

Consultation on Adult Disability Payment See Me response

About See Me

See Me is Scotland's national programme to end mental health stigma and discrimination. Our vision is to enable people who experience mental health problems to live fulfilled lives. We are working to change negative attitudes, behaviours, and cultures towards mental health by creating a movement for change, bringing people together across Scotland who are passionate about tackling stigma to work as one.

***In this response we refer to ADP (Adult Disability Payment) and PIP (Personal Independence Payments)**

Summary of Recommendations

Q2: The description 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.

Q8: The criteria around safety, acceptable standard, repetition, and reasonable time period used to judge whether an individual can undertake daily living and mobility tasks (regulations 6 and 8) should be altered to acknowledge the difficulties mental health problems create, rather than just looking at physical capability.

Q10: The 52-week "required period" (13 weeks prior to and 39 *predicted* weeks following assessment) over which a condition must be present to receive ADP (see regulations 10 and 11) should be altered to take into account the fluctuating effect of mental health problems.

The requirement that an applicant must be experiencing a condition for thirteen weeks prior to ADP eligibility (regulation 13) should be removed in the case of severely inhibiting conditions that can appear suddenly, such as mental health problems.

Scottish Government should allow five rather than two years of eligibility to ADP without a 13-week qualifying period following the end of a previous PIP or ADP award (see regulation 13).

Q22: 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.

Q30: For young people living with a mental health condition, Scottish Government should mitigate the potentially traumatic and stigmatising effects of transferral from Disability Living Allowance or Child Disability Payment to ADP at 16, either: by offering a single Disability Payment system for children and adults; or, allowing individuals to decide the point at which they transfer their award within a longer time-frame (for example, between the ages of 16 and 21).

Q31: The lists of activities in column 1 and measurement categories in column 2 of the daily living and mobility tables (schedule 1) should be amended as far as possible ahead of a larger-scale review (in 2023 or sooner) to take account of the particular challenges that mental health problems present.

Q33. Scottish Government should inaugurate a wholesale review of ADP, most importantly of all the aspects of the assessment and application process inherited from PIP, as soon as possible after transferring all clients to ADP.

Q35. This review should scrap the PIP points-based criteria and measurement system and replace it with a system offering a holistic, person-centred overview of a clients' needs, rooted in respect for their human rights (including those in the UNCRD) and designed to enable them to enjoy those rights to the full.

Q35: A 'right to reply' should be offered on draft ADP assessment write-ups prior to an award being applied.

All applicants should be informed of their right to record ADP assessments, and recordings should be offered pre-emptively to all in-person, phone, or video-call applicants for potential use in tribunals and appeals.

Introduction

We welcome the chance to respond to this consultation on the draft Disability Assistance for Working Age People (Scotland) Regulations. Evidence gathered for this review includes a focus group undertaken with See Me's Community Champion and Youth Champion volunteers (all of whom have lived experience of mental health problems) on 4 March 2021, and a survey which ran during 2-10 March to gather the views of volunteers unable to attend the focus group.

Our focus group was attended by six volunteers, with a further three responding through our survey. Given this small sample size, participants' responses should be seen as giving colour and detail to broader patterns and contexts established through larger-scale research projects conducted by See Me and other organisations. These include SAMH's reports *Personal Independence Payment: What's the Problem* (2017) and *Fit for Purpose? SAMH Redhall Trainees' Experiences of Welfare Reform* (2017).¹

We gathered opinions on the process of applying for Personal Independence Payment (PIP), including how assessment processes and criteria could feel

¹ www.samh.org.uk/documents/personal_independence_payment_report.pdf.

stigmatising and discriminatory, and whether or not awards seemed to reflect the conditions experienced at point of applications. We also asked volunteers what they felt needed to change with the introduction of Adult Disability Payment (ADP) through Social Security Scotland (SSS).

Question responses

Not all of the consultation questions are answered below. All of the answers given are informed by the responses to our focus group and survey. However, most of the views we received were not so much about the details of the draft ADP regulations as what needs to change in the longer term to create a less stigmatising and discriminatory benefit model than PIP presents for many people with mental health problems. As such, many of the answers are guided towards the planned 2023 review of ADP, and/or any earlier points for review of the system following the transfer of PIP clients to ADP. Many of these points are included or reiterated in response to questions 33 & 35.

Part 1: Introductory and Interpretation (regulations 1 and 2)

Q 1: Do you agree the regulations reflect this policy intent? YES

Q 2: If you have any further comments please provide them here.

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. (See Q7-8 responses for evidence.)

Determination of ability to carry out activities (regulation 6) Scoring for daily living and mobility activities (regulations 7 and 8) Scoring: further provision (regulation 9)

Q 7: Do you agree the regulations reflect this policy intent? YES

Q 8: If you have any further comments please provide them here.

With regards to regulations 6 and 8, the criteria around safety, acceptable standard, repetition, and reasonable time period used to judge whether an individual can undertake daily living and mobility tasks are open to subjective interpretation, which may discriminate against people with mental health issues. For example, an assessor may consciously or unconsciously hold stigmatising attitudes towards mental health issues, viewing them as a question of attitude or choice rather than as legitimate inhibiting factors, resulting in lower needs assessment scores. The applicant themselves may hold similar, self-stigmatising attitudes, with similar results.

"The application criteria do not challenge the stigma around mental health problems being seen as temporary 'battles' that we can easily overcome if we simply *do* things to get better." Survey respondent

The categories may also be difficult to apply within the context of a time-bound assessment. This is particularly true in the case of mental health problems, which can be fluctuating and subtle in their effects, such that an applicant and/or assessor may feel that a certain activity can be performed on the day of assessment and therefore as a general rule, when it often cannot. This may result in assessed effects seeming to falling shy of the 50% rule in terms of regularity when they do not, or when it is simply impossible to make this measurement so clinically.

"I was never allowed the opportunity to express on the application form that while I can physically carry out some activities, the lasting impact on my mental wellbeing or serious distress it would cause prevents me from doing this on a regular basis, and I therefore have to seek a carer or more expensive alternative." Survey respondent

See Me appreciates the changes the Scottish Government has put in place to mitigate some of these issues. For example, the move to allow applicants to determine assessment channel (online, paper, telephone, or face-to-face) will help to erase the stigma and self-stigma that many people have reported in face-to-face PIP assessments, and potential issues around time-bound assessment. The end of functional examinations is welcomed for the same reasons. We also appreciate the addition of a regulation requiring that a suitably qualified assessor – with mental health specialism where necessary – will carry out the assessment.

"I think some of the changes that have been announced in the draft are positive. So, things like people having the option about how assessment is done." Focus group participant

However, the measurement criteria inherited from the PIP system are too skewed towards physical disability. They are not geared to adequately capture the effects of mental health on someone's ability to perform the tasks listed, and have mental health discrimination baked into them. We would urge the reassessment of the measurement criteria to take a more holistic and person-centred approach. In particular, any system for measuring the effects of mental health on the performance of daily living and mobility tasks must explicitly acknowledge emotional or cognitive aversion to certain tasks – for example, ones that feel pressurising or traumatic – as inhibiting factors as significant as physical disability.

The required period condition: daily living component and mobility component (regulation 10 and 11) The relevant date (regulation 12) The relevant date: after an interval (regulation 13)

Q 9: Do you agree the regulations reflect this policy intent? YES

Q 10: If you have any further comments please provide them here.

With regards to regulations 10 and 11, the designation of a 52-week “required period” over which effects must be present to receive either component of ADP (13 weeks prior to and 39 *predicted* weeks following assessment) may discriminate against people with mental health problems facing award review. Mental health conditions can fluctuate such that, for example, symptoms are not experienced for a long time and are then experienced suddenly and intensely. Prior to such a relapse, it is often natural for people with mental health problems to assume or hope that problems will not return. While it is possible to argue that someone would probably not apply for ADP during a long period of positive mental health, the above description may disadvantage people already receiving ADP or PIP facing an award review during such a period, who may lose eligibility to the award before experiencing poor mental health symptoms again.

Accepting the Scottish Government’s welcome move to a light-touch rolling review system, devised with the client’s needs in mind, this definition of a required period should be qualified to take into account the highly fluctuating way in which mental health problems impact on people.

With regards to regulation 12, the requirement that the “relevant date” at which award eligibility may begin must be at least thirteen weeks after a condition begins to be experienced, is also potentially discriminatory in its oversight of the nature of mental health problems. It does not take into account the speed with which such problems can occur, often in a very severe way. Regulation 13 allows for the removal of the 13-week qualifying period in cases where an ADP or PIP claim of the same type has ended less than two years ago. This is welcome, but does not mitigate the problem outlined above, which may well apply to people experiencing mental health problems for the first time.

“Mental health doesn’t really work like that.” Survey respondent on 13-week qualifying period rule.

The requirement that an applicant must be experiencing a condition for thirteen weeks prior to ADP eligibility should be removed in cases of severely inhibiting conditions that manifest themselves suddenly such as mental health problems.

Also with regards to regulation 13, given that the effects of mental health problems can be fluctuating and irregular, two years is a short period to allow ongoing eligibility without a 13-week qualifying period following a previous ADP or PIP. There would be a case for lengthening this period to 5 years of ongoing eligibility after a previous award without the 13-week qualifying period.

Part 11: Qualifications and Experience Necessary to Carry out Assessments (regulation 38)

Q 21: Do you agree the regulations reflect this policy intent? YES

Q 22: If you have any further comments please provide them here.

We are pleased that a legal commitment has been made to providing assessors with relevant training for ADP assessments, in particular mental health training where needed (38.2.b). We are also pleased with the provisions to ensure that

assessors have had two years' experience of health and social care delivery (38.2.a.)

"Anyone doing a mental health PIP review has to have mental health training and experience in the same way that somebody dealing with someone with MS or neurological conditions would have to be in their bag as it were. So, I think a lot of those things, for me, are very positive, and I'm hopeful." Focus group participant

However, it is important to ensure that the period of two years referred is not so long ago as to render the skills gained irrelevant. For example, the development of a rights-based approach to mental health treatment is a relatively recent phenomenon in clinical, public, and third-sector policy, and an individual working in the sector some years ago may not be equipped to undertake an assessment with rights in mind. We would suggest, therefore, that the regulation is amended to ensure that the two years' experienced gained was within the last five years.

It is also important to bear in mind that many ADP applicants will have more than one condition or disability, including a mental health problem. Some of these people currently prefer to apply for PIP in relation to a physical than mental health condition, because of the very trauma associated with mental health-related PIP applications. Many non-mental health assessors will therefore be dealing with applicants whose mental health issues nonetheless impact on the way they complete an application. It is important that these applicants are not discriminated against. As such, 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.

"For the people doing these assessments, mental health training should be one of their compulsory trainings, whether they're doing physical or mental, whatever conditions they're assessing." Focus group participant

"Ensure that all assessors receive specific training on mental health, including stigma and discrimination, particularly given the number of applicants with dual conditions including mental health, where the latter is not a primary condition." Survey respondent

Liability for assistance given in error (regulation 46) Determination to effect a deduction decision (regulation 47)

Q 29: Do you agree the regulations reflect this policy intent? YES

Q 30: If you have any further comments please provide them here.

With regards to the ongoing drafting of part 15, transfer from child to adult disability benefits can be a traumatic and confusing process. Individuals may feel the burden of the transfer process is too great to bear, and fail to take up adult awards to which they are entitled. This is particularly like to be true when benefits are transferred at the young age of 16, as is the case with Disability Living Allowance for Children to PIP. Mental health problems can also make it harder to complete the transfer process, due to effects on energy, motivation, and cognitive processing. The current DLA-to-PIP transfer process is therefore potentially

discriminatory to young people with mental health problems, and should not be replicated.

Solutions the Scottish Government ought to consider include: creating a single disability payment award for children and adults; and allowing individuals to decide the point at which they transfer their award within a longer time-frame (for example, between the ages of 16 and 21), making that decision on the basis of discussion at a light-touch review falling within that period. This would prevent individuals with mental health problems falling through the cracks of the disability payment system at point of transferral.

Schedule 1 – Adult Disability Assistance Determination

Q 31: If you have any comments Schedule 1 please provide them here.

With regards to Schedule 1 Part 2, the examples of daily activity and mobility lists and terms of measurement included here are heavily biased towards the assessment of physical disability, in spite of the fact that recent PIP data (January 2019) shows that in Scotland 39.2% of all people in receipt of PIP have a psychiatric condition as their primary disability, higher than any other disability.²

This problem has many aspects to it. Firstly, although mental health problems may prevent some of the activities listed from being undertaken effectively (such as communicating verbally or reading and understanding signs words and symbols) the way in which this manifests itself may be uneven and changeable, and may not apply evenly across a single day, let alone a period of weeks or months. It may also be very hard to measure the frequency with which such symptoms have occurred and are expected to recur in order to apply the “50% rule.”

“If you start writing the application on your good days, you think oh, well, if I try really hard I could do this once, but then I’ll have to sleep for three days before I can do it again, which would actually be over 50% of the time.” Focus group participant

On top of this, the inability to undertake certain tasks may be hard to gauge at point of assessment—particularly if assessment is undertaken face to face by an individual without mental health training. For example, an assessor may feel that the applicant looks “normal”—although we would hope to see this mitigated to some extent by the emphasis on channel choice in assessment and the requirement of mental health training for relevant assessments. Someone with mental health problems may also feel they have the ability to perform certain tasks at the point of assessment in a way that is not typical of their condition.

“Assessments need to take more into account than just how you’ve turned up on the day for your assessment and how you look. On the day I went the assessor could tell I was absolutely shattered. I was in excruciating pain. But, because you’re dressed, it means you’re well-dressed.” Focus group participant

² StatXplore [Dataset PIP Claims in Payment](#) [accessed April 2019]. Quoted in SAMH, Response to: Social Security: A Consultation on Disability Assistance in Scotland, P6.

Finally, because of the physical emphasis of the tasks listed and of the measurement criteria, ADP applicants with mental health problems may feel that inability to perform a task is purely a reflection of their physical capabilities, rather than one potentially related to mood or mental state. They may therefore self-stigmatise and feel that their problems do not meet the requirements of the measurement system. In other words, the measurement system discriminates against those struggling with their mental health.

“For example, I can cook dinner in the sense that I can physically lift a pot and know how to boil water without putting myself in danger, but I cannot get out of my bed most days due to depression in order to get the pot, and the list of tasks in front of me often appear too overwhelming. I don’t know how to show that on the form.” Survey respondent

For all these reasons the list of activities in column 1 and measurement categories in column 2 of the daily living and mobility tables should be significantly amended to take account of the particular challenges that mental health problems present, which are often likely to be less about functional aptitude and more about cognitive and emotional states. The measurements should also be amended to make it clear that terms such as “can” and “cannot” can refer to emotional or cognitive mood or aversion as well as a physical aptitude. Unless they do, the measurements themselves will be seen by many to continue to unfairly discriminate against ADP applicants with mental health problems.

Q 33: If you have any comments about the proposed review of Adult Disability Payment please provide them here.

Scottish Government should not underestimate the level of frustration and trauma associated with the PIP application process by people with mental health problems across Scotland, and the desire for change to come as soon as possible. While See Me accepts Scottish Government’s reasons for not revisiting many fundamental aspects of the PIP application and assessment process until the transferral of all clients to ADP – notably the desire not to create a two-tier system – a large-scale review should happen as soon as possible.

This review should go further than many of the recommendations above. Most significantly, the PIP points-based criteria and measurement system, rather than being amended to take into account mental health, should be scrapped and replaced with a system that offers a holistic, person-centred overview of a clients’ needs. This system should be rooted in the idea of enabling human rights (such as those enshrined in the UNCRPD) and should focus on helping people to enjoy those rights to their full, rather forcing them to confront their perceived limitations in what is often a highly stigmatising way.

“To get the points, you’re forced to look at the negative sides of you, rather than the recovery.” Focus group participant.

“So, actually, to start from the ethos of assuming you should have the payment and then we’ll work out if actually there’s some of it we should be taking off or something, rather than starting with nothing and working up.” Focus group participant.

Q 35: If there is anything else you would like to tell us about the regulations, impact assessments or Adult Disability Payment in general, please do so here.

Our survey and focus group yielded many other practical suggestions for how ADP should differ from the PIP system, some of which could be incorporated into the regulation prior to the review. These included:

Offering a 'right to reply' on draft assessments prior to an award being applied:

"When you need a doctor's report for occupational health, and you have the option to see it before it's sent, and you have to consent before it goes. Something like that would be good because that generic write-up in my PIP assessment results had so much in it that you would just look at and go: no you've totally got the wrong end of the stick." Focus group participant

Inform all participants of their right to record ADP assessments and pre-emptively offer recordings to all in-person, phone, or video-based, for potential use in tribunals and appeals:

"I think that would be a good idea to make sure it's recorded. That way it's there as a hard copy and, if it comes to tribunal, they can listen to it, and both sides can be heard. I know some people do record their assessments which I've never been able to do. I think that should probably be a rule that it should be recorded by them, whether it be video recorded or just audio recorded." Focus group participant