# Adult Disability Payment (ADP) Regulations: Analysis of Consultation Responses

Final Report
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# **Executive Summary**

#### **Background**

Adult Disability Payment is a new Scottish benefit which will replace the existing Personal Independence Payment for people from the age of 16 living with a disability in Scotland. It will be delivered by Social Security Scotland and the first payments are due to be made in summer 2022.

Adult Disability Payment is intended to be person-centred, taking into account the specific needs of each applicant. While the eligibility rules for Adult Disability Payment will remain largely the same as under Personal Independence Payment, the Scottish Government will make changes to both policy and administrative aspects of the delivery of Adult Disability Payment in order to provide disabled people in Scotland with a fundamentally different experience of accessing the social security system.

#### The Consultation

Following an earlier consultation on Disability Assistance in Scotland in 2019, draft regulations were prepared to support the new Adult Disability Payment and the Scottish Government ran an online public consultation to gather feedback prior to finalising the regulations. The consultation ran for 12 weeks, between 21 December 2020 and 15 March 2021, and attracted a strong response from a broad range of contributors.

A total of 127 consultation responses were received overall - 78 from individuals and 49 from organisations (including Disabled People's Organisations, Deaf People's Organisations, local authorities, third sector charities/groups and others). To support the online consultation, the Scottish Government also ran a series of stakeholder engagement events attended by a broad range of organisations and individuals with lived experience of disability. Feedback from these events was summarised by the Scottish Government for consideration alongside the main consultation data.

An independent analysis of findings from the consultation and engagement events was commissioned, and this report presents the main findings to emerge.

#### Main Findings in Support of the Draft Regulations

Overall, the proposed Adult Disability Payment was seen as a significant improvement on the existing Personal Independence Payment process, content and approach. The new payment was seen as being more accessible and to be designed in a way that would potentially reduce burdens, stress and anxiety on the most vulnerable disabled people, especially in relation to the process of application.

Aspects of the draft regulations that respondents particularly welcomed included that eligibility decisions would be informed by supporting information from professionals known to the applicant, and from friends and family. This was seen as particularly important for those with mental health disabilities and learning disabilities. The strengthening of rules around skills, experience and training of those involved in eligibility decision making was also welcomed, as well as the fact that existing data and information would be used to inform eligibility decisions. Respondents welcomed the idea of consultations forming part of the application process and the fact that these would be undertaken in a range of accessible formats with the voices of informal carers being heard. It was suggested that the regulations could, however, more clearly set out potential for including third sector organisations and people with lived experience directly in consultations.

Respondents welcomed that all awards would be made on a rolling basis, with no set date for an award ending. Indefinite awards were welcomed as potentially providing stability and financial certainty for applicants with degenerative conditions, or who have conditions that will not improve. It was felt that regulations linked to terminal illness would remove uncertainty in relation to eligibility and provide greater dignity for applicants.

The Motability scheme was considered by several organisations and individuals as a vital form of support for disabled people to allow them to enjoy independence. It was felt that continuity with existing provision was important, and respondents were reassured that no one should lose such provision as a result of the move from the Department for Work and Pensions to Social Security Scotland (although more detail on how this would work in practice may be welcomed).

While a few were happy to see the provision for the payment to be made to a welfare/financial guardian and direct to service providers in the case of Motability leases, others were concerned about the possibility for applicants to suffer financial abuse. It was considered important to have independent advocates and specialist advisors available throughout the application process to mitigate this risk.

The proposed introduction of 'Short-Term Assistance' was welcomed, to ensure individuals continue to receive their previous payment amount until the outcome of a re-determination or appeal has concluded. This was applauded as it removed the penalising effect of requesting their application be considered again when an individual believes their award to be inappropriate.

Most respondents welcomed the 42 calendar day time limit for clients to request a re-determination, and the 56 calendar day time frame for re-determinations to be carried out by Social Security Scotland. This, however, was one area where disagreement was noted in the consultation with some arguing that the time periods should be shortened and others arguing that they should be longer. All agreed, however, that there was a need to provide transparent timeframes for the period of re-determination requests, and to communicate this information in an accessible and inclusive way.

#### Main Concerns and Suggested Areas for Improvement

Despite largely positive feedback, a number of changes and improvements to the draft regulations were suggested ahead of roll out. The main frustrations expressed were linked to what respondents perceived to be insufficient change to the activities, descriptors and supporting eligibility criteria contained in the regulations, compared to existing Personal Independence Payment rules. Respondents expressed views that it was wrong to retain a reliance on the 20 metre rule (relating to the distance in metres an individual can walk to determine eligibility for the mobility component of Personal Independence Payment) and the 50% rule (relating to the proportion of time during which an individual satisfies a descriptor needing to amount to 50% of the days in a month). There was a strong desire for reverting to the 50 metre rule to make the system fairer/more realistic. Many individuals and organisations felt that these regulations should be amended from the outset of Adult Disability Payment. It was expressed that more nuanced measures of mobility and daily living indicators should be applied to better take account of a fuller range of conditions. Organisations, in particular, suggested that a system based on functional consideration of disability would be limited in its effectiveness, and felt that a rights based approach which was developed around the social model of disability would be preferable.

More general comments included that 'changing' or 'variable' conditions had not been given sufficient attention or thought within the regulations overall. Similarly, mental health conditions had been overlooked to a large degree, it was felt, with some of the complexities around capturing the impact mental health conditions have on daily life not being sufficiently well recognised or addressed.

Several respondents felt that there should be no 13 week qualifying period for the payment. Some also felt that 13 weeks was too long for applicants to be made to wait in general. This was especially true for those with severe and permanent disabilities/conditions, those that may incur significant costs over this time period as a result of their condition, and for conditions that can appear suddenly. It was argued that the 13 week qualifying criteria should be removed, with applicants instead being eligible as soon as they become disabled.

Another specific concern to emerge was that the 'past presence test', relating to the residency criteria, had been retained and was too rigid. Disappointment was expressed that the Scottish Government had not taken the opportunity to relax the past presence test or create further exceptions to it during drafting of the regulations.

Liability for overpayment made in error had also not been sufficiently well addressed, it was perceived, and more clarity was required in the regulations in this regard. Several respondents sought reassurances that individuals would be given sufficient notice and time to question the circumstances of any overpayment and that appropriate measures would be in place to ensure that no individual was financially disadvantaged through the recovery of overpayments.

A final recurring theme was that the new benefit may be too similar (especially around eligibility and determination) to the existing Personal Independence Payment, and there were concerns that opportunities had been missed to improve the system even further (and to move away from a points-based system). This included views that the proposed review of Adult Disability Payment may be too late and many suggested that the review be brought forward or that changes be made before implementation. In particular, reassurance was sought that no one would suffer a loss of eligibility as a result of transferring from benefits provided by the Department for Work and Pensions to Scottish Disability Assistance.

#### Feedback on the Consultation

While valuable feedback was gathered from the consultation which will be used to inform the redrafting and finalisation of the regulations, several organisations and individuals indicated that they had found the consultation to be inaccessible. Comments were made that the regulations were difficult to understand and contained too much jargon and that the consultation document was too complex and lengthy. This may have impacted on the quality and quantity of data generated, and this should be considered when interpreting the findings from the analysis.

#### **Conclusions**

While most respondents welcomed the majority of the proposed changes, there was some scepticism that sufficient change had been built into the regulations to accommodate a full range of disabilities and individuals' unique needs. There was, many felt, potential to design an even more nuanced approach which would reflect the social model of disability and be based on human rights principles. It was urged that this should happen, ideally before roll out of Adult Disability Payment, rather than during any review. Despite this, several respondents commended the Scottish Government on the level of consultation already undertaken and the inclusive manner in which the draft policy and regulations had been designed. There were calls for the Scottish Government to continue consultations with disabled people and relevant organisations throughout the planning, staff training and implementation of Adult Disability Payment, with several organisations offering support in this respect, to ensure that it runs smoothly.

# Introduction

### Background

Adult Disability Payment is a new Scottish benefit which will replace the existing Personal Independence Payment for people living in Scotland and will be delivered by Social Security Scotland (the 'agency'). This form of assistance will ordinarily be available for disabled individuals between the ages of 16 and state pension age to apply for, with entitlement arising prior to state pension age continuing beyond that age. It is intended to mitigate the additional costs of living with a disability or health condition.

In reflecting the Scottish Government's approach to social security, Adult Disability Payment is intended to be person-centred, taking into account the specific needs of each individual. It also aims to follow the principles of dignity, fairness and respect.

The eligibility rules for Adult Disability Payment will remain largely the same as under Personal Independence Payment in order to ensure a smooth and secure transition between the two. However, the Scottish Government will make changes to both the application and decision making processes linked to delivery of Adult Disability Payment in order to provide disabled people in Scotland with a fundamentally different experience of accessing the social security system.

#### The Consultation

Following an earlier consultation on Disability Assistance in Scotland in 2019<sup>1</sup>, draft regulations were prepared to support the new Adult Disability Payment. These provide detailed rules relating to Adult Disability Payment, including eligibility, what assistance is available, the value of the payment, and the making of applications and determinations.

The Scottish Government ran a public consultation to gather feedback on the draft regulations, and to identify any gaps, issues or unintended consequences. The consultation ran for 12 weeks, between 21 December 2020 and 15 March 2021, and asked 35 questions in total, broken down as follows:

- 15 questions were closed (i.e. invited yes/no/don't know responses); and
- 20 questions were open (i.e. invited a free text response).

In addition to the online consultation, the Scottish Government ran a series of stakeholder engagement events in order to maximise opportunities for disabled people and representative organisations to take part.

<sup>&</sup>lt;sup>1</sup> See: Disability assistance in Scotland: response to consultation - gov.scot (www.gov.scot)

## Methodology

The analysis and reporting of responses was carried out independently by a research team contracted by the Scottish Government.

All responses were logged into a database and screened to identify any campaign, blank, duplicate or non-valid responses (i.e. where responses were not relevant to the current consultation) - none were identified. Feedback was then analysed, and is presented under the appropriate sections below.

Closed question responses were quantified and the number of respondents who selected each response option is reported. Given the high number of 'non responses' to many of the consultation questions, both the raw percentage and the valid percentage are shown (i.e. the percentage of people who gave 'yes', 'no' and 'don't know' responses once the non-respondents had been removed).

Qualitative comments given at each question were read in their entirety and manually examined to identify the range of themes and issues discussed. Analysis was also conducted to identify any differences in views between respondent groups (i.e. between individuals and organisations, or between organisational sectors). Recurring themes that emerged throughout the consultation were recorded, and verbatim quotes were extracted in some cases to illustrate findings. Where there was strong consensus or where there were conflicting views, more than one quote was used to provide further illustration. Only extracts where the respondent consented for their response to be published were used.

## **Respondent Profiles**

A total of 127 consultation responses were received - 78 from individuals and 49 from organisations. In addition, a total of six stakeholder events were run by the Scottish Government, with one large, mixed stakeholder event including four separate breakout groups. Overall, nine event summaries were made available for analysis. In order to aid accessibility for individuals participating in consultation events, a shorter version of the main consultation document which asked fewer, more specific questions was provided and two participants provided written responses to these questions.

Breakdown of responses by affiliation

|               | Number of Responses | % of<br>Responses |
|---------------|---------------------|-------------------|
| Individuals   | 78                  | 57%               |
| Organisations | 49                  | 36%               |
| Events        | 9                   | 7%                |
| Total         | 136                 | 100%              |

Some of those who attended the events may have also provided written consultation responses and so some duplication in views can be expected.

Among the organisations that took part, there was a broad mix of Disabled People's Organisations, Deaf People's Organisations, third sector groups/charities and local authorities, among others.

It should be noted that several organisations undertook wider consultation with members in order to inform their consultation response. In some cases this involved surveys and webinars, while others collated feedback and comments and included this in their organisational response. As such, the true number of people who had contributed feedback to the consultation is unknown, but can be assumed to be higher than the number outlined above.

#### **Report Presentation and Caveats**

Findings are presented as they relate to each question in the consultation. Where individual respondents offered views at the open questions that differed from those submitted by organisations, or where views differed between the different organisational sectors, this was identified and outlined in the narrative of the report.

Some respondents opted not to answer closed questions, but did offer open-ended responses to the same question meaning that there was not always a direct correlation between the number of people who supported/did not support a particular statement and the number of people who gave a qualifying comment. For fullness, all responses were included in the analysis, even where the closed component of the question had not been answered.

While most respondents agreed with the Scottish Government proposals and provided supportive closed question responses, most of the open-ended comments that were provided came from people seeking greater clarification on specific regulations or people questioning the meaning, context and scope of specific draft regulations. The absence of positive open-ended comments provided by people who gave positive closed responses means that the detailed analysis presented below often appears 'negative' or presents a critical view of the draft regulations. To understand the balance of views, the closed and open responses must be considered with equal weight.

As a qualitative analysis exercise, responses to open questions were not quantified. As a guide, however, where reference is made in the report to 'few' respondents, this relates to five or less respondents. The term 'several' refers to more than five, but typically less than ten. Any views that were expressed by large numbers of respondents (i.e. ten or more) are highlighted throughout. It should be noted that, in all cases, less than half of respondents gave an open-ended comment to the questions and these were often very disparate. This means that the term 'several' often represents a relatively large proportion of the qualitative data generated for each question, even though the actual number of respondents is small. Any views expressed by only one respondent each are highlighted throughout.

Stakeholder event attendees were asked to comment on only some of the draft regulations, and more general prompt questions on themes raised in the consultation were asked instead of the consultation questions themselves. This means that event feedback is only available for some of the sections presented in the report, and is flagged where relevant.

For almost all of the substantive questions relating to different draft regulations, the same closed question was asked, i.e. "Do you agree the regulations reflect this policy intent?" Respondents were then invited to provide any additional comments to support their response. It should be noted that, at several places in the consultation, comments were made that this question was difficult to understand and some respondents were unsure exactly which regulations were being referred to at times. This meant that there were several instances of individuals and organisations providing a positive or supportive closed question response, but giving negative or caveated open-ended comments. Conversely, some people provided a negative or neutral closed response, but went on to provide positive supporting comments. While the tables that follow show the responses that were given, these should be interpreted with caution and should always be read alongside the wider context of the qualitative narrative.

Similarly, while the draft regulations were included as Annex C to the main consultation, some responses were vague in their nature and several were indicative that the regulations had not been read. Instead, responses were sometimes provided based on the summary information given in Annex B of the consultation document and therefore contained some misunderstanding or factual inaccuracies which affected the response given. Where such misunderstanding was evident, this is noted in the report.

In addition, several respondents gave answers to specific questions which would have been more relevant if given in response to other questions across the consultation, again often reflecting a misunderstanding of which part of the regulations were being referred to at each question. While qualitative data were extracted and moved in the reporting to ensure that it appears in the most appropriate place, some repetition of key themes raised at different questions does remain.

Throughout the consultation, respondents identified some specific anomalies within the draft Adult Disability Payment regulations (including typographical errors, inconsistency in wording, etc.) which they felt needed further consideration, editing or clarification. This feedback was collated and provided to the Scottish Government for consideration under separate coverage and is also attached as Appendix A.

Finally, the findings here reflect only the views of those who chose to respond to this consultation. It should be noted that respondents to a consultation are a self-selecting group. The findings should not, therefore, be considered as representative of the views of the wider population.

# **Outline of the Regulations**

### **Citation, Commencement and Interpretation**

Regulations 1 and 2 provide the formal citation for the regulations, set out when the regulations will come into force, as well as providing interpretations for the key terms used with reference to the new payment. Respondents were asked if the draft regulations, as written, met the policy intent of clearly explaining how the payment would be introduced and what key interpretations would apply.

More than three quarters of respondents who answered this question (77%) agreed that regulations 1 and 2, as currently drafted, would meet their policy intent. It is worth noting that, while only 10% of respondents said 'no', several of those who gave a positive or 'don't know' response went on to raise doubts about some aspects of the overall approach to these provisions in their qualitative comments.

|            | Number of<br>Respondents | % of Respondents | Valid % |
|------------|--------------------------|------------------|---------|
| Yes        | 77                       | 61%              | 77%     |
| No         | 10                       | 8%               | 10%     |
| Don't know | 13                       | 10%              | 13%     |
| Missing    | 27                       | 21%              | -       |
| Total      | 127                      | 100%             | 100%    |

The majority of respondents (both organisations and individuals) who provided additional comments to support their response generally commented that they found the proposed new payment to:

- be more accessible and be an overall improvement on the existing Personal Independence Payment system; and
- potentially reduce burdens, stress and anxiety on the most vulnerable disabled people, especially in relation to the process of application and determination.

Several who provided support overall did, however, suggest that there may be scope for even greater clarity around some of the key terminology used, to ensure that the regulations could be understood by all. One specific suggestion was for a single clear definition of 'Adult Disability Payment (ADP)', and another was for a clearer definition of 'determination' (i.e. as it refers to a determination of entitlement). An emerging theme throughout the consultation was that having a clear definition of Adult Disability Payment would help to set it more clearly apart from Personal Independence Payment and give it a unique identity.

There were mixed views regarding the notion of a 'pilot scheme' for the new payment. A few respondents indicated that they felt a 'pilot scheme' was a "bad idea", mainly on the basis that it would slow down the introduction of the new payment and leave some people on Personal Independence Payment for longer. Two others welcomed the pilot on the basis that it would provide essential pre-implementation learning, while another respondent indicated that they would have liked more information on what the pilot would entail, and what/who it would involve.

More general comments were provided that focussed on eligibility and lack of clarity around eligibility criteria (and are discussed elsewhere in the report), with the other main comments, including that:

- definitions of physical or mental function or disability within the regulations may be too vague, too simplistic and not accurately capture such things as hidden disabilities or fluctuating conditions in sufficient detail; and
- more detail on eligibility, determination and application of the payment to adults with mental health disabilities was needed (including the prospect of consultations being carried out by specially trained mental health workers).

Finally, several respondents picked up on the point that some aspects of the Personal Independence Payment framework would remain unchanged. This, they felt, was an oversight and left room for some of the existing confusion, ambiguities and weaknesses of the Personal Independence Payment system (especially the points-based eligibility criteria) to beset this new form of assistance:

"We would prefer to see a stated end point to the replacement of this reliance on the PIP [Personal Independence Payment] framework... The stated intent of the ethos of the Adult Disability Payment will be diluted by keeping a reliance on PIP [Personal Independence Payment]." (Health Organisation)

# **Disability Assistance for Working Age People Overview**

Regulation 3 provides that a client is entitled to Adult Disability Payment when they meet the following eligibility rules:

- the daily living component and/or the mobility component criteria;
- the required period condition;
- the residence and presence conditions; and
- the age criteria.

It also sets out the component parts of the payment and specifies the application requirements. Respondents were asked for views on whether the regulation, as specified, met its policy intent.

Again, the majority of respondents (76%) felt that regulation 3 was clear in its intent and agreed with the eligibility rules. Despite strong support, several qualitative comments were made that greater clarity was required in the regulations linked to

eligibility. Specifically, there were calls for some aspects of the regulations to be changed to be more flexible and to move away from what some perceived to be too rigid criteria which may not take account of constant changes to people's conditions and different impacts on their daily lives.

|            | Number of<br>Respondents | % of<br>Respondents | Valid % |
|------------|--------------------------|---------------------|---------|
| Yes        | 74                       | 58%                 | 76%     |
| No         | 9                        | 7%                  | 9%      |
| Don't know | 14                       | 11%                 | 15%     |
| Missing    | 30                       | 24%                 | -       |
| Total      | 127                      | 100%                | 100%    |

A key theme was that consultations must more accurately take into consideration the impact of a disability or condition on daily tasks/daily living. It was felt that a more flexible approach to understanding clients' daily living and mobility needs was required for those with significant mental health and cognitive disabilities. Similarly, it was felt that flexibility would be important for those with variability in function.

Other more general comments made to this question showed some confusion regarding the transition between Personal Independence Payment and Adult Disability Payment. This included concern that someone already awarded Personal Independence Payment would not qualify for Adult Disability Payment, that someone previously denied Personal Independence Payment and in the process of appeal may be ineligible to apply for the new Adult Disability Payment, and concern that 'light touch' reviews for over 65s would not continue to be honoured under the new payment. It was suggested that such issues could be clarified and strengthened in the regulations.

Some respondents focused on the age criteria, with specific concerns that there may be complications for those over retirement age receiving only Attendance Allowance with no mobility component (which was perceived as unfair), and concerns that the Scottish Government had not agreed to reinstate the Disability Living Allowance scheme for working-age people.

Some more general comments were made at this question regarding application forms. There were concerns among respondents that, even if redesigned under the new system, these may still be unsuitable and inaccessible for some adults. Views were also expressed that Social Security Scotland would need to ensure that suitable mechanisms were in place to allow everyone to make a fair and transparent application, and to be aided by the agency to do so. This may include a review of the questions asked, one suggested, to remove repetition and reduce burdens for applicants.

Overall, responses to this question indicated that a more 'person-centred' approach could be adopted and conveyed in the regulations in relation to eligibility criteria:

"Whilst the components of and eligibility for Adult Disability Payment are clearly stated here, again, it is at odds with the Scottish Government's specified aim of ensuring a more person-centred approach. A functional points-based eligibility system conflicts with the way many disabled people experience their disability and so inhibit and conflicts with the way they would opt to explain it." (Health Organisation)

The following chapter provides more detailed feedback in relation to specific eligibility and entitlement criteria.

# **Eligibility and Entitlement**

### **Daily Living Component and Mobility Component**

Regulations 4 and 5 set out the Daily Living Component and Mobility Component, and outline individuals' eligibility and entitlement to the standard and enhanced rates.

Around three quarters (76%) of the respondents that provided an answer agreed that the regulations related to the Daily Living Component and Mobility Component reflected the policy intent.

|            | Number of<br>Respondents | % of<br>Respondents | Valid % |
|------------|--------------------------|---------------------|---------|
| Yes        | 74                       | 59%                 | 76%     |
| No         | 12                       | 9%                  | 12%     |
| Don't know | 12                       | 9%                  | 12%     |
| Missing    | 29                       | 23%                 | -       |
| Total      | 127                      | 100%                | 100%    |

It should be noted that many comments made in response to this question related to the detail contained in Schedule 1, or were more relevant to other parts of the consultation. These comments are therefore presented elsewhere in the report, as appropriate. Also, many of the remaining respondents provided unique responses which were not repeated by others, making it difficult to identify a range of key themes and issues at this question. Typically, individuals discussed their personal circumstances and experiences under the Personal Independence Payment system, or outlined their preferences for how specific elements of the system should operate, rather than commenting on the regulations specifically.

Several respondents highlighted issues and problematic elements of Personal Independence Payment and associated assessments. While a few respondents appreciated the need for a smooth transition between reserved and devolved benefits, there was concern that this meant many of the issues related to eligibility would be transferred to the new system, and therefore would not represent a significant improvement:

"...the principles set out in Part 1 of the Social Security (Scotland) Act include that 'respect for the dignity of individuals is to be at the heart of the Scottish social security system'. We are concerned that ADP [Adult Disability Payment] continuing the current model of PIP [Personal Independence Payment], albeit with the proposed modifications, will not do enough to ensure the dignity of disabled

people in Scotland." (Organisation Representing Adults with Lived Experience)

"It is still a concern that the use of PIP [Personal Independence Payment] framework is being used despite the clear feedback that it violates dignity and compassion." (Individual)

As above, several respondents felt that the eligibility criteria were too narrow in their scope, both in terms of the daily activities covered, and because they did not adequately reflect the impact of certain conditions and the needs of such applicants.

Perhaps the main area of discontent was with the '20 metre rule', i.e. the distance in metres an individual can walk to determine eligibility for the mobility component of Personal Independence Payment. Some respondents suggested that this should be reconsidered or removed to make the eligibility criteria fairer and more inclusive:

"The 20-metre rule is an arbitrary distance measure that fails to recognise and capture fluctuation and hidden symptoms... Retaining the 20-metre rule contradicts the commitment to create a system that is underpinned by dignity, respect and a human rights-based approach." (Disabled People's Organisation)

More specifically, several individuals and organisations wanted to see the 20 metre mobility measure/walking test increased to 50 metres, in line with the previous Disability Living Allowance criteria. Others suggested that the 20 metre measure was a significant barrier for those with neurological conditions, mental health issues, learning disabilities, and fluctuating conditions:

"The retention of the 20 metre rule will have a substantial impact on disabled people with variable or fluctuating conditions - such as epilepsy or MS [Muscular Sclerosis]." (Disabled People's Organisation)

"For fair and inclusive support, the arbitrary mobility measurement of 20m must be removed from all criteria. The international, generally accepted standard of mobility impairment is measured at inability to walk 50m unaided or without pain. Scotland's new disability support must meet the same standards." (Individual)

The second main area of disagreement was with the '50% rule' (i.e. that an individual must be impacted by their condition on at least half the days in every month to qualify for Adult Disability Payment). A few organisations, stressed that they viewed this as inflexible. Instead, they supported a 'social model approach' to the impact of variable conditions on daily life rather than the medical/functional approach which was adopted under Personal Independence Payment and which was being proposed under Adult Disability Payment.

A few also sought clarity over how the impact of undertaking activities would be taken into account.

Ultimately, most respondents wanted a clear, easily understood and transparent system, which would not cause stress and anxiety to applicants. They also sought reassurance that no one would suffer a loss of eligibility as a result of the change-over from Personal Independence Payment to Adult Disability Payment.

## **Determination of Ability to Carry Out Activities**

Regulation 6 explains that the determination about a person's ability to carry out daily living or mobility activities will be considered with reference to any aid or appliance that the person could reasonably be expected to wear or use, regardless of whether they actually do or not. It also states that a person can carry out an activity if they can do so safely, to an acceptable standard, repeatedly, and within a reasonable time period. Regulations 7, 8 and 9 set out the scoring criteria for the determination (including scoring for daily living activities, mobility activities and further provisions). A series of descriptors relating to the distance in metres an individual can walk determine eligibility for the mobility component of the payment, with the enhanced rate provided to clients who are unable to walk more than 20 metres. The proportion of time during which an individual satisfies a descriptor must amount to 50% of the days in a month. Adult Disability Payment will consist of a daily living component and a mobility component and a person may be entitled to either component or both.

Over half (58%) of those respondents that provided an answer agreed that these regulations reflected the policy intent.

|            | Number of<br>Respondents | % of Respondents | Valid % |
|------------|--------------------------|------------------|---------|
| Yes        | 59                       | 46%              | 58%     |
| No         | 23                       | 18%              | 22%     |
| Don't know | 20                       | 16%              | 20%     |
| Missing    | 25                       | 20%              | -       |
| Total      | 127                      | 100%             | 100%    |

The main issue to generate qualitative comments at this question was the 50% rule, which respondents argued should be amended from the outset of Adult Disability Payment. Some felt this would not accurately take account of the nature or true impact of living with some conditions, for example epilepsy, Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (ME), Multiple Sclerosis, Rheumatoid Arthritis, neurological conditions, mental health conditions and other conditions which fluctuate in their occurrence and/or severity. It was noted that not all conditions have the same impacts day-to-day, and for others, environmental issues, such as the weather or amount of light available, can impact on their condition:

"Those who suffer less than 50% of the time should be included. This is extremely harsh and will leave many vulnerable people at risk." (Individual)

Similarly, it was noted that, while the physical or mental effects of some conditions may not impact applicants 100% of the time, they were unpredictable, and so individuals had to live with the risk, medication and lifestyle/social restrictions imposed by such conditions every day. As such, it was felt that the 50% rule might not be flexible enough to recognise and provide entitlement to people with variable conditions, but rather a broader and more holistic analysis of the applicant's circumstances would be required:

"[Our members] are concerned by the decision to retain the 50% rule... The rule is particularly concerning for disabled people with fluctuating conditions where it is difficult to predict when their condition will impact them. For example, if a person has a condition which affects them differently hour by hour over the day, day by day over the week, and week by week over the year, it may not be practicable to calculate the total number of hours in relation to each descriptor." (Disabled People's Organisation)

A few were also concerned that the use of strategies and aids should not be used as barriers to eligibility or incur penalties in the points-based system. It was felt that the regulations had failed to take account of unpredictable and variable conditions, and that these applicants would require the use of aids and/or support at all times and not just when the condition presented. Similarly, it was suggested that an individual's ability to carry out an activity should not be based on the individual's ability whilst wearing or using any aid or appliance which the individual normally wears or uses (since this may be discriminatory).

More specifically, for those with visual impairments, it was highlighted that assistive technology should be considered as supporting individuals to maintain a level of independence rather than penalising them for such use, and that considerations which determine mobility based on specific journeys using a cane, taxi or guide dog were unfair as they would face many other challenges and costs in other circumstances/environments/journeys:

"Use of strategies and aids to make an individual's environment safer and to manage their condition to an acceptable standard should not lead to them being penalised by being incorrectly deemed as not being at risk." (Disabled People's Organisation)

Other minority concerns discussed by just a few respondents each included that:

- terms such as 'minimal or fleeting' would need to be closely defined in order to avoid subjective determinations being made and to avoid ambiguity for applicants with variable conditions;
- some applicants find the reliability criteria to be confusing and unclear and so there was a need to make these easier to understand and more transparent.
   It was also felt that these needed to be made more inclusive and holistic;

- being able to conduct tasks 'safely' needed to take into account wider implications than just pain. For example, it was suggested that fatigue and other impacts could be felt as a result of undertaking a task and this needed to be recognised;
- being able to undertake a task 'to an acceptable standard', 'repeatedly', and 'within a reasonable time period' were again subjective. It was felt that these terms or measurements needed to be clarified, and perhaps be made in comparison to either what the applicant was able to do before they developed their condition, or in comparison to someone with no physical or mental health conditions; and
- in relation to undertaking a task 'safely, 'to an acceptable standard',
   'repeatedly', and 'within a reasonable time period', as well as the section on
   'Moving Around', it was suggested that these needed to be amended to be
   applicable for those with fluctuating conditions and mental health conditions
   so they take account of more than physical capability.

A few also suggested that this element of Adult Disability Payment felt very similar to the criteria, determinations and scoring used for the Personal Independence Payment, which were considered stressful for applicants and inappropriate for a number of different conditions as it relied on a 'medical model of disability'. It was felt that this was a missed opportunity to improve the system for the future:

"This sounds a lot like the degrading sort of tests required by the PIP [Personal Independence Payment] application assessments." (Individual)

## **The Qualifying Period Conditions**

Regulations 10-13 define the required period condition which must be satisfied to be eligible for each of the components of Adult Disability Payment. This includes outlining the relevant time period before and after the 'relevant date', which is typically the date of the application.

Around three quarters (74%) of respondents who provided an answer at the closed element of this question agreed that that these regulations met the policy aim.

|            | Number of<br>Respondents | % of Respondents | Valid % |
|------------|--------------------------|------------------|---------|
| Yes        | 72                       | 57%              | 74%     |
| No         | 12                       | 9%               | 12%     |
| Don't know | 14                       | 11%              | 14%     |
| Missing    | 29                       | 23%              | -       |
| Total      | 127                      | 100%             | 100%    |

For this question, a few respondents provided comments in support of the regulations, indicating that these mirrored the Personal Independence Payment system, and therefore provided transparency. It was also felt that the regulations would assist those whose condition improved then relapsed.

Respondents' main concern was that the 13 week period to be considered before the relevant date was not suitable for applicants with unpredictable and fluctuating conditions. It was felt that this time period may not represent the full impact or severity of their conditions. This was seen as particularly unsuitable for those newly diagnosed with epilepsy, where the frequency of seizures may be limited, but the impact on the individual's life would be significant and immediate. It was also argued that the fluctuating effects of mental health conditions were not well suited to this timescale measure. As such, it was felt that this 'blanket policy' should not apply to all conditions.

Some also felt that 13 weeks was too long for applicants to be made to wait, particularly those with severe and permanent disabilities/conditions, those that may incur significant costs over this time period as a result of their condition, and for conditions that can appear suddenly and have a dramatic impact on daily life (such as strokes and mental health problems). It was argued that the 13 week qualifying criteria should be removed with applicants eligible as soon as they become disabled. In addition, one organisation suggested that the qualifying criteria should only require that someone would be expected to have the condition for at least nine months, whilst another argued that the benefit should be backdated to when the person became disabled:

"If a person gets a condition or becomes disabled, why do they have to wait 13 weeks in every case, for some cases it will be very clear that the person will be entitled from day one, such as losing both legs in a car accident." (Individual)

A few were also uncertain of the inclusion of the 39 weeks post-application. One felt that it would be difficult for some applicants to foresee how/when their condition may occur or impact them over this future timescale. Another felt that those with shorter-term issues should also be eligible during their period of disability and recovery, or that this timescale could exclude eligibility for those expected to recover within this time period but who subsequently require longer. It was suggested that awards should be made based on the impact of a condition on the individual rather than timescale or number of instances within a set time period.

#### Residence and Presence Conditions

Regulations 14-21 set out the residence and presence requirements that must be satisfied for eligibility, along with the circumstances where exceptions would be made. Regulation 18 specifically covers further provision for serving members of Her Majesty's forces and their family members (although no specific feedback was received on this regulation).

Over three quarters (79%) of those who answered the question agreed that these regulations met the policy intent.

|            | Number of Respondents | % of<br>Respondents | Valid % |
|------------|-----------------------|---------------------|---------|
| Yes        | 72                    | 57%                 | 79%     |
| No         | 9                     | 7%                  | 10%     |
| Don't know | 10                    | 8%                  | 11%     |
| Missing    | 36                    | 28%                 | -       |
| Total      | 127                   | 100%                | 100%    |

Several respondents provided supportive comments, suggesting that the regulations would ensure the system was 'fair', would help stop fraud, provided flexibility to allow disabled applicants to take holidays, and provided key exemptions to the 'past presence test' for certain groups of applicants (such as for people with terminal illness, people awarded refugee status, and where someone can 'demonstrate a genuine and sufficient link to Scotland').

The main area which respondents commented on was the 'past presence test', i.e. which requires the individual to have been resident in Great Britain for 104 weeks in the last 156 weeks. Seven organisations, representing a broad range of interests, suggested that this be removed as it may be discriminatory and unfairly exclude some individuals. For example, concerns were raised over the impacts this would have on refugees, asylum seekers and other immigrants granted Discretionary Leave to Remain; those subject to immigration control who would have no recourse to public funds; international students; Scottish citizens returning from living abroad; those with dual nationalities; and newly resident disabled people. It was also suggested that those impacted by COVID-19 travel restrictions could be negatively impacted:

"...the test should be removed as it represents an unnecessary barrier to newly resident disabled people in Scotland accessing essential social security support." (Third Sector Organisation)

Respondents were unclear as to the purpose of requiring the individual to have been in Great Britain for 104 weeks in the last 156 weeks. Among the seven organisations that suggested it be removed, it was argued that the test was incompatible with the principles of dignity, fairness and respect; was inconsistent with eligibility criteria for other Scottish social security benefits; went against the principal that social security was a human right; and that such a rule had proven to be untenable in relation to the Human Rights Act 1998 for child applicants, and so would have a similar impact on adults:

"This unduly restricts people's rights to social security, and is inconsistent with other Scottish social security payments, which do not include this restriction. There does not appear to be any practical reason for this rule to be included." (Third Sector Organisation)

Rather, it was suggested that this aspect should be dropped and that no qualifying period for eligibility be required. A few suggested shorter time periods would be preferrable, with residency of 26 weeks (or six months) in the past 52 would be more acceptable. Alternatively, one organisation suggested that the 'habitual residence test' would provide a suitable alternative. It was felt that this would be sufficient to ensure that only those who have made their home in the UK would be entitled to apply, and exclude those who were only in the country temporarily.

### **Entitlement Under Special Rules Relating to Age**

Regulations 22-25 set out information in relation to eligibility and entitlement linked to age. Over three quarters (78%) of respondents that provided a response agreed that the regulations, as written, were clear and reflected the policy intent in this regard.

|            | Number of<br>Respondents | % of Respondents | Valid % |
|------------|--------------------------|------------------|---------|
| Yes        | 72                       | 57%              | 78%     |
| No         | 8                        | 6%               | 9%      |
| Don't know | 12                       | 9%               | 13%     |
| Missing    | 35                       | 28%              | -       |
| Total      | 127                      | 100%             | 100%    |

Among those who offered support, it was felt that the regulations were straightforward and would help adult applicants. The move to starting eligibility at age 16 was seen as sensible as it linked with guardianship/transition, as well as provided flexibility and choice for young people aged 16-18 where they could choose to remain on Child Disability Payment. Bringing the upper age limit in line with state pension age was also welcomed by some, while the ability to retain entitlement to the mobility component beyond state retirement was seen as a helpful safeguard against financial hardship:

"We welcome the proposal for people of retirement age to retain their entitlement to the Mobility Component of Adult Disability Payment. This will safeguard clients from a gap in support or loss of income at the point of retirement." (Disabled People's Organisation)

The main concerns were linked to the upper age limit. There was some misunderstanding that the regulations meant that Adult Disability Payment would cease when an applicant reached retirement age, that those who became disabled

after retirement age would not be eligible for support, or that those whose mobility worsened as a result of an existing degenerative condition would not be eligible for an uplift in their entitlement. Such misunderstanding may indicate a need for greater clarity of communications in this regard.

Further, it was suggested that, if applicants were expected to move to another benefit on retirement, this needed to be made clearer within the regulations:

"A disabled person should be entitled to the same level of financial support received prior to reaching State Pension Age, as after, or a transfer to another benefit without financial loss." (Individual)

"People may become disabled after reaching pension age, what protection is in place for them?" (Individual)

"In our view, it is discriminatory not to provide mobility support when an individual's mobility has deteriorated after they have reached state pension age." (Disabled People's Organisation)

Similarly, one respondent questioned whether the age based regulations would result in financial penalties for disabled people who chose to continue working beyond retirement age.

The system for progression from Child Disability Payment to Adult Disability Payment was also discussed by a few respondents. One suggested that a smooth transition system would be needed, while another felt that this should be an automatic transition in order to avoid stress and support the pursuit of higher/further education (or that the age of transition should be raised to 21 to avoid any impact on education). For young people living with a mental health condition, a suggestion was made that the Scottish Government should mitigate the potentially traumatic and stigmatising effects of transferring from Disability Living Allowance or Child Disability Payment to Adult Disability Payment at 16. To achieve this, it was suggested that either a single Disability Payment system for children and adults should be offered or that individuals should be allowed to decide the point at which they transfer their award within a longer time-frame (for example, between the ages of 16 and 21).

Again, a few respondents felt the regulations simply matched the existing system, which was not seen as a positive step. Similarly, several respondents had found this section and the eligibility criteria confusing, with a few noting it had been difficult to understand and contained too much jargon.

# **Entitlement Under Special Rules Related to Terminal Illness**

Regulation 26 outlines eligibility and entitlement criteria for applicants who are terminally ill and whose entitlement to Adult Disability Payment is still to be determined. It also outlines the requirements for the daily living and mobility component criteria that are dis-applied in such circumstances.

Of those who provided a response to the closed question, most (89%) agreed that the regulations reflected the policy intent.

|            | Number of Respondents | % of Respondents | Valid % |
|------------|-----------------------|------------------|---------|
| Yes        | 83                    | 65%              | 89%     |
| No         | 2                     | 2%               | 2%      |
| Don't know | 8                     | 6%               | 9%      |
| Missing    | 34                    | 27%              | -       |
| Total      | 127                   | 100%             | 100%    |

This was the most supported regulation and several supportive comments were made in relation to the regulations for terminal illness. In particular, these regulations were considered to be 'straightforward', 'easy to understand', 'reasonable' and 'welcomed'. It was felt they would create a smoother process for people with a terminal illness, remove ongoing uncertainty in relation to eligibility, would provide greater dignity for applicants, and create an 'improved and fairer system':

"This is a very positive and well needed change from the current system." (Disabled People's Organisation)

Specific areas of this regulation which were welcomed included:

- the revision/extension of the definition of 'terminal illness' to reflect clinical judgement rather than life expectancy/the removal of the six month time-limit for life expectancy;
- the consideration of replacing 'terminal illness' with 'life limiting condition' as this was felt to be more inclusive and would be consistent with terminology used within palliative care settings in Scotland;
- the use of healthcare professionals' own clinical judgement in determining eligibility and supporting a 'fast-track' application, and the extension of the definition of 'appropriate healthcare professional to include registered nurses;
- the 26 week 'backdating' of awards and the decision to pay both components at the higher rate without the need for any consultation; and
- there being no need for further clinical judgement when an applicant transitions from Child Disability Payment to Adult Disability Payment.

The only common concern, noted by a few respondents, was that the regulations made no reference to awards for those with terminal illnesses being life-long awards. It was felt this needed to be amended before the regulations were finalised so that life-long awards with no reviews were standard practice for such applicants.

Similarly, it was suggested that the regulations should more explicitly and clearly reference the Chief Medical Officer's guidance on terminal illness.

Other specific areas for concern, clarification or issues for further consideration, as noted by one respondent each, included:

- that legislation or regulations were needed to define 'terminal illness' in order to 'future-proof' Adult Disability Payment and protect the definition from future changes, and ultimately ensuring continuity for applicants;
- the need to put measures in place to avoid delays in the application and consultation process for terminally ill adults;
- disappointment that the 'backdating' of Adult Disability Payment would not be available where a patient had been symptomatic prior to confirmation of diagnosis/prognosis; and
- the potential to consider increasing the 28 day protection of Adult Disability Payment before, during and after residing in any facility like a hospital or hospice.

# **Variations**

## **Payability and Residency Variations**

Regulations 27-29 set out how time spent residing in certain accommodation (such as care homes or as a hospital in-patient) would impact Adult Disability Payments, as well as the related exclusionary criteria. Regulation 30 outlines the impact of legal detention on the payments. The period of residence in such accommodation (including clarification over the start and end date of residence), and the payment of Adult Disability Payment between two periods of residence is covered in Regulations 31-32.

While 63% agreed that the regulations reflected this policy intent, this was one of the least supported regulations.

|            | Number of<br>Respondents | % of<br>Respondents | Valid % |
|------------|--------------------------|---------------------|---------|
| Yes        | 58                       | 46%                 | 63%     |
| No         | 17                       | 13%                 | 18.5%   |
| Don't know | 17                       | 13%                 | 18.5%   |
| Missing    | 35                       | 28%                 | -       |
| Total      | 127                      | 100%                | 100%    |

Respondents were generally concerned over the loss of payments in particular situations or for particular groups. Several were concerned about the impact that these regulations would have on individuals that needed recurring stays in hospital, and/or that the loss of Adult Disability Payments after 28 days could lead to longer-term impacts on an applicant's wellbeing. Respondents noted that applicants will have existing financial commitments and continuing needs whilst in a hospital/care home/in custody, and which if not met during this time would have a detrimental impact upon being discharged. Examples included paying for accommodation, their car/Motability agreement, mobility equipment, household bills, maintenance of community based services, specialist clothing, dietary requirements, etc.:

"They may lose accommodation that they are paying for and have nowhere to go back to when they get out of hospital or care... People rely on a certain level of income and when it is taken away arbitrarily during what is sure to be a very stressful time, people suffer and it makes more stress." (Individual)

Two organisations were also concerned that the potential for Adult Disability Payment to cease could result in individuals being reluctant, or turning down certain specialist in-patient treatments for fear of the financial implications.

One organisation urged that any costs incurred by these groups should be met by the Scottish Government, if possible, i.e. Ministers should ensure that alternative financial support is available for patients in these circumstances. It was suggested that this could be done on a discretionary and locally-administered basis.

Other respondents were concerned about the welfare of specific groups who could face further isolation and other negative impacts where establishments are unable to meet the individual's needs. For example, it was suggested that care homes were typically unable to cater for deaf peoples' communication needs, and that additional support/costs would still be incurred:

"There are no care homes that cater for the needs of deaf people, nor specialise or have adequate training in deaf awareness or sign language proficiency." (Deaf People's Organisation)

A few respondents highlighted that not all care home residents are disabled or elderly. These respondents noted that some younger people require the accessible/supported living environment, but they continue to work and maintain a level of independence. There was concern that such individuals would lose access to Adult Disability Payment, their car, and their independence under these regulations. It was also noted by two disabled people's organisations that the care home test period was typically six weeks, therefore it seemed inappropriate that Adult Disability Payments could be stopped prior to this ending.

One organisation suggested that disability benefits should continue, or that there should be a smooth transition to another, more suitable means of support (with 'Self-Directed Support' suggested as an option) to help ensure that people are not left in financial difficulty or isolated due to a change of circumstance. Others felt that a more flexible approach was required generally, and more specifically to support those with Motability agreements, or that the time period needed to be significantly extended before payments were stopped.

Unintended consequences were also highlighted. One respondent suggested that the break in eligibility for Adult Disability Payment during a period in hospital/care home could negatively affect an unpaid carers eligibility for Carers Allowance. Other respondents felt that the stoppage of Adult Disability Payment would impact other family members/housemates by reducing overall household income. Family members may also continue to face the costs of providing certain products etc. for the applicant during their stay in hospital/a care home/prison.

It should be noted that some felt that the regulations were fair, provided the establishments were able to provide the necessary care - although a few expressed doubts over the extent to which this could be provided currently:

"As long as these residential establishments maintain the needs of the individual." (Individual)

# **Making of Applications and Payments**

Regulations 33-37 outline the weekly payment rates for Adult Disability Payment, including the standard and enhanced rates for both the daily living and mobility components. They also outline any deductions required as a result of people receiving the Constant Attendance Allowance. In addition, these regulations set out the rules around who can receive the payment, the date of application/when entitlement should be taken to begin, and defines the period covered by an application. They also detail the timing of the payments, and the need for continuing eligibility.

Most respondents (83%) who answered the closed element of the question agreed that these regulations reflected their policy intent.

|            | Number of<br>Respondents | % of Respondents | Valid % |
|------------|--------------------------|------------------|---------|
| Yes        | 82                       | 65%              | 83%     |
| No         | 8                        | 6%               | 8%      |
| Don't know | 9                        | 7%               | 9%      |
| Missing    | 28                       | 22%              | -       |
| Total      | 127                      | 100%             | 100%    |

Several elements of these regulations were welcomed, including that:

- the application was recognised and considered as actioned from the date it was received;
- where entitlement was expected to be met soon, the application would be actioned and not denied due to non-entitlement;
- there would be flexibility in decisions around when payments start;
- the proposal to pay those in receipt of Adult Disability Payment under the special rules for terminal illness was weekly in advance;
- there was a continuing eligibility clause and no set end date for payments;
- individuals would continue to receive payments during appeals or reconsiderations:
- there was an eight-week window for completion of the application form; and
- there would be a range of application channels including online, paper and face-to-face applications, as well as a local delivery service that would provide support and information to clients and stakeholders at a community level (although it was suggested that specific support for veterans could be

provided by mirroring the Department for Work and Pensions Armed Forces Champion Network).

However, several respondents were concerned about the four-weekly nature of the payments as it was felt this could make financial management more difficult for people. One suggested that monthly payments which fall on the same date each month would be more beneficial, while two suggested that fortnightly payments should be considered. Others were against weekly payments which were considered to be too insecure.

Some respondents felt that the payment rates were not high enough to cover the costs of living with a disability or health condition, or the costs of purchasing care services, with respondents suggesting that the rates needed to be increased. Two respondents also questioned why the rates had been reduced from those available via Personal Independence Payment. They noted the stated rates would represent a reduction of £52 or £78 per year for a person in receipt of the standard rate or enhanced rate of the daily living component. Others, however, highlighted the rates referenced were out of date and needed to be updated to the current Personal Independence Payment levels:

"The rates should reflect reality, not some arbitrary number that seems to have been pulled out of a hat." (Individual)

It was also noted that the rates would need to be subject to annual uplifts to account for the rising cost of living and inflation. However, one organisation suggested this may be difficult if the rates were included in the regulations rather than as a separate schedule. One organisation suggested an independent body/committee should be set up to recommend the level of payment that disability and other benefits should be set at in Scotland.

While a few were happy to see the provision for the payment to be made to a welfare/financial guardian and direct to service providers in the case of Motability leases, others were concerned about the possibility for applicants to suffer financial abuse. It was considered important to have independent advocates and specialist advisors throughout the application process to mitigate this risk. There was concern that the current provision of disability assistance carried an element of risk and that Adult Disability Payment regulations did not adequately mitigate this risk:

"I have seen time and time again, and acted as advocate on more than one occasion to assist young people take back control of their payment from family... In many cases children with good mental capacity are simply not aware the payment is theirs." (Individual)

A few also noted that significant delays were currently experienced in the processing of Personal Independence Payment applications with long gaps in achieving increased entitlements. It was hoped that this could be avoided under the new system.

Several respondents also discussed the issue of continuing eligibility, 'light touch' reviews, and the use of indefinite awards. A few sought further information about

how decisions of continuing eligibility would be made, details on what a 'light touch' review would involve, and commitments for Social Security Scotland to provide clear justifications for reducing awards following 'light touch' reviews. One organisation also suggested that there should be flexibility built in to 'light touch' reviews, so that these could happen earlier than the five-year review point where an applicant's condition had changed. Similarly, another sought clarity on how an applicant would be able to submit changes to the initial application at a later stage if their circumstances changed.

Indefinite awards would be welcomed, and were expected to provide stability and financial certainty for adults with degenerative conditions, or who have conditions that will not improve. It was also stressed that any indefinite/long-term awards already granted through Disability Living Allowance or Personal Independence Payment should be honoured when transferring to Adult Disability Payment, and that explicit confirmation of this would be welcomed from Social Security Scotland:

"There are blind and partially sighted people... who have no prospect of recovering their sight or of their visual impairment improving... We believe it is not appropriate or necessary for reviews to be undertaken at any point in such circumstances, and agree with a number of other organisations who have supported the case for life-long awards and the removal of reviews where the individual's condition will not change." (Disabled People's Organisation)

Indeed, several comments were provided throughout the consultation which stressed the importance of implementing long-term/life-long awards and 'light touch' review periods, and sought reassurances that these would be included in the regulations in order to protect such provision. This included making such provisions in general, as well as ensuring that 'light touch' reviews for those aged over 65 (as planned by the Department for Work and Pensions) would be mirrored in the Scottish system:

"We are disappointed that the draft regulations themselves don't include any reference to review periods of 5-10 years... We believe the draft regulations should be amended to include longer term reviews (5-10 years), so they are a matter of law. If this is not done any future administration could introduce shorter awards without any parliamentary process of scrutiny." (Third Sector Organisation)

Event attendees were separately asked for their views on reviews happening five to ten years after an award is made for those whose condition or disability is unlikely to change, as well as their views on whether people should get indefinite awards. For the most part, stakeholders felt that routine reviews would give applicants and their families/carers more stability knowing roughly when their review would take place. Five to ten years was seen as a reasonable time period to accommodate changing conditions - having a shorter review date may cause unnecessary concern and anxiety. It was expressed that more clarity could however be provided around opportunities for people to re-apply or have an earlier review, if their condition worsens quickly.

Like some of the consultation respondents, event delegates also felt that those with life-long conditions/disabilities should not be reviewed or reassessed (and should also not be subject to 'light touch' reviews), and that indefinite awards were appropriate in these cases.

Overall, the new payment was seen as a good opportunity to change the culture of reviews and to reflect them in a more positive light. Social Security Scotland should make clear that reviews are about supporting clients and ensuring that they are getting the highest award they can, it was felt, rather than trying to take their award away from them.

# **Practitioner Qualifications and Experience**

## Qualifications and experience necessary to carry out Assessments

Where a consultation is required in order to determine whether an individual is entitled to receive Adult Disability Payment, this must be carried out by a qualified practitioner. Regulation 38 sets out the requirement for practitioners to have been employed for a cumulative period of at least two years, in the direct provision to individuals of health care or social care services. It also sets out the specific experience required in cases that require consideration of the individual's mental health condition or conditions, and/or individual's learning disability or disabilities.

Just over two thirds (69%) of respondents who answered the question believed that the regulations relating to qualifications and experiences reflected the policy intent.

|            | Number of<br>Respondents | % of Respondents | Valid % |
|------------|--------------------------|------------------|---------|
| Yes        | 72                       | 57%              | 69%     |
| No         | 25                       | 20%              | 24%     |
| Don't know | 7                        | 5%               | 7%      |
| Missing    | 23                       | 18%              | -       |
| Total      | 127                      | 100%             | 100%    |

Many respondents considered the proposals to engage expert practitioners to be an improvement on current process but sought more detail in the regulations.

#### Removing negative experiences

Importantly, it was hoped this approach would reduce or remove negative experiences similar to those that had been experienced in the past, including practitioners being condescending; demeaning; insensitive; restricted by the Personal Independence Payment script; arranging unnecessary case reviews; informed by outdated research; failing to recognise the severity of the condition; or making incorrect rejection decisions.

Event stakeholders reported that existing examinations were often degrading and distressing. Assessors were described as being unsympathetic and stakeholders felt it was unfair that a stranger had the power to overrule what a doctor or other medical practitioner may decide. Views were expressed that, historically, examinations and assessments often made people feel that they were being judged or treated as being dishonest, with a perception that the process was designed to fail people or catch them out. Applicants often felt pressured to give 'correct' answers to what were often confusing questions, and the existing assessment

system was seen as particularly challenging for those with mental health conditions or disabilities.

It was suggested that individuals who were less articulate or less able to explain their health condition historically fared worse in their eligibility considerations, but it was felt that Adult Disability Payment had the potential to help alleviate this problem:

"We believe this has potential to radically improve both the quality of decisions on entitlement and the overall experience of the assessment process for people with mental health problems." (Third Sector Organisation)

#### Consultations more flexible and person-centred

Consultation respondents and event attendees welcomed the proposals for more flexible consultations as this was more in keeping with the principles of Social Security Scotland, was seen as more person-centred and holistic, allowing people to express themselves more freely than more formal formats allow.

An added benefit of consultations was that they could be carried out remotely (benefitting some of the most remote and isolated individuals), with telephone or virtual consultations also seen as preferable to face-to-face engagement by many (i.e. conducted on a setting that they are familiar and comfortable with). Remote or virtual consultations would also be more accessible for people living with certain types of disabilities and would reduce what people perceived was them being judged informally before the official determination had even begun. It was agreed that the option for in-person consultations should however always be offered, (especially for those who find telephone communication challenging) and retaining 'choice' was key.

One group of event attendees raised concerns that a 'consultation' was just another form of 'assessment' and that people would still have to explain and answer questions about their disability. Being questioned automatically makes people stressed and defensive, it was suggested, and a more suitable method would be to use supporting information so that a consultation did not have to take place at all.

Consideration was also given to the determination tools employed and the appropriateness of these. The challenge of assessing invisible symptoms was highlighted by a number of consultation respondents. The availability of appropriate tools was queried by individuals with autism diagnoses, one had been advised their autism was not severe enough to merit support, another was assessed by a physiotherapist that they believed had no knowledge of neurological development conditions. Additional examples were provided:

"While someone may be able to walk 20 metres the impact that walking that distance may have on an individual needs to be considered when a practitioner is assessing a claim." (Third Sector Organisation)

"I still feel concerned that conditions such as autism will be overlooked and denied if eligibility is based on physical capacity and limitations rather than social and emotional." (Disabled People's Organisation)

"The functional impact of sensory loss is often conducted by individuals that have no knowledge, experience or expertise in the area and failure to assess adequately is compounded by lack of attention to sensory loss in the diagnosis of other conditions (or misdiagnosis). Ideally the review will address these structural flaws." (Disabled People's Organisation)

#### Recognising the importance of expertise

When asked for views on whether health and social care practitioners should be able to undertake consultations, there was broad support. The proposal to have practitioners with expertise in specific areas was also welcomed by many consultation respondents and event attendees alike.

Importantly, respondents agreed that practitioners should have awareness of the condition they are assessing. All practitioners should not be expected to have indepth knowledge of every condition, and so consultation should be undertaken only by a relevant practitioner with an understanding of the condition being consulted on. It was suggested that this may require involving people with lived experience in carrying out consultations.

It was recommended by consultation respondents and event attendees that the professional with the most specialised knowledge of a patient's circumstances should be engaged, rather than a more general health professional, e.g. a psychiatrist for an in-patient in a psychiatric ward would be more appropriate than the patient's General Practitioner. It was also considered essential for practitioners to have a strong understanding of the varying impacts the condition can have on a person's engagement outwith their primary environment.

Although there was a general consensus that the move to consultations conducted by health and social care practitioners was a step in the right direction, several contributors expressed strong objections to being assessed by a social worker or by non-specialist nurses in future consultations.

It was also urged that the quality of engagement with practitioners needed to be consistent. There was some reported inconsistency in historical assessments, and respondents were keen that this should not be carried forward to a model that involves consultations.

Finally, there were some concerns around the impact on the health and social care sector or broadening scope for who could undertake consultations. It was suggested that this was particularly important to consider in a post-COVID-19 environment and policymakers needed to ensure that they did not put a heavy burden on the sector to provide supporting information for disabled people.

#### **Specific training**

Event attendees, like consultation respondents, stressed that appropriate training and education of those undertaking consultations was vital. A number of recommendations were made in relation to the skills and training practitioners should possess. In particular, this included themes of mental health; fluctuating and progressive conditions; disability law; stigma; dementia training; independent advocacy; Post Traumatic Stress Disorder; discrimination; equality and diversity; death, dying and bereavement; and social models of disability. In particular, it was felt that practitioners should receive training in appropriate communication. Having practitioners who are supportive, empathetic and compassionate would also help to build trust in the system. It was recommended that training also involve or be led by individuals with lived experience of disability, where possible.

#### **Duration of experience**

Despite welcoming the change overall, several respondents suggested the regulations could be more robust than currently proposed, specifically in relation to duration of experience. A number of respondents believed that the duration of experience should be greater than two years. One organisation suggested that this lack of professional experience may be detrimental when patients were less aware of their condition and treatment, as their condition could be misidentified. Concern was also expressed that the current wording implied that individuals from the health and social care sector with limited experience in disability could carry out consultations for Adult Disability Payment. It was recommended that the criteria be amended from 'cumulative' to 'continuous' or that there be a limit set on the period of time over which experience can be gained.

Indeed, a concern was raised by a number of responders about lack of transparency in the regulations about suitable training and expertise for individuals working in the care environment where formal qualifications may not be required:

"There is a considerable difference between a trained and qualified nurse or occupational therapist with 2 years' experience in their field and an unqualified, minimally trained social care assistant working for 2 years in a care home." (Disabled People's Organisation).

## **Experts through experience and third sector support**

Conversely, it was also suggested that 'experts through experience' should also be considered for this role rather than solely engaging health or social care professionals:

"Disabled people have had a mixed range of experience with health and social care professionals, not all of it positive, and we don't think that employing former health and social care staff necessarily guarantees a more understanding approach. Disabled people don't want a paternalistic 'carer's perspective', they want the perspective of other disabled people." (Third Sector Organisation) In addition, clarity was sought about the role of Disabled People's Organisations and Third Sector organisations in supporting applicants through the process:

"It is not clear within the text if [organisation] staff would be considered and included in decision making alongside statutory health and social care staff. We would hope that this could be included." (Disabled People's Organisation)

### Use of existing data and information

The use of existing data and information which already exists in the public sector to inform decisions was welcomed by consultation respondents and those attending stakeholder events alike.

Respondents welcomed the change to gather information from a broad range of sources, as well as accepting input from informal sources. It was suggested that this would help to shift the burden from the individual and allow those who knew them best to provide information on the real impact that their condition has on their abilities. It was felt that this would make the process less stressful for the applicant.

Some organisations did, however, seek clarity on how any data-sharing process would work and the point at which the applicant would give permission for this. Another organisation cautioned that it would be important for Social Security Scotland to consider health inequalities in access to primary care which may affect the quality and availability of information about the person.

### **Need for further change**

While regulation 38 was broadly welcomed, concerns were raised that reference to learning disability and mental health explicitly within the regulations had resulted in the introduction of discrimination. It was argued that other categories of conditions should be specifically identified for specialist input. Adding to this argument, concern was raised that input from specialists from a range of disability backgrounds was not apparent in the regulations, as currently written.

Organisations supporting individuals with mental health problems, autism, Muscular Sclerosis, epilepsy, deafness, Parkinson's, visual impairment, people with profound and multiple learning disabilities with the most complex care issues, military veterans and chronic fatigue syndrome highlighted that practitioners lacking an understanding of their lived experiences made the process particularly challenging:

"In their current form, the regulations set alongside the consultation document do not provide the clarity we believe is required on ensuring the right priority is given to specialist knowledge in making assessments with regard to visual impairment conditions." (Disabled People's Organisation)

Clarification was also sought about the allocation of a person's application to a practitioner in relation to their specific disability. In addition, a number of

respondents had concerns about co-morbid presentations, questioning if a practitioner would only be required to have expertise in one facet of their difficulty.

In addition, it was suggested that if medical documentation provides sufficient detail then applicants should be spared the emotional and intrusive experience of a face-to-face or physical consultations. The current risk of COVID-19 transmission was raised to reinforce the importance of avoiding additional unnecessary face-to-face contact.

Finally, the inclusion of a right to access independent advocacy for those undergoing face-to-face consultations for disability assistance was welcomed, although it was stressed that all applicants must be made aware of this right:

"It is still really important that people are able take someone with them for support such as an advocacy worker or trusted family member or friend. Some people need this support for practical and emotional reasons. The process and timescale has to allow for this to happen and to make arrangements." (Disabled People's Organisation)

One organisation also urged that a 'right to reply' should be offered on draft Adult Disability Payment consultation write-ups prior to an award being applied.

## **Determinations of Entitlement**

## **Entitlement without application**

Regulation 39 sets out that the Scottish Ministers must make a determination of an individual's entitlement to Adult Disability Payment, without receiving an application, after the end of the period specified (if any) in the individual's notice of determination under section 40 of the Social Security (Scotland) Act 2018.

Regulations 40-43 set out other situations requiring a determination without an application including determinations following under and over-payment errors. The timescales relating to when changes in entitlement take effect are also set out.

Overall, 72% of respondents believed that the regulations relating to entitlement without application reflected the policy intent, although comments made at this question were disparate.

|            | Number of<br>Respondents | % of Respondents | Valid % |
|------------|--------------------------|------------------|---------|
| Yes        | 69                       | 54%              | 72%     |
| No         | 11                       | 9%               | 12%     |
| Don't know | 15                       | 12%              | 16%     |
| Missing    | 32                       | 25%              | -       |
| Total      | 127                      | 100%             | 100%    |

### **Under and Overpayments**

Additional clarification was sought on the process of determination following overor under-payment made in error, including details about if this decision-making would be automatic. It was recommended that underpayments be backdated to the date of application rather than the date the error became apparent. Any overpayment sought by the Department for Work and Pensions should be undertaken in a fair and dignified way. It was recommended that a person be given considerable notice of a requirement to repay an overpayment made in error and clear information if their account was going to be automatically debited.

A number of respondents suggested that if the award had been made in error it was inappropriate and unethical for it to be necessary to repay these monies as this caused additional stress to people who already had considerable challenges to overcome and were at higher risk of experiencing material deprivation. The adoption of the new system was suggested by one organisation as an opportunity to regain and secure the trust of clients, as well as improve the public perception of the benefits system, by avoiding recovering overpayments made in error to the detriment of applicants.

### **Indefinite Awards and Changes in Condition**

Several respondents were keen for indefinite awards to be made in other circumstances to that outlined<sup>2</sup>. Related to this, it was recommended that indefinite awards should automatically be awarded to people with degenerative conditions without application. It was suggested that these circumstances relating to award without application should be incorporated into law to make it more difficult for future administrations to change the policy. Similarly, some organisations wished to see to see a policy of safeguarding awards of a suitable length fixed in law.

A few suggested that some flexibility may be needed to review awards for certain individuals who may have experienced reduced support as a result of the move from the Disability Living Allowance to the Personal Independence Payment. It was felt that some of the Personal Independence Payment assessments and awards were unfair, and that carrying this over to Adult Disability Payments was wrong.

More generally, it was felt that if an individual's condition was not going to improve over time, then the need for future reviews should be removed. It was suggested that in cases where an individual's condition had deteriorated, they should be able to seek additional support and there should be an obligation for the agency to engage with this request and make a fresh determination:

"Rolling 5-year light touch is okay for conditions that may improve but a waste of time, money and stress regarding those with a deteriorating condition." (Disabled People's Organisation)

"Lifetime awards need to be reinstated and stop the stress, anxiety and burden on all involved; from the individual to the GP [General Practitioner] and person looking through the application." (Disabled People's Organisation)

Although it was considered appropriate to report changes in circumstance, it was suggested that an adaptation should be made to the 28-day rule. It was believed that this timeframe could unduly disadvantage individuals in relation to specialised treatment. There was also concern that to be eligible for enhanced rates from the day a person's condition deteriorated, an individual would need to report this within four weeks, and it was believed this did not give fair consideration to fluctuating conditions:

"This is a relatively small timeframe, in which individuals who experience a deterioration may want to 'wait out' as it may be perceived and hoped by them as an increasingly difficult period that will return to normal levels. If this however were not the case and their condition did not return to said normal levels, individuals would be unfairly penalised by only being awarded the enhanced rate of

<sup>&</sup>lt;sup>2</sup> There was no evidence of support for only people on the highest rate of Adult Disability Payment to get an indefinite award.

payment from the day they reported the change if this was outside the specified four weeks." (Disabled People's Organisation)

It was recommended that clearer rules should be introduced to protect people who may not have realised that a gradual change has affected their eligibility, and that recovery of overpayment was not sought in such cases. It was felt that support from Social Security Scotland and other agencies was likely to be required to help an individual consider whether their condition has changed such that their level of award might be affected.

Finally, it was suggested that people should be able to appeal an entitlement decision without concern that they may lose the current entitlement decision. Fear of losing any entitlement may make individuals reluctant to engage with the review process, it was suggested.

## **Re-determination requests**

Regulation 44 outlines the periods in respect of a re-determination request. Periods in respect of a re-determination request and reviews are outlined as 42 days and 56 day respectively.

Overall, 77% of respondents believed that the regulations relating to redetermination requests reflected their policy intent.

|            | Number of Respondents | % of Respondents | Valid % |
|------------|-----------------------|------------------|---------|
| Yes        | 71                    | 56%              | 77%     |
| No         | 10                    | 8%               | 11%     |
| Don't know | 11                    | 9%               | 12%     |
| Missing    | 35                    | 27%              | -       |
| Total      | 127                   | 100%             | 100%    |

Many respondents indicated that it was helpful to provide transparent timeframes. A number of organisations, in particular, highlighted that the timescales proposed were an improvement from the Personal Independence Payment arrangements. Importantly, the availability of a clear timeframe for Social Security Scotland to respond to re-determination requests would provide clarity to advice agencies about when their clients/service users may need support to go to appeal. It was also suggested that it would be useful for advice agencies to have a direct helpline or email access to Social Security Scotland in order to establish their client's current position or find out additional information in relation to re-determinations and appeals.

Some respondents considered the 42 days for requests to be submitted as appropriate given the array of tasks that needed to be completed and the potential risk in postal delays:

"The regulations, with the proposed time limit of 42 days for requesting a re-determination of entitlement, reflect the different challenges and circumstances which will be unique to each individual undertaking this process. Many disabled people will require significant time to gather relevant information and access support and advice. We believe that the regulations take this into account." (Organisation, Disabled People's Organisation)

In contrast, some indicated that the proposed time periods may be excessively long, particularly if people were left without the help and assistance they require. It was highlighted by one individual that support, as previously awarded, should be paid for the period of time waiting for re-determination as payment in arrears is insufficient to prevent hardship in the interim period.

Flexibility in the proposed permitted period for re-determination requests was considered important by many of the respondents, who purported that gathering necessary information to support the re-determination may require a longer period of time. A number of situations which raised concerns with this cut-off period if there was no option for the initial period to be extended, included if:

- someone was reliant on an interpreter who they may not be able to engage with immediately;
- someone was facing difficult personal circumstances;
- someone's condition had deteriorated; and
- someone was experiencing a flare-up in their condition.

While most accepted that 56 days was fair to make a re-determination of entitlement, one organisation questioned whether 56 days was a realistic timescale for a response from Social Security Scotland and one individual with lived experience also queried this timeframe (and associated impacts):

"56 days is far too long to wait for a re-determination of entitlement. When I had to switch from DLA [Disability Living Allowance] to PIP [Personal Independence Payment] the process took a year...That year nearly killed me, and the stress of how long everything took played a large part in that. I think the whole process has to become a lot more efficient and take a lot less time." (Individual)

Although applicants required flexibility to collate further information it was not felt that those engaged to undertake the re-determination should require eight weeks as this delay could significantly impact on people's lives. It was highlighted that waiting for re-determination was incredibly stressful for clients.

The proposed introduction of 'Short-Term Assistance' was welcomed, to ensure individuals continue to receive their previous payment amount until the outcome of

a re-determination has concluded. This was applauded as it removed the penalising effect of requesting a re-determination when an individual believes their award to be inappropriate.

Disappointment was, however, expressed that no prescribed period has been proposed for the initial determination to be made when clients first make an application. For many disabled people, particularly those who have had a life-changing event or diagnosis, it was suggested that a predictable timeframe would be extremely helpful.

A number of respondents highlighted that they were confused by this area of the consultation and the regulations (e.g. not understanding the difference between the two timeframes and finding the content contradictory). It was also recommended that the language used in any redrafting be as transparent as possible, for example, when referring to 'days' is this 'working days' or all days of the week:

"What is not clear is that the award will continue until that redetermination is completed to ensure there is no gap in payment. Regulation 26 seems to provide for this but is far from clear. To give people confidence that they will not be left without money, very clear information and guidance will be required." (Third Sector Organisation)

It was highlighted that the period of re-determination requests needs to be communicated in a variety of accessible channels using formats that incorporate the principles of inclusive communication. In addition, it was stated that all information to clients must include accessible methods of communication to empower clients to contact Social Security Scotland independently.

Transparency of processing was also suggested as key during the re-determination stage. Adherence to published timescales was considered critical to avoid added stress or disappointment to applicants. One organisation suggested that, if Social Security Scotland were unlikely to consistently adhere to the proposed timescale, a longer time-frame for turnaround should be published to ensure that clients could be assured of a decision by the end of the cut-off period. Linked to this, concern was raised that there was no accountability in relation to adhering to timeframes. There appeared to be limited awareness of existing reporting requirements, as it was recommended that legislation be introduced requiring timescales and reports to be provided to parliament detailing why and how timeframes are or are not met.

Finally, it was suggested by one individual that Social Security Scotland may have concerns about people trying to use the system illegally. In these circumstances it was recommended that the award should be withheld until an investigation is carried out rather than a low award being made which could then be reduced further following re-determination.

### **Provision of Vehicles**

Regulation 45 sets out the mechanisms for the provision of vehicles and other equipment (such as accessible cars, scooters and powered wheelchairs) linked to the Motability scheme, which will help to meet the mobility needs of eligible individuals.

Most respondents (85%) who provided a response to the closed question, agreed that the regulations reflected the policy intent and this was one of the most widely supported regulations.

|            | Number of<br>Respondents | % of<br>Respondents | Valid % |
|------------|--------------------------|---------------------|---------|
| Yes        | 75                       | 59%                 | 85%     |
| No         | 2                        | 1%                  | 2%      |
| Don't know | 11                       | 9%                  | 13%     |
| Missing    | 39                       | 31%                 | -       |
| Total      | 127                      | 100%                | 100%    |

The Motability scheme was considered by several organisations and individuals as a vital form of support for disabled people to allow them to enjoy independence. It was felt that continuity with existing provision would be important, with some respondents reassured that no one should lose such provision as a result of the move from the Department for Work and Pensions to Social Security Scotland management.

A few, however, felt that greater clarity was needed in relation to the management and mechanics of this provision. In particular, respondents were keen to know which organisation(s) would deliver the scheme, where garages/suppliers would be located, whether standard cars would be included or only 'accessible' or 'adapted' cars, what the insurance arrangements and excesses would be, and if payments could be made to adapt applicants' standard cars rather than purchasing new adapted ones.

A few respondents suggested that the payments made to suppliers should stipulate the vehicle should be suitably adapted to the individual's needs, without the need for the applicant to make 'top-up payments' for this.

Similar to responses at earlier questions, the 20 metre walking rule was discussed, and in particular how this would impact an applicant's eligibility for the mobility component and access to a vehicle/equipment and the liability to the vehicle provider. Similarly, the 28 days in hospital or care home setting rule was again mentioned, and queries over how the liability to the vehicle provider would be managed when Adult Disability Payments were suspended:

"By retaining the 20-metre rule, this means that if a person can walk one step over 20 metres, they will not receive the higher rate of the mobility component and will lose out on vital financial support and access to the Motability scheme." (Organisation, Disabled People's Organisation)

Other aspects mentioned by one respondent each included:

- a desire to see protections for clients so that they have a set period to try out the vehicle and return it if it was not suitable;
- a preference that the scheme should not be means tested and that no deposit should be required for vehicles/equipment;
- a preference for vehicles to be provided separately to financial support;
- that competition in suppliers was welcomed, although another suggested that the current UK supplier should continue delivery of this in Scotland;
- that the current enhanced mobility payments did not cover a car and an electric wheelchair, and some applicants may need both;
- a desire to extend and promote the National Entitlement Card to enable applicants on the standard rate of Adult Disability Payment to access free public transport; and
- a desire to ensure profits from the scheme can be reinvested to benefit disabled people, for example via reductions in the cost of Motability vehicles, assistance to those losing entitlement to Enhanced Mobility payments upon transferring from Disability Living Allowance to Personal Independence Payment, and investment in/grants to accessible community transport initiatives.

## **Liability for Overpayment**

Regulations 46 and 47 outline arrangements relating to liability for assistance given in error and arrangements to recover overpayments. In addition, factors influencing the determination to affect a deduction decision are outlined.

In total, 65% of respondents believed that the regulations relating to liability for overpayment reflected the policy intent.

|            | Number of Respondents | % of Respondents | Valid % |
|------------|-----------------------|------------------|---------|
| Yes        | 59                    | 47%              | 65%     |
| No         | 12                    | 9%               | 13%     |
| Don't know | 20                    | 16%              | 22%     |
| Missing    | 36                    | 28%              | -       |
| Total      | 127                   | 100%             | 100%    |

A few respondents were satisfied with the arrangements proposed and felt that adequate flexibility was outlined, with a person-centred approach being the driver, to address any concerns relating to repayments:

"We note that the key element here is that reasonable reductions will be made with the individual's agreement, and therefore the individual's financial circumstances are being taken into account." (Local Authority)

A greater number of respondents, however, indicated that they found these regulations difficult to comprehend and were confused by the message being given:

"I'm still in the dark regards how the government will compensate a claimant for underpayments or compensate themselves for overpayments." (Individual)

Considerable concern was raised about people being obliged to pay back money given to them in error. Recovering these overpayments was considered to be ethically wrong and likely to further disadvantage disabled people:

"The Scottish Government has stated a desire to reform aspects of current social security delivery which 'cause stress, anxiety and pain' for disabled people. If it is to meet that ambition, the Scottish Government must put in place stronger regulations with regards to liability for overpayment and liability for assistance given in error... Many disabled people face high living costs, insecure employment and fluctuating income levels. This is perhaps reflected in the overwhelming support (87%), within the Scottish Government's Consultation on Disability Assistance in Scotland, for the proposal that Short-Term Assistance should not be recoverable." (Disabled People's Organisation)

A number of respondents highlighted that disabled people were potentially already more likely to be living in poverty and to be vulnerable. Being required to repay erroneous payments was therefore likely to increase financial hardship. Particular concern related to overpayments being recovered even when an official from Social Security Scotland had made the mistake, as it was believed that this was completely inappropriate. Further disappointment was expressed that there was no provision for discretion not to recover, particularly in a situation where official errors were made. It was suggested that if the applicant had completed the process appropriately and the agency had made the error then overpayment should not be recovered:

"If an individual has given all the information asked for or informed of any changes and an error still takes place, they should not be held liable to repay any monies. Official error or bad advice from the Social Security Agency should not result in recoverable overpayments." (Health Organisation) "The regulations allow the government to recoup the overpayment. This is the case even when the overpayment is through no fault of the disabled person and caused by an error from the government. Due to the risk of creating financial hardship for an already disadvantaged group, over payments should not be reclaimed when the disabled person was not at fault." (Third Sector Organisation)

One organisation recommended that a specific entry in the legislation should be added to account for departmental error and to ease people's concerns. Several others stressed that it was appropriate for legislation related to repayments to be updated to ensure protection of disabled individuals in line with the Social Security Administration Act 1992.

Clarification was also sought about how a 'reasonable level' of repayment instalments would be determined, particularly since Adult Disability Payment is not means tested:

"...an explanation of how a "reasonable level" will be assessed in respect of a claimant's ability to repay an overpayment is needed - we would like to see income and expenditure both being considered as income alone is not an indicator of affordability. Further clarification on whether income from other benefit payments and/or salaries etc., will be considered is needed and reflections on the appropriateness of this given that Adult Disability Payment is not means tested." (Disabled People's Organisation)

One organisation also expressed that there may be value in the Scottish Government setting out a framework for recovery rates:

"We acknowledge that it may not be appropriate to include such a framework in regulations, although the requirement for such a framework could be included. It may also provide comfort and certainty to claimants if a maximum recovery rate is set in regulations...There should also be an obligation on Scottish Ministers to provide individuals with a period of notice prior to making direct deductions from awards." (Public Organisation)

This same organisation, suggested that a further framework, the need for which could also be provided for in regulations, should set out what is and is not reasonable in terms of consent and would help to provide the necessary clarity.

Few respondents considered it appropriate that overpayments should be returned. In such cases, respondents emphasised that if repayment was necessary this should be arranged in small, manageable instalments, with a proviso that the repayments should not be so onerous as to affect the individual from being able to manage the costs of daily life. Importantly, it was considered important to provide individuals with sufficient time to make repayments.

## **Other Comments**

### Feedback in relation to Schedule 1

Schedule 1 provides tables detailing the activities, descriptors and scores to be allocated for each of the Daily Living Activities and Mobility Activities for Adult Disability Payment. These were drawn from the activities and scores allocated for Personal Independence Payment, but contain changes to reflect significant developments in case law which affected how the criteria was applied for Personal Independence Payment.

A few respondents provided positive/supportive comments in relation to Schedule 1. They welcomed that the descriptors had been updated to reflect case law, or welcomed specific changes that had been made, e.g. that the mobility descriptor 'Planning and following journeys' would take into account the presence of another person.

While the information in Schedule 1 was 'as expected' for some respondents, the fact that this matched or was closely aligned to descriptors and scoring used for the Personal Independence Payment system was not always welcomed. Indeed, a few respondents expressed disappointment that the Personal Independence Payment descriptors had been retained and felt that nothing had really changed:

"Nothing has really changed for the better here at all. Variable conditions are being nodded at, but not really understood or accommodated." (Individual)

"That there are no significant changes to the activities, descriptors and supporting eligibility criteria was felt to be a missed opportunity to significantly improve the support provided to disabled people." (Disabled People's Organisation)

In particular, there was disagreement with the application of the 50% rule and 20 metre walking test (consistent with earlier questions). The 20 metre walking rule was also said to lack any foundation and was argued to be a largely discredited measure. As such, there was disappointment that this would be retained by the Scottish Government. Concern was also raised that some of the justifications given for not changing this rule in the draft regulations may simply be repeated again during the proposed review, thus constraining the opportunity for any radical change in approach in the future:

"[We] disagree with the application of the 50% rule and 20 metre walking test. Though disabled people understand the need for a safe and secure transition they also believe that these rules unfairly penalise disabled people and deprive them of benefits to which they should be entitled." (Disabled People's Organisation)

"We are genuinely surprised that the 20 metre rule has been retained despite widespread awareness of its adverse impacts on

disabled benefit claimants, and for example this was not increased to the 50 metres that exists within DLA [Disability Living Allowance] and ESA [Employment and Support Allowance]." (Third Sector Organisation)

One organisation also argued that it was difficult for applicants to focus on tasks they could not do, and to try to quantify the impact of their condition. A common theme throughout the consultation responses was that this had a negative impact on individuals' mental health:

"Many of our members commented upon the difficulties of trying to assess and quantify the impact of their condition or impairment on their ability to carry out daily living activities when this can be unpredictable, variable and when to focus on "your worst days" is so dispiriting." (Disabled People's Organisation)

It was suggested that the descriptors (both for daily living and mobility) were not flexible enough for different people and different conditions. In particular, it was felt that there was a lack of recognition for some conditions, and that the descriptors generally did not fit well with some conditions, e.g. Muscular Sclerosis, epilepsy, and other fluctuating conditions; autism; hidden disabilities; sensory impairments (other than sight and hearing loss); learning disabilities; and mental health conditions. It was suggested that the descriptors and scoring needed to be revised to take account of these conditions, or that a more flexible and person-centred approach needed to be taken:

"The scoring system does not work, each case should be individually looked at, not determined by a "general" scoring criteria." (Individual)

The mobility descriptors were flagged as being particularly unfair for people with mental health conditions, with respondents often focusing on the "Planning and Following a Journey". There was concern that the criteria for going out/making journeys explicitly excluded impacts arising from psychological difficulties. It was noted that, while some applicants could manage some journeys, others would be impossible or would generate negative effects, such as panic attacks, feeling trapped, low motivation, etc. It was expressed that those experiencing difficulties with mobility due to mental health issues may score unfairly low compared to those with physical disabilities, based on the draft version of Schedule 1.

Some respondents believed there were still gaps in the draft legislation and that they had not fully taken account of recent case law. The main issue discussed by several respondents related to the use of the term "for reasons other than psychological distress" at Mobility Activity 1, Descriptors c, d and f. It was noted that this was the same wording used in an attempted amendment to Personal Independence Payment mobility regulations, but which was subsequently declared unlawful and discriminatory as it treated people with mental health problems less favourably than people with physical health problems. It was stressed that the wording needed to be changed to reflect this.

Many other areas were also identified, some as requiring further consideration and others which were considered not to meet current case law (see Appendix A).

In addition, several respondents raised more general concerns, including:

- the scoring of some aspects, and in particular that only one point was awarded for needing assistance to take or manage medication. It was noted that this was more restrictive than Personal Independence Payment;
- the impact on variable conditions needed to be further considered and incorporated including that undertaking the activities may be possible but the wider impact on the person needed to be considered;
- that there was not sufficient description provided for what each part meant;
- that often the reliability test was ignored in assessments and scoring under the Department for Work and Pensions system; and
- there was a need for the system to allow for updates and changes in conditions.

Again, a few respondents discussed difficulty in accessing Schedule 1. A few noted that they had been unable to find it as part of the consultation, while one had found it very difficult to understand:

"I'm disabled and completing this on my own and I found this quite difficult to understand and required a lot of re-reading, because it was not provided with adequate descriptor appendix." (Individual)

### Feedback in relation to Schedule 2

Schedule 2 defines the persons who are excluded from the definition of Members of Her Majesty's forces, for the purposes of the regulations.

While a few respondents agreed that these exclusions were straightforward and fair, a few others felt there should be no exclusions, and that eligibility should be based purely on a person's condition or disability:

"If a citizen, regardless of job, is in a situation where they have a need for disability it should be awarded." (Individual)

Other comments made by one respondent each included:

- a preference that payments for current and former armed forces personnel should not be less than they would receive if they were civilians;
- a query over whether there was capacity for an individual who has been denied assistance from Her Majesty's Armed Forces health and disability care provision to then be able to apply to Adult Disability Payment; and
- agreement that relatives of serving members of Her Majesty's Forces should be able to apply.

Comments were made elsewhere in the consultation that there needed to be more clarity about the transfer from legacy benefits to Adult Disability Payment within the regulations (including, for example, Armed Forces Compensation Scheme (AFCS), the War Disablement Pension Scheme (WPS) associated allowances, War Pensioners' Mobility Supplement (WPMS) and Constant Attendance Allowance (CAA)).

## **Proposed Review**

In order to address any emerging concerns with the existing framework, a substantial independent review of Adult Disability Payment is intended, a year after it is rolled out nationwide. Details of the review were included in the consultation and views on it were sought.

Many who provided a response to this question welcomed the idea of a review in principle and supported its aims to improve and enhance the benefit to maximise effectiveness, impact and reach. Several also welcomed that the independent report and recommendations from the review would be available for public scrutiny. This would help to build trust in the system, it was felt. Similarly, event participants welcomed the proposal to undertake the review, which it was stated was also recommended in the Scottish Campaign on Rights to Social Security published in 2020.

While broadly supported, views were put forward that the review may be timed too distantly in the future, and should be carried out either before implementation or as soon as possible, and be done at a pace:

"We welcome the proposed review of Adult Disability Payment and believe this will be an essential component of the transition process and will ensure Scotland's social security system upholds the vision of dignity, fairness and respect. However, we feel it necessary to recommend that this must be done at pace. We recommend a schedule be published, outlining a 12-month period whereby the review is conducted, recommendations are made, and changes start to be implemented. This must be done at in a timely manner to ensure the scars of DWP [the Department for Work and Pensions] are not further deepened." (Disabled People's Organisation)

One respondent suggested a rolling review rather than a single review which takes place after 12 months (which they felt was too long after implementation), and another suggested that the review could be run in parallel with the rollout. A more general comment was made that there should be robust and clear mechanisms for feedback once the new payment is rolled out, and the regulations and any associated guidelines must be 'living documents' that the government should have a willingness to monitor and amend, as appropriate. Another organisation suggested that the review be supported by substantial data collection around the first year of operation of the benefit, as well as wider research within Scotland to understand the needs of the population in relation to disability assistance.

Another emerging theme from both consultation responses and the events was the centrality of including people with lived experience in the review process. Stakeholders were keen that the review should be wide ranging, and that service users and organisations who support service users should be involved (to reflect the population that Adult Disability Payment is serving). Importantly, 'securing input' to the review from people with lived experience was seen as not enough and the review group should include people with lived experience as integral members (to promote democratic participation by disabled people and their carers). There should also be provision for applicants to voice any emerging issues to the independent review panel, it was suggested.

Event attendees also questioned how experience panels would fit in with reviews. Overall, it was felt that involving disabled people in the co-production of future guidance and administrative changes should help make the new payment human-rights based and appropriately focused.

Other emerging themes (from the consultation responses and events) included that:

- the review must be independent of government;
- the timing of the review would need to be well thought out to ensure that the new payment had sufficient time to bed in and for people to have sufficient experience of the new payment to be able to provide meaningful feedback;
- the review should be comprehensive and have an all-encompassing remit
  which explores every aspect of the benefit (from who is accessing it, who is
  missing out, the financial needs of those applying), including adequacy,
  purpose, relationship to wider UK and Scottish social security systems, and
  retention of a points-based system or alternatives;
- that the Scottish Government should inaugurate a wholescale review of Adult Disability Payment, most importantly of all the aspects of the consultation and application process inherited from Personal Independence Payment, as soon as possible after transferring all clients to Adult Disability Payment;
- that the terms of reference of the proposed review should include an explicit consideration of Adult Disability Payment's compliance with the accessibility and adequacy elements of the right to social security; and
- that the review (and commitment to ongoing review) be explicitly written into the regulations:

"We hope that the scope of the review goes beyond the impact of the regulations, important as their operation in practice will be, but will also consider how the new, more accessible approach to applications which is being planned has worked in practice, consider any challenges there have been in the new system, where further improvements can be made, and new policy developments which should be considered." (Disabled People's Organisation) Importantly, as emphasised by one group of event attendees, the review must be undertaken in an accessible way and over a period of time to ensure that there is sufficient time to gather people's views.

A specific request was made to see "greater accountability" for the Ministerial commitment to review Adult Disability Payment in 2023, since this was a key opportunity to ensure that the new Adult Disability Payment was rights compliant (although no further detail on exactly how this should be achieved was given).

A few organisations felt that the review should explore different approaches to determining eligibility for disability entitlements, and develop a more inclusive and holistic approach which adopted alternative approaches to a points-based system. It was suggested this would be needed in order to create a system which reflected the Social Security Scotland principles:

"An application process which is focused on what people can't do rather than what they can do is demotivating and debilitating in itself. We believe that the Scottish Government should further consider an approach which is more progressive and promotes independent living." (Disabled People's Organisation)

The need to increase scrutiny of the determination and application processes before and during any review was also stressed:

"...the Government has an opportunity to design a fairer system to assess mobility now. Delaying a review in to what is acknowledged as an unfair framework until 2023 while waiting until then to assess if the changes to the system actually make it fairer is questionable at best. This is approach is a complete contradiction to the principles of dignity, fairness and respect which are said to underpin the Government's approach." (Third Sector Organisation)

One event group recommended the review be extended to Child Disability Payment and Pension Age Disability Payment in the future.

Finally, several organisations commented that they would be keen to work with the Scottish Government to facilitate an ongoing dialogue to ensure that they could meaningfully participate in and contribute to the review process.

## **Impact Assessments**

The consultation document contained a series of Impact Assessments, including:

- Equalities Impact Assessment;
- Children's Rights and Wellbeing Impact Assessment (CRWIA);
- Business and Regulatory Impact Assessment;
- Islands Communities Impact Assessment; and
- Fairer Scotland Duty Assessment.

Respondents were offered the opportunity to provide feedback or comments on each of these.

Almost all comments were general in nature or focused on elements of the regulations/Adult Disability Payment system itself, rather than reflecting the specific impact assessments. Overall, it was suggested that the impact assessments illustrated a human rights approach, with particularly positive elements including:

- introducing a multi-channel approach for consultations;
- consultations being carried out by professional practitioners;
- using informal sources of information regarding the client's needs, such as accounts from carers or family members, including the ability to challenge and contest informal observations where necessary; and
- minimising the need for excessive consultations and reviews whilst also providing continuing eligibility/awards.

Concerns generally focused on the Personal Independence Payment assessment process, with respondents arguing that this was often stressful and degrading (especially for those with life-long conditions). Again, it was felt that this should not be continued under Adult Disability Payment, and a few respondents welcomed the Scottish Government's commitment to end such face-to-face functional tests.

As discussed at earlier questions, the appropriateness of the eligibility criteria was highlighted. In particular, respondents focused on how they believed that the current draft regulations were exclusionary towards certain conditions, including mental health, autism, variable conditions, and those with collection devices<sup>3</sup>. It was felt that the eligibility criteria and the determination process needed to be fairer, more inclusive, relevant and sensitively applied in all situations. It was also felt that there could be further consideration of particular conditions within the disability analysis of the impact assessments.

Several respondents welcomed that the equalities impact assessment reflected the experiences of those who use English as a second language. However, it was suggested that those supporting people to make applications, those receiving and assessing applications, and those tasked with taking on the responsibility for consultation with those who have applied, are often unaware of those challenges. As such, it was recommended that the regulations make clear the right to a suitable interpreter, that training on working with interpreters should be provided to all agency staff and those taking part in the consultation process, and that the right to access an interpreter and offering one as a matter of course should be promoted. It was also suggested that the access needs for consultations needed to include interpretation services, British Sign Language, other languages, etc., and that such adjustments may also be required in the provision of the consultation recordings to the client.

<sup>&</sup>lt;sup>3</sup> Including Colostomies, Ileostomies and Urostomies

One organisation also felt that the impact assessments should identify areas in the regulations which may cause disadvantage to protected characteristics in practice, such as gendered application of the descriptors and eligibility criteria. Another commented that women (and especially carers) were more likely to be disadvantaged by many aspects of the regulations and urged for greater gender sensitivity to be applied. In particular it was argued that, data collection and analysis, including the production of gender-sensitive sex-disaggregated data, should be built into the system to ensure compliance with the continuous improvement equality and non-discrimination principles. Similarly, it was argued that a gendered analysis of the daily living and mobility descriptors should also be undertaken in advance of their application in order to ensure they move away from gendered assumptions as to who undertakes which role in each household.

Another organisation suggested that barriers or impact should be identified as part of the Equality Impact Assessment and that the existing impact assessment provided no estimate of whether the new Scottish system will reduce negative impacts. In this respect, they felt it would have been useful to have had access to the full Equality Impact Assessment.

In relation to the Fairer Scotland Duty Assessment, one respondent welcomed the commitment that the possibility of introducing lifetime awards was being reviewed. Another felt that this assessment made some findings which could be explored further in order to ensure that Adult Disability Payment delivers on the policy intent of tackling inequality. The same respondent suggested that the Fairer Scotland Duty Assessment could help identify data that Social Security Scotland could collect to measure the success of the policy, i.e. to tackle inequality:

"By collecting data on socio-economic disadvantage and looking at the outcomes for individuals who experience significant socioeconomic disadvantage the Scottish Government can assess the success of this policy." (Third Sector Organisation)

### **Miscellaneous**

All respondents were offered the opportunity to provide any other comments in relation to the regulations, impact assessments or Adult Disability Payment in general. Many reiterated points already raised in response to earlier questions and a few organisations again argued for the need to adopt the social model of disability:

"We need to move away from a needs-based system that asks what people are unable to do, to a more right-based model focused on what a person is entitled to, able to do and the support that enables them." (Third Sector Organisation)

A few respondents sought assurances or more information on the specifics of how the system would operate in practice, while others provided recommendations on how to ensure the system was accessible, operated fairly, and supported applicants. Some of these recommendations focused on the practical implementation of the draft regulations as planned, while others focused on changes they would prefer to see implemented ahead of Adult Disability Payment being introduced. It was suggested that greater discussion of the costs of delivering the new payment could also have been given in the consultation.

Going forward, a few respondents suggested that robust promotion would be required to ensure that those eligible for Adult Disability Payment were aware of it and how to switch over from Personal Independence Payment or apply. It was suggested that this promotion should extend to health and social care practitioners who would be in a position to advise and support those who might be eligible.

There was also one suggestion that more information about the change was needed in general to ensure that there was a smooth transition to the new payment. It was felt that the process needed to be clearly explained to recipients, and cause as little disruption as possible to current awards:

"I feel there should be more information given out, as early as possible, in order to reassure people that there shouldn't be too much disruption to their claims at the moment. A lot of people are going to be anxious about this and what impact it will have for them. So as much clear, easy to understand information given as early as possible would be a great help." (Individual)

One organisation stressed that all communications about the new payment should follow existing Principles of Inclusive Communication, to be as accessible as possible.

Other respondents were concerned about the transition period between the Personal Independence Payment and Adult Disability Payment, and were worried that applicants would have to fill in complex forms or undergo new scrutiny in order to transfer. It was felt this would be highly stressful for applicants and that clarity was needed regarding the process.

### Feedback on the Consultation

Several respondents noted that they had found the information in the consultation difficult to follow or understand. It was suggested that the need to constantly refer between different sections of the consultation document, and being asked to comment on information contained later in the document than the question, was particularly confusing, challenging and 'stressful'.

It was also felt that there was a large amount of information that respondents were required to digest, and that the language used was often technical/contained jargon. The consultation document was also considered to contradict itself in places, with respondents feeling that some issues were not well explained/lacked the necessary information in order for respondents to provide informed feedback:

"It's inappropriate to ask to read and understand a 157 page document that is written in jargon, making this question impossible." (Individual)

One respondent felt that the consultation had not been advertised or promoted widely enough or directly to disabled people. They felt this was an important issue but that too many Personal Independence Payment applicants would be unaware of the planned change:

"With something so major it would have been nice if a letter could have been sent out to people receiving PIP [Personal Independence Payment], DLA [Disability Living Allowance] and carers allowance to let people know what was happening and to contribute." (Individual)

Finally, one organisation was disappointed that "the regulatory framework describing the manner, timeliness, and methods of assessment" had not been set out in the draft regulations. Similarly, two others were disappointed that the regulations for the new Short-Term Assistance were not included, were concerned that the regulations lacked detail in relation to the transfer from Child Disability Payment to Adult Disability Payment, and lacked detail on the transfer of cases between Scotland and the rest of the UK. As such, they felt these (and future drafts of the regulations) would require careful scrutiny and further consultation.

## **Overview, Next Steps and Conclusions**

### **Overview**

The consultation attracted a strong response from a broad range of contributors. Overall, the proposed Adult Disability Payment was seen as a significant improvement on the Personal Independence Payment process, content and approach and, across the consultation, there was notable agreement that most regulations would meet their policy intent (as summarised below). Despite this, however, there was also support for more changes and improvements to the draft regulations to be made ahead of roll out.

| Regulation   | Yes | No    | Don't<br>Know |
|--|-----|-------|---------------|
| Part 1 - Introduction and Interpretation (Regulations 1 and 2)   | 77% | 10%   | 13%           |
| Part 2 - Disability Assistance for Working Age People (Regulation 3)   | 76% | 9%    | 15%           |
| Daily Living Component (Regulations 4 and 5)   | 76% | 12%   | 12%           |
| Determination of ability to carry out activities (Regulation 6),<br>Scoring for daily living and mobility activities (Regulations 7 and<br>8) and Scoring: further provision (Regulation 9)  | 58% | 22%   | 20%           |
| The required period condition: daily living component and mobility component (Regulations 10 and 11), The relevant date (Regulation 12), The relevant date: after an interval (Regulation 13) and Residence and presence conditions (Regulation 14)  | 74% | 12%   | 14%           |
| Absence from the United Kingdom (Regulation 15), Absence from the United Kingdom including medical treatment (Regulation 16), Absence from the United Kingdom in special cases (Regulation 17), Serving members of Her Majesty's forces and their family members - further provision (Regulation 18), Persons habitually resident in the United Kingdom (Regulation 19), Persons habitually resident in outside of the UK (Regulation 20) and Refugees (Regulation 21) | 79% | 10%   | 11%           |
| Age Criteria (Regulation 22), Persons of pensionable age: exceptions (Regulation 23), Adult Disability Payment after an interval and after reaching the relevant age (Regulation 24), Determination of an award after the person has reached the relevant age (Regulation 25)  | 78% | 9%    | 13%           |
| Terminal Illness (Regulation 26)   | 89% | 2%    | 9%            |
| Care home residents (Regulation 27), Hospital in-patients (Regulation 28), Exceptions: care homes and hospitals (Regulation 29), Legal Detention (Regulation 30), Periods of residence (Regulation 31)   | 63% | 18.5% | 18.5%         |

| Regulation  | Yes | No  | Don't<br>Know |
|---|-----|-----|---------------|
| Rate of Adult Disability Payment and Making Payments (Regulation 33), Making Payments (Regulation 34), When an application is treated as made and beginning of entitlement to assistance (Regulation 35), Time of Payment (Regulation 36), Continuing Eligibility (Regulation 37)   | 83% | 8%  | 9%            |
| Part 11: Qualifications and Experience Necessary to Carry out Assessments (Regulation 38)   | 69% | 24% | 7%            |
| Consideration of entitlement after specified period (Regulation 39), Other situations requiring a determination without an application (Regulation 40), Determination following official error - underpayments (Regulation 41), Determination following error - overpayments (Regulation 42), When changes in entitlement take effect (Regulation 43) | 72% | 12% | 16%           |
| Periods in respect of a re-determination request (Regulation 44)  | 77% | 11% | 12%           |
| Part 14: Provision of vehicles (Regulation 45)  | 85% | 2%  | 13%           |
| Liability for assistance given in error (regulation 46)  Determination to affect a deduction decision (regulation 47)   | 65% | 13% | 22%           |

### Aspects of the draft regulations that people welcomed included that:

- consultations could/would be undertaken by medical professionals/by specialists more familiar with particular conditions and who may be more empathetic/understanding of unique needs;
- existing social care data and information would be used to inform decisions;
- that practitioner skills, qualifications and training would be monitored/regulated (although even greater clarity on what skills and experience would be required could be built into the regulations). The need for input from people with lived experience in any training given was also stressed:
- consultations would be undertaken in a range of accessible formats and the voices of informal carers could/would be heard (although the regulations could more clearly set out potential for including the third sector and people with lived experience in the decision-making process);
- applications would have more flexible timescales and the process would be made accessible (including alternative format application routes);
- that rolling payments and five-year 'light touch' reviews would be undertaken (although this could be more clearly explained and protected in the regulations);

- indefinite awards would be available and were expected to provide stability and financial certainty for those with degenerative conditions, or who have conditions that will not improve, in particular;
- regulations linked to terminal illness would create a smoother process for people with a terminal illness, remove ongoing uncertainty in relation to eligibility and providing greater dignity for applicants;
- the proposed introduction of 'Short-Term Assistance' would ensure individuals continue to receive their previous payment amount until the outcome of a re-determination has concluded; and
- a scheme similar to the Motability scheme would be continued and no one should lose such provision as a result of the move to Social Security Scotland management (although more detail on how this would work in practice may be welcomed).

Aspects of the draft regulations that were not welcomed or attracted discontent included that:

- it was wrong to retain a reliance on the 20 metre rule and the 50% rule, which
  many individuals and organisations felt should be amended from the outset
  of Adult Disability Payment. There was a strong desire for reverting to the 50metre rule to make the system fairer/more realistic, and for more nuanced
  measures of mobility and daily living indicators to be applied to better take
  account of a fuller range of conditions;
- 'changing' or 'variable' conditions had not been given sufficient attention or thought within the regulations overall;
- mental health conditions had been overlooked to a large degree with some of the complexities around eligibility, determination and daily living associated with mental health conditions not being sufficiently well addressed;
- the 13 week qualifying criteria was not suitable for those with unpredictable and fluctuating conditions and was too long in general for applicants to be made to wait:
- residency variations may result in loss of payments in particular situations or for particular groups;
- the 'past presence test' had been retained and was still too rigid.
   Disappointment was expressed that the Scottish Government had not taken the opportunity to relax the past presence test or create further exceptions to it; and
- liability for overpayment had not been sufficiently well addressed and more clarity was required in the regulations.

A recurring theme was that the new benefit may be too similar (especially around eligibility and determination) to the existing Personal Independence Payment and there were concerns that opportunities had been missed to improve the system for

the future (and to move away from a points-based system). This included views that the proposed review of Adult Disability Payment may be too late. Despite the calls for further changes however respondents were keen to stress that no one should suffer a loss of eligibility as a result of the change-over from Personal Independence Payment to Adult Disability Payment.

Overall, both individuals and organisations expressed strong views that they wanted a clear, easily understood and transparent system, which would not cause stress and anxiety to applicants, and would not repeat errors of the past.

### **Next Steps**

Findings from the analysis of consultation responses will be reviewed by the Scottish Government alongside other information to adjust the draft regulations, as appropriate. In accordance with the Social Security (Scotland) Act 2018, the draft regulations will later be scrutinised by the independent Scottish Commission on Social Security with further revisions made by the Scottish Government, as required, following the Commission's report. The draft regulations will then be laid for approval by the Scottish Parliament.

### **Conclusions**

While most respondents welcomed the majority of the proposed changes, there was some scepticism that sufficient change had been built into the regulations to accommodate the full range of disabilities and individuals' unique needs. There was, many felt, potential to design an even more nuanced approach which would reflect the social and human rights models of disability, and this was urged, ideally before roll out of Adult Disability Payment, rather than during any review. Despite this, several respondents commended the Scottish Government on the level of consultation already undertaken and the inclusive manner in which the draft policy and regulations had been designed. There were calls for the Scottish Government to continue consultations with disabled people and relevant organisations throughout the planning, staff training and implementation of Adult Disability Payment, with several organisations offering support in this respect, to ensure that it runs smoothly.

# Appendix A - Comments on Specific Regulations

### Q2

- Definitions provided within this regulation are still too vague and generic.
   Based on previous experience of the disability benefit system epilepsy has not fit into either of the categories of physical or mental function or disability.
- Part 1, Regulation 2 (d) In addition to prothesis, it may be appropriate to consider 'orthotics' such as specialist braces?
- Part 1, Regulation 2. It is noted that there is reference to the Armed Forces Compensation Scheme, Armed Forces Independence Payment (AFIP) however, there is no specific reference to the War Disablement Pension Scheme (WPS), and the associated allowances: Constant Attendance Allowance (CAA) (which can also be payable within Industrial Injuries Disablement Benefit) or War Pensioners Mobility Supplement (WPMS).
- Regulation 39 "Qualifications and Experience Necessary to Carry out Assessments" should be amended to ensure practitioners should have previously been working in the health or social care role within the five years prior to becoming a case manager/specialist advisor.
- Draft regulations should be amended to provide a maximum 42-day period for the agency to undertake a re-determination.
- Draft regulations should be amended to prevent repayment of overpayments in cases of official error.
- Daily Living Activities and associated descriptors should be amended to include direct reference to psychological distress.
- Descriptors for Mobility Activity 1: "Planning and following journeys" should
  urgently be redrafted to remove the exclusion of psychological distress as a
  means to gain points in descriptors (c), (d) and (f). The associated PIP
  descriptors were found unlawful and in contravention of international human
  rights law.
- Option of "aids and appliances" listed in schedules 2 and 3 is too focused on physical health needs, which could discriminate against those who experience mental health problems. The schedules should be amended to take into account the way that activities, interactions, and behaviours may help someone with a mental health problem undertake daily living and mobility tasks. With regards to the description of "aids and appliances" that may help people to carry out the activities listed in the tables in schedules 2 and 3, the definition of these aids and appliances as "objects and devices" in Regulation 2 is skewed towards physical disability. It does not take into account the way that certain activities, interactions, and behaviours (such as a certain informal routine) may help someone with a mental health problem undertake the tasks listed. Of course, someone with mental health problems

- may want to be assessed in relation to their capacities when such routines are not being applied. But the definition still indicates the general sense in which the regulations are not geared around mental health. They could therefore be considered discriminatory in concept, and should be amended.
- On a similar note, the connecting words in the definitions of other types of disability benefit in regulation 2 are not consistent with each other (e.g. 'in terms of' for CDP, 'under' for disability living allowance [DLA], 'in accordance with' for armed forces independence payment [AFIP] and personal independence payment [PIP]). Making them consistent in their form would avoid the reader assuming that the difference was meant to be meaningful in some way.
- In the definition of 'aid and appliance': consider whether the definition should exclude artificial heart valves, retinal implants, hip replacements, etc.
- Consider adding a reference to use of a stoma to subparagraph (c), to reflect the Upper Tribunal's decision in JM v SSWP (PIP) [2016] UKUT 296 (AAC).
- The definition of 'determination' may cause difficulties. This is because that
  word is used elsewhere in the Regulations in a sense that is clearly not
  referring to a determination of entitlement, but rather in the sense used in
  reserved benefits one of the building blocks that leads to an outcome
  decision.
- There is no definition of 'Adult Disability Payment' (ADP). The draftsperson of the draft Child Disability Payment (CDP) regulations considered that this was necessary, so including it for the avoidance of doubt would seem to be helpful. On a similar note, the connecting words in the definitions of other types of disability benefit in regulation 2 are not consistent with each other (e.g. 'in terms of' for CDP, 'under' for disability living allowance [DLA], 'in accordance with' for armed forces independence payment [AFIP] and personal independence payment [PIP]). Making them consistent in their form would avoid the reader assuming that the difference was meant to be meaningful in some way.
- Also, you refer to the person claiming the benefit as 'the client'. Just say person.

- Regulation 3(5) could perhaps be made more useful to the reader as a signpost by adding 'in accordance with Part 12' at the end.
- Part 2, Regulation 3 It is suggested that it may be appropriate to mention in this section, as a sub paragraph, 'overlapping benefits' and provide an overview of the Armed Forces Compensation Scheme (AFCS) and the War Disablement Pension Scheme (WPS) associated allowances; War Pensioners' Mobility Supplement (WPMS) overlaps with PIP mobility supplement and thus expected to overlap with Adult Disability Payment. The rate for WPMS is higher than the rate of Adult Disability Payment so it is assumed that there is no payment of Adult Disability Payment mobility component if there is an award of War Pensioners Mobility Supplement.

Constant Attendance Allowance (CAA) overlaps with PIP daily living supplement and thus expected to overlap with Adult Disability Payment. CAA has four rates and dependent on which rate has been awarded, there may be a 'top up' of PIP daily living and so it is expected Adult Disability Payment will provide the same 'top up'.

### Q6

 As they stand, the current regulations demonstrate a medical model approach in which the following definition is not compliant with a human rights based approach: 'ability to carry out the daily living and/or mobility activities is limited by their physical or mental health condition or conditions.' This definition requires to be redrawn to something like 'support may be required to overcome barriers to carrying out daily living or mobility activities.' This would also have the benefit of recognising that people often experience multiple barriers at the same time.

### **Q8**

- Regulation 6 use of the word 'determined' could create confusion with 'determination of entitlement'. To avoid this, it was suggested this should be changed, with 'established' provided as a suitable option.
- Regulation 6(4)9b) it was suggested that this should specify that 'fatigue, pain and psychological distress' will be amongst the impacts to be considered.
- Regulation 7 variability between descriptors needed to be better accounted for, for example it was noted that for epilepsy the risks needed to be considered and not just the time and frequency of seizures.
- Regulation 7 include a duty to take into account and record the extent to which a person can undertake a specific task 'reliably'.
- Regulation 9 the use of "on over 50% of the days" was considered a
  retrograde step from Personal Independence Payment where 50% of days
  was sufficient to satisfy the criteria. It was suggested that this should be
  changed to "50% or more" or "at least 50% of the days" to avoid ambiguity
  and need for case law.
- Regulation 9 the use of the words 'required period' could be confused with 'required period condition' in Part 4. It was suggested different language was needed to avoid confusion, with 'time under consideration' suggested as an alternative.
- Ordinary meaning of 'assistance' is not in point, because the definition is an exhaustive one, being in the form 'assistance means', rather than one that extends the ordinary meaning, which would be in the form 'assistance includes'. The important word is 'intervention'.

### Q10

 Regulations 12 and 13 - these were considered to be poorly worded, overly complicated and difficult to understand.  Regulation 12(b) - it was suggested this be redrafted in line with case law, i.e. that it must be constructed as 'any day of the award'.

### Q12

- Section 1G This should be explored and defined to protect all categories of status who can reside in Scotland, and clarifying when and why some benefits do not hold the same restrictions.
- Section 1G should be explored and defined to protect all categories of status who can reside in Scotland with cherry picking what we do and don't when some benefits do not hold the same restrictions.
- Regulation 14 (b) Unlike the Child Disability Payment regulations (Disability Assistance for Children and Young People in Scotland: Regulation 6) there was no definition of the common travel area.
- Regulation 15 (3) This was considered more restrictive than the Personal Independence Payment approach in that claims could be made in advance for Personal Independence Payment by people not yet habitually resident.
- Regulations 18 (b) and 19(c) There was inconsistency between different regulations.
- The rules on temporary absence should make it clear that individuals who remain ordinarily resident in Scotland, whilst present in the rest of the UK, remain eligible for disability assistance.
- Clear guidance is needed on defining a "genuine and sufficient link to Scotland". It was suggested this should be defined in broad terms so as not to act as a barrier to disabled people accessing the Adult Disability Payment.

### Q14

- Regulation 26, Paragraph 10 It was suggested this should be removed as it
  was considered inappropriate and unrealistic to expect healthcare
  professionals to make any consideration of their patient's residence
  conditions when determining eligibility. It was felt this was an area for
  decision incumbent on the Scottish Ministers, not healthcare staff, and should
  remain this way.
- Regulation 26, Paragraph 12 it was noted this referred to "regulation X", so it was unclear what this provision was intended to do.
- That the regulations in this section referred to "the assistance". It was suggested this needed to be better defined.

### Q16

No specific changes.

#### Q18

 Regulation 26(3)(b) - The intention is that the Adult Disability Payment under these rules would remain payable while the [client] is in hospital or in a hospice. It might be useful if the 'payability' (as well as entitlement) was made clear.

- Regulation 26(3)(b) The wording may be problematic for someone already in hospital and is applying for the Adult Disability Payment. If the intention is for people to be able to get the Adult Disability Payment in this situation, it could perhaps be clearer, either here, or in regulation 29(3).
- Regulations 27(2)(c) and (f) and Regulation 28(2)(a)(i) and (ii) These do not appear to apply in Scotland. It was unclear if this was a drafting error or whether the intention was that time spent in a care home or hospital in England and Wales, whilst the individual remained ordinarily resident in Scotland, counted as time spent in a care home or hospital.
- Regulation 27(6)(d) Replicated the wording in section 85(4) of the Welfare Reform Act 2012 (regarding Personal Independence Payment), however it was felt this did not seem relevant to these regulations.
- Regulations 27(1) and 28(1) It was suggested that these did not match the
  intended policy which was felt to be better expressed under Regulation 31(2),
  i.e. after 28 days, starting the day after admission, etc. It was also suggested
  that Regulations 27 and 28 needed to be clearly conditional on the
  determination of residence (as under Regulation 31), otherwise the
  Regulations could appear to contradict one another.
- Regulation 29 There was inconsistency between specified exemptions for terminally ill claimants at different parts of the regulations. It was noted that those in hospital were specifically excluded from the exceptions made at Regulation 29(4)(c) when it was felt they should be treated the same as those in a hospice. It was also suggested that this contradicted Regulation 26 which stated that those terminally ill and in hospital would be exempt from Regulation 28. One respondent suggested it would be better to say that if the client satisfies Regulation 26 then the Regulation 29 exceptions apply.
- Regulation 30(1) Inconsistent with earlier regulations. I.e. Regulation 2 says "legal detention" means detention in legal custody within the meaning of section 295 of the Criminal Procedure (Scotland) Act 1995(3)" but Regulation 30(1) talks about legal detention within the UK. It was suggested that, if the intention was that an individual who remains ordinarily resident in Scotland, but who is detained in another part of the UK is covered by regulations 30(1), then the definition in Regulation 2 may need to be amended.
- Regulation 30(5) It was felt that there was no consistent reason why terminal illness (satisfaction of Regulation 26) was not likewise included here, in order to avoid potentially contradicting provisions.
- Regulation 31(3) Contained a possible drafting error which should instead say 'a period of leave from the home, hospital or from legal detention'.
- That the 28 day rule and transferring should only take into account the transfer time if being transferred otherwise the date of departure should be the date that is accepted. It was felt that the regulations treated disabled people leaving detention differently to those leaving hospitals in terms of when the day starts to count. This may have human rights consequences in treating people differently. It was also suggested that the regulations should

- state that, if no charges were brought, or people were exonerated, no loss of payments should apply.
- We welcome the provision whereby [clients] can receive a new determination when their period of residence ends without the need for them to make a fresh application (regulation 31(8)). We suggest that Ministers consider extending such provision to the other scenarios outlined in Part 8, particularly legal detention.

- Regulation 33(3)(b) This mentions Constant Attendance Allowance, which
  was believed to be in relation to the Industrial Injuries Scheme (footnote 41
  was noted as being missing, so it was unclear what the intent was), however,
  for clarity, it was suggested this should also reflect the Constant Attendance
  Allowance linked to the War Disablement Pension Scheme. Additionally, it
  was felt that it would be appropriate to add the War Pensioners Mobility
  Supplement (WPMS) and Armed Forces Independent Payment as they also
  overlap and impact on the payment rates.
- Regulation 33(4) For clarity, it was suggested that this should be expanded to add Constant Attendance Allowance and War Pensioners Mobility Supplement from the War Pension Scheme as well as they are 'overlapping'.
- Regulation 33(4) It was suggested that a separate sub paragraph was added to allow for the possibility of a Constant Attendance Allowance 'top-up' via the Adult Disability Payment where this is appropriate, e.g. for those on a lower rate of Constant Attendance Allowance (Part Payment) through the War Disablement Pension Scheme.
- Regulation 33(5) This referred to Regulation 46, however, it was felt this may be an error and should refer to Regulation 45 (i.e. the Motability scheme).
- Regulation 35 One respondent queried how the eight-week period was identified, and what process Scottish Ministers would use to identify this date to ensure consistency across the board.
- Regulation 35(6) It was suggested that guidance was needed around what a 'good reason' would be, and suggested this this should be defined broadly, and include it being as a result of the symptoms/effects of the applicant's medical condition or disability.
- Regulation 37 It was suggested that uses the word 'must' (rather than 'may') could be used to provide clarity and avoid ambiguity.

### **Q22**

 To avoid unnecessary reviewing of applications such as where it has been determined that, "A person's entitlement was made in ignorance of, or by mistake as to, a material fact which existed at the time of the determination was made;" regulation 40B (iii), it would be prudent, when possible, to include [organisation] in decisions when the determination involves a person with profound and multiple learning disabilities.

- Regulation 38 should be amended to ensure that mental health-focused ADP
  assessors have two years' experience of mental health-related health and
  social care delivery within the last five years. Scottish Government should
  ensure a decent level of mental health training for all ADP assessors whether
  they are dealing with mental health-oriented applications or not, including
  training on stigma and discrimination.
- We suggest that changing the criteria within Part 11, r38 (a) from 'cumulative' to 'continuous' may be advantageous or alternatively specifying a cap on the period of time over which cumulative experience could have been gained. We would also suggest that there be some inclusion of values based criteria for assessors, such as an understanding of the social model of disability and of the right to independent living as set out in the UNCRPD.
- The word 'practitioner' is too vague when dealing with someone who has severe mental illness.
- The Scottish Government's Adult Disability Payment draft regulations state: "A practitioner is suitably qualified to carry out an assessment of an individual if they have been employed for a cumulative period of at least two years, in the direct provision to individuals of health care or social care services." This suggests that individuals in the health and social care sector who have limited experience in disability can carry out consultations for Adult Disability Payment. We posit that this regulation should be strengthened to ensure that only [practitioners] who have the necessary specialist experience and knowledge are able to make judgements with regards to a disabled person's right to financial assistance.

- Paragraph 80 Will there be two appeals, as happens under Personal Independence Payment, one for entitlement and one for recoverability. What is the equivalent law for s71 SSA Act?
- Paragraph 86 How are Scottish Ministers defining unjust?
- Regulation 43(1)(a) refers to a reg X.
- Paragraph 76. How will this light touch review date and guidance be set for people with fluctuating conditions? Seizures may reduce during certain periods of time but the risk of seizures and associated effects are always present.
- Paragraph 77. iv How will this work if there are minor differences between ADP and PIP (i.e., changes in descriptors and interpretation as outlined in Schedule 1).
- vii How will Scottish Ministers ensure any overpayment sought by the DWP is done in a fair and dignified way given the client is now supported by Social Security Scotland.
- Paragraph 80. Will there be two appeals as happens under PIP, one for entitlement and one for recoverability. What is the equivalent law for s71 SSA Act?

- Paragraph 84. This is unfair, payments should be backdated to date of application not when Scottish Ministers become aware of the error.
- Paragraph 86. How are Scottish Ministers defining unjust?
- Reg 43(1)(a) refers to a reg X.

- Paragraph 89 How will extensions to this time limit be managed?
- Paragraph 90 Will Short Term Assistance still be applied after the 56 days?
- Paragraph 77c This appears to duplicate rather than provide a vice versa scenario.
- Regulation 39 suggests that a DWA must be done after the end of an award period where the award has been set by Social Security Scotland, but not when an award has been set by a Tribunal.
- This regulation is worded very differently from the equivalent regulation for child disability payment (Reg 26 draft DACYP Regs).
- We understand that it may be necessary for Social Security Scotland to collect additional information and that this may take some time. However, the Scottish Government should consider whether it is possible to reduce the period specified in regulation 44(2).

### **Q28**

• No specific changes.

### **Q30**

- Reg 46(5)(b) is not clear in meaning and needs reworded. The same applies for 47(2).
- In Regulation 46(5)(a)(ii) the phrase 'an assumption which proves to be wrong', and in (b) the phrase 'a new determination not being made after an assumption on the basis of which an earlier decision was made has proved to be wrong' could both be clarified to make their intent clear.

### Schedule 1

- Mobility Activity 1, Descriptors c, d and f this was noted to be the same wording used in an attempted amendment to Personal Independence Payment mobility regulations, but which was subsequently declared unlawful and discriminatory. It was recommended that the wording needed to be changed to reflect this.
- Assistance dogs are now used for wider things than sensory impairments and so this definition in part 48 needs to be amended to be more inclusive.
- an 'inability to take nutrition due to psychological distress' descriptor should be added to the taking nutrition daily activity.
- "Basic verbal information" needs to include visual and tactile languages such as British Sign Language (BSL) and tactile BSL.

- "Communication support" needs a more expansive definition of what this can mean.
- "Cook" means heat food at or above waist height should be altered to be prepare and heat. Disabled people should be supported to enjoy a full range of food preparation.
- recommend that the social engagement activity is amended to include maintaining relationships. This would make it clear that the activity should take into account the need to be able to build social networks in a long term and meaningful sense.
- recommend that reading be amended to "read and act on". At present if a
  [client] with a learning disability reads and understands the letter they have
  been sent then they get zero points. This is despite the fact that there may be
  a disconnect in them then actually acting on it. We feel that the inclusion of
  "act on" will ensure that the ability to read is tested in a more meaningful
  sense.
- Mobility Activity 1, Descriptor 1(b) 'Needs the presence or prompting of another person to be able to undertake any journey to avoid overwhelming psychological distress to the individual', this represents a departure from the established scope of this activity under the Personal Independence Payment regulations that may disadvantage claimants. It was also considered to treat claimants unfairly in terms of scores awarded compared to those satisfying descriptors 1d or 1f.
- Mobility Activity 1, Descriptor 1(e) the change here is more restrictive than the current Personal Independence Payment descriptor. Whilst the Department for Work and Pensions' interpretation is that if a [client] can leave the house once during the day descriptor 1e cannot be satisfied, this is not settled law. It remains arguable that the correct approach is to apply the Upper Tribunal decision TR v SSWP (PIP) [2015] UKUT 623 (AAC), reported as [2016] AACR 23. It is clear that the policy intent is to incorporate the ratio of this decision (as demonstrated by the inclusion of Reg 9(2)(a)).
- The new definition of 'follow the route of a journey' also risks restricting its scope compared to the current state of the caselaw, as it does not make explicit that the passive presence of another person can allow descriptors 1d and 1f to be awarded.
- Engaging socially with other people face-to-face expand sub-paragraph (c)
  to be clearer what nature of relationships are considered. For example,
  making it 'establish close personal relationships' would make it less likely that
  First-tier Tribunals will fall into error.
- The definition of 'communication support' is not currently grammatically correct, and requires a further word after the first 'with' for example 'people' or 'individuals'.
- In the definition of 'prompting' inserting at the end 'whether or not given in the physical presence of the individual' would make the definition clearer.

- Replace 'and' with 'or' in the definitions of 'dress and undress' and 'toilet needs'.
- In the definition of 'assistance' insert 'with part but not all of a task' after the word 'intervention.
- In the definition of 'supervision' insert at the end 'whether or not that risk directly results from carrying out the activity in question'.
- To an "acceptable standard" Acceptable standard should also be defined on the basis of the claimant's ability to undertake activities when they wish. More consideration could be given to the claimant's acceptable standard and enjoyment of life, which their disability prevents them from doing to an acceptable standard.
- "basic written information" "dares"? Should this read "dates"? Also consider confirming that making guesses is not reading to an acceptable standard. Consideration should also be given to the fact that in general, people without disabilities can read and understand signs "instantaneously".
- "communication support" Consider updating the interpretation section to read "and could include a friend or family member" or "does not exclude a friend or family member".
- "complex budgeting decisions" and "simple budgeting decisions" Could a
  definition of simple budgeting decisions be included and consideration of
  whether the individual has sufficient understanding of the outcome and
  implications to take a decision based on it?
- "engage socially" or "engaging with others face to face" it was suggested
  that this should mean more than an ability to engage with people known to
  the claimant (family and existing friends), or with whom they need to engage
  with for a limited purpose such as health care professionals or a tribunal
  panel. Also, that this engaging socially must be to an acceptable standard
  and as often as is reasonably required.
- "monitor a health condition" it was suggested there was a missed opportunity to recognise the supervision and monitoring of the health condition specifically excluded under the therapy definition and thus only attracting 1 point in Activity 3.
- Could the "therapy" definition be widened to include the supervision necessary in severe epilepsy cases? They felt this was an opportunity to recognise physical input from another person which goes beyond "supervision", and queried why there was more recognition for 3.5 hours of "therapy" per week than for continuous monitoring of a health condition by another person and/or intervention by another person in severe circumstances (status epilepticus) to administer emergency medication.
- "object and device" (Regulation 2(a) and 2(b)) Due to the importance of diet, people with epilepsy and diabetes often use apps to record food intake and seizure activity. As such, it was requested that such apps should fall within

- the definition of "object and device", and to specifically include the apps as an aid in the regulations.
- "prepare" and "simple meal" definitions with a proposal to also include a definition of "use of a microwave" in context of Activity 1. It could be added here that this means more than just heating up a ready meal in the microwave. Also, it was felt unfair that people were often not awarded the four points for supervision that their circumstances warrant because there was a belief that the use of a microwave eliminates the risk of harm, but people with epilepsy are still at risk of scalds and burns should they lose awareness of their surroundings or have an absence, a cluster of absences or a tonic clonic seizure while using a microwave.
- "safety" This includes "consideration of the likelihood and severity of consequences of the harm". For epilepsy claimants this is often misapplied. The word likelihood here could be given a definition in the interpretation section to include the case of RJ & others v SSWP - "An assessment that an activity cannot be carried out safely does not require that the occurrence of harm is "more likely than not"" (at para 56).
- "simple meal" there is an opportunity here to clarify the law and rule out snacks, sandwiches and ready meals.
- "social support" there could be added to the interpretation section "and can include friends or family" or "does not exclude friends or family" where a friend or family member is experienced or the best person to provide that support.
- "take nutrition" The interpretation section could be amended to ensure it is recognised that points can be awarded for needing prompting to eat a sufficient quantity of food.
- "therapy" Why is managing therapy given more points than monitoring a health condition in order to take emergency remedial action for a [client] to save their life? "Therapy" can mean engagement with other people if recommended by a health care professional so this would score more than continuous monitoring of an epileptic health condition, with the possibility of having to administer lifesaving medication. Could the points for Activity 3(b) be upgraded to two points? It is this one point which is rendered otiose and often leaves our service users one point away from a standard daily living award. Our experience is that this descriptor is rarely awarded at the initial stages, even when the client has advised in their claim form, they are prescribed emergency rescue medication and a protocol is in place.
- "toilet needs" Does (a) include getting a [client] to the toilet themselves after a seizure? Many [clients] with epilepsy have sudden bladder/bowel urgency directly following a seizure but need assistance to get to the toilet as they can be very confused and disorientated. This scenario could be made clear in the interpretation section as falling under the "toilet needs" interpretation.
- The word "likelihood" could be given a definition in the interpretation section to include "likelihood does not have to mean more often than not". Otherwise,

it was felt that [clients] could face a misunderstanding of the law by decision makers.

- Fatigue consideration should be given to fatigue stemming from a medical condition. The interpretation section should have a definition of fatigue.
- Dressing and undressing the 'bed' is not regarded as an aid, yet nondisabled people would not normally use the bed as a means to dress or undress.
- Planning and following Journeys The 'Sat Nav' is not regarded as an aid and some people with mental health conditions cannot remember a route and thus use the sat nav or mobile to get to their destination.
- Moving around There appears to be no recognition of the effort needed to stand and move to a certain distance. (such as 'out of breath, impact from pain and 'bravado').
- Interpretation section give more consideration to this section so that the law can be clarified and confirmed, without needing to amend the Activities and Descriptors. Comprehensive guidelines whilst welcomed, are often not considered law and not given appropriate weight by decision makers.
- We note that the wording of descriptors 1c, 1d, and 1f in part 4 of schedule 1 apparently derive from what was regulation 2(4) of the Social Security (Personal Independence Payment) (Amendment) Regulations 2017. That regulation sought to introduce the phrase "for reasons other than psychological distress" into the descriptors for three of the mobility activities. However, the regulation was quashed following judicial review proceedings (RF v Secretary of State for Work and Pensions [2017] EWHC 3375 (Admin)), in which we intervened. The court found that the phrase 'for reasons other than psychological distress' was discriminatory in that it drew an 'unprincipled distinction' between different categories of disabled person, unconnected to their level of need or their level of functional impairment. The court also concluded that such discrimination could not be objectively justified. As a result, PIP continues to be awarded on the basis of the descriptors in the original legislation (Social Security (Personal Independence Payment) Regulations 2013 (SI 2013 No.377). However, as noted the phrase at issue in that case is found in three descriptors (1c, 1d, and 1f) in part 4 of schedule 1 of these draft regulations.

### Schedule 2

- Regulation 50 It was not clear what this was aiming to achieve or the reasons for this.
- Perceived inconsistency between Regulations 17 and 50 It was noted that Regulation 17 made provision to allow people in the armed forces who were abroad on duty to be treated as being in the UK so as to allow them to apply, but Regulation 50 then excluded anyone who has previously paid National Insurance.

### Other

 Descriptors for Mobility Activity 1: "Planning and following journeys" should urgently be redrafted to remove the exclusion of psychological distress as a means to gain points in descriptors (c), (d) and (f). The associated PIP descriptors were found unlawful and in contravention of international human rights law.

Below are examples of areas where existing caselaw has not been fully captured in the current draft Regulations:

- Regulation 6(4)(b) Caselaw (PS v SSWP (PIP) [2016] UKUT 326 (AAC))
  has established, for PIP, that the pain experience when you undertake an
  activity is one factor that should be taken into account when considering if the
  activity can be done to an acceptable standard. If the policy intent in Scotland
  matches this then Reg 4(6)(b) could specify that pain and distress are
  amongst the impacts to be considered.
- Reg 12(b) Caselaw (BM v SSWP (PI P) [2017] UKUT 486 (AAC)) has found that for the equivalent regulation in PIP (Reg 14(b) SI 2013/377) must be constructed as 'any day of the award'. In the interests of clarity, and to ensure the policy intent is met, this regulation could be redrafted in line with caselaw.



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