confidence in the service provided
- Difficulties in getting an appointment with the service.
- Some concerns expressed about VoiceAbility's lack of knowledge of Scotland and the context of social security benefits within a devolved Scottish system.
- Concerns about the independence of advocacy services (and Local Delivery teams) were raised repeatedly, with some people perceiving them as extensions of the state rather than advocates for the individuals they support.

There are repeated concerns raised about the clarity of the role of advisers and advocates especially when compared to the more holistic role played by the plethora of organisations who employ welfare rights advisers (either as volunteers or paid members of staff) in the third sector.

During the second stage of the Review, I will be spending time with Local Delivery advisers and colleagues from the Independent Advocacy Service to shadow them at work and further research will be conducted on the performance and effectiveness of both services, as perceived by clients.

Contacting Social Security Scotland

Trust in Social Security Scotland will take time to develop and will be impacted by a variety of interactions with clients, beyond the case transfer process. Whilst there is positive evidence of clients feeling increasingly comfortable with getting in touch with Social Security Scotland for general information or to report a change in circumstances, more time and further data is needed to assess this fully.

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The issue of contacting Social Security Scotland regarding client applications from welfare benefits advisers generated a mixed response. Whilst some reported a neutral attitude, others, both clients and support organisations, reflected interactions with staff that had helped them to develop a positive attitude towards Social Security Scotland.

Engagement with third sector stakeholders generated responses such as:

- Social Security Scotland colleagues refusing to speak to third party representatives who had a mandate unless the client was present to authorise the interaction (please see The role of independent supporting organisations and other third parties section for more information on this).
- Another respondent questioned whether it was worth calling Social Security Scotland as they felt advice from client advisers was so variable.
- The length of time spent waiting to speak to someone at Social Security Scotland was highlighted often as an issue, especially in instances where people were on hold for long periods of time and then found that either their query could not be answered, or the call disconnected as soon as it was connected to an adviser.
- The lack of an escalation route for advocates and third sector organisations was regarded as an issue. The Department for Work and Pensions provides benefit-specific escalation routes using non-public telephone numbers for escalating issues that cannot be resolved through contact centres.
- There was a recurring feeling amongst stakeholders and people with lived experience of applying for Adult Disability Payment that Social Security Scotland did convey more kindness when engaging with people, than the Department for Work and Pensions.

Between 1 April 2023 and 31 March 2024, Social Security Scotland management information⁴⁶ shows that 397,485 calls about Adult Disability Payment were handled (excluding case transfer enquiries). This represents 58% of all calls that Social Security Scotland receives.

The total number of calls each month has declined since January 2024 for Adult Disability Payment, from a peak of 41,366 in January to 35,678 in March. Across the year, most callers waited between 10-20 minutes (30%), followed by callers waiting 20-30 minutes (29%). Average call waiting times steadily decreased from a peak of 44 minutes in April 2023 to 20 minutes in March 2024.

Colleagues at Social Security Scotland acknowledge that clients want to hear updates about their applications. Improving how Social Security Scotland communicate with people applying for all Scottish benefits will improve their experience while making the organisation operate more efficiently.

Social Security Scotland has recently introduced new application progress updates by text or email for Adult Disability Payment clients. It plans to develop and deliver a new online portal making it easier for clients to apply for Adult Disability Payment⁴⁷.

Processing Times

Processing times were a recurring theme with many stakeholders 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.

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 processing times have increased from 49 to 61 days in the most recent quarterly statistics, and stakeholders commented that processing times were excessively longer than the Department for Work and Pensions times for Personal Independence Payment. The Department for Work and Pensions reported that clearance time for new Personal Independence Payment applications is 10 weeks, which has reduced from 26 weeks in August 2021⁴⁸.

As of 20 March 2024, there were 3,728 cases where an Adult Disability Payment application was waiting for supporting information from a client's GP or other medical person.

This number includes re-determination and appeals where an original decision may have been reached but additional supporting information has been requested from a GP or a hospital to support this.

In the 2024-2025 Business Plan⁴⁹ the Chief Executive of Social Security Scotland, David Wallace states:

feedback from our clients and stakeholders is invaluable and helps us make continuous improvements. This year, we have listened and taken significant steps to improve processing times for applications. We have also worked hard to reduce waiting times on our phone lines and webchat, while ensuring our clients continue to be treated with dignity, fairness and respect¹.

It may be that the improvements Social Security Scotland says it has made to the processing of Adult Disability Payment applications will take time to be reflected in stakeholder responses and may be an area for further consideration.

The Application Form

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

Some stakeholders suggested that the stress associated with the application process resulted in a negative impact for applicants in that it can exacerbate their health condition(s). The length of the form was viewed as an issue, in that it resulted in a bulkier document causing difficulty for some applicants, especially for those who

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have conditions which affect their manual dexterity or for those who suffer from fatigue.

The 56-day deadline to submit the second part of the application adds to stress and confusion for many applicants although it was noted throughout our conversations that Social Security Scotland staff were usually helpful on the phone when it comes to granting extensions and there is a palpable cultural change from the Department for Work and Pensions.

Ahead of the national launch of Adult Disability Payment, Social Security Scotland carried out user research with people who had experience of applying for Personal Independence Payment and Disability Living Allowance. They engaged with stakeholder groups with the intention of designing a more user friendly and accessible application form for Adult Disability Payment, that includes clear guidance on how questions should be answered. The application form was co-produced and all feedback at the time of the user research was taken on board, where it was appropriate and feasible to do so.

Preliminary themes from my engagement with stakeholders highlighted the following:

- Access to the internet is not universal, especially with the current cost of living crisis.
- People have issues with log-in and passwords, with some clients having difficulty recalling their username 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.
- When uploading supporting information online, there is not enough file space to upload multiple documents.
- The inclusion of guidance and pictures on the form was thought to be helpful for clients who will not be experts in completing application forms.
- 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.
- The larger font on the paper form is appreciated, especially for people with a visual disability.
- 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 difficult for applicants to see which sections have been completed, what questions are coming up and the answers they have already provided.
- 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.
- Questions are repetitive and can be easily misinterpreted, especially terms such as 'sometimes' and 'always' which can lead to confusion.
- The questions seem binary in some cases and people sometimes feel that they cannot answer a straight 'yes' or 'no' to a question.

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- Questions can be difficult for people who have fluctuating conditions as they are closed and leave no space to better explain the impact of their condition or disability on their day-to-day life. Paper forms do have space for additional information people might wish to add.
- Representatives from support organisations said they need to ask a lot of prompting questions about the impact of a person's condition as people are uncertain how to respond to some of the questions.
- Supporting someone to fill in the application form can take as long as four hours, often needing to be spread over multiple appointments because some individuals are exhausted and/or stressed by the process. 'This takes time and resources away from other clients and is stressful for both the adviser and the client'⁵⁰.

Some people thought it was a waste of resources to be on the phone for three hours answering questions and one person described the process as 'soul destroying'. The length of the form was consistently raised as an issue however when pressed no-one was able to suggest what could be done to reduce the size of the form unless there was a significant move away from points-based eligibility criteria.

In a recent client survey conducted by Social Security Scotland 60% of Adult Disability Payment applicants agreed or strongly agreed that the eligibility criteria were clear before they applied⁵¹. 64% of respondents said the application process enabled them to fully explain their daily living and mobility needs and 72% stated that they were treated fairly and respectfully throughout the application process and interestingly, only 49% of respondents said that filling in and submitting the application did not take too long.

Welfare benefits advisers reported that there was a general preference amongst their clients for the paper format however the most recent [Adult Disability Payment statistics](#) to 31 July 2024 show that since launch, clients have made:

- 68% online applications,
- 22% of applications by telephone and
- only 10% through paper form (applications commenced by telephone will then involve a paper-based form being issued to clients to complete).

Some disabled people I spoke to asked for greater transparency at the application stage about decision making. They were concerned that the descriptors are not presented to clients during the application process but used by case managers to make decisions. They thought clients should be able to see and understand the descriptors when they are applying.

At one meeting it was suggested that although available on-line if searched for, the activities and descriptors and associated points could be given to applicants and a simple question asked of them as to where they see themselves against the set criteria. The current application process was likened to a game where 'one needs to hit a target, but the target is hidden from view'.

It was suggested that clarifying complex language which accompanies/is included in questions to explain their meaning more clearly would assist clients. Maybe provide

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examples of abilities that might mean lower or higher scores and explain terms like 'sometimes' and 'always'.

One stakeholder commented that their clients felt Social Security Scotland could proactively aid them in partially completing the forms with personal data it already had access to, before sending the form on to clients. This was referenced in the context of initiating an application by telephone and then having to put in all the personal data again by hand when the form arrives.

A few people commented on the equalities data part of the form particularly its length and the fact that not completing it, although not compulsory, may impact on the outcome of the decision. It was suggested that equalities questions add another layer of complexity, especially for people who do not want to answer the questions. Online forms however do require completion of the equalities survey because a person cannot submit the application without completing that part.

Social Security Scotland stress that whilst clients are asked to complete an Equality Monitoring and Feedback form along with the application form, the information gathered is stored anonymously and is not accessible to case managers making decisions. The data collected is used to identify who is using the service and to investigate how Social Security Scotland processes work for different groups of people. The information provided is used anonymously for statistical purposes and does not affect the outcome of the application.

It is important to acknowledge that the Scottish Government has taken a best practice approach to service design and that 'user-needs' are at the centre of the application process design. The current forms were co-produced with people with lived experience and with input from third sector organisations. The user design team I met with acknowledged the technological constraints they operate within and that it is a constant challenge to match user needs with the needs of the business. It is almost impossible to design a form that meets the individual needs of all applicants however, they see the application process as 'work in progress' and are very willing to receive feedback on how the application form can be improved.

I will consider the application form further during the second stage of the Review to consider any ways in which the client experience could be enhanced.

The role of independent supporting organisations and other third parties

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. The current absence of a dedicated helpline or escalation route (other than the complaints process) 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 assessment process.

Some stakeholders providing advice services expressed a view that contacting Social Security Scotland led to excessive waiting times for an appointment to discuss an application. Social Security Scotland does not have a separate phone line for third parties as other agencies (including the Department for Work and Pensions) do. One Welfare Benefits Adviser told us that someone within Social Security Scotland has provided them with an email address so they can escalate issues, but this arrangement is outside operational policy and relies on a relationship being formed with an individual rather than a recognised and approved process.

The 'Declaration of Liability' section¹ that is available on the paper form is not available on the on-line form which results in case managers having to follow up with a phone call to the third party which potentially delays decision making. Some concerns were raised by third sector supporting organisations about Social Security Scotland's reluctance to accept liability for the accuracy of the information.

There were not many occasions when people wanted to praise the Department for Work and Pensions but the use of implicit consent with Personal Independence Payment was something some stakeholders wished was available in the Adult Disability Payment process. Social Security Scotland require explicit consent which requires a mandate. There appears to be some divergence between Social Security Scotland's operational guidance and people's experiences.

The position has been clarified with Social Security Scotland and, it has explained that third party mandates are acceptable even on an organisation's own templates, provided:

- they explicitly state Social Security Scotland may share information about the specific benefit with the third-party representative the duration of the mandate is specified and be signed by the client
- written mandates that are not blank, incomplete or that only reference the Department for Work and Pensions will not be accepted.

However, one adviser said that in their experience even when they complete a mandate and send it in, Social Security Scotland will not accept a third party completed mandate unless it is on the Social Security Scotland mandate form.

You can see from the points noted above that engagements undertaken with stakeholder organisations and people with lived experience of Adult Disability Payment have highlighted that some people have had experiences that diverge from the policy or delivery intention in relation to Social Security Scotland not accepting certain mandates from third sector organisations, including for Webchat.

¹ This section of the form asks the individual to sign a declaration that the information they have given is correct as far as they know and may be prosecuted if they provide details that are incomplete or wrong. It also states that they agree to pay any money paid to them in error by Social Security Scotland (unless it was neither their fault nor the kind of error they or someone acting on their behalf could be reasonably be expected to notice.)

Discussions with Scottish Government and Social Security Scotland colleagues have indicated that Social Security Scotland's policy is that it will accept mandates to act from third party representatives even if they are not on the organisation's own mandate, provided certain conditions are met (see above).

Communication via 'Webchat' can be facilitated on the provision that identification and verification is answered correctly, based on guidance to client advisers and case managers.

I also heard of welfare benefits advisers receiving copies of decision letters with all personal information redacted so they have no way of knowing which case or person the letter applies to. Although the decision letters being available in languages other than English was commended, welfare benefits advisers told us that a copy for them, in English would be helpful as they are not able to help their clients if they can't translate the recipient's letter.

In the second stage of the Independent Review, I will consider in more detail the role of third parties including appointees, and related communication with Social Security Scotland.

Reviews, Change of Circumstances and Award Periods

'Light touch' reviews which don't require a re-assessment were broadly welcomed as is the use of a diagnosis, in some cases, to determine award periods. Some anxiety about the review process remains particularly uncertainty around timescales and backdating of payments as well as communication errors or impacts on access to other benefits.

Comments from stakeholders raised the following issues:

- Confusion amongst clients as to the inclusion of a review form with the case transfer or scheduled review letter, making some feel they needed to complete the form again when they could instead tick a box saying that there had been no changes.
- People reported feeling intimidated by the prospect of a review, even when there had been no changes.
- Issues with downloading and printing forms, especially when internet access may be an issue in some cases.

On a more positive note, stakeholders noted:

- Clients felt relieved at not being required to complete a review form if there were no changes.
- The ability to download a review form was widely regarded as a positive development.
- Indefinite awards were universally welcomed providing a greater sense of security and stability, with many people saying how this reduced anxiety and introduced some common sense to the system with one woman saying 'I am not going to get better. I have lived with my disability since birth'.

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- There was a positive response from stakeholder groups representing people with neurological conditions, to the introduction of indefinite awards for people whose needs are highly unlikely to change, and who receive the enhanced rate of the daily living and mobility components. However, some people felt there needed to be greater clarity in the award letter enabling people to better understand indefinite awards.
- Confusion persists regarding the information and the form filling required before a review is carried out. There was some confusion amongst clients about which form to fill in. Social Security Scotland colleagues repeatedly had to circle back to clients who had experienced a change of circumstance to ask them to fill in both the short declaration form (yes - tick to confirm there had been a change) and then also to submit the Change of Circumstance form with further details on those changes.
- Additionally, the Change of Circumstance form, which many people say is too long, wouldn't be used, as people had either not experienced a change or preferred to fill in the form online or over the phone. A lot of the cost of the review packs is being spent on paper that goes to waste.

Towards the end of last year, the Decision-Making Programme team at Scottish Government agreed to change the review pack and the associated guidance. The review pack now only contains the short declaration (Is there a change? Yes/ No). If there has been a change, the client can either go online and fill in the form or call Social Security Scotland to do so over the phone. If they prefer a paper version, they can request one to be sent out to them. Some welfare benefits advisers do not appear to be aware of this change.

I was also told that the Change of Circumstance form, is delivered on a different system and does not have the save facility that is found on the main application form, which is delivered through the Digital Portal. It may appear to look the same to clients at the point of entry, but they will not be aware the two systems operate differently. The Scottish Government has no plans to amend the Portal to include change of circumstances or to make any other changes.

In a few stakeholder sessions participants had raised 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).

Typically, someone who reports a change of circumstances and then transfers will have their case reviewed. Backdated provision should mean that the client is not left financially worse off, provided they meet certain criteria. A change of circumstances will be taken into consideration at the end of the case transfer window and a person's award will be adjusted and backdated accordingly.

The idea of automatic entitlement has been mooted a few times. This would be 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. Automatic entitlement would reduce the effort required by individuals applying for benefits (for example, by simplifying the application process and reducing the amount of supporting information they would need to gather). It could

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also help reduce the volume of consultations carried out. There are challenges with this approach including the emphasis on a medical model of disability.

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 they were given their award for 2 years even though their previous Department for Work and Pensions award had been for 4 years. This, they said caused them a lot of anxiety and they were constantly worrying about dates when needing to renew their Blue Badge and Motability vehicle contract, for example. The person had cancer and suggested the 2-year award was because “(Social Security Scotland) thought I was going to die.”

I will return to this in the second stage of the Review.

Consultations

During the initial stage of the Review, I haven't spent much time looking at the consultation process other than reading the guidance provided to case managers and practitioners and getting the views from Social Security colleagues on the process. Because the Scottish Government is still in the 'safe and secure' transition phase, the issue of consultations didn't come up very often in our conversations with disabled people, unless prompted.

Awareness of the consultation process also appears to be low amongst many of the people I spoke to, as well as some confusion about whether someone has had a consultation.

Some people responded to us saying they have had a consultation when they have in fact, just had a follow up phone call with a case manager.

There is universal praise for the cessation of Department-for-Work-and-Pensions-style assessments when applying for Adult Disability Payment. Many people commented on the smooth transfer of their case from Personal Independence Payment to Adult Disability Payment without the requirement for a review or a consultation.

While in-person meetings being offered is valued, there appears to be a preference (on behalf of staff at Social Security Scotland) for telephone engagement by default, which can disadvantage individuals with communication challenges or anxiety. It appears that more can be done to balance the benefits of in-person interactions with the fears associated with previous Department for Work and Pensions practices to get the process right for the individual in a way that gives them the best opportunity to convey vital information.

The perceived lack of an option of offering a face-to-face consultation for some people was often discussed, as stakeholders felt some people's health condition or disability can't always be captured on the application form. In some ways the lack of a face-to-face assessment is seen as detrimental because when a Social Security Scotland practitioner is involved in supporting the decision making, they may not

have spoken to the client personally so general advice is being given that isn't necessarily relevant to the applicant's circumstances.

It was noted that some people don't see themselves as disabled, so the best way to get the detail required to make a good decision, is to have the option to speak to someone about their condition and its impact on their daily life.

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 offered in the invitation to consultation letter. However, all letters offer clients the opportunity to change the format of their consultation by contacting the agency.

Although stakeholders mainly spoke of the confusion clients face with regards to consultations, more positive feedback focused on people's relief that it was a move away from the traditional Personal Independence Payment style face-to-face assessments.

In the most recent client survey conducted on behalf of Social Security Scotland around one in five (21%) of respondents who had applied for Adult Disability Payment said that they had had a consultation, and the majority of respondents (86%) rated their overall experience of the consultation as very good or good⁵².

I specifically asked about people's experiences of the consultation process in the online Review Consultation and Call for Evidence. Therefore, I will have more to say on this in the second stage of the Review.

Re-determinations

In the UK Government's social security system, if a person is unhappy with a decision taken about entitlement by the Department for Work and Pensions, they must ask for a mandatory reconsideration before they can appeal to an independent tribunal. The request for a mandatory reconsideration can be made in writing, in person, or by telephone. The request must also be made within a set time limit that means any delay can result in it not being possible to request a mandatory reconsideration.

The Department for Work and Pensions says it introduced the mandatory reconsideration process in 2013 for all benefits, including Personal Independence Payment to reduce demand on tribunals, as well as enabling disputes to be resolved as early as possible⁵³. However, unlike a re-determination in the Scottish social security system (see below), the Department for Work and Pensions has no time limit within which to conduct a mandatory reconsideration. Prior to this, if a person was unhappy about a Department for Work and Pensions decision, they could directly lodge an appeal with an independent tribunal.

If someone is unhappy with a decision about entitlement taken by Social Security Scotland, they must ask for a re-determination. Social Security Scotland say their key priority is to treat people with dignity and respect and that means striving to get decisions right first time and quickly correcting errors if they occur. All their processes have been co-designed with people who have lived experience of the Department for

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Work and Pensions system, and their approach to challenge a decision marks a significant departure from the Department for Work and Pensions' system of mandatory reconsiderations.

The re-determination process involves completing and submitting an online or hard copy form and returning it to Social Security Scotland. The form can also be completed over the phone with an advisor. A re-determination is considered independently and afresh from the original case manager and a person can choose to request a re-determination by post, telephone or online via mygov.scot.

Social Security Scotland has 56 calendar days to reach a decision once it has received a re-determination request. If the redetermination process is not completed within 56 calendar days, a person has the right to appeal directly to the First-tier Tribunal for Scotland (Social Security Chamber).

The most recent [Adult Disability Payment statistics to 31 July 2024](#) show 95% of re-determinations for new applications in the month July 2024 were completed within the 56-day time limit. This had increased from 48% in the month of January 2024 to 95% in the month of July 2024⁵⁴.

There are 31 calendar days to make an appeal from the date a person was informed of their re-determination outcome, or from the date that Social Security Scotland informs them that it has not completed their re-determination in time. 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 First-tier Tribunal is independent of Social Security Scotland and makes its own determination. This may result in a different level of entitlement (including removal of entitlement) for the client. In my meeting with the Challenge Rights Policy team in the Scottish Government, I discussed the Social Security (Amendment) (Scotland) Bill⁵⁵ and the proposed amendments to the legislative structure that should address some of the issues raised during the first phase of the Review and are outlined below.

These amendments include:

- the ability for people to request a re-determination or bring an appeal more than a year later in exceptional circumstances,
- allowing Social Security Scotland to make a new, more advantageous determination after a person has lodged an appeal with the appeal stopping (called 'lapsing') as a result rather than the case having to proceed to a full appeal hearing,
- allowing an option for people to withdraw their re-determination request,
- creating a legal duty for Social Security Scotland to complete an out-of-time re-determination.

The intention behind these changes was explained in the policy memorandum to the Bill as 'to empower clients and give them choice and flexibility⁵⁶'.

Social Security Scotland has conducted a survey on clients' experiences of the challenge process, including re-determinations and appeals. The survey results will

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be available before the end of the Review, and I will consider the findings in the second phase.

Discussions with stakeholders identified the following issues that have impacted their clients:

- Inconsistency in Social Security Scotland decision making in relation to extending the deadline for some late re-determinations. Many people told me about refusals although other stakeholders and clients have told me that granting extensions to the time limit for completing an application form or submitting a re-determination request, is appreciated.
- Client files being closed once the deadline for re-determination has expired.
- 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.
- Several stakeholders spoke of being contacted by clients who were advised by Social Security Scotland to waive their right to an appeal, allowing more time for a decision on their re-determination. They were told that this would allow for a faster decision than going through the appeals process.
- I also heard stories of people being contacted by Social Security Scotland when the 56 days had not been met encouraging them to 'skip the re-determination stage' and pursue an appeal.
- Data from Social Security Scotland also reveals some issues with re-determinations and appeals, including concerns about processing times and lengthy phone wait times (I note that Social Security Scotland publishes information on telephony waiting times, but this is only at individual benefit levels and not in the context of issue-specific levels, such as applications, re-determinations, etc.⁵⁷).
- Some stakeholders thought that the re-determination process acted to discourage clients from challenging decisions and should be removed (a view echoed by Citizens Advice Scotland in their written evidence to the Social Justice and Social Security Committee⁵⁸).

The fear of reduced awards if the re-determination process is initiated may deter some people from appealing decisions and I will re-visit this in the second stage of the Review.

Short Term Assistance

The principal intention behind short-term assistance is to protect a person's right to challenge decisions and to access administrative justice, by having to manage for a period on a reduced income.

Short-term assistance is a temporary payment that is unique to Scotland. A person can access short-term assistance if in relation to Adult Disability Payment:

- 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.

Short-term assistance tops up the value of payments to the person to match their longstanding award level for the duration of the re-determination and/or appeal.

If a client is receiving short-term assistance, this allows access to certain devolved 'passported' benefits or schemes, provided the client was in receipt of the qualifying component or rate as part of their longstanding award. These include: the blue badge, national entitlement card, council tax reduction or proxy votes in Scottish parliamentary and local government elections. It will also be disregarded as income or capital for children's legal assistance, civil legal aid, advice and assistance, council tax discounts, assessment of liability to pay care home charges and NHS remission of charges.

If a person is receiving passported benefit payments or assistance from Social Security Scotland and the UK Government system, short-term assistance will only apply to Scottish Government passported benefits and not those in the UK Government system.

In terms of the Accessible Vehicles and Equipment Scheme, Social Security Scotland does not pay directly for the vehicle lease while a client is receiving Short-term Assistance. The amount Social Security Scotland used to pay for the vehicle lease on a client's behalf as part of their longstanding award, is instead included in their short-term assistance payments. As such, the client will have to pay for the vehicle lease using their short-term assistance payments.

People will not have to repay short short-term assistance they were entitled to, regardless of their challenge outcome.

The introduction of short-term assistance was welcomed by disabled people and other stakeholders and seen as an improvement on the Department for Work and Pensions 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.

Decision Making

Social Security Scotland must send a determination letter to applicants with the outcome of their application. In the case of a successful application, the letter describes the payments an applicant will receive. In the case of an unsuccessful application, the letter will explain the reasons why the application was denied. All determination letters, whether the person is awarded or denied Adult Disability Payment, include information about the person's right to request a re-determination, and of their right to appeal to the First-tier Tribunal for Scotland if Social Security Scotland do not make the re-determination in the time allowed in regulations.

Stakeholders provided a mixed response to the issue of decision letters. Some felt determination letters were too long and information about appeals and re-determination 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.

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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. Some concerns were expressed about the number of applications denied for people who English is not their first language. Social Security Scotland could not provide any data on this.

Some stakeholders felt that there was a lack of consistency in how Social Security Scotland made decisions but there was little evidence, or examples provided, to understand this better. Some welfare benefits advisers told us that they are finding it difficult in some cases to see rationale in the application of the eligibility criteria, with no clarity on the reason why wildly different decisions have been reached.

Attendees at one event discussed the issue of entirely different decisions being reached between application, re-determination and appeal stages.

The impact of housing and living environments on individuals' disabilities or conditions is significant and it is felt that there is a need for decision-makers to consider these factors and potentially use more discretion in assessing applications that do not strictly meet points-based criteria.

There was a general point made that the use of case managers' discretion means that it feels like a "free for all" because advisers no longer know if someone is likely to qualify for a higher award when reporting either a change of circumstances or seeking an appeal. It was also felt that the Decision-Making Guidance was not always being followed, which is eroding trust between advisers and clients when they lose an award.

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 on-going 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, there are still several re-determination decisions that are vastly different to the original case manager decision. This may be because of additional supporting or other information being made available at redetermination stage. Equally I have seen evidence of some secondary decisions varying from the initial decision due to a different interpretation of the criteria or 'reading between the lines' (as described by a practitioner), the second time around.

The Scottish Government and Social Security Scotland have set up a feedback process. The aim of this is to ensure any key learning from re-determinations and appeals is captured between different areas within both organisations to continuously improve the service offered to clients.

Social Security Scotland's Organisational Development team is responsible for delivering high quality learning materials and activities to teams so the organisation can fulfil its commitment to the citizens of Scotland.

There is a fundamental requirement for a continuous improvement process to ensure learning is fit for purpose and caters to all learning styles. As the organisation evolves, the Organisational Development team must remain adaptable and agile, adopting a proactive approach to collating, reviewing and acting on feedback received.

I was impressed by the amount and quality of the training provided to case managers and practitioners at induction stage, consolidation and on-the-job, although some case managers did point out that their initial training bears little resemblance to the training being offered to new recruits. I took some comfort from this as it demonstrates that the training is being constantly updated and reviewed as new learning is embedded in the system.

The training and guidance provided to case managers and practitioners require further attention to ensure consistency in decision-making. Perceived discrepancies and interpretative variations may lead to inconsistent outcomes, which might undermine the fairness of the process. The guidance and training that is available for case managers and practitioners needs to be as clear as possible to enable staff to make consistent high-quality decisions that minimises the need for re-determinations and appeals.

In the context of a system that allows 'discretion' and one that brings in practitioners precisely because they have knowledge and experience of specific disabilities and conditions, it is likely that decision making will continue, at times, to be inconsistent. As one person suggested, it is possible to have two different decisions that are both correct.

I will look into this further in the second stage of the Review and consider how one can balance the need for fairness and equity with the discretion that is currently applied when considering the impact of a disability or long-term impairment on a person's individual life.

Eligibility

The Scottish Government has not made any significant changes to the eligibility criteria for Adult Disability Payment whilst the transfer process is in place, although it has endeavoured to apply more transparency and clarity to the decision-making process. Eligibility and the detail surrounding the activities and descriptors was the most discussed part of Adult Disability Payment during the first stage of the Review.

Feedback from stakeholders highlighted the need for a more person-centred and holistic approach to descriptors assessing people's needs. Preliminary comments included:

- Conditions such as anorexia nervosa, incontinence and epilepsy were considered by some stakeholders to be difficult to appropriately fit into the daily living and mobility criteria and questions.
- It was felt there needed to be a better way to aid consideration of issues such as pain and fatigue and the daily impact this can have on a person.

- It was felt that descriptors reflecting real-life would be better, such as ability to shop for ingredients.
- Some stakeholders felt that other conditions that impacted mobility, such as mental health, need to be better represented.
- Differing experiences with terminology and how there was confusion in the wording, especially between terms such as 'aids' and 'adaptations'.
- As expected, there was considerable discussion about the 20-metre and 50-metre rules with stakeholders (see Mobility Component section below)

In previous research, panel members on the Experience Panels gave very similar feedback when asked about the eligibility criteria for the mobility component of Adult Disability Payment⁵⁹.

The use of function-based criteria that has limited ability to capture the realities of daily living, came up consistently in our conversations as did the fact that current assessment and decision making does not consider how performance on one activity can affect performance on another, and therefore case managers assess people as though there is no such effect.

There is a proposal being mooted that is designed to support case managers to identify cases where the client is not defined by the functional test alone but if there is a real or perceived risk of suicide, self-harm or dangerous levels of social isolation an award could be made.

During the second phase of the Review, I will be considering eligibility criteria in far more detail, and this will include some analysis on the potential of introducing what is being called by Citizens Advice Scotland a 'substantial risk' provision⁶⁰. Some critics of the idea feel that the proposal as currently put forward reinforces the functional and deficits-based model to some extent, and it also introduces an element of subjectivity that I was consistently told is an issue in decision making.

There will be a lot more work done on this aspect of the system in the next phase however I have set out below some of the recurring themes and issues.

Fluctuating Conditions

We know that under current Personal Independence Payment and 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). This standard is difficult for clients with fluctuating conditions for a wide range of reasons including it being difficult to quantify how your condition affects you in such a set way. Some disabled people find it hard to focus on the negative impact of their impairment or condition, especially where this fluctuates over time and people with unpredictable conditions, for example Myalgic Encephalomyelitis, multiple sclerosis (MS), or epilepsy, may not always have acute symptoms that fit neatly within this rule, but nevertheless require significant support when symptoms do occur.

In addition, the effort of walking or moving can bring on symptoms such as fatigue.

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The washing and bathing section is also very focussed on functional ability and doesn't consider the daily living implications if you have a fluctuating condition. Some people find washing and bathing so tiring that they hardly ever shower, or only use dry shampoo, or I was told, they shave their hair off completely to avoid having to wash it.

Many people commented on their difficulty understanding the criteria for fluctuating conditions, which they felt were unclear and overly complex. Respondents 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 clarify the criteria⁶¹.

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 conditions, particularly for those with multiple conditions.

Some stakeholders suggested that many of these problems arise not from the 50% rule itself, but they are due to decision makers failing to properly apply the other relevant rules of Adult Disability Payment.

Regulations state an activity descriptor applies if the client can (or cannot depending on the descriptor) carry out an activity 'reliably' which is defined to mean safely, to an acceptable standard, repeatedly, and within a reasonable time period. Ensuring these rules are properly applied may, in the short term, address many of the issues discussed above. There are some examples of places in the Adult Disability Payment guidance where wording could be enhanced to better support people with fluctuating conditions.

It should be noted that several people 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.

Mobility Component

A public consultation⁶² on the eligibility criteria for the mobility component of Adult Disability Payment (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 [analysis](#) from the mobility component consultation have been considered during the course of this Review.

Across the consultation, many respondents suggested or called for broad improvements to Adult Disability Payment. Some suggestions were raised repeatedly, including:

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- 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 conditions, and a wider range of mobility aids.
- That the mobility eligibility criteria are not appropriate for those with fluctuating conditions.
- 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.

There was positive feedback on changes made to the Adult Disability Payment application guidance. Respondents thought the changes would lead to more accurate decisions, allowing clients to receive benefits that fit their needs.

The rigid nature of the mobility component is something I am keen to address. People explained they find it hard to meaningfully appreciate distance set out in terms of metres, and they 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 considered fails to consider the realities 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. People told us 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 correctly.

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, necessity⁶³.

In 2013 when Disability Living Allowance (DLA) was replaced by Personal Independence Payment for people of working age, many of the rules which allowed a person to receive an award of the higher rate of the mobility component for Disability Living Allowance changed.

In particular, one of routes to the higher rate of the mobility component, of 'being virtually unable to walk without severe discomfort⁶⁴' was removed. Personal Independence Payment 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 metres⁶⁵. However, when the UK Government responded to the consultation⁶⁶, the threshold was subsequently replaced with 20 metres. At the time, the UK Government estimated savings of £2.2bn because of this change.

It should be noted that whilst there was no formal rule under the rules for Disability Living Allowance specifying a distance walked beyond which someone would cease to be eligible for the higher rate of the mobility component through being virtually

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unable to walk, case law established that if a person could walk more than 50-metres they were unlikely to qualify for the higher rate mobility component⁶⁷

The 20-metre rule was duplicated by the Scottish Government when devising the criteria for Adult Disability Payment on the basis that it sought to avoid a two-tier system, whilst case transfer was on-going. Many stakeholders feel strongly that an insistence on maintaining arbitrary and subjective measurements like being able to walk 20 metres on a flat, even surface, with or without aids, is not in any way reflective of being able to manage to live reasonably from day to day, and is not demonstrating dignity, fairness or respect.

The 'planning and following a journey' descriptor was raised in several conversations. It was felt that the descriptor 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.

I will return to the mobility component in the second phase of the Review.

Daily Living component

The consultation and call for evidence focused in detail on the Daily Living component of Adult Disability Payment so I will have more information and feedback to share in the final report.

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 suggested that sleep, engaging socially and managing unplanned events could be included. Participants at engagement events suggested additional areas could be housekeeping, IT literacy, quality of life, communication support, filling in forms, being part of a community, whether assistance is needed to take medication and the impact of medication side effects.

Calls were made at engagement events for the eligibility criteria to be more aspirational or modernised. There appears to be a desire generally 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 daily living, reflect people's lived experience of real-life scenarios, and reduce confusion around fluctuating conditions.

In my early stakeholder meetings and initial consultation events I was told that there are places in the daily living guidance where wording could be enhanced to better support people with their application.

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.

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. They highlighted that if you cannot cook a simple meal using a conventional cooker, but can do so with a microwave, you score 2 points. However, if the microwave meal is overly processed and lacking in nutritional value it is not a balanced, healthy meal. It was also felt an individual's ability to shop for ingredients for a healthy meal should be considered.

Some people suggested that providing more examples on the application form of how the descriptors apply when someone has a mental health condition or is neurodiverse, would be helpful as it can be more difficult to relate the activities to their condition. For example, someone who is suicidal a lot of the time may not be motivated to eat or to get out of bed.

Many people I spoke to are confused as to why the 'washing and bathing' criteria are written in the way that they are. The wording and eligibility for scoring points is very focussed on functional ability and takes no account of other limitations.

One participant with a mental health condition told us 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.

Some apparent anomalies were pointed out to me including the allocating of 3 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 questioned the logic.

It was noted that the form can't capture 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 you can't get all that on the form."

In activities such as 'taking nutrition' and 'washing and bathing' some people confuse the use of aids and assistance from another person, as being the same thing and it appears to them that the form is repeating itself. More could be done to highlight the difference.

I will do further and more in-depth analysis of the feedback I receive on the daily living component from the on-line consultation and call for evidence and bring my findings to the final report.

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 move away from the medical model of disability that underpinned the previous system, to a social model. It was argued that moving away from this narrow 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.

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I will return to this in the second stage of the Review.

Supporting Information

Supporting information can be provided with an individual's application or review form, or after an individual has submitted their application or review form. It is information that describes how an individual's situation, condition, or disability affects them and what support they need. Supporting information is therefore instrumental in helping staff make decisions over entitlement to an award.

There are two main types of supporting information:

- Supporting information from a professional.
- Supporting information from an individual's wider support network. This can give insight into the impact the condition or disability has on the individual daily. This can include, amongst others, family, partner, friends and unpaid carers.

Providing Supporting Information is raised as a recurring theme by people going through the Adult Disability Payment process and by staff members working in both Social Security Scotland and the policy team at Scottish Government.

It was the number one area of frustration when I spoke to case managers particularly in relation to the reliance on GPs to provide most of the supporting information. The process of gathering information on an individual's behalf was cited by staff as the main cause of lengthy processing times. This highlights the importance of individuals supplying supporting information themselves, where possible. The capacity of GPs to respond timely and the relevance of the information they provide are also significant issues.

In the recent Social Security Scotland Client Survey⁶⁸ most respondents who applied for Adult Disability Payment provided Supporting Information (69%), whilst 16% did not. The most common forms of Supporting Information provided were: 'confirmation of diagnosis' (71%) 'medical or social work reports' (58%), and 'test results' (27%).

Respondents most often got their Supporting Information from: 'a GP' (66%), 'a hospital (including from doctors, consultants or nurses)' (60%), and 'a therapist' (19%).

Citizens Advice Scotland told me that in some instances the provision of fees to GP practices when additional supporting information is requested by Social Security Scotland can act as a disincentive to practices in providing such information directly to applicants or those supporting them.

Individuals do not fully know how to access supporting information. Understandably, the guidance on the application form is the most utilised form of guidance, however, there is a lot less awareness of the other forms of guidance available.

Many applications arrive without supporting information, individuals sometimes provide contradictory or partial information as well as partial or blurry photos of documents. Welfare Benefits Advisers also commented on the lack of awareness individuals have about different types of supporting information.

Evidence suggests that the majority of determinations are being made without the need for a consultation, highlighting the importance of supporting information to the decision-making process.

An evaluation of Supporting Information was commissioned by the Scottish Government and the report⁶⁹ was published in September 2023. The findings of the evaluation have been used to inform this Review.

Some of the key findings of the 2023 evaluation included staff's unconscious bias towards supporting information from professionals, and in particular GPs, which may impact on the supporting information process. This was backed up in my meetings with case managers and practitioners. They were consistent in their view that supporting information from family or carers was not given equal consideration with one case manager suggesting that a family member may 'exaggerate or lie'.

Successful applicants tended to feel a trust-based approach had been applied to the collection and use of their supporting information. They reported that Social Security Scotland did not question any aspects of the application and did not ask for any further information⁷⁰.

Stakeholders reported to us that in their experience:

- Supporting information from non-medical sources was still not being routinely sought and gathered.
- Where non-medical sources had been approached, there was little guidance as to the information they should provide despite Social Security Scotland [publishing a range of guidance](#) on completing supporting information online for GPs, local authorities, health boards and third sector organisations.
- Some stakeholders felt that the prioritising of medical information such as GP reports or prescription lists was a legacy from the bio-medical model employed by the Department for Work and Pensions.
- Stakeholders noted that Social Security Scotland appeared to put clinicians in a hierarchy, with GPs being the most preferred.
- Lack of resources at GP level may mean a long wait for supporting information. Therefore, potentially increasing processing times.
- Some GPs are uncertain of what kind of information may be most helpful when/if something changes about the patient's condition.
- Some clinical practitioners (e.g., talking therapists) were not on the list of acceptable providers for supporting information, which may impact clients with specific conditions.

I have been told that supporting information from private healthcare providers may be rejected if it does not provide the information the case manager is seeking. For

example, where an internet-based medical company provides medical supporting information based on an online consultation.

Discussions with Scottish Government policy colleagues have confirmed that whether a practitioner works for the National Health Service/public or private sector is not a relevant criterion. However, it is important that the practitioner is familiar with the client, their condition and that the practitioner can speak to the period relevant to the client's application or review.

Stakeholders suggested that improvements to the process of collecting supporting information could include:

- Supporting information such as prescriptions or letters of inclusion on waiting lists should suffice as confirmation of the impact of a condition or disability.
- Alternative methods of providing supporting information should be considered, such as telephone conversations.
- Better guidance as to what constitutes 'acceptable supporting information'.
- More discretion for GPs to better describe the daily impact of a person's condition or disability – rather than what they can or cannot do.

One stakeholder viewed the fact that clients can source and provide supporting information themselves as a positive example of empowering clients.

You can see from the points noted above that engagements undertaken with stakeholder organisations and people with lived experience of Adult Disability Payment have highlighted that some people have had experiences that diverge from the policy or delivery intention in relation to client advisers or case managers rejecting supporting information from professionals working out-with the public sector.

Discussions with Scottish Government and Social Security Scotland colleagues has indicated that there is not a policy to automatically reject supporting information from private practitioners. A practitioner must be familiar with the client and their circumstances in their professional capacity and the information must be relevant.

Some stakeholders and disabled people have highlighted possible divergence from these policies in practice: This divergence may be a combination of factors such as:

- Individual interpretation of guidance
- Possible issues occurring linked to training and/or operational practices within local teams.

These are areas for potential further exploration in the second stage of the Independent Review.

I will re-visit the theme of supporting information as it applies to Adult Disability Payment, in phase two of the Review and will examine the key recommendations identified from the 2023 evaluation to see if they have been actioned and what, if any, difference those changes are making to the client experience.

Condition-specific issues

Research by Citizens Advice Scotland into how Adult Disability Payment is operating on the ground has identified that certain impairment types, such as people with undiagnosed behavioural and learning difficulties or unpredictably fluctuating conditions, are at greater risk of being refused what is often a lifeline or being awarded benefit at a level that does not reflect actual need⁷¹.

There are significant variations in whether certain conditions associated with an application are generally more likely to see an award, amongst the conditions making up the largest proportion of applications⁷²:

- Applications received based on clients having a mental health or behavioural condition (73,850) resulted in 38 percent of applications being refused.
- Applications based on clients having a musculoskeletal condition (32,635) resulted in a more modest refusal rate of 32 per cent.

Data indicates higher refusal rates for individuals with hidden disabilities, fluctuating conditions, and specific disorders like digestive issues. This suggests there may be a need for a more nuanced understanding and evaluation of these conditions⁷³.

Feedback from stakeholders consistently highlighted the need for a more person-centred and holistic approach to descriptors assessing people's needs. Conditions such as anorexia nervosa, incontinence, Myalgic Encephalomyelitis, Long Covid and epilepsy were considered by some stakeholders to be difficult to appropriately fit into the daily living and mobility criteria and questions.

Long Covid is emerging as a significant issue, with affected individuals facing challenges in securing mobility awards. Social Security Scotland does not currently record the numbers of applications for Long Covid; they sit within the 'other' category.

Further data on how this condition is being addressed within the Adult Disability Payment system is necessary to ensure fair treatment.

There is a general view that Adult Disability Payment case managers ask people how they perform on certain activities in order to measure a range of cognitive and physical functions. They reduce 'evidence' of incapacity to observable, static forms of impairment and as a result may disregard impairment experiences that are not always apparent within the decision-making context, such as fatigue and pain. The impact of energy impairment, for example, can only be measured if considering the holistic context of daily living, and over a longer period of time.

In my meeting with clinically vulnerable people and those representing people with Myalgic Encephalomyelitis and Long Covid a point was made several times about decision making being decontextualised from daily living with no consideration of how limited energy has to be managed across the different foundational life tasks before any work is possible.

A key principle in decision-making stipulates that any activity must be considered against whether it can be performed 'repeatedly, reliably and safely'. However, some participants' experiences were that these criteria were not being properly applied to Adult Disability Payment. There appears to be a lack of consideration of the cumulative impact of activity; the post-exertional effects experienced during or for some time after activity ('payback'); the added time taken up by resting; and the unreliability of being able to perform an activity when required to do so⁷⁴.

Energy limiting difficulties can impact an individual's ability to chop food, stand at a cooker, and concentrate through the process of the task or someone might be able physically to prepare or cook food, but doing so could put them in danger of delayed fatigue so it is not safe for them to do so. There is nowhere on the form to articulate this and currently it wouldn't be considered when awarding points for this activity. This point, although specific here to a particular set of conditions, was repeated more generally in relation to people who live with other fluctuating conditions.

'Brain fog', or fatigue-related cognitive dysfunction, is not considered specifically as part of Adult Disability Payment and it was felt by some that the language used does not reflect the seriousness of the condition.

There is no consideration of safety risks in the eligibility criteria, when someone becomes overly fatigued and falls whilst out on a journey due to symptoms flaring up, or suffers from a seizure, and needs help to get home.

Sensory impairment

Citizens Advice Scotland told me of the vital role of ensuring that the appropriate communication method is recorded at the outset of an application and acted upon consistently through the application journey. Failure to do so can undermine people's agency and their ability to provide all relevant information in support of an application.

Understanding and evidencing the functional impact of a sensory impairment within Adult Disability Payment functional criteria can be challenging. This can result in applications being refused or awards failing to reflect real need in context.

Some people with sensory impairments can face barriers to obtaining supporting information to progress their application. Guidance specific to people making an application and use of their informal network to provide supporting information is not currently available in braille, British Sign Language, or Easy Read format.

Social Security Scotland told me that that it proactively translates all client facing factsheets into Easy Read and video/British Sign Language, although I couldn't find a British Sign Language version for guidance on Supporting Information. If a client called asking for an Easy Read or British Sign Language/video flyer it would direct them to these resources. The on-line views on British Sign Language factsheets are very low (five for Adult Disability Payment and zero for Adult Disability Terminal Illness) and it has never had any requests for factsheets in audio.

Mental Health

Many respondents repeatedly criticised the term 'overwhelming psychological distress', which they found to be limiting, subjective and unclear, and suggested it should be defined, amended or removed.

It seems that mental health conditions and how they affect people are not given as much weight in the mobility activities as they should. Many believe a large part of the problem is due to the reliability criteria not being consistently applied, but there are potentially other ways mental health could be better represented in the Adult Disability Payment descriptors.

Eating Disorders

Following my meeting with a member of the Executive Committee for the Faculty of Eating Disorders at the Royal College of Psychiatrists it is evident that there are several places in the eligibility criteria and within the guidance for case managers where the use of language may be problematic. As with other mental health conditions, eating disorders such as anorexia are complex by nature and will impact in different ways on the daily lives of those who experience them. Stories were shared of people not being able to access the support available to assist in making an application; the fluctuating nature of the condition; the consequences of eating or not eating related to fatigue and energy depletion not being accounted for in the eligibility criteria; having the cognitive ability to prepare a meal; the guidance covering eating to excess but not taking into account the opposite; the definition of 'choice'; the definition of 'serious' eating disorder and the important role of the right supporting information, taking into account that the level or amount of care a person is receiving from the medical profession is not necessarily an indication of disability or impairment.

Dementia

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, they 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.

Learning Disability

Stakeholders I spoke to who were representing people who have a learning disability and learning-disabled people themselves, spoke about a massively complex system that is hard to navigate without a great deal of help. They welcomed the introduction of the Advocacy service although there were mixed reviews from learning disabled people who had used it with the majority stating that they would prefer to get support and advocacy from an organisation or charity that they are already familiar with.

Information being available in Easy Read formats was welcomed but some people reported a 'lack of awareness or understanding of learning disability' being displayed by some call handlers. Some stakeholders felt that face to face consultations would assist with communication and that the default for phone calls does not help most people who have a learning disability.

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The deficit-based eligibility criteria were mentioned several times with a parent of a person with a learning disability at our Edinburgh consultation event telling us that in order to qualify for Adult Disability Payment they have to spell out all that is wrong with their adult child. They found the process ‘heart-breaking but necessary’.

In my conversations with members of the Fragile X Society it was noted and appreciated that health and care experts are employed by Social Security Scotland and how refreshing it was that staff seemed to be aware of Fragile X and parents/appointees didn’t have the usual ‘hassle’ of explaining a relatively rare genetic condition to those making the Adult Disability Payment decision⁷⁵.

The Stakeholder Engagement team at Social Security Scotland has, in the past, invited external stakeholders into their premises to deliver awareness raising sessions to operational staff who interact with clients. The idea was to raise awareness of some of the specifics of each condition, discuss sensitivities and nurture a greater sense of empathy when asking questions. This should result in the best possible information from clients being made available to support them in making a successful application.

The organisations mentioned below delivered awareness sessions and delivered an information stall in the main reception area where they distributed information and were available to answers any questions.

- National Deaf Children’s Society
- Epilepsy Scotland
- Versus Arthritis
- MS Society Scotland
- Macmillan Cancer Support
- Alzheimer’s Scotland.

Special Rules for Terminal Illness

A new approach to terminal illness has been introduced by the Scottish Government which allows medical professionals to use their clinical judgement to determine entitlement. This decision is a change from the time-limited definition currently in use by the UK Government. Social Security Scotland automatically awards the maximum rate of Adult Disability Payment to clients with a terminal illness and there is no review of awards made under these rules.

Individuals with terminal illnesses often 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.

In a meeting with the Terminal Illness Implementation Group concerns were raised about Social Security Scotland client advisers placing inappropriate workload onto GP practices by seeking to progress Benefits Assessment under Special Rules in Scotland (BASRiS) forms by phone. It was noted that there is a lack of capacity in general practice to meet the needs of patients and time spent progressing Adult

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Disability Payment application forms by phone is time that cannot be spent seeing patients.

GP practices are under no contractual obligation to progress forms by phone or accept appointments to discuss applications and while they clearly recognise the need to ensure terminally ill patients receive appropriate benefits in a timely manner, they feel that the system used should allow the healthcare professional to complete the Benefits Assessment under Special Rules in Scotland form when time is available, rather than disrupting time dedicated to consulting. Telephone calls frequently seem to duplicate work, showing the new system to be markedly less efficient than the previous approach.

It appears that the Department for Work and Pensions accept a copy of the electronic version of the SR1 form (equivalent to the Benefits Assessment under Special Rules in Scotland form) via email from a secure email address but there are understandable and relevant data protection reasons as to why Social Security Scotland do not. Social Security Scotland's Business Plan for 2024-25⁷⁶ notes:

we will focus on cyber security, ensuring personal data and information continue to be stored securely. We will commission an independent assessment of our core digital services to discover how they meet our current and future business and service needs. As part of this process...we will identify any digital services that will need to be updated to manage future demand for benefits. This assessment of our technical backlog will help us clarify our plans for future digital investment.

Next steps

Building on the initial findings from the Independent Review into Adult Disability Payment and the insights provided in the interim report, my focus for phase two will be to further develop and refine the delivery of Adult Disability Payment.

This next phase will be guided by a continued commitment to engagement with disabled people and those with lived experience of Adult Disability Payment. Their perspectives are critical to ensuring the system is fit for purpose and reflects the realities of their experiences.



Phase two will place particular emphasis on reviewing and improving the eligibility criteria. The aim is to ensure that the criteria are not only transparent and fair but also inclusive, ensuring that they reflect the diversity of disabled people's circumstances and needs. We will continue to apply a human rights-based approach and uphold the social model of disability throughout this review, recognising that societal barriers, rather than impairments, are often the primary source of disadvantage for disabled individuals.

Engagement with stakeholders will remain central to our approach. We are committed to maintaining strong and ongoing dialogue with disabled individuals, campaigning organisations, advocacy groups, and other key partners. This engagement will help us ensure that the evolving Adult Disability Payment system and approach continues to meet the needs of disabled people in Scotland, while supporting the Scottish Government's broader commitment to creating a more inclusive and equitable society.

I look forward to producing my final report in July 2025.

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Initial Actions Capable of Early Implementation

Pre-application support

- Consider an Adult Disability Payment-specific take up strategy.
- Implement better promotion of pre-application services.
- Continue to proactively share information about Adult Disability Payment at community locations throughout Scotland.
- Consider alternative routes to access and referral pathways in respect of the Local Delivery service, to include an alternative way of booking an appointment, providing more local information and allowing third party referrals.
- Further develop the plan to proactively reach out to and engage effectively with seldom heard groups to try to address the societal and sometimes cultural stigma associated with applying for Adult Disability Payment to ensure broader and fairer access.
- As part of on-going continuous improvement activity, maintain the relevance of training and guidance provided for staff in Social Security Scotland so that the client experience is consistent and provides a faster route to resolution when clients receive conflicting advice from the Department for Work and Pensions and Social Security Scotland.
- Ensure information on interpretation services is easily accessible.
- Continue to be responsive to user needs in ensuring that the language used on the Social Security Scotland website and in literature is always accessible.

Application process

- Consider conducting some user research into why people don't use the online application process, including (for example) advocates, welfare benefits advisers, etc. in order to understand the best ways to encourage less paper-based applications and identify routes to tackling any barriers to using the on-line form as first preference.
- As indicated in Social Security Scotland's Business Plan 2024- 25 undertake an exercise to determine if a self-service portal (to let people know what stage their application is at) could be introduced to potentially reduce phone calls to Social Security Scotland.
- As indicated in Social Security Scotland's Business Plan 2024- 25 consider the introduction of automatic communication from Social Security Scotland telling an applicant what stage their application is at.
- As part of on-going continuous improvement activity, consider updating the guidance that accompanies the application form to better prompt people to complete free text boxes and/or consider providing more space on the on-line application form in the fluctuating conditions section to allow for further explanation of how a disability or other impairment affects daily life.
- As part of on-going continuous improvement activity, ensure language is always accessible, particularly the language included in questions on the application form.
- Although available on-line if searched for, consider how to make the activities and descriptors and associated points more prominent and accessible for applicants.

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- Improve awareness of the ability to make the choice to undergo an in-person consultation and provide greater clarity that video conferencing is an option for people.

Communications and engagement

- Continue to make reducing phone wait times a priority to improve the client experience.
- Consider updating the suite of guidance and/or provide support to third sector organisations, to ensure information is available in braille, BSL, Easy Read and other accessible formats.
- Consider undertaking further user research to ensure that people with terminal illness see themselves appropriately reflected in communications.
- Highlight the option to request written translations of re-determinations letters to ensure the needs of minority communities are better met.
- As indicated in Social Security Scotland's Business Plan 2024- 25 consider providing advanced communication when someone is due a call from Social Security Scotland, outlining what the client can expect the call to be about.

Decision-making Guidance

- As part of continues improvement consider reviewing Adult Disability Payment training and guidance for case managers to ensure it meets the needs of people with fluctuating conditions.
- As part of the commitment to continuous improvement, ensure that information provided to clients and staff in support organisations, is clear and consistent in relation to backdating payments.

Quality Assurance

- Enhance the quality assurance processes to ensure the 'reliability' rules are properly and consistently applied.
- Improve the use of health and social care practitioners' input as part of the decision-making process.
- To supplement the quality assurance process, undertake a review of decision statements to assess if standardised text is being used when relating to the general manifestations associated with some conditions or disabilities.
- Clarity to be given to Social Security Scotland staff on performance measures to emphasise the balance between outputs, outcomes and quality.

Supporting Information

- Consider making better use of health and social care practitioners to reduce the need for follow up telephone calls to medical professionals.
- Review and if necessary, update the training for Social Security colleagues to ensure they are aware of the need for cultural awareness and intersectionality in the administration of Adult Disability Payment.
- Re-visit the guidance for GPs in relation to providing Supporting Information for Adult Disability Payment to improve the timeliness and usefulness of the information provided.
- Consider ways to improve relationships between Social Security Scotland and medical professionals through BMA Scotland, GMC, local medical committees.

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Consider ways to reinforce the messaging in relation to GPs/other medical professionals working more closely with Social Security Scotland to reduce clients stress and reduce the number of required appointments, acknowledging that when awards are made it can often promote better longer-term health outcomes for clients.

- Review and if necessary, update the guidance for non-medical sources providing Supporting Information.
- Improve the guidance for case managers on 'equal consideration' being given to nonmedical sources when supplying Supporting Information.

Processing applications

- 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.
- As indicated in Social Security Scotland's Business Plan 2024- 25 proactively provide updates on likely wait time for processing an application, review or a change of circumstances.

Decision Notices

- Consider as part of continuous improvement the feasibility of changing the ordering of information and messaging in an award letter to allow people to better understand the important and relevant information.
- Consider as part of continuous improvement the feasibility of providing greater clarity in the award letter to allow people to better understand indefinite awards.

Re-determinations

- Assess the benefits or otherwise of enhancing the communication around the risk that a re-determination decision may result in Adult Disability Payment payments being reduced.

Third-party Representatives

- Consider the feasibility of reviewing existing policy and guidance regarding completion of declaration (paper form and on-line) and third-party mandate and re-visit the mandate process for support organisations to ensure it works for the client and their representative.
- Consider the feasibility of introducing 'implicit consent' as is available with PIP and/or update the guidance on Social Security Scotland staff speaking with third party representatives when the client is not present to authorise the interaction.
- Consider the introduction of dedicated phone or online route for support services (welfare benefits advisers, third party advocates).

Research and Data

- Social Security Scotland to consider the recording and publication of the number of applications and awards for people with Long Covid.
- The Scottish Government to consider conducting some in-depth research to provide evidence on the additional costs of disability in Scotland.

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- Craig Smith, SAMH (Scottish Action for Mental Health)
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- Christele Geuffroy, Lothian Centre for Inclusive Living

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- Allan Faulds, The ALLIANCE
- Rob Gowans, The ALLIANCE
- Fragile X Society
- Emma Jackson, Citizens Advice Scotland
- Stephanie Millar, Citizens Advice Scotland
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- Stuart McIver, Long Covid Scotland
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- Charlie Adams, My Aware
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- Annmarie Roberts, Mentor, Wise Group
- Conor Coulter, Wise Group
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- Stewart Glass, All in Edinburgh, The Action Group
- Shirley Morris, VOCAL
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- Alisa Jaakkola, The Action Group)
- Louise Donaldson, The Action Group
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- Andy Egerton, The Action Group
- Marwa Turkumany, The Action Group
- Claudia Codioli, The Action Group
- Jo Kirby, The Action Group
- Andy Watson, The Action Group

Parliamentary Interests:

- Members of the Social Justice and Social Security Committee
- Members of the Cross Party Group on Disability
- Members of the Cross Party Group on Older People, Age and Ageing

Public Sector, Independent and Advisory Bodies:

- Ed Pybus, Chair of the Scottish Commission on Social Security
- Martin Taulbut, Public Health Scotland
- Members of the National Implementation Group on Terminal Illness
- Member of the Executive Committee for the Faculty of Eating Disorders at the Royal College of Psychiatrists

Academia:

- Professor Simon Halliday, Professor of Socio-Legal Studies, University of Strathclyde

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