Independent Review of Adult Disability Payment: Call for Evidence

Executive Summary

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Citizen's Advice Scotland welcomes this opportunity to present our evidence of the Adult Disability Payment (ADP) experience: in particular to shine a light on the impact of ADP on seldom heard groups. As Scotland's largest independent advice network and third largest source of ADP application support, our insight is significant and unique.

Our key findings are: -

- > Delivering ADP based on the values of dignity, fairness and respect is having a transformative impact. However, stigma remains a powerful disincentive to claim.
- > Navigating, understanding and applying criteria to specific circumstances can be especially challenging for people with invisible conditions and those who do not define themselves as a disabled person. This is a barrier in the way of ADP reaching everyone who needs it.
- > The process of claiming ADP and challenging a decision can be protracted and overwhelming. For many, it involves repeating sensitive information multiple times, which can itself be traumatic.
- > Having access to a network, whether family and friends or professional services including advice agencies, is positively correlated with seldom heard groups progressing applications.
- > Our evidence on re-determinations and appeals is revealing the extent to which decision making can be inconsistent and requires improvement.

Question 1

(a)Levels of awareness and barriers to awareness of Adult Disability Payment amongst seldom-heard groups?

Our advisers, with their ariel view of the ADP journey, have provided rich insights into the experience of those living in remote rural areas, those living with mental health and learning difficulties, and those caring for a disabled person, including disabled people who are also carers.

7% of our ADP clients live in remote or rural area. In remote areas, logistical challenges accessing local services can combine with low or no digital access to negatively impact on awareness of ADP.

Citizens ALERT Julie¹ approached her local CAB to understand what support might be available to her. The CAB identified ADP as a key benefit that she may be eligible to receive. Julie lives in a remote rural part of Scotland. She relies on a landline phone. Julie has no internet access at all and would not have been aware of ADP had she not attended the CAB. Julie does not travel frequently as she has Fibromyalgia, the symptoms of an underactive thyroid, migraines, asthma, and severe arthritis affecting her hips, causing mobility issues and limiting how far she can walk. Her adviser notes that "having information only online limits a clients' ability to learn more about it".

For disabled people who are also carers, the complexity of their daily lives, the subtlety of the eligibility criteria, and the interaction between benefits can represent significant barriers to awareness. Jordan's experience reveals the pivotal points at which there is an opportunity to break down these barriers, for example when an ADP review decision is issued that has the effect of increasing entitlement.

Citizens ALERT Jordan contacted our Help to Claim service for support managing a move from legacy benefit to Universal Credit and Adult Disability Payment. Jordan is a long-standing recipient of Child Tax Credit, income related-Employment and Support Allowance and Personal Independence Payment (Enhanced Rate of both components). Jordan's partner Michelle is his carer, but she is not in receipt of Carer's Allowance. Jordan was not aware of Scottish Child Payment, although an underlying entitlement stretched back a year. Jordan's original Personal Independence award did not include a Daily Living component, which was awarded at review; had he been in receipt of advice at this time Michelle would have become aware of an entitlement to claim Carer's Allowance linked to Jordan's new Daily Living component award.

(b) The particular barriers to application facing people in specific seldom-heard groups?

Navigating, understanding and applying the criteria to their specific circumstances can be especially challenging for people with invisible conditions not immediately associated with functional limitations. This includes people with learning difficulties and mental health conditions.

The psychological and practical barriers faced by people with such invisible conditions, and the role of CABs in supporting them to overcome these barriers, is richly illustrated by James's experiences.

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James attended his local CAB for support to complete an Adult Disability Payment application. James explained to the CAB that he had "put something in some boxes" and needed reassurance and guidance that he had completed the application correctly and is eligible to receive an award. His concern is primarily that his issues are with his mental, not physical, health. He has recently moved back in with his former partner and mother of his four children as he was not managing his health well, frequently staying in bed for weeks at a time. James has PTSD, anxiety, depression and insomnia, related to childhood trauma and his experiences as a looked after child. His home is his safe space, and he very rarely leaves it. When he had to stop working he gave up his car because he could no longer afford to run it, which has greatly increased the extent of his social isolation. He is no longer able to take his boys to the park due to anxiety; he then feels guilty, further exacerbating his mental ill health. He has had some counselling sessions by phone and is on a waiting list to be seen by mental health professionals. James is not currently in receipt of prescribed medication, which he is concerned about in relation to his application. The adviser was able to encourage and tease out information from James to expand on his responses to the application questions.

Many people living with mental health conditions have had negative experiences of professional support and have disengaged, while others feel unable to engage with such support. For those seeking mental health support, delays can be severe and finding a service that meets individual need challenging. Oliver's situation illustrates the problem.

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Oliver attended his local CAB for support as he is struggling to complete an ADP application. Oliver lives with severe depression and anxiety, alongside issues with mobility related his hip function. He is struggling to access the mental health support that he needs. He has been referred to a community mental health nurse, but he finds this support limited, a conclusion which is itself having a negative impact on his mental health.

The impact on this group of attempting to complete the form can itself be a barrier to claiming or progressing a claim. It can exacerbate a person's condition.

Kate attended her local CAB for support to challenge an ADP decision. Kate completed Citizens an application for ADP without support and while awaiting access to services to obtain a diagnosis. When she originally received the decision letter, Kate had not challenged it; she had not understood the decision letter or her options and since she had no diagnosis at that time had assumed that she was not entitled. She advised the CAB that she did not understand the claim process or the meaning of the questions on the form. She had not provided any additional supporting information; she was not confident that she understood what to provide and who might be responsible for providing it. She has since received a diagnosis of autism, anxiety, disordered eating (Avoidant Restrictive Food Intake Disorder), dyslexia and dysgraphia. She is in part-time employment and education. Kate has complex needs in relation to social interaction, understanding and interpreting complex written information and navigating unfamiliar journeys, unexpected changes and reversing a route, which can trigger debilitating anxiety. Kate has found the process overwhelming, which is why she was unable to reconsider it for some time.

The impact of completing the application and the role of support demonstrated by these experiences is echoed by Jane, one of three people with whom we conducted in depth interviews during November and December 2023. For Jane, an award would confirm the severity of her condition, rendering it real. Only following regular prompting from her GP and social network and engaging with her local CAB was she finally persuaded to apply. Jane, who lives with the effects of a complex interaction of Obsessive Compulsive Disorder (OCD), kidney disease, gout and arthritis, describes how

¹ Real names have not been used.

"horrible" the form is to complete in that it "picks out the worst things in your life, what you can't do, and you realise how much you depend on others". "It's hard to admit you are not who you used to be" is her devastating conclusion.

Likewise, many people with learning difficulties did not benefit from diagnosis and intervention in childhood. That lack of a diagnosis and the experience of having lived within a set of barriers throughout a lifetime can present a formidable challenge to accessing ADP.

Citizens ALERT Jim attended his local CAB for support to complete an ADP application. His concern is that a surgeon with whom he had interacted when in hospital had recorded that he had learning disabilities, but Jim has never been formally assessed. A letter from Jim's GP practice indicated that he has known learning difficulties and kidney stones, but no further additional supporting information was available to the CAB. The CAB contacted the client's GP to request a summary of his medical conditions and medications, and thereafter they contacted Social Security Scotland (SSS) and requested the Local Area Delivery service to assist the client with the form at his home.

Having access to a network, whether composed of family and friends or professional services including advice agencies, is in our evidence positively correlated with seldom heard groups progressing applications. These networks offer support that breaks down barriers.

Question 2

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

(a) awareness

(b) take-up?

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

During the financial year 2023-24, 6,280 people received advice from a CAB adviser embedded in a health care setting, from an adviser working on an outreach basis in a health setting or having been formally referred to a CAB from a health setting. The potential value of this approach in relation to reach, take-up and awareness is indicated by looking at what advice is given:

- > 37% of the advice provided to this group of people concerned both components of Adult Disability Payment. The equivalent figure for the network as a whole is 26%.
- > 31% of the advice provided concerned Attendance Allowance, more than double the network wide figure of 12%.
- > 13% of the advice provided concerned Carers Allowance, again more than double the network wide figure of 6%.
- 16% concerned Blue Badge eligibility and applications. Blue Badge enquiries represent just
 4% of advice work provided by the network overall.

The nature of this service delivered at present means it is disproportionately reaching those in large urban areas; 42% of the people who benefited during 2023-24 were based in large urban areas, compared to 6% in remote rural areas. The value of extending the reach of this type of initiative in remote rural areas is illustrated by the example below.

Citizens

Ruth attended her local CAB for support to report a change of circumstances in respect of her ADP award. Ruth had been receiving PIP (Standard Rate Daily Living component), an award which was transferred to ADP. Ruth contracted a severe

chest infection, which was followed by a significant deterioration in her health. She experienced a series of seizures resulting in a stay in hospital. Ruth now experiences seizures several times a week in addition to having to manage bipolar disorder. She is unable to drive and has been advised not to leave home alone. Ruth lives in a remote rural village, so attending the CAB for the necessary support to report the change involves her asking a friend to accompany her; the journey by public transport takes much of an entire day by two connecting buses with very limited running times.

The CAB network has observed the value of in person interaction in identifying and understanding the impact of learning difficulties that are otherwise insufficiently evidenced. This can be achieved in person by observing, for example, body language, responses and expression, underlining the role of engaging with people where they are and services which come to people.

Our network has also observed the impact on take-up of advice delivered on a stable, consistent basis. Jane, for example, explained that being able to access the same adviser who had supported her through a gruelling PIP journey was a significant factor in her decision to proceed with an ADP application, persuading her of the value of obtaining additional supporting information.

Question 3

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

The factors influencing a decision to proceed with an application for ADP can be varied, complex and interact with one another to further compound issues.

We conducted structured telephone interviews during November and December 2023 with three clients from three different CABs with the objective of understanding people's lived experience of claiming both ADP and Personal Independence Payment (PIP). In all cases an award of ADP was achieved, reducing the extent to which critical insights into the ADP journey were informed by negative outcomes. The findings of this research included:

- > The interviewees recounted complex barriers to proceeding with a claim; none of them actively searched out this type of support, and all were prompted and encouraged.
- The interviewees vividly narrated negative experiences of claiming PIP, which affected their perceptions of ADP prior to claiming. They expressed disillusionment largely generated by what were felt as exhausting, intrusive medical assessments that started from a position of distrust in the client's evidence of their condition.
- > Interviewees recounted positive interactions with Social Security Scotland (SSS) staff, and that such interactions helped break down barriers to claiming.
- > Interviewees articulated the often-overwhelming complexity of the ADP journey, and the challenges of providing the depth of information required.
- > Interviewees spoke to the value of strategic agency information sharing in reducing the burden of making and progressing a claim.
- > Interviewees clearly expressed the essential role of advice in supporting them to navigate the claims process.

All three interviewees revealed that without support they would not have proceeded with their applications, demonstrating the importance of independent, whole person focused advice in increasing benefit take-up. The interviewees all described the ways in which the support of the

CAB went beyond practical support to communicate. The support helped them to both understand and navigate the process while deepening their understanding of their personal circumstances, alleviating severe distress and restoring a sense of control.

These insights support academic analysis that has found that a lack of awareness, inaccurate assumptions about eligibility, the burden of applying, agency interactions, stigma and resistance are interactive barriers to claiming support associated with rigorous qualification criteria²

The ability to access services and obtain a diagnosis influences confidence in applying, as reflected in Rebecca's experiences.

Citizens ALERT Rebecca attended her local CAB to better understand what support might be available to her. She has searched online for "disability benefits" but is not confident that she would qualify and is therefore reluctant to apply. This is because Rebecca's symptoms are subject to substantial fluctuation, and she is concerned that since she is a carer for her parents and her 13-year-old daughter she cannot be considered ill enough. Rebecca provides this care with the help of her sister, at times at the expense of meeting her own needs. Rebecca lives with an undiagnosed suspected neurological disease, the manifestations of which can be debilitating and include daily headaches and muscular weakness.

Stigma is a powerful disincentive to proceeding with a claim, and typically interacts with anxiety around the eligibility criteria and what actions can trigger a loss of benefit.

- Citizens ALERT Caitlin and Brian were advised by their local CAB that they are eligible for ADP, which they expressed a deep-rooted reluctance to engage with on grounds that they might be perceived as "lazy fraudsters, as seen on TV". Caitlin and Brian both have physical disabilities and learning difficulties. The CAB invested substantial time in what the adviser describes as "gentle persuasion and encouragement". Both members of the couple were subsequently awarded ADP, but the adviser explains that the anxiety remains about under surveillance as potential fraudsters.
- **Citizens** ALERT Janet contacted our Help To Claim service. She is thinking about returning to work and she would like to know how it will affect her benefits. Janet declined to provide her personal details as she lives in a small community and doesn't want others to know about what benefits she receives or anything about her health. Janet also has family members who work within her local CAB and she is therefore concerned about them knowing her business. Janet was previously in receipt of PIP but she had not completed scheduled review paperwork due to anxiety about having to undergo a reassessment process. Janet is also concerned that her ESA will stop if she starts work.

Many people with complex needs do not identify themselves as a disabled person. For those who do not define themselves as a disabled person, but who are incurring health-related additional costs, it can be difficult to understand how ADP and its functional criteria apply to them.

Citizens ALERT

James is a carer for his partner Sophie and their seven-month-old daughter. Sophie had to stop working following a high-risk pregnancy. During an in-depth interaction with a CAB adviser, James revealed that he has a genetic condition that his daughter has inherited. The condition is rare and results in additional growth of bone and increased risk of cancer. It necessitates regular surgery; James has undergone nine operations and engages in physiotherapy. James has never considered himself a

³ <u>Take-up rates of Scottish benefits: November 2023 - gov.scot (www.gov.scot) and Take-up of social security benefits: past, present – and future? in: Journal of Poverty and Social Justice - Ahead of print (bristoluniversitypressdigital.com)</u>

disabled person and never thought of applying for disability benefits. He was also unaware that he can apply for disability benefit on behalf of his daughter. Nor was he aware that disability benefits are not income related. James recounted to the CAB adviser that he tries "to live each day", that he has adapted his life around his conditions and had not previously considered how his life could improve "with a little support".

Building trust in Social Security Scotland over time will be critical in encouraging people to take-up ADP. Negative past experiences of PIP continue to frame how people perceive the experience of accessing disability benefits.

Citizens ALERT Kenny attended his local CAB and was advised that he is eligible to apply for ADP; he declined to do so. He had previously applied for PIP, but in the run up to his health assessment (which was to take place in Kenny's home) he was unable to sleep for two days. On the appointment date the DWP assessor did not appear. The DWP later indicated a cancelled ferry was responsible, but this transpired not to be an accurate account. Kenny has chosen to try and manage on a low income rather than attempt another application. Kenny became agitated when the CAB raised the subject.

Our work with advisers and our interviewees has indicated how positive staff behaviour and word of mouth is making a difference. Our interviewee, David, was impressed by the care taken by Social Security Scotland staff to actively encourage him to update the agency regarding a forthcoming change likely to increase his award level. He described his interaction with the agency as feeling "much more individually tailored and not about the organisation". Jane meanwhile described the SSS staff member that she engaged with as "amazing" and recounted an effective use of empathy, which influenced her motivation to continue.

Question 4

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

(a) Parts of those services that are working well?

The capacity of Social Security Scotland's (SSS) Local Area Delivery service to conduct home visits is highly valued by our network. Face to face interaction can be important in understanding a person's needs.

Citizens ALERT George had requested support from an SSS Local Area Delivery service to complete a Stage 2 ADP form. He was advised by SSS that the only way to initiate contact from the Local Delivery Team was by phone. In response, George attended his local CAB, explaining that he finds it very difficult to receive phone calls and the anticipation of receiving a call raises his anxiety level and worsens his health. He did not feel that he would be able to express his needs by telephone. The CAB was able to arrange for a Local Area Delivery staff member to visit George in his home, not having the capacity to provide this service themselves.

(b) Parts of those services that don't work, are confusing or could be further improved?

To explore what works and what could be improved in relation to Local Area Delivery, we held an online roundtable event and had individual discussions with managers, welfare rights project advisers and Social Policy Co-ordinators.

The key recommendations for change that emerged from this work are:

- > The provision of a referral pathway to help ensure optimal reach of the service. Presently, people who are seeking, or who would benefit from, support from the service can only access it via the main SSS call handling centre. Appointments cannot be booked through the local locations in which the services are based or in which they have informal operational agreements, such as CABs.
- > The provision of a drop-in service to improve accessibility and reach.
- > The strengthening of relationships with independent services such as CABs to reduce the risk of there being a perceived conflict of interest in the same agency that delivers the benefit providing support to apply for it while improving understanding of the distinct role of different services i.e. Local Area Delivery, advice providers and advocacy services.

Question 6

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

A survey conducted by SSS from 13th February 2024 to 11th March 2024 found that half of respondents had support with their application. 16% of those who received such support received it from CABs, making us the third largest provider of support with the ADP application process to this survey sample, after family and friends and SSS.³

ADP advice is a steadily growing component of the work being undertaken by our network. It represents 25% off all benefit related advice provided by the network; by volume it has increase by 30% from Quarter 1 of 2023-2024 to Quarter 1 of 2024-2025. In total we logged 19,349 ADP Daily Living component and 13,449 ADP Mobility component advice contacts in Quarter 1 of 2024-2025, distributed across 8,605 and 6,047 respectively individual clients. The number of individual clients advised on the Daily Living component alone is a figure equivalent to one third of the 26,090 Part 2 ADP applications received by Social Security Scotland in the three months to April 2024.

Support with the initial steps in making an application still represents the largest single segment of ADP advice work; advice on reporting changes, re-determinations and appeals continues to grow as a proportion of the overall ADP workload.

³ Social Security Scotland - Client Survey: Disability Payments

From a sample of 65 ADP advice focused Social Policy Feedback reports that were logged by the network from the 1st of May to 1st July inclusive, an important underlying motivator to seek advice can be identified as the length, complexity and depth of the ADP journey. The Stage 2 Form, for example, can be perceived as overwhelming, confusing and distressing.

Citizens

S Kevin attended his local CAB for support. Kevin is seeking to apply for ADP but finds the questions confusing, especially in relation to washing and bathing, getting dressed and undressed and communicating verbally. Kevin feels unable to answer these questions and that his condition does not "fit into these boxes". Kevin advised the CAB that he that he feels intimated by the form.

The critical role of advice in supporting people to navigate what can be an overwhelming journey was movingly described by participants in our focused interviews. John, for example, explained that without the support of the CAB he would "not have known what to do next". His adviser helped him to understand what makes good additional supporting information and helped him to gather it. He was clear that without representation he would have been unable to proceed to appeal, observing that the documentation alone would have been impossible for him to navigate; "how would I have dealt with the appeal bundle?".

Question 7

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

Delays can have a particularly acute impact on those caring for the disabled person in question, who in certain cases will have had to give up work or move home with little opportunity to prepare.

Citizens ALERT Kerry approached her local CAB for help managing her UC claim; she has been sanctioned having given up work to care for her partner. The sanction is of 91 days duration. Kerry's partner is now living with her; he has been referred for a Work Capability Assessment and has applied for ADP. Kerry is not able to get the Carer's Element of UC until the ADP application has been processed. The household is severely struggling. Kerry is considering submitting a Mandatory Reconsideration in respect of the sanction, but such a challenge will also take considerable time to process.

The impact of delays on young carer's ability to meet their own needs is potentially dhetrimental to their future, as Callum and Catherine's experiences shows.

Citizens ALERT Callum approached his local CAB for support understanding what benefit he might be entitled to. Callum is eighteen and receives Universal Credit (UC) at a reduced rate since he is under the age of twenty-five. Callum is a carer for both his mother and his twenty-year-old brother. In addition to home care, Callum supports his brother to attend college four days a week to ensure his brother's safety. His brother has previously applied for Adult Disability Payment (ADP), but the application was not authorised. Callum's mother has applied for ADP and has recently been advised that she should know the outcome within ten weeks. The CAB adviser had to explain to Callum that an application for Carer's Allowance cannot yet be made since neither his brother nor his mother receive a qualifying benefit; the wait also means that he cannot access the Scottish Young Carer's Grant and Carer's Support Payment. In the absence of adequate and secure financial resources Callum is not accessing education, training or employment.

Catherine attended her local CAB for support to maximise her income. Catherine works in social care but has been off sick after collapsing at work. She has now been diagnosed with probable neurosarcoidosis. This is an inflammation of the brain which causes headache, ataxia, visual disturbances, fatigue, nausea and vomiting. Catherine's daughter, who is only sixteen years old, has left school and is now a young carer. Catherine receives Universal Credit to supplement her income, but this will reduce since Child Benefit will cease now that her daughter is no longer in education. Until now the benefit has been helping with rent. ADP is therefore a financial lifeline for Catherine and will allow her daughter to access Carer's Allowance and the Young Carer's Grant. The CAB supported Catherine to initiate a claim but was obliged to inform her of general processing times.

For those experiencing homelessness managing delays can be very difficult from a practical perspective. Waiting for vital additional income can have a severe impact on this group, who are already struggling to meet their needs and deal with extreme financial insecurity.

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Brian was finally awarded ADP in April 2024 having originally applied in May 2023. During that year, Brian has been homeless without a fixed address. He relied on the CAB to update SSS concerning his various addresses and professional input. The wait has had a detrimental impact on Brian; his mental health has deteriorated as he has been pulled further into destitution.

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

Regular but not overwhelming, appropriate communication is key to provide reassurance and reduce anxiety.

Citizens ALERT Jess approached her local CAB for support to make a claim for ADP. Jess has a diagnosis of dementia and is unable to leave home safely without supervision. Jess was seeking to use any award to help her to pay for taxis and a carer to accompany her to professional appointments and activities in the community. With the help of the CAB Jess was awarded the Enhanced Rate of both components; however, from the initial claim to decision took over six months. Throughout this six-month period Jess was consumed with anxiety that she would be refused ADP and became increasingly isolated.

Regular communication, for example text message progress updates and an online account tracking facility can be expected to have a positive impact on people living with mental health conditions or neurodivergence who are frequently also dealing with delays accessing health services while juggling work or caring responsibilities. Rachael's story is an illustration of how challenging being in "limbo" can be for this group in the context of multiple pressure points.

Citizens

Rachael approached her local CAB for seeking re-assurance about what is happening with her claim for ADP and a claim for Child Disability Payment (CDP) concerning her eldest son. Rachael is a single parent of two boys, both of whom have complex needs related to developmental delays. The youngest was awarded CDP with the help of the CAB following a six-month application process. Rachael's eldest son has been waiting on a referral to CAMHS for twelve months and therefore Rachael has not yet received a formal diagnosis confirming the child's needs. Rachael manages physical health conditions and severe depression. She has been supported by the CAB for several years to cope with benefit changes. Rachael lately underwent a transfer from PIP to ADP, a nine-month process; she is now awaiting the outcome of a review. These multiple waits have had a significant impact on the intensity and manageability of Rachael's anxiety. The CAB notes that the lack of updates throughout the process has exacerbated this detrimental impact, and that Rachael has really appreciated that the CAB has maintained contact throughout.

Our evidence reveals the vital role of ensuring that the person 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 a claim. Failure to use the most suitable communication tool can worsen the impact of delays.

ALERT Angela attended her local CAB to progress a review of her ADP award. Angela is Deaf and is undergoing tests for early on-set dementia; she relies on her partner James, who is also deaf, to help her communicate. The couple attempted to report a change of circumstances to the DWP in June 2023, which eventually triggered a transfer to ADP. To subsequently request a review, the CAB adviser was told by a call handler at SSS that the client would need to use the Relay App or Contact BSL to request support. The adviser explained Angela's circumstances and that she is not able to work a mobile phone or laptop, to no avail. The adviser attempted to support Angela, in an appointment of over two hours duration, to use the Relay app. Angela found this distressing. When no steps were taken by SSS to proceed with a home visit, the CAB arranged to support Angela to complete the review request. Angela later received a letter from SSS requesting a signed ID photograph to access a home visit; she contacted the CAB confused.

Appropriate communication with individuals claiming ADP must be combined with a consistent approach to providing information to authorised representatives and escalation routes capable of improving responses to operational problems and, crucially, improve the safeguarding capacity of SSS.

Question 8

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

Re-determinations and appeals data

- Re-determinations and appeals together represent 18% of the CAS ADP advice workload and represent the fastest growing areas of ADP work being undertaken by the network. Advice work related to appeals increased by 20% from Quarter 4 of Financial Year 2023-24 and Quarter 1 of 2024-25, on re-determinations the equivalent figure is 4%.
- > SSS data shows that the number of re-determinations being submitted has been increasing month on month, most notably since June 2023. Of the redeterminations requested, 6,610 were requested in the Quarter ending in April 2024, representing a 19% increase on the previous Quarter ending in January 2024.

- SSS data also shows the number of appeals being lodged is increasing significantly, from 270 in January 2024 to 525 in April 2024, while the number of Stage 2 applications being lodged has remained steady since October 2022.⁴
- Since September 2023, the proportion of re-determination requests made that have been upheld or partially upheld has been consistently around 50%. The proportion of appeals in which the decision is favourable to the appellant has varied substantially, from 78% in November 2023 to 41% in December 2023, averaging 55% across financial year 2023-2024.
- > Combined, the data indicate the extent to which initial decision making could be improved.

While our advisers are positive about the production of thorough, justified decisions, they are clear that these are not entirely comprehensible to their clients.

Michael sought support from his local CAB looking to submit a redetermination in Citizens relation to an ADP decision. He applied for ADP with the help of a Social Security **ALERT** Scotland (SSS) staff member, who visited him at home. He was awarded 6 points for Daily Living and no points for Mobility and so was refused an award. Michael reported to the CAB that the staff member did not convey all the information that he provided, and that his GP advised him that SSS did not attempt to contact the practice for information. Michael received twelve re-determination booklets, envelopes and covering letters over the course of a two weeks. This caused confusion and upset at a time when Michael was already distressed and baffled by the original decision. Michael has had to stop working for health reasons. Michael had a lung removed having been the victim of a violent assault. His immune system is compromised as a result; he is prone to multiple infections. Recently he has developed Raynaud's Syndrome severe enough to impact his manual dexterity and mobility. He is also impacted by bowel incontinence. The trauma of what happened to him has so affected his mental health that he does not leave home without support. Michael felt overwhelmed by the ADP journey so far.

Citizens ALERT Angela approached her local CAB for support with her ADP application. Angela had applied for ADP and was awarded Standard Rate Daily Living component. Angela wishes to challenge the decision as she does not believe that all her circumstances were taken into consideration. Angela has a diagnosed learning disability but this was not assessed by SSS as it had not been documented by the Angela's GP. Angela advised that she had listed her mother and partner as sources of additional supporting information, but neither were contacted by SSS as requested. Angela was left confused as to the basis of the decision made.

Evidence is emerging from our adviser's experience that some language is being used in decision notices that is not well understood by their clients. One example cited is "there are no reports of any cognitive condition to impact your ability to recognise hunger and thirst and respond."

In relation to decisions being challenged, difficulty in understanding the basis of decisions has clustered around the interpretation of descriptors within one Mobility and one Daily Living component Activity in particular. The complex nature of the functional criteria and the extent to which the objective and subjective aspects of their interpretation can be in tension is well illustrated by what has emerged in relation to these two Activities. The impact is primarily on those living with mental health conditions, neurodivergent people and people who have learning difficulties.

⁴ Social Security Scotland - Adult Disability Payment: high level statistics to 30 April 2024

Planning and Following Journeys

- "Follow a route" incorporates making one's way along a route. This is included in the ADP Regulations, and not in the PIP Regulations.
- > Descriptors 1d and 1f are clearly intended to apply to, amongst others, those who are visually impaired and so have difficulty navigating, whereas descriptors 1b and 1e apply to those liable to experience overwhelming psychological distress if they go outside unaccompanied or at all. A liability to get lost due to a physical or mental health condition is relevant to whether a claimant can follow the route of a journey for the purpose of descriptors 1d and 1f.
- Descriptor 1d appears to be being interpreted in a restrictive manner, construing PIP caselaw as meaning that only if a claimant is experiencing "overwhelming psychological distress" would anxiety be a cause of being unable to follow the route of a journey.
- > The argument presented in the landmark case MH v Secretary of State for Work and Pensions was that where claimants have anxiety, descriptors 1(d) and 1(f) are applied in the light of descriptors 1(b) and 1(e), with due regard being had to the term "overwhelming psychological distress". However, it is acknowledged that this is only one scenario in which these descriptors apply.⁵
- Claimants can potentially score in several descriptors in the activity if they cannot commence journeys because of their condition or need prompting or another person to accompany them to make a journey. The points variation across the descriptors reflects the difference between someone who requires prompting to leave the house and someone who is unable to follow a journey unless accompanied by another person.
- > The SSS Decision Makers Guidance, through the illustrations used, gives the impression that these descriptors 1(d) and 1(f) only apply on mental health grounds where restrictions constitute overwhelming psychological distress. People who do not meet the reliability criteria, or who are experiencing a complex interaction of symptoms affecting their ability to navigate and make their way along a route, would be inappropriately potentially excluded by such an interpretation.⁶
- > egal clarity is therefore being sought on the extent to which anxiety amounting to less than overwhelming psychological distress may well on the facts of a case mean that a claimant cannot follow a route safely or to an acceptable standard.

Social Engagement

> The key case exploring Activity 9, descriptor c was decided by the Supreme Court.⁷ The main finding was that "Responding to the greater degree of disability [envisaged] requires the attention not just of another person, but of a person trained or experienced in assisting people to engage in social situations. That is what differentiates prompting for the purposes of 9b from prompting which is social support for the purposes of 9c. And where the support takes a form other than prompting, it will similarly only qualify for 9c if the claimant needs it to come from a person so trained or experience".

⁵ 2018__AACR_12ws.pdf (publishing.service.gov.uk)

⁶ <u>14.-11.-Mobility-component-activity-1-for-Adult-Disability-Payment---planning-and-following-journeys.pdf (socialsecurity.gov.scot)</u>

⁷ 2019__AACR_26ws.pdf (publishing.service.gov.uk)

In contrast, the SSS guidance states: "The threshold for awarding daily living component activity 9 descriptor C for mental health conditions is much higher",⁸ which is not suggested by the Supreme Court case. The guidance has a clear clinical focus in the summary it provides of what might be "expected" to be available to establish that the descriptor applies. This might lead a case manager to conclude that the social support must be provided by a professional, which is explicitly not the case.

Question 10

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

The administrative complexity and duration of the re-determination and appeal process can be a significant determinant of whether a person proceeds to challenge a decision.

The necessity of repeating sensitive information and continually confronting limitations, which has been defined as the trauma of "re-telling",⁹ and by one of our advisers as "the pressure of intense scrutiny", is a formidable barrier. People considering requesting a re-determination are weighing up the extent to which they feel able to undertake "re-telling" to progress a re-determination, knowing that they may have to go through the same process a third time if the re-determination is unsuccessful and an appeal is required.

Inaccurate information about the possibility of requesting a re-determination can act as a significant influence on a person's decision to progress a challenge to an ADP decision.

Citizens ALERT Janet attended her local CAB to enquire about the possibility of submitting a redetermination of a decision to refuse her an award of ADP. Janet had contacted Social Security Scotland and was informed by a call handler that due to the 6-week deadline to submit a re-determination having passed she will have to submit a new claim. The call handler had not explained that submissions can be made within 12 months of the original decision where there is a good reason for the delay. Janet is living with ADHD, which has just recently been diagnosed, anxiety and depression to the point of suicide ideation and difficult to control Type 1 Diabetes. She attended the CAB due to the distress that the call to SSS has caused and would not have proceeded with her claim has she not been able to access this support.

The risk of being in a worse position financially at the conclusion of an arduous process is a deterrent to challenging awards that do not appear to reflect the level of need.

Citizens ALERT James applied for Adult Disability Payment in February 2023. He received a decision in June 2023. It awarded him the Enhanced rate of the Daily Living component but no Mobility component. James requested a re-determination. The re-determination notice, received in September 2023, refused him an award altogether, though awarding some points for Daily Living needs. James submitted an appeal. The hearing was adjourned to provide James with an opportunity to participate in a video hearing, seek representation and submit supplementary medical records. SSS in their initial submission to the Tribunal supported a return to the original award of the Enhanced rate of the Daily Living component. On the day of the hearing the SSS representative

⁹ <u>Get-Heard-Scotland-Report-Impact-of-Stigma-on-Benefit-Take-Up-for-Publication-May-2024-1.pdf (povertyalliance.org)</u>

⁸ <u>48.-Daily-living-component-activity-9-for-Adult-Disability-Payment_-Engaging-socially-with-other-people-face-to-face-change.pdf</u> (socialsecurity.gov.scot) pages 4-5

supported an award of the Enhanced Rate of both components. The Tribunal decision, made in June 2024, awarded the Standard rate of Daily Living and no Mobility, leaving him worse off then had he not submitted a re-determination. James is deaf in his right ear and has only 50% hearing in his left ear. He also has an anxiety disorder. He found the process confusing and overwhelming.

Balanced against these deterrent factors, obtaining a diagnosis, and support, can steer people in the other direction, as Kate's story in answer to question 1(b) shows.

Question 11

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

In addition to the factors discussed in answer to question 10, the prospect of an imminent review date almost immediately following a lengthy appeal process can amplify other deterrent factors.

Citizens ALERT Sandra sought the assistance of her local CAB for support to appeal a re-determined decision refusing an award of ADP. She was awarded 2 points only for Activity 5 (Toilet Needs). Sandra is a lone parent of two children. She is employed full-time, although currently on sick leave. She has been diagnosed with Type 1 Diabetes following a five-year investigation of her symptoms. She struggles with severe anxiety and an eating disorder linked to childhood trauma. She is finding managing the diabetes overwhelming and a trigger of both anxiety and disordered eating. Fourteen months passed from the date of Sandra's original application for ADP and the date of the appeal hearing. The appeal was successful, and Sandra was awarded the Standard Rate of the Daily Living component. SSS sought an 18-month review date on the award, meaning that since that review date would operate from the date of application Sandra would face a review almost immediately. Ultimately, the tribunal set a two-year review date, but this still leaves very little breathing space for Sandra.

These potential deterrents are being balanced against the depth of need for the support provided by ADP, which acts as a "push" factor. Access to advice to navigate the appeals process can be a determinative factor.

Citizens ALERT ALERT Anna attended an outreach session for advice about challenging an Adult Disability (ADP) decision. Anna presented a re-determination notice reducing her award of ADP from Standard Rate Daily Living component to nil. Anna's CAB adviser describes her as being "shocked, upset and angry". Anna wishes to proceed to an appeal. She attends a Long Covid clinic, which could be a source of additional information relevant to the appeal. Anna has lost a weekly income of £68.10 and is now facing an application for short-term assistance and appeal process.

Question 12

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

(b) What could be improved (if anything)?

Managing a change of circumstances has become established as a significant area of ADP advice. Of the 19, 349 Daily Living component advice contacts logged in Quarter 1 of Financial Year 2024-2025, 1,583 related to this issue. This represents a 7% increase on the previous Quater and is nearly double the volume recorded in Quarter 1 of Financial Year 2023-2024.

Fear of losing existing benefit or ending up with a reduced award can deter people from reporting a deterioration in their circumstances. The psychological imprint of negative PIP experiences can be a driver of this fear. It can also be driven by the highly restrictive nature of some Activities; Simone's experience concerns the Mobility component, Activity 1 (Moving Around).

Citizens ALERT Simone approached her local CAB for support to manage her ADP claim. When Simone was transferred from PIP to ADP she did not report a deterioration in her abilities to SSS as she feared having to go through an intrusive review process that may have risked her award. This fear was grounded in her previous experience as a PIP recipient; she lost the Mobility component of PIP following a scheduled review which determined that she could walk further than 50 meters. Simone's circumstances are significantly worse even than they were prior to the DWP review of her award, but she is still minded to wait the five years for a scheduled review rather than report the change.

Delays in processing reported changes in circumstances are being widely reported by our advisers. Further changes can happen during protracted review periods and people struggle to manage their conditions optimally since they are receiving a level of support that does not reflect their needs. In some circumstances access to Carer's Allowance (dependent upon a Daily Living award), a Blue Badge or a Motability vehicle are being anxiously awaited.

Citizens ALERT

Adam received support from his local CAB to notify SSS of a change in his circumstances relevant to his ADP award. Documentation was completed in March 2023 and as of June 2024 Adam was still waiting for an outcome, a delay of over one year. Adam has had a heart attack since notifying SSS of the change, and his condition has deteriorated further.

Citizens ALERT John approached his local CAB for support with his ADP application. John has been living with severe long Covid since 2020. Since he contracted the virus when knowledge and understanding of its impact was limited, getting a diagnosis was a protracted process. The Standard rate of both components of PIP was eventually awarded in the summer of 2021 in response to a Mandatory Reconsideration. John was transferred to ADP in the summer of 2023. He was issued an ADP review form, which he completed with the support of the CAB. Nine months later John still does not know the outcome. Although he is being paid ADP, his circumstances are now significantly more complex, and he is hoping that at least one of the components will be increased to the Enhanced rate. The CAB have been regularly following up the case seeking progress updates.

Question 14

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

Adult Disability Payment is being delivered by an agency that has been built with the explicit objective of treating Scotland's people with dignity, fairness and respect, guided by a Charter against which the public can measure its performance. The impact of this has been profound, as the experience of our interviewees David and Jane in particular highlighted. At its best this approach can result in people feeling listened to and valued. Where interagency communication has happened, the improvement in outcomes is manifest.

• ALERT A CAB adviser supporting Caitlin happily reports that a decision had been made about Caitlin's ADP application in less than three months and that the outcome had been communicated to the relevant local authority to support a Housing Benefit and Council Tax Reduction claim, noting the positive impact on the wellbeing of Caitlin, whose circumstances and needs are complex.

The necessity of moving towards a whole-of-life, whole person approach

The specific, narrow focus and framing of the functional criteria has been identified by our network as a barrier to access, and as posing limitations on the extent to which need can be reflected in the points allocated. An example provided by advisers to illustrate this is of a person who requires multiple aids but who can only be allocated the maximum award associated with the use of an aid to carry out that activity; another person who requires only one aid to carry out the same activity will be allocated an identical number of points. When functional restriction is concentrated in one Activity, this can pose a real challenge to obtaining an award. The need for holistic, well-being and quality of life-based criteria that reduces the need for people to envisage hypotheticals that they do not fully understand is the prevalent theme in discussion with advisers working on the frontline.

A model for how such an assessment might be framed is provided by the legislative framework governing assessments of social care needs in England¹⁰. These assessments must identify the individual's priorities and desired outcomes in relation to nine areas of wellbeing.

- > personal dignity (including treatment of the individual with respect)
- > physical and mental health and emotional wellbeing
- > protection from abuse and neglect
- control by the individual over day-to-day life (including over care and support provided and the way it is provided)
- > participation in work, education, training or recreation
- > social and economic wellbeing
- > domestic, family and personal
- > suitability of living accommodation
- > the individual's contribution to society

¹⁰ Care Act 2014 (legislation.gov.uk) Sections 1 and 9

Through active listening conversation, social workers explore the individual's understanding of their strengths, skills and capabilities, and whether these can be utilised or developed to enable them to achieve their desired personal outcomes, as well as needs and barriers. The aim is to obtain a full picture of the individual's needs from the points of view of all those involved in the assessment process (i.e. assessor, individual, professionals, carer, etc.) and individual personal outcomes in relation to the nine areas of wellbeing. The assessments has been found to be most effective "when the practitioner spent time getting to know the person; when they did this without reference to the assessment form; and when they involved family members in the person's plan, but in an ancillary way."¹¹

This person-centred approach to assessments of eligibility has been embraced and the legal framework is considered to have been successful, albeit in the context of broad challenges to the delivery of social care.¹²

Supporting the transition to ADP at a key life stage

Jennifer's story encapsulates the potentially transformative impact on disabled people and their network of a dynamic benefit that responds seamlessly to changes through the life cycle.

Citizens ALERT Jennifer approached her local CAB to try and understand what help she might be able to access. She is struggling to support a teenage child, Josh, with complex needs. Josh will be leaving school this summer and is unable to work or to look for work. Whilst there has been social work and health involvement to negotiate the transition to adulthood, there has been no advice provided on the benefits Josh will potentially be entitled to. Josh is moving from DLA to ADP. Jennifer receives Carers Allowance; her partner is in full time work. Jennifer feels very unclear about whether the couple will be expected to continue to meet Josh's costs indefinitely; she is concerned about the future.

The gaps in a functional criterion: A focus on eating disorders

Eating disorders have been identified by our advisers working on an outreach basis in health settings and others representing people at appeal as illustrating the ways in which people can fall through the gaps of the current criteria and find themselves without the financial support that they need. Considering experiences such as Nicole's should also prompt more general reflections on the fact that the criteria do not consider the ability of a person to access a diet likely to optimise health.

Citizens ALERT Nicole sought the support of a CAB outreach adviser to complete an ADP application. Nicole has applied for ADP in the past but was not allocated sufficient points to be awarded the benefit. Nicole has anorexia; her weight is still too low for her to be safely discharged from hospital. The only possibility in terms of points allocation directly linked to eating available to Nicole is 4 (Daily Living Activity 2, descriptor D) due to the prompting she requires to take nutrition. Dressing has a significant relationship to Nicole's health since the fit of clothes can be used as a proxy for weight gain. Bathing can have a similar impact, since it places complete focus on the body. These impacts do not constitute functional restriction as defined by the criteria. Similar challenges are posed by the Social Engagement Activity, since Nicole's ability to engage socially is shaped by the role of food in social life. Nicole's ability to move around in a healthy way is impacted by her compulsion to exercise to maintain a low body weight. Nicole has received medical advice to limit her movements, and she sometimes must use

¹¹ Making person-centred assessments - Jon Symonds, Caroline Miles, Mike Steel, Sue Porter, Val Williams, 2020 (sagepub.com)

¹² The Care Act 2014: Ten years on from Royal Assent | Local Government Association

a wheelchair to support her return to a sustainable body weight. Again, this is not accommodated by the criteria as it is not within its definition of functional restriction. The generalised cognitive impairment associated with a very low BMI is not easily accommodated, nor is the extent to which eating, calories and weight consume Nicole's daily life and thought processes.

In numbers

Available data is beginning to reveal the extent to which people may be falling through these gaps and finding themselves being refused an award or being awarded a lower level of support than they would benefit from. The available data is also beginning to reveal the extent to which ADP may not be reaching everyone who is entitled to it.

Invisible and fluctuating conditions

Data extending to the end of April 2024 shows that diseases of the digestive system (including Chron's disease and IBS), known to have high degrees of unpredictable fluctuation and to be associated with chronic pain, have the highest award refusal rate at 51%. Mental health/behavioural, musculoskeletal, and nervous system (largely unpredictably fluctuating conditions such as MS) cases have approximately equivalent refusal rates of 30% despite the wide difference in the caseload across these groups (mental health/behavioural impairment types represent 34% of the ADP caseload, nervous system impairment types represent 5%).

At 56%, the proportion of mental health and behavioural impairment type cases that are awarded both components is the lowest of all impairment types for which data is available by some margin. Within this cohort, Daily Living awards are more likely to be granted at the Enhanced Rate to those with autistic spectrum profiles, 72%, and least likely to be granted at the Enhanced Rate to those with stress related profiles, 43%.¹³

Many clients do not fully understand how their Daily Living needs impact upon their ability to get around reliably and independently to the extent that eligibility for the Mobility component arises.¹⁴ In contrast, the impact of physical mobilisation restrictions on Daily Living needs is more readily grasped. This is reflected in our data. In Quarter 1 of financial year 2024-2025, 60% of those receiving advice about ADP, Daily Living component, were also receiving advice about the Mobility component. In contrast, 90% of those advised on the Mobility component were also being advised on the Daily Living component.

It is noteworthy that just 6% of awards granted so far during financial year 2024-25 have been Mobility component only awards, whereas 42% of awards have been Daily Living component only. Of those receiving an Enhanced Mobility award in April 2024, just 25% were accessing the Motability scheme.¹⁵ This reflects the responses of advisers who participated in our focus groups and broader anecdotal evidence of our network that the Mobility component is harder to obtain and that its distribution is not reflecting actual need. This experience contributes to how highly it is valued by the people that we support.

¹³ Adult-Disability-Payment-Tables-to-30-April-2024.xlsx (live.com) Table 5, 19, 20, 21

Sensory: Visual and Hearing

Caseload (total number of people in receipt of ADP, not a robust indicator but useful nonetheless) shows that 1% of people in receipt of ADP by April 2024 had as a primary condition a visual impairment (2,405 people out of a total of 254, 285). This mirrors PIP caseload data.¹⁶ This suggests a wide disparity between the volume of people accessing ADP with a visual impairment and the prevalence of visual impairment in the working age population, estimated to be 10% in the most recent Family Resources Survey. ¹⁷

Similarly, caseload data shows that 1% of people in receipt of ADP by April 2024 had as a primary condition a hearing impairment (2,200 people out of a total of 254, 285). Again, this mirrors PIP caseload data and suggests a disparity in between the volume of people accessing ADP with a hearing impairment and the prevalence of hearing impairment in the working age population, estimated to be 7% in the most recent Family Resources Survey.¹⁸

Understanding this further would require more granular data within the categories of Disease of the Eye and Adnexa (ICD-10)/ Disease of the Ear and Mastoid Process (ICD-10), used by SSS, and Visual Disease/Hearing Disorders, used by the DWP.

- ¹⁵ Social Security Scotland Adult Disability Payment: high level statistics to 30 April 2024 (tables 2 & 14)
- ¹⁶ <u>Personal Independence Payment: Official Statistics to April 2024 GOV.UK (www.gov.uk)</u>
- ¹⁷ Family Resources Survey: financial year 2022 to 2023 GOV.UK (www.gov.uk) (Table 4.6)
- ¹⁸ Family Resources Survey: financial year 2022 to 2023 GOV.UK (www.gov.uk) (Table 4.6)

¹⁴ ADP: Mobility Component Consultation | Citizens Advice Scotland (cas.org.uk)

Our key recommendations

- > Continued development and roll out of text message conveyed progress updates and an online progress tracker linked to a person's online my.scot account.
- > Clear and accessible communication to claimants at the outset so that they may receive informal contact to clarify gaps in evidence will improve trust and efficiency. Advance notification of this contact via the appropriate communication channel (typically text message) will allow claimants to prepare, access support, and re-arrange the contact as required.
- Relationships between Social Security Scotland and the Third Sector could be further developed to establish consistent links between Local Area Delivery services and frontline advice and representation services. The creation of alternative routes to access Local Area Delivery services would optimise this potential.
- > Recording assessment method (telephone, video, in person) combined with award type could help identify possible discrepancies in outcomes.
- > Auditing of individual decisions and representative samples of decisions is necessary.
- > The development of escalation routes to support advice provision while also building operational issue responsiveness and safeguarding capacity.
- > To minimise the risk of claimants "falling through the cracks" a "safety net" provision for cases in which the functional test has not been satisfied should be developed, modelled on that used to determine work capability for means tested benefit.
- In the medium to longer term, anchoring ADP to its purpose to support people to break-down barriers to promote full participation in society and flourishing, requires a re-design of the criteria to better focus on how this can be achieved.

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