

# Health and Social Care Alliance Scotland (the ALLIANCE)

## Scottish Government Consultation Response: Draft Adult Disability Payment Regulations March 2021

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### Introduction

The Health and Social Care Alliance Scotland (the ALLIANCE) welcomes the opportunity to respond to this consultation by the Scottish Government on draft regulations for the forthcoming Adult Disability Payment (ADP). The ALLIANCE is a national third sector intermediary for a range of health and social care organisations, as well as disabled people, people living with long term conditions and unpaid carers.

### Daily Living Component and Mobility Component (regulations 4 and 5)

#### Q 5: Do you agree the regulations reflect this policy intent?

Yes

#### Q 6: If you have any further comments please provide them here.

Although these descriptions are in keeping with the ‘safe and secure transition’ approach, as part of a future review, the ALLIANCE would recommend the approach to the design of Adult Disability Payment is reviewed to reflect a rights based approach and the social model of disability. The current approach, which describes a person’s condition as limiting their ability to carry out daily living or mobility activities is not in keeping with this – it is society’s barriers that limit disabled people’s, rather than their condition.<sup>1</sup>

#### 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?

No

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<sup>1</sup> [Beyond a Safe and Secure Transition: A Long Term Vision for Disability Assistance in Scotland](#) – Scottish Campaign on Rights to Social Security, August 2020.

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

Whilst there are areas of the regulations that largely replicate those for Personal Independence Payment due to the safe and secure transition approach, the ALLIANCE recommends that the current '20 metre rule' for mobility, and '50% rule' specifying for how long descriptors must be fulfilled, should be revised from the outset of Adult Disability Payment.

ALLIANCE members and other stakeholders have repeatedly raised concerns about the requirement for a person being unable to walk more than 20 metres to qualify for the enhanced mobility rate of PIP. As MS Society have noted, the reduction in support as a result of the introduction of the rules had a negative effect on their condition, required people to increase their use of GP services, and reduce spending on food and therapies. They also calculated that the rule increased, rather than reduced, the cost to government due to additional costs to the NHS<sup>2</sup>. There is no clear evidence-based rationale for making the criteria 20 metres in Adult Disability Payment, and the ALLIANCE would recommend it is increased to 50 metres to qualify for the enhanced rate.

Similarly, the ALLIANCE believes that the '50% rule' should be revised at this stage to address the problems it has created in the current system for people living with fluctuating long term conditions. Although people may not experience symptoms on at least 50% of days, the barriers they face – and consequent requirement for financial support - remain due to being unable to predict when 'good days' and 'bad days' will occur. The ALLIANCE recommends the rule should be amended to avoid a reference to an arbitrary figure of 50%.

In addition, longer term changes should be made to the eligibility criteria and points system for assessment. As detailed in our 2019 response to the Scottish Government's consultation on Disability Assistance<sup>3</sup>, ALLIANCE members have expressed concern that the descriptors used at present and included in the command paper don't work for people living with fluctuating conditions (particularly the emphasis on doing "these safely, to an acceptable standard, as often as you need to and in a reasonable time" – which can change depending on the nature of a fluctuating condition). We are also concerned that for each descriptor the only mental health consideration taken into account is "a lack of motivation" which does not appropriately describe the nature of mental health problems and their broader impact on a person's daily living.

As detailed elsewhere in this response, the ALLIANCE recommends that the forthcoming review of Adult Disability Payment explore different approaches to

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<sup>2</sup> [PIP: A Step Too Far – MS Society, June 2018](#)

<sup>3</sup> [ALLIANCE response – Consultation on Disability Assistance in Scotland, May 2019](#)

determining eligibility for disability entitlements, and alternative approaches that could be taken to a points based system. In order to best reflect the Social Security Principles and welcome ambition to create a system based on person centredness, rights, dignity and respect, alternatives to a system based on points, descriptors and scoring must be explored.

A gendered analysis of the 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. This is further detailed in our comment on the Equalities Impact Assessment below.

**Residence and presence conditions (regulation 14)**

**Absence from the United Kingdom (regulation 15)**

**Absence from the United Kingdom including medical treatment (regulations 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)**

**Refugees (regulation 21)**

**Q 11: Do you agree the regulations reflect this policy intent?**

No.

**Q 12: If you have any further comments please provide them here.**

The 'past presence test', which requires a person to have lived in the UK for at least two of the past three years to qualify for Adult Disability Payment, should be removed. 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.

**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)**

**Q 13: Do you agree the regulations reflect this policy intent?**

Yes

**Q 14: If you have any further comments please provide them here.**

The ALLIANCE is content with the draft regulations, and the changes that have been made to the upper age limit for ADP to bring it into line with the state pension age. However, we recommend that long term changes to the social security system in Scotland should consider how to address the problems that having separate age payments creates and how best to resolve these issues<sup>4</sup>, and that this should be considered as part of the Scottish Government's review in 2023.

**Terminal Illness (regulation 26)**

**Q 15: Do you agree the regulations reflect this policy intent?**

Yes

**Q 16: If you have any further comments please provide them here.**

The ALLIANCE welcomes the changes that have been made to 'special rules' for people who are terminally ill. These enable a person to qualify for the enhanced rate of Adult Disability Payment following a clinician's judgement that they are terminally ill, without requiring a further assessment, and does not require a judgement to be made on how long they have to live.

**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)**

**Payment of Adult Disability Payment between two periods of residence (regulation 32)**

**Q 17: Do you agree the regulations reflect this policy intent?**

Yes

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<sup>4</sup> P29-30, [Beyond a Safe and Secure Transition: A Long Term Vision for Disability Assistance in Scotland](#) – Scottish Campaign on Rights to Social Security, August 2020.

**Q 18: If you have any further comments please provide them here.**

The Scottish Government should consider how eligibility can be retained for unpaid carers in relation to a range of passported entitlements whilst someone is in residential care. We believe that breaking eligibility to receive the entitlement also risks the eligibility of unpaid carers to receive Carers Allowance in particular. There is a danger that this could have the unintended consequence of financial hardship for unpaid carers, even though their caring role would not cease after this period. This should be considered carefully as part of the development of regulations for Carers Assistance.

**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)**

**Q 19: Do you agree the regulations reflect this policy intent?**

Yes

**Q 20: If you have any further comments please provide them here.**

Whilst the regulations provide for ADP to be initially set at the same rates as PIP, the ALLIANCE believes that the amounts should be assessed as part of the forthcoming review of ADP to ensure they are adequate. As detailed in the Scottish Campaign on Rights to Social Security's 'Beyond a Safe and Secure Transition' report<sup>5</sup>, one of the fundamental tenets of designing a rights based social security system is that the amounts provided are adequate.

A number of studies have aimed to measure the extra costs incurred by disabled people in order to enjoy the same standard of living as a non-disabled person, and although these estimates have varied, it would appear that the social security support provided by disability assistance may not bear a good relation to the extra costs associated with an impairment. They may in fact significantly underestimate the actual costs, which means that people's human rights cannot be realised.<sup>6</sup>

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

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<sup>5</sup> P26 – 28, Ibid.

<sup>6</sup> P27 Ibid.

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

Yes

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

The most frequent suggestions for change to the social security system made by ALLIANCE members in consultation on these issues has long related to the need for those making decisions about eligibility to be properly trained, qualified and supported to do so. The current approach doesn't do enough to understand the condition the individual is experiencing and isn't proactive enough at identifying when a face to face assessment may be unnecessary and dehumanising.

Based on this, the requirement for a practitioner to have been employed for two years in direct provision to individuals of health or social care services, and if an assessment will involve consideration of mental health conditions or a learning disability that the practitioner must have particular experience of those areas, is a welcome step in the right direction.

**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)**

**Q 23: Do you agree the regulations reflect this policy intent?**

Yes

**Q 24: If you have any further comments please provide them here.**

The ALLIANCE welcomes a move to longer term awards, and away from the current system where an award is re-assessed after a relatively short period (such as three years). A review date of between 5 and 10 years after the date of initial award would appear appropriate, though we would recommend a person centred approach is taken, with the date chosen reflects the individual's condition and circumstances, rather than an arbitrary date being chosen.

ALLIANCE members have suggested that in some cases, it will be more appropriate to set no review date, with an indefinite award being made. For instance, if a person's condition is permanent with a typical prognosis that the functional effect on their daily living and mobility will not improve, and their award is at the highest rate

(and therefore no possibility of the award being increased on review), then it might be appropriate to set no review date.

It is also important that reviews are conducted on a 'light-touch' basis to minimise the stress and worry that disabled people currently experience in the current PIP process. This should include taking a person centred approach and seeking only to identify any areas of significant change since the award was made. Where possible, this should be on the basis of existing evidence, such as medical records, or evidence from people who are familiar with the functional impact of a person's condition.

### **Periods in respect of a re-determination request (regulation 44)**

#### **Q 25: Do you agree the regulations reflect this policy intent?**

Yes

#### **Q 26: If you have any further comments please provide them here.**

In our response to the Scottish Government's 2019 consultation on Disability Assistance<sup>7</sup>, the ALLIANCE suggested that the timescales proposed for a person to make re-determination request should be extended, and time for Social Security Scotland to consider it should be reduced. Many people accessing disability entitlements will require additional time to request a redetermination, possibly because of difficult personal circumstances or the nature of their illness. The timescale set out for considering a redetermination should also allow for discussion with the individual's advice worker and/or independent advocate.

Although we had previously suggested that there should be an equalisation of the acceptable timescales for people accessing social security and the Social Security Agency delivering it, we are content with the proposals in the draft regulations (42 days to make a re-determination request and 56 days for a decision to be made on it), as these represent a significant improvement on the current rules, and an improvement on the previous proposals.

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

The ALLIANCE welcomes the Scottish Government's commitment to undertake an independent review of Adult Disability Payment, once the safe and secure transition is complete. As part of the Scottish Campaign on Rights to Social Security (SCoRSS), the ALLIANCE contributed to a joint report which recommended this

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<sup>7</sup> [ALLIANCE response – Consultation on Disability Assistance in Scotland, May 2019](#)

review should take place<sup>8</sup>. We see this as an opportunity to create a world-leading rights based system of social security support for disabled people and people with long term conditions.

The ALLIANCE recommends that the review should consider the system of disability assistance in its entirety – not just Adult Disability Payment – and should be conducted with references to the six principles highlighted in the SCoRSS report, with a view to creating a system of social security for disabled people that:

- Has a clear purpose
- Is human rights based
- Supports equal participation in society and independent living
- Is adequate
- Provides whole-of-life support
- Interacts well with future social security developments and is well connected to other services.

We also recommend the review should be:

- Fully independent and fully resourced
- Undertaken in line with a human rights based approach as detailed in the SCoRSS report
- Accountable to, and co-produced with, people in Scotland including both those currently entitled, and those who are not entitled, to disability assistance. It should also include the participation of disabled peoples' organisations, human rights experts, unpaid carers, family members, independent advocates and welfare rights workers.
- Incorporate the evidence gathered during the safe and secure transition to disability assistance. This evidence should be used to identify areas of the Scottish system that are working well, those that are causing difficulties to claimants and those who are not currently entitled to disability assistance. This can be used to inform the debate about entitlement criteria and identify groups that disproportionately struggle to enjoy their right to social security, with particular reference to the six principles outlined above.

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<sup>8</sup> [Beyond a Safe and Secure Transition: A Long Term Vision for Disability Assistance in Scotland](#) – Scottish Campaign on Rights to Social Security, August 2020.



- Informed by examples of social security innovation in other countries, and international good practice in the development of social security for disabled people.<sup>9</sup>

**Q 34: If you have any comments about the impact assessments please provide them here.**

It is welcome that impact assessments have been prepared at this stage of the process. It is important that they are used to identify areas in the regulations which may give cause disadvantage to protected characteristics in practice – such as gendered application of the descriptors and eligibility criteria causing disadvantage to women, as highlighted by Engender.

There could also be further consideration within the impact assessments of particular conditions within the disability analysis. For instance, there does not seem to be a detailed analysis of the specific impact on people living with sensory loss, or experiencing communication or language barriers.

**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.**

**Independent Advocacy**

The inclusion of a right to access independent advocacy for everyone going through face to face assessments for disability assistance, including ADP, is a welcome move. We believe that this right must be communicated directly to all claimants ahead of any claim for disability assistance in order that any interaction with the agency can be supported by an independent advocate. Further information on a responsible individual who should inform people of their rights to access advocacy and advice should be laid out in guidance and information to people applying for disability assistance.

**Assessments and consultations**

Current PIP face-to-face assessments do not treat people with dignity and respect, and we welcome the efforts the Scottish Government has made to create alternatives to them, as well as for ADP. It is important however, that full use is made of existing evidence from people who know the person best to make decisions, to minimise the number of consultations required, and that a person centred approach is taken at all times.

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<sup>9</sup> Ibid.

ALLIANCE members Mydex have also highlighted opportunities for person centred digital services as part of this process. Any replacement for face-to-face assessments should take advantage of innovations in person-centred data management. The [Smart Entitlements report](#), published by Scottish Government in July 2020, gives a description of how empowering citizens to make use of pre-existing evidence and attributes will lead to transformative reductions in friction, effort, risk, and cost that improve outcomes for citizens, carers and organisations. This is now being implemented as part of Beta service across Scotland called the [Scottish Attribute Provider Service](#).

### Inclusive communications and correspondence

Social Security Scotland are keen to promote inclusive communication and have already have an Inclusive Communication Strategy in place. However, it would be good to reinforce and remind staff of the importance of this from time to time.

Correspondence with Social Security Scotland is usually by letter or telephone call. However many individuals, particularly deaf people cannot do telephone calls, unless they have access to appropriate technology to do VRS (Video Relay Service) / VRI (Video Remote Interpreting), contact SCOTLAND-BSL, Relay UK (formerly Text Relay UK and previously NGT / TextDirect). In addition a significant number of people are digitally excluded and do not have access to a computer, email account or smartphone, creating a barrier to email or SMS contact.

Another consideration includes communication, language and access support for deafblind people, such as who covers the costs for Guide Communication support. Currently, deafblind individuals have to use their PIP and Self Directed Support to deal with personal matters, whereas a BSL user can request a BSL / English Interpreter and don't have to pay for it, themselves as it is paid from the public purse.

Consideration should also be given to how Adult Disability Payment can promote independence, empowerment and self-esteem for those want to deal with matters themselves, particularly individuals who are deafblind or have a dual sensory loss, as the resources are not currently accessible to them, due to some of them requiring human support to do things like Tactile BSL. However due to language and communication barriers, there will be a longer delay in dealing with matters. A BSL user may have to wait three to four weeks longer for a meeting with the social security agency, compared with a hearing person.

It is also important that Social Security Scotland ensures that people's right to a supporter in meetings and consultation is facilitated and encouraged. In the current system, DWP staff have refused to talk or share information with a third party present in the meeting with the individual. On some occasions, deafscotland report they have had colleagues refusing to work with Language Service Professionals

(BSL / English Interpreters, Electronic Note-takers), because they felt undermined or overwhelmed. This is due to a lack of awareness and understanding, and we would recommend specialist expertise is employed when working with specific cases and individuals.

## About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of nearly 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces, Libraries and Access Panels are also members.

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.

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