



## **SAMH (SCOTTISH ASSOCIATION FOR MENTAL HEALTH)**

### **RESPONSE TO: SOCIAL SECURITY: A CONSULTATION ON DISABILITY ASSISTANCE IN SCOTLAND**

SAMH is Scotland's largest mental health charity. Around since 1923, SAMH currently operates over 60 services in communities across Scotland providing mental health social care support, primary care, addictions and employment services, among others. These services together with our national programme work in See Me, respectme, suicide prevention, sport and physical activity, inform our public affairs work to influence positive social change.

SAMH is delighted to respond to this consultation. SAMH has supported the devolution of non-income related disability benefits to Scotland and has played a constructive role during the Social Security (Scotland) Bill process. This included supporting the development of the Suitably Qualified Assessors provision. SAMH is also a member of the Disability and Carers Benefits Expert Advisory Group (DCBEAG).

SAMH broadly welcomes the proposals for Disability Assistance set out in the consultation, but with a number of caveats and additional suggestions. Our response is informed by a workshop attended by people supported by SAMH to gather their views about the consultation, as well as our previous research. The key points from our response are set out below:

- No-one should be forced to apply online: all application methods for the three Disability Assistances should be equally valid.
- Social Security Scotland must make sure that disabled people, including people with mental health problems, can access independent advice and advocacy.
- There must be enough Specialist Advisers whose expertise is in mental health to ensure that everyone who needs their input can get it.
- There should be no three month qualifying period for the benefits.
- People should be able to identify their primary condition in the application form.
- Reviews for people whose condition is unlikely to change should be limited to every ten years and should focus on offering additional support if needed.
- People with mental health problems should not be disadvantaged if they don't let the Agency know about a change in their circumstances because their mental health was poor at the time.
- The period people can request a redetermination should be extended to a minimum of six weeks.
- We recommend a maximum period of 28 days for the Agency to undertake a reconsideration.
- Carers should not struggle financially because the person they care for is in hospital.
- There should be a maximum rate at which money can be recovered from a person, and no-one should be left in financial crisis.
- The Scottish Government should replace the points based system in the medium to long term.
- The descriptors used to assess someone's claim do not adequately assess mental health and should be rewritten.
- The 50% rule should be abolished for all descriptors including those for daily living.
- Regulations should be introduced to allow someone to be eligible for DAWAP in exceptional circumstances even when they do not meet the point requirement for eligibility.

- We are glad to see that more people will have the right to a home assessment.

## **Section 1 - Disability Assistance in Scotland**

### **Question 1. Do you agree or disagree with the proposal to name Disability Assistance for clients aged 0-18 years old Disability Assistance for Children and Young People (DACYP)?**

Disagree.

### **Question 2. If you disagreed, please could you explain why.**

Including the term 'disabled' in the title for all three Disability Assistances may be a disincentive to take up by groups who do not consider themselves disabled, including many people with mental health problems. If the proposed names are retained the Scottish Government must ensure those potentially eligible who do not consider themselves disabled are targeted during future take up campaigns. Evidence from an DWP ad-hoc study in 2013 found that only 25.9% of people who fit the DWP's definition of disability described themselves as 'disabled' with a further 11.4% describing themselves as 'sometimes disabled'.<sup>1</sup> In regards to mental health we know that not everyone with a mental health problem consider themselves disabled.

These issues also apply to the naming on Disability Assistance for Working-Age People (DAWAP) and Disability Assistance for Older People (DAOP).

### **Question 3. Do you agree or disagree with the proposal to name Disability Assistance for clients aged 16 years old to state pension age Disability Assistance for Working-Age People (DAWAP)?**

Disagree.

### **Question 4. If you disagreed, please could you explain why.**

See answer to question two.

### **Question 5. Do you agree or disagree with the proposal to name Disability Assistance for clients who are state pension age or older Disability Assistance for Older People (DAOP)?**

Disagree.

### **Question 6. If you disagreed, please could you explain why.**

See answer to question two.

### **Question 7. Do you agree or disagree with the proposal to enable multiple application channels for Disability Assistance?**

Yes. SAMH welcomes the Scottish Government's proposals to provide a variety of application methods for Disability Assistance. Application methods should include: online; telephone; written; and face to face.

The recent damaging experience of the 'digital by default' approach to applying for and managing Universal Credit highlights the importance of having multiple, equally valid, application options. Evidence from the DWP found that 24% of people with long term conditions (including mental health problems) could not register to make an online claim to Universal Credit and 53% required support to claim online.<sup>2</sup> People with mental health or other cognitive problems also face particular challenges when having to apply for Universal Credit online

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<sup>1</sup> DWP [Ad Hoc Analysis \(table 10\)](#) 2013

<sup>2</sup> DWP [Universal Credit Full Service Survey](#) 2018

including increased anxiety and practical issues arising from their mental health problem, such as difficulty remembering log in details.<sup>3</sup> We welcome that the digital by default approach will not be used for Disability Assistance.

While we welcome the development of a personalised online application channel as outlined in the consultation document, online applications should not be the preferred method of application. All application methods should be equally valid and offered to people applying for the benefits

We know that the existing PIP application process, including the PIP1 and PIP2 forms, can be challenging for people with mental health problems. SAMH community service managers and people supported by SAMH services told us that the current process was confusing and focused on physical impairment, leaving little opportunity for people to discuss the impact of their mental health on their day to day living.<sup>4</sup>

*“Absolutely no account of mental health problems ... Asking you if you can lift a cardboard box and how many stairs you can walk up”* (SAMH Service User)<sup>5</sup>

Future application forms and processes should be co-designed with the Experience Panel to ensure they are accessible to people with mental health problems.

In line with the Scottish Social Security Charter (A People’s Service commitments 5 and 6<sup>6</sup>) the agency should be proactive in ensuring disabled people, including people with mental health problems, can access independent advice and advocacy. This support should be available at the earliest opportunity to ensure people are given the most appropriate support to complete an application for Disability Assistance.

**Question 8. If you disagreed, please could you explain why.**

N/A

**Question 9. Do you agree or disagree with the proposal to broadly replicate the current temporary absence rules?**  
Agree.

**Question 10. If you disagreed, please could you explain why?**

N/A

### **Making Decisions About Entitlement**

**Question 11. Do you agree or disagree with the proposal to implement a person-centred approach to making decisions about entitlement for Disability Assistance?**

SAMH agrees that a person-centred approach to making decisions on entitlement is required. SAMH campaigned hard during the Social Security (Scotland) Bill process for assessors in the Scottish System to have experience and expertise in mental health where the person’s primary condition was related to their mental health.<sup>7</sup> We were instrumental in the development of the Suitably Qualified Assessor provisions of the Act and welcomed the opportunity to contribute to the Disability and Carers Benefits Expert Advisory Group (DCBEAG), which has provided advice to the Government on these provisions.<sup>8</sup> We are happy that the Scottish Government

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<sup>3</sup> SAMH ‘It Was A Confusion’ Universal Credit and Mental Health:

<sup>4</sup> SAMH [Personal independence Payment: What’s the Problem?](#) 2016

<sup>5</sup> SAMH [Personal independence Payment: What’s the Problem?](#) 2016

<sup>6</sup> Scottish Government Our Charter

<sup>7</sup> SAMH [SAMH response to Social Security Committee consultation on Social Security Bill \(Scotland\)](#) 2017

<sup>8</sup> Scottish Government [Disability and Carers Benefits Expert Advisory Group: suitably qualified assessors](#) 2019

has accepted our position on the need for assessors to have relevant experience and training in mental health, which we believe will go a long way to ensuring the decision making process is person-centred and effective. We also warmly welcome the commitment from the Scottish Government to reduce the number of face to face assessments in comparison to the PIP system.

The current assessment and decision making process for PIP is not working for people with mental health problems. Through research with people affected, we know that the current assessment process, particularly the face to face medical assessment, is contributing to peoples' distress and does not adequately assess the impact of mental health problems or other fluctuating conditions.<sup>9</sup> One of the most significant issues contributing to the problems of the current PIP system is assessors' lack of understanding of or expertise in mental health.<sup>10</sup> Indeed Mind, SAMH's sister charity in England, surveyed 800 people with mental health problems on their experience of PIP. Only 8% felt that their assessor understood the impact their mental health problem had on them.<sup>11</sup> For this reason the role of the proposed Case Managers and Specialist Advisors will be critical in creating a system that is dignified, efficient and accessible, in line with the Scottish Social Security Principles.

In addition to the Case Manager training and skills requirements set out in section 4.9 of the consultation document we believe there should be a number of additions. As part of the training for "dealing with vulnerable clients, their friends and relatives" we believe all Case Managers should be provided with suicide prevention training. Disability awareness training should also include robust mental health training – both in regards to mental health awareness and on the impact of specific mental health conditions.

Identification of someone's' primary condition will be crucial to the person's evidence (written and face to face where necessary) being assessed by the most appropriate Case Manager and Specialist Advisor. We believe that the application form, for all types of Disability Assistance, should provide a clear opportunity for someone to self-declare what they believe is their primary disabling condition. Under the current PIP system the applicant's disabling conditions are only designated as primary by the Department of Work and Pensions for recording purposes and not at the initial application stage.<sup>12</sup> There is no opportunity for the applicant to self-declare their primary condition. The current PIP application (PIP2 form<sup>13</sup>) only allows applicants to list, not rank, medical and disabling conditions. We have additional comments on the role and requirements for Specialist Advisors in answer to question 13.

In our 2017 consultation submission to the Social Security Bill we called for automatic entitlement and life time awards for the new disability benefits for particular conditions.<sup>14</sup> Where entitlement is automatic based on an applicant's condition, we called for the relevant medical professional to only have to confirm the diagnosis to ensure eligibility.<sup>15</sup> Following advice from the DCBEAG we accept the Government's rationale for not incorporating a system of automatic entitlement, using instead a system of rolling awards and light touch reviews. In accordance with the Social Security Principles, recognising Social Security as a human right and placing the dignity of individuals at the heart of the system, we have a number of suggestions regarding the light touch reviews. We believe, particularly in instances where someone's condition has not changed, that the review should be an opportunity to signpost people to additional support – financial or support more generally in

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<sup>9</sup> SAMH [Personal independence Payment: What's the Problem?](#) 2016

<sup>10</sup> Mind and SAMH [Mind and SAMH submission to the Work and Pensions Committee inquiry on PIP and ESA assessments](#) 2017

<sup>11</sup> MIND [Written evidence from Mind \(PIP0016\) to Work and Pensions Committee inquiry on Personal Independence Payment](#) 2017

<sup>12</sup> House of Commons [Personal Independence Payment: Chronic Fatigue Syndrome – Written Question 119031](#) - 12 December 2017

<sup>13</sup> DWP, [Making a claim for PIP: example PIP2 form](#)

<sup>14</sup> SAMH [SAMH response to Social Security Committee consultation on Social Security Bill \(Scotland\)](#) 2017

<sup>15</sup> SAMH [SAMH response to Social Security Committee consultation on Social Security Bill \(Scotland\)](#) 2017

regards to managing the impact of their disability. We believe the reviews should be paper based except in exceptional circumstances where evidence of a change in condition cannot be gathered in written form by the Agency.

The Scottish Government's proposals for both DAWAP and DACYP replicate existing PIP rules on eligibility requiring the applicant to have had a physical or mental difficulty for at least 3 months, with an expectation it should last at least 9 months. SAMH believes that there should be no three month qualifying period for the benefits. This view is shared by the DCBEAG.<sup>16</sup> The retention of a qualifying period discriminates against people who become suddenly disabled. In line with the recommendations of the DCBEAG we agree with the premise that someone should be expected to have the condition for at least nine months, as this is in line with the purpose of Disability Assistance to mitigate the extra costs of disability.

**Question 12. If you disagreed, please could you explain why?**

N/A

**Question 13. Do you agree or disagree with our proposed approach to the involvement of Specialist Advisors in Decision Making?**

SAMH broadly agrees with the proposed role for Specialist Advisors as outlined in the consultation. During the Social Security (Scotland) Bill process SAMH contributed to the development and supported the successful amendment at stage 3 to ensure Disability Assistance assessments are carried out by "Suitably Qualified Assessors".<sup>17, 18</sup> This provision provides for the Government to make regulations determining the training; experience and particular position required for someone to be an assessor. The Act also requires different provision regarding the required training, experience, and particular position depending on what the assessment is about.<sup>19</sup> This introduces the possibility of condition specific assessors, something SAMH has called for in regards to mental health.

The DCBEAG provided advice to the Government on the training and experience requirements for suitably qualified assessors, but did not advice about holding specific particular position.<sup>20</sup> Instead the group advised that the Agency should determine what particular professional positions assessors would need to have held to meet the suitably qualified assessor criteria.<sup>21</sup> SAMH believes all three aspects of the suitably qualified assessor provisions – training, experience and holding a particular position – are important and that all Specialist Advisors should meet all three criteria.

We agree with the DCBEAG advice that training for all assessors should where possible be co-produced with people with lived experience of health conditions and disabilities.<sup>22</sup> In regards to mental health training for Case Managers this should at a minimum include general mental health awareness as well as training on how common mental health problems affect someone's functionality. Mental health training for Specialist Advisors should at a minimum include detailed information on how a broad range of common and rare mental health problems can affect someone's functionality.

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<sup>16</sup> Scottish Government [Disability and Carers Benefits Expert Advisory Group: Assessments Workstream Duration of awards](#) 2019

<sup>17</sup> SAMH [Social Security \(Scotland\) Bill Stage 3 – SAMH Briefing](#)

<sup>18</sup> SAMH Mental health assessments: disability assistance – Stage 3 Briefing 2018

<sup>19</sup> The National Archives [Social Security \(Scotland\) Act 2018 part 1 section 13](#)

<sup>20</sup> Scottish Government [Disability and Carers Benefits Expert Advisory Group: suitably qualified assessors](#) 2018

<sup>21</sup> Scottish Government [Disability and Carers Benefits Expert Advisory Group: suitably qualified assessors](#) 2018

<sup>22</sup> Scottish Government [Disability and Carers Benefits Expert Advisory Group: suitably qualified assessors](#) 2018

Evidence from the Experience Panel found that condition specific assessors were a key priority for panel members.<sup>23</sup> This view is widely shared by people we consulted who felt PIP assessments undertaken by people without a professional background in mental health contributed to an inappropriate focus on physical functionality and increased distrust in the PIP assessment process.<sup>24</sup> It is crucial that this distrust is not replicated in the new Scottish System and that people with mental health problems are treated fairly, with dignity and respect.

We believe the Scottish Government and Agency should take further advice from health and disability experts, as well as people with lived experience to determine a list of particular positions that Specialist Advisors should hold to meet the criteria under the Act as suitably qualified. This should include:

- Social Workers with a mental health expertise (e.g. Mental Health Officer)
- Occupational Health professionals with a mental health specialism
- Social care staff with a mental health specialism (including those employed in the third sector)
- Community Psychiatric Nurses
- Psychiatrists
- Psychologists

We believe that Specialist Advisors should either currently be working in the particular professional role or have previously been working in the role within the three years prior to becoming a Specialist Advisor. This will ensure the skills and knowledge gained through the particular professional position are still relevant.

The Scottish Government has proposed that a proportion of Specialist Advisors will be trained specifically in the impact of mental health conditions, to enable them to carry out face-to-face assessments of people with these conditions (section 4.9 of consultation). This is very welcome. The latest 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.<sup>25</sup> It is essential that the Scottish Government recruits and trains an adequate proportion of Specialist Advisors with a mental health expertise to ensure all applicants with a mental health problem benefit, in time for new Disability Assistance opening for new claims in 2020/21.

**Question 14. If you disagreed, please could you explain why.**

N/A

**Question 15. What factors should Case Managers take into account in deciding when a Specialist Advisor should be involved?**

Where a gap (or conflict) in evidence relates to mental health then a Specialist Advisor should always be used

Ensuring Specialist Advisors are correctly deployed will be critical to delivering a fair, consistent determination process, both when examining the application and any additional written evidence, and when undertaking a face to face assessment. We agree with the approach set out in the consultation paper that Case Managers should take advice from Specialist Advisors where: there is conflicting evidence on someone's functionality (including conflicts between diagnosis and reported functionality); co-morbid conditions; complex/rare conditions; or where the applicant has a fluctuating condition.

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<sup>23</sup> Scottish Government [Social security experience panels - About Your Benefits and You: qualitative research findings](#) 2018

<sup>24</sup> SAMH [Personal independence Payment: What's the Problem?](#) 2016

<sup>25</sup> StatXplore [Dataset PIP Claims in Payment](#) [accessed April 2019]

Specialist Advisors' input should not be limited to cases where a face to face assessment is required, though any face to face assessment should be undertaken by a Specialist Advisor. We welcome the commitment to reduce face to face assessments and believe they should only be carried out where there is a clear purpose. We propose this should be either to fill in any gaps in information which can't be gained through additional written evidence; or where there appear to be discrepancies between the person's reported condition and the impact of the condition they describe.

The 2017 second independent review of the personal independence payment assessment found that there were substantial problems with the consistency of outcomes of assessment, including through the inconsistent use of additional evidence and difference in approach of individual assessors.<sup>26</sup> To help avoid these inconsistencies being replicated in the Scottish system, the role of condition specific Specialist Advisors will be key. The independent review found that the approach of individual assessors when determining functional impairment could disadvantage particular groups – principally those with fluctuating conditions including mental health problems, by not always allowing opportunities for the applicant to articulate impairment against the descriptors in a personalised way.<sup>27</sup>

As outlined in question 11 we believe people should be able to identify their primary condition in the application form. Specialist Advisors, with specialist training, experience and professional experience in mental health should be used for all applicants where their main condition relates to their mental health and where there is a gap in information or discrepancies in their evidence relating to their mental health. This is of particular importance if, as the Scottish Government plans, Disability Assistance remains a point based system like PIP, due to the challenges of correctly applying a descriptor based system to, often fluctuating, mental health problems.

**Question 16. Do you agree or disagree that the decision making process for Disability Assistance for Children and Young People, and for Older People should use existing supporting information and not through face-to-face assessments?**

Yes. We agree that decisions for Disability Assistance for Children and Young People (DACYP) and for Older People (DAOP) should use existing supporting information and not face-to-face assessments. We note that eligibility for DACYP and DAOP will broadly mirror current eligibility criteria for Child DLA and Attendance Allowance (AA) so will not be based on a points based system. The Scottish Government should appraise the accuracy of decision making of DACYP and DAOP to determine if similar assessment approaches could replace the planned points based structure of Disability Assistance for Working Age People (DAWAP) in the long term, following the safe and secure case transfer of people currently in receipt of PIP. This would allow a long term aspiration for no face to face assessments for DAWAP.

**Question 17. If you disagreed, please could you explain why.**

N/A

**Question 18. What types of supporting information would be relevant in assessing an application for Disability Assistance eg. social work report, medical report?**

During the consultation for the Social Security (Scotland) Bill SAMH called for assessments to be paper based where possible, using a wide range of additional evidence.<sup>28</sup> We warmly welcome the commitment from the Scottish Government that this will be the case, and that the rate of face to face assessments will be substantially

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<sup>26</sup> Paul Gray [The Second Independent Review of the Personal Independence Payment Assessment](#) 2017

<sup>27</sup> Paul Gray [The Second Independent Review of the Personal Independence Payment Assessment](#) 2017

<sup>28</sup> SAMH [SAMH response to Social Security Committee consultation on Social Security Bill \(Scotland\)](#) 2017

reduced. In common with other third sector disability organisations we believe that where possible someone's own explanation of the impact of their disability (including their mental health problem) should be central to determining eligibility. Despite this, the role of additional evidence will be crucial to ensuring fair decisions on eligibility. For example we know that people with mental health problems may not always recognise or be able to confidently articulate the full impact of their mental health problem on their daily living and mobility – particularly if this evidence is being assessed against a set of descriptors which may not appear relevant to the person. The role of additional evidence will be crucial to provide a more complete picture of the person's functionality and impact of their mental health.

We agree with the advice from the DACBEAG that there should be no hierarchy of additional evidence. In particular, medical evidence should not be privileged above other sources of evidence including from the person's families and friends, who may have a greater understanding of the impact of the person's disability on their day to day life. Not everyone applying for the various Disability Assistances will have a medical diagnosis. As eligibility will be based on an assessment of functionality, it should be possible to make robust decisions on eligibility from evidence (including self-assessment) of the impact of their impairment or condition. Diagnostic evidence should be used only to support an understanding of the person's functionality.

In our view sources of evidence should include information which confirms the person's own account, including diagnostic information (if the person has a diagnosis), and information which supports the person's self-assessment or their functionality, for example from family or friends. The Agency should provide guidance of the types of evidence that are and are not useful. Examples of specific sources related to mental health should include:

- Medical reports from practitioners/services in contact with the applicant. For example reports from the person's GP; Community Mental Health Team (CMHT); psychiatrist; psychological service; occupational health service reports
- Social Care reports. For example reports from the person's social worker; recent social care assessment report, summary of existing/recent social care package
- Third sector care providers: for example reports summarising care package and evidence from service staff/key worker
- Previous social security reports. For example Access to Work packages and past DWP assessments (where consent is given)
- Accounts from family and friends

We welcome the Government's commitment that where possible the Scottish Social Security Agency will assume responsibility for gathering additional evidence (4.11 of consultation). This represents a substantive improvement from the PIP system where the applicant is responsible, often at cost, for gathering additional evidence to support their claim. Consequentially where someone chooses to gather additional evidence the Agency should make it clear to them that if possible the Agency will gather the information on their behalf. For people with mental health problems, gathering additional information can be a particular challenge. Citizen Advice Scotland reports that their clients have difficulties obtaining additional evidence in the current system. CAB advisors found evidence could be gathered from mental health providers with ease in only 23% of cases, with difficulty in 59% of cases, and with great difficulty in 18% of cases.<sup>29</sup>

To ensure a person centred approach, the Agency should gain consent from the person, ensuring full data protection compliance, before gathering additional evidence.

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<sup>29</sup> CAB Scotland [Burden of Proof: The role of medical evidence in the benefits system](#) 2017



It may be beneficial for the Agency to gather past DWP assessment reports (for example Employment Support Allowance reports), where they present an accurate source of information on the persons functionality. Due to the lack of trust many people with mental health problems have with the DWP, and possible distressing previous DWP benefit assessment any sharing of past DWP assessment reports should only be undertaken with the person's consent. Evidence from the Experience Panel found that two thirds wanted previous DWP evidence to be used by Social Security Scotland while 35 per cent did not.<sup>30</sup> Panel members raised concerns about the accuracy of previous DWP reports and the distress DWP assessments caused.<sup>31</sup>

### **Duration of Awards**

#### **Question 19. Do you agree or disagree with the proposal to have no set award durations but to set an award review date when a decision on a Disability Assistance application is made?**

Yes. We agree with the Government's general position that there should be no end dates to awards, with award review dates in place instead.

The frequency of short term awards under the current UK PIP system, and the need for lengthy reassessments, including face to face assessment is a cause of distress for many people.<sup>32</sup> This can be a particular problem for people with mental health problems such as depression or anxiety where short term awards of two years or less are often granted.<sup>33</sup> We would expect that in most cases, two years would be too short. For people applying for (or currently in receipt of) both PIP and ESA the problem of repeated and frequent assessment is compounded.

We welcome the Government's position that reviews will be "light touch" in an effort to minimise stress and are happy that payment of Disability Assistance will not stop while a review is underway.<sup>34</sup> As with determining initial eligibility, we believe the Scottish Social Security Agency should be responsible for the collection of any additional evidence during a review. Face to face assessments should also not be required during a review.

#### **Question 20. If you disagreed, please could you explain why.**

N/A

#### **Question 21. Do you agree or disagree with the proposal to set an award review date 5-10 years in the future for a person with a condition unlikely to change?**

Five to ten years is an appropriate minimum length prior to a review, unless there is clear evidence that the person's condition is likely to change within a shorter period. For people whose condition is unlikely to change we believe there should be very limited occasions where shorter review periods are given (for example where someone has a degenerative condition), with clear guidance to decision makers reflecting this.

We agree with recommendations from the DCBEAG that where the Agency reviews an award prior to the review date the Agency should have to justify this.<sup>35</sup> We also agree with the recommendation that the Agency should have to publish the number of early reviews undertaken, to allow audit and continual improvement of the review process.

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<sup>30</sup> Scottish Government [Social Security Experience Panels: award duration and automatic entitlement](#) 2018

<sup>31</sup> Scottish Government [Social Security Experience Panels: award duration and automatic entitlement](#) 2018

<sup>32</sup> SAMH [Personal independence Payment – What's the Problem?](#) 2016

<sup>33</sup> Mind [Mental health problems and benefits reassessments](#) 2017

<sup>34</sup> Scottish Government [Scottish Government Position Paper: Duration of Awards and Automatic Entitlement for Disability Assistance](#) 2019

<sup>35</sup> Scottish Government [Disability and Carers Benefits Expert Advisory Group: award duration](#) 2019

Setting appropriate review periods for people with mental health problems or other fluctuating conditions should require guidance from Specialist Advisors with training and professional experience in mental health, informed by the person's additional evidence. While mental health often fluctuates, guidance to decision makers on review periods should ensure that the long term prognosis of someone's health is the determining factor when setting the timescale of review. The probability of short term improvements in mental health should not justify short review periods.

A similar provision to the 'severe conditions guidance' for ESA could be used to achieve long term awards.<sup>36</sup> This Guidance, introduced in 2017, outlines where someone in the ESA Support Group or Universal Credit LCWRA group will not have to undergo reassessment. This is a four condition test requiring the person to have: a lifelong condition; level of function that they will always meet the Support Group/LCWRA threshold; no realistic prospect of recovery of function; and an unambiguous condition with recognised diagnosis.<sup>37</sup> Someone with schizophrenia is provided as an example in the guidance as someone who may qualify for the provision.<sup>38</sup> A similar provision for Disability Assistance should be developed to remove the need for review from people with long-term conditions which are unlikely to change. Guidance developed for the Agency around an 'Exceptional Circumstances' provision in regards to mental health would need to reflect the fact that in most cases people can recover from mental health problems, and live full independent lives. This provision should therefore only be applicable to those in the limited circumstances where evidence is clear a functional recovery would not be possible.

**Question 22. If you disagreed, please could you explain why.**

N/A

**Question 23. Do you agree or disagree with the proposal that a change of circumstances should be defined as a change which has an impact on the level of assistance a person receives?**

SAMH agrees with the definition of a change of circumstance and welcomes the fact that a change in address or employment status will not be regarded as a change of circumstances.

Changes in circumstances can be challenging for people with mental health problems, as can engaging with official systems and processes. Regulations need to be developed that are inclusive and do not stigmatise or punish people who have made a mistake in the notification process due to their mental health. A flexible approach should be taken in regards to section 72 of the Act which makes failure to notify a change of circumstance an offence.<sup>39</sup> For example the "reasonable excuse" provision in section 77 (1(a)) should be inclusive of medical reasons for failure to recognise and notify a change in circumstance.

SAMH believes that where someone notifies the Agency of a change of circumstance or requests a review of their entitlement, they should be afforded the right to appeal at all stages of the process, at a minimum replicating the UK system. This should include an opportunity to appeal a decision by the Agency if it decides not to undertake a review.

**Question 24. If you disagreed, please could you explain why.**

N/A

**Rate if Benefits and redetermination**

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<sup>36</sup> Disability Rights UK, [Guidance on Work Capability Assessment reassessment](#) 2017

<sup>37</sup> Disability Rights UK, [Guidance on Work Capability Assessment reassessment](#) 2017

<sup>38</sup> Mind [Mental health problems and benefits reassessments](#) 2017

<sup>39</sup> National Archives [Social Security \(Scotland\) Act 2018 section 72](#)

**Question 25. Do you agree or disagree with the proposal that clients have 31 days to request a redetermination?**

Disagree.

**Question 26. If you disagreed, please could you explain why.**

SAMH believes the period people can request a redetermination should be extended to a minimum of six weeks. Some people may require significant support and advice when considering whether to request a redetermination. We feel that 31 days may not be sufficient to ensure access to advice and advocacy support.

**Question 27. We have proposed that Social Security Scotland have a period of between 40 and 60 days to consider a redetermination of Disability Assistance. Do you agree or disagree with this proposal?**

Disagree.

**Question 28. If you disagreed, please explain why**

SAMH welcomes the fact that there will be a maximum period for the Agency to undertake a redetermination. This is an improvement on the UK system where there is no limit to the time the DWP can take to complete a mandatory reconsideration.<sup>40</sup>

However, SAMH believes 40 to 60 working days is too long a period for the Agency to consider a redetermination. Two months is an excessive period for someone to be left without certainty over their award level or eligibility. We recommend a maximum period to undertake a reconsideration of 28 days.

#### **Short-term Assistance**

**Question 29. Do you agree or disagree that STA should not be paid to people who are not living or present in Scotland?**

Agree

**Question 30. If you disagreed, please could you explain why**

N/A

**Question 31. Do you agree or disagree that STA should not be recoverable except where it is later established that the principal assistance type was claimed fraudulently when STA was awarded?**

Agree

SAMH agrees that STA should not be recoverable except in cases of fraud. Any recovery beyond cases of fraud would undermine the purpose of STA in supporting someone financially, for example during appeal, as it would be a disincentive to challenge decisions regarding their Disability Assistance.

Where someone has been found to have claimed their original Disability Assistance award fraudulently, we believe that the Agency in line with the principles of the Act should take a human rights and person centred approach to recovery of STA. Rates of recovery should be set to a level that would not leave the person destitute.

**Question 32. If you disagreed, please could you explain why.**

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<sup>40</sup> Citizens Advice [Challenging a benefit or tax credit decision - asking for a mandatory reconsideration](#) [accessed May 2019]

N/A

**Question 33. Do you agree or disagree that STA should not be available where an investigation by Social Security Scotland has determined that the original payment was claimed fraudulently?**

Agree

**Question 34. If you disagreed, please could you explain why**

N/A

**Question 35. Do you agree or disagree that any deductions being made from an on-going assistance type to service an overpayment liability should also be applied to STA?**

Agree

**Question 36. If you disagreed, please could you explain why.**

N/A

**Question 37. Do you agree or disagree that for successful process decision appeals where the tribunal has overturned Social Security Scotland's decision, STA should become available at the point the decision is overturned rather than the date of the original request?**

Agree

**Question 38. If you disagreed, please could you explain why.**

N/A

### **Breaks in Disability Benefits**

**Question 39. Do you agree or disagree with the proposed approach that, generally, where there is a break in a client's eligibility to receive the benefit, eg. due to being in residential care, they will cease to receive the benefit?**

SAMH is a social care provider. People in our residential supported accommodation services will meet the criteria for breaks in Disability Assistance care component. We agree with the proposed with the criteria for a break set out by the Scottish Government, which broadly mirror the current UK system for PIP. As in the current PIP system we welcome that the mobility component of DAWAP will continue to be paid where someone is living in a residential setting for care.

As in the current UK system for PIP it is crucial that people retain an underlying entitlement to Disability Assistance while on a break. Once conditions for a break are no longer met (e.g. discharge from hospital or supported accommodation) full payment of Disability Assistance must be resumed at the earliest opportunity. The consultation document does not make it clear if the PIP 'linking rules' regarding breaks in eligibility will be mirrored in the Scottish system. Under PIP, spells in hospital are linked if the gap between them is no more than 28 days. The daily living component for spells in a care home is also linked if the gap between them is no more than 28 days.<sup>41</sup> This means that someone loses eligibility for the care component of PIP if the total of the linked spells is over 28 days, rather than 28 days after the latest admission to hospital or social care accommodation. We believe breaks in eligibility should occur 28 days after the latest admission rather than after a total of shorter admissions.

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<sup>41</sup> DWP [Personal Independence Payment \(PIP\) handbook](#) 2018

The Scottish Government should ensure breaks in Disability Assistance do not negatively affect carers. Current eligibility to Carers Allowance requires the person being cared for to be in receipt of the PIP daily living component or the middle or highest care rate of DLA.<sup>42</sup> Carers Allowance – which may be a carer’s only source of income - is stopped where there is a break in the cared for person’s PIP or DLA. We believe this is unjust and does not reflect the day to day experience of carers whose responsibilities do not stop just because someone is in hospital or social care. Eligibility for Carers Allowance (and the carers supplement) should be retained during breaks in Disability Assistance, once responsibility for Carers Allowance is devolved.

**Question 40. If you disagreed, please could you explain why.**

N/A

### **Overpayments and Deductions**

**Question 41. Please outline any comments or experience you would like to share with us about overpayment recovery and the current DWP approach to deductions?**

SAMH recently published research on Universal Credit and mental health – “It Was A Confusion” Universal credit and Mental health Recommendations for Change.<sup>43</sup> One of the findings of the report was the adverse effects, in terms of finances and mental health, of high and inflexible repayment rates for overpayments or advance payments. Under the Universal Credit system, the rate of repayment is high - up to 40% of a standard monthly Universal Credit payment or 15% if someone is not in any employment. The repayments are automatically deducted from someone’s Universal Credit.<sup>44</sup>

The impact of these rates of repayment is can exacerbate financial hardship, debt and increase emotional distress over an extended period of time.<sup>45</sup> We believe that recovery under the Scottish Social Security system should be person centred, flexible and not leave anyone in financial or emotional crisis. We believe there should be clear maximum and minimum rates of repayment, established in regulations, with the person having a right to change the rate during the period of repayment. Maximum and minimum repayment rates should be developed through consultation with people affected by disability and other stakeholders. The person, in partnership with the Agency, should be able to set the repayment schedule in a person centred manner, to minimise any negative financial and emotional effects.

### **Disability Assistance for Children and Young People (DACYP)**

**Question 42. Do you agree or disagree with our proposal to provide entitlement to Disability Assistance for Children and Young People to clients aged 0-18 years?**

Agree

**Question 43. If you disagreed, please could you explain why.**

N/A

**Question 44. Do you agree or disagree with our proposal to extending eligibility, for those in receipt of Disability Assistance for Children and Young People before the age of 16, to age 18?**

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<sup>42</sup> UK Government [Carer's Allowance](#) [accessed May 2019]

<sup>43</sup> SAMH [“It Was A Confusion”](#) 2019

<sup>44</sup> UK Government. (2013) The Social Security (Overpayments and Recovery) Regulations 201. <http://www.legislation.gov.uk/ukxi/2013/384/contents/made> [accessed January 2019]

<sup>45</sup> SAMH [“It Was A Confusion”](#) 2019

Agree

**Question 45. If you disagreed, please could you explain why**

N/A

**Question 46. Do you agree or disagree with our approach to the eligibility rules for the different components of Disability Assistance for Children and Young People?**

Disagree

**Question 47. If you disagreed, please could you explain why.**

The current case load for child DLA recipients compared to adult PIP recipients contrasts significantly by primary disability. Latest figures show that the largest group of people in receipt of PIP in Scotland are people with a psychiatric condition, 39.2% of all cases in payment<sup>46</sup>. This compares to 22.5% of DLA recipients in Scotland between the ages of 0-18 receiving the benefit due to their mental health.<sup>47</sup> Of those receiving due to their mental health 48.4% have a behavioural disorder and 47.5% Hyperkinetic Syndrome (ADHD).<sup>48</sup>

We know that mental health is a significant issue for young people in Scotland, with half of all mental health problems in adulthood beginning before the age of 14; and three quarters before 25.<sup>49</sup> Eligibility criteria for DACYP need to be inclusive to young people with a mental health problem.

We are concerned that criteria as drafted does not adequately provide opportunity for people and their families to share the impact of the young person's mental health. In particular the criteria for middle rate care component focuses almost exclusively on physical functionality (e.g. supervision in connection with bodily functions). We believe the Scottish Government should consult with the Experience Panel and other stakeholders to coproduce eligibility criteria for DACYP which is more inclusive of mental health. Guidance for Case Managers and Specialist Advisors must be produced to assist them to apply the eligibility criteria to young people with mental health problems.

**Question 48. Do you agree or disagree with the proposal to make a £200 Winter Heating Assistance payment to families in receipt of the highest rate care component of Disability Assistance for Children and Young People?**

Agree

**Question 49. If you disagreed, please could you explain why.**

N/A

**Disability Assistance for Working Age People (DAWAP)**

**Question 50. Do you agree or disagree with our proposal to use a points based system to assess eligibility in relation to Disability Assistance for Working-Age People?**

Agree in the short term, subject to revision of the descriptors.

SAMH is clear that the current PIP system is not working for people with mental health problems. One of the biggest problems with PIP is the assessment's inaccurate application of the persons experience and evidence

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<sup>46</sup> StatXplore [Dataset PIP Claims in Payment](#) [accessed April 2019]

<sup>47</sup> StatXplore [DLA Cases in Payment – Data from May 2018](#) [accessed April 2019]

<sup>48</sup> StatXplore [DLA Cases in Payment – Data from May 2018](#) [accessed April 2019]

<sup>49</sup> Kim-Cohen et al., 2003; Kessler et al., 2005

against the descriptors, resulting in incorrect scoring.<sup>50</sup> It is clear from the high number of successful appeals against PIP decisions (73% of PIP appeals October –December 2018<sup>51</sup>) that the system as currently constituted is not working effectively.

We believe that in the medium to long term the points based system should be replaced.

While recognising the importance of the safe and secure transfer of people currently receiving PIP and DLA we believe that the retention of a points system will only be acceptable if the descriptors are substantially altered in comparison to current PIP descriptors. This is necessary to allow equal opportunity for the impact of mental and physical health to be accurately reported. We provide a detailed comment on the PIP descriptors in our answer to question 53.

Alongside producing an improved set of descriptors, a points based system will only be acceptable if those applying the descriptors through the assessment process have adequate experience and training in mental health. As outlined in our answers to questions 11-15, we believe the suitably qualified assessor provisions will be able to achieve this.

We welcome the Government's desire to move away from the "50% rule" (considered over a 12-month period, looking back 3 months and forward 9 months) for qualification against descriptors. The consultation outlines the Government's concerns with the rule in regards to mobility activities. SAMH believes that the 50% rule should be abolished for all descriptors including those for daily living. Mental health conditions often fluctuate, this and practical problems with memory and recall can make it difficult for people with mental health problems to accurately determine what proportion of time they are unable to complete an activity (outlined in a descriptor).

Indeed case law (Case No UK/972/2015) has found that in the case of comorbid conditions mathematical probability theory may be needed to calculate whether someone satisfies the 50% rule.<sup>52</sup> If a points system is retained, SAMH is in favour of points to be awarded against descriptors based on a broader more holistic analysis of the person's circumstances.

SAMH believes that if a points based system is retained, regulations should be introduced to allow someone to be eligible for DAWAP in exceptional circumstances even when they do not meet the point requirement for eligibility. This would be a safeguard against potential serious harm from being found ineligible for DAWAP. This provision would mirror regulation 29 of the Employment and Support Allowance Regulations where someone who fails to achieve enough points to be placed in the Limited Capability For Work group (LCW) from must still be treated as having limited capability for work if they suffer from some specific bodily or mental disablement which means there would be a substantial risk to their health, if they were found not to have LCW.<sup>53</sup>

**Question 51. If you disagreed, please could you explain why.**

N/A

**Question 52. Do you have any suggestions about the most appropriate way to assess eligibility in relation to mobility for Disability Assistance for Working Age People?**

The DAWAP application and assessment process must be designed to allow the impact of someone's mental health on their mobility to be accurately assessed. Stigmatising changes to PIP regulations, (reversed after legal

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<sup>50</sup> Mind and SAMH [submission to the Work and Pensions Committee inquiry on PIP and ESA assessments](#) 2017

<sup>51</sup> Ministry of Justice [Tribunals and Gender Recognition Statistics Quarterly, October to December 2018 \(Provisional\)](#) 2019

<sup>52</sup> Tribunals Judiciary [AK v Secretary of State for Work and Pensions Case No UK/972/2015](#)

<sup>53</sup> National Archives [The Employment and Support Allowance Regulations 2008 regulation 29](#)

challenge<sup>54</sup>), highlighted the challenges to adequately assessing someone's mobility in relation to their mental health in the current system. These changes meant people who experienced psychological distress when making a journey were awarded fewer points than people requiring support to make journeys due to their physical disability.<sup>55</sup>

Even following the reversal of the 2017 changes to the PIP regulations, only two descriptors (Planning and following journeys (b) and (e)) used to assess mobility have clear relevance to mental health. In both instances these refer to psychological distress to people in regards to making "any journey". We believe this is overly restrictive and does not cover the full circumstances where someone's mental health may impact their mobility. For example, this may be due to the side effects of medication. New mobility descriptors should be co-produced with people with mental health problems as well as expert stakeholders.

Guidance to Case Managers and Specialist Advisors should also be co-produced with people with lived experience of mental health problems to ensure any set of mobility descriptors apply in a non-discriminatory way.

**Question 53. Do you have any comments on the full list of descriptors (provided at page 36) currently used to assess claims for Personal Independence Payments?**

As outlined in our answer to question 50, we do not believe the descriptors for PIP adequately allow the impact of someone's mental health on their daily activity and mobility to be assessed. If retaining a points based system we believe at a minimum the descriptors need to be rewritten to better allow the impact of mental health to be assessed. This should be done in partnership with people with lived experience and stakeholders across the disability and mental health sector.

The descriptors as currently used in PIP are primarily focused on physical functionality. Where mental health and cognitive function more broadly is assessed, the focus is generally on whether the person requires 'prompting' or 'supervision' when undertaking a daily activity. In our view this narrows the impact of someone's mental health problems, in the context of the descriptors, to one of the person's motivation. For example, in regards to the daily activity descriptors, "psychological distress" is only used once, in relation to the activity 'Engaging with other people face-to-face'. Other daily activity such as "taking nutrition" and "managing therapy or monitoring a health condition" do not have an associated psychological distress descriptor – despite these activities being likely to cause psychological distress to a cohort of people with mental health problems (e.g. people living with an eating disorder will likely find preparing meals and taking nutrition highly distressing, which goes beyond a need for prompting).

When designing a new set of descriptors, learning should be taken from the 2013 Evidence Based Review of the Work Capability Assessment.<sup>56</sup> While this review and trial was in relation to ESA, its findings have relevance to PIP descriptors and scoring methodologies. The purpose of the trial was to improve the assessment of fluctuations in physical and mental health conditions, and the effects of cognitive limitations on work-related functioning.<sup>57</sup> The 2013 trial used an alternative version of the work capability assessment (including descriptors and how the frequency of impairment/limitation was scored) that was developed by specialist disability

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<sup>54</sup> Mind [PIP ruling a 'victory for people with mental health problems', says Mind](#) 2017

<sup>55</sup> UK Government [Changes to Personal Independence Payment regulations](#) 2017

<sup>56</sup> DWP [Evidence Based Review of the Work Capability Assessment A study of assessments for Employment and Support Allowance](#) 2013

<sup>57</sup> DWP [Evidence Based Review of the Work Capability Assessment A study of assessments for Employment and Support Allowance](#) 2013



representative groups including our sister charity Mind.<sup>58</sup> The trial found that people using the alternative assessment were more likely to score points and the assessment was also more likely to pick up limitations with specific areas of functioning even if they were relatively moderate or would not affect work capability.<sup>59</sup> The alternative assessment also resulted in greater satisfaction from people assessed during the trial in comparison to the standard WCA. We were disappointed the UK Government did not implement the alternative assessment following conclusion of the trial.

### **Face to face Assessment DAWP**

#### **Question 54. What types of observations, as part of a face to face assessment, do you believe are inappropriate?**

People who are supported by SAMH services, including those who attended our recent workshop regarding the consultation, have told us that the use of informal observations as part of their PIP assessment has been highly distressing and at times stigmatising.<sup>60</sup> Similar experiences have been reported by our sister charity Mind.<sup>61</sup> Experiences reported by people supported by SAMH and Mind included assessment reports containing comments about the person's demeanour, punctuality and cleanliness:

*"It said I was well-kempt, I was an average build, although I said both hands shook she noticed only one shook, [the report said] she volunteers so it shows I can do familiar journeys"* (SAMH service user)<sup>62</sup>

A person's appearance is not an indication of their mental health, and how someone seems during an assessment will not necessarily reflect how they are on most days or in most situations. It is entirely inappropriate for these observations to make up any part of the assessment process.

We believe the use of informal observations should only be used within a clear framework, recognising that assessors will make observations on a human level. Guidance should be produced (in partnership with people with lived experience of disabilities) regarding the use of observations in a face to face assessment. We believe this should instruct assessors to verbalise (and so formalise) their observation to the person being assessed in order to allow the opportunity to comment on the observation. Clear information should be provided to the person being assessed on how observations will be used and what impact they will have on any decision. All observations should be recorded and all observations should be strictly limited to the assessment itself. Observations should not be allowed regarding someone's journey to the assessment or their behaviour in the waiting room etc.

All assessors should be provided detailed training on informal observations and unconscious bias to mitigate the risks of assessor bias.

#### **Question 55. In relation to assessments, what are your views on acceptable distances to travel?**

Travel to PIP face to face assessment can be distressing for people with mental health problems. Assessment centres are often in unfamiliar areas and at substantial distances from the person's home, adding to the overall anxiety and distress of the assessment process.<sup>63</sup> Many people with mental health problems also have

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<sup>58</sup> DWP [Evidence Based Review of the Work Capability Assessment A study of assessments for Employment and Support Allowance](#) 2013

<sup>59</sup> DWP [Evidence Based Review of the Work Capability Assessment A study of assessments for Employment and Support Allowance](#) 2013

<sup>60</sup> SAMH [Personal independence Payment: What's the Problem?](#) 2016

<sup>61</sup> Mind and SAMH [submission to the Work and Pensions Committee inquiry on PIP and ESA assessments](#) 2017

<sup>62</sup> SAMH [Personal independence Payment: What's the Problem?](#) 2016

<sup>63</sup> SAMH [Personal independence Payment: What's the Problem?](#) 2016

difficulties using public transport due to their condition making it difficult and costly for them to attend their assessment.

We welcome the Scottish Government's commitment to introduce choice and flexibility into the assessment process including greater rights to a home assessment. In terms of an acceptable distance to travel we believe this should be handled in a person centred manner, with everyone given the opportunity to change their allocated assessment centre irrespective of distance.

Any travel costs associated with attending an assessment should be paid in advance, or if necessary be repaid at the time of the assessment.

**Question 56. What other circumstances should the Agency take into account?**

In line with the previous answer, where travelling to an assessment centre (irrespective of distance) will cause a person psychological distress they should be offered a home assessment.

**Question 57. In relation to assessments, how many times to do you think an individual should be able to reschedule, or fail to attend, an appointment?**

Similar to our position on acceptable distance to travel for an assessment, the number of opportunities to reschedule should be person centred depending on the individual's circumstances. This would be caveated by a requirement for a "good reason" for multiple reschedules, including the impact of their health.

In regards to failure to attend, SAMH believes that a flexible approach must be taken, with the Agency proactively contacting the person to enquire about reasons for failing to attend. In cases of failure to attend alternative arrangements, including assessment location and home assessments, should be proactively offered. Ending someone's claim due to failure to attend an assessment should only be done after a rigorous investigation by the Agency into the circumstances for regular failure to attend. No one should lose eligibility if they fail to attend due to their health or disability.

**Question 58. In relation to a missed assessment, do you have any comments on what should amount to exceptional circumstances (e.g. hospital admissions)?**

In line with the Social Security Scotland principles and person centred approach, exceptional circumstances should be generously understood. Examples should include hospital admission or medical appointments, deterioration of health making attendance challenging, recent trauma, bereavement and caring responsibilities.

**Question 59. Please provide any comments you wish to make about the audio recording of assessments.**

We welcome the Scottish Government's decision to record face to face assessments as standard. We believe this will help build trust and transparency in the assessment process. While we welcome the commitment to record, there must be an option to opt out. We know that paranoia can be a distressing symptom of some mental health problems, such as psychosis, which may be exacerbated by the presence of recording equipment. People should be made aware of the recording in advance of their assessment with an option to opt out.