



Consultation Response

Consultation on the draft regulations for the Adult Disability Payment

The Scottish Commission for
People with Learning Disabilities
March 2021



Introduction

SCLD is an independent charitable organisation and partner to the Scottish Government in the delivery of Scotland's learning disability strategy, *The keys to life* (2013)¹ and *The keys to life* Implementation Framework (2019-2021)². The implementation framework defines a learning disability as follows:

"A learning disability is significant and lifelong. It starts before adulthood and affects a person's development. This means that a person with a learning disability will be likely to need help to understand information, learn skills and live a fulfilling life. Some people with learning disabilities will also have healthcare needs and require support to communicate." (The keys to life, 2019-2021, p.9)

SCLD is committed to creating an environment in Scotland in which systems and culture are changed to ensure people with learning disabilities have opportunities and are empowered to live the life they want in line with existing human rights conventions. SCLD believes that the discrimination and barriers faced by people with learning disabilities and other disabled people are not inevitable. These barriers stop people with learning disabilities and other disabled people being included in society and participating on an equal basis.

SCLD is focused on sharing innovation and good practice so that those providing services and interventions can learn from each other. SCLD is a knowledge hub - building an evidence base, sharing how policy is being implemented and developing a shared understanding of what really works.

We welcome the opportunity to respond to the Scottish Government consultation on the draft regulations for Adult Disability Payment.

Overview

The social and economic consequences of the Covid-19 pandemic are likely to have a significantly disproportionate impact on those groups already facing significant inequality and disadvantage. In the long-term, those hit hardest by the crisis will include black and minority ethnic (BAME) communities, women, families living in poverty, carers, those with poor mental and physical health, older people, and people with learning disabilities and other disabled people.

A recent report highlighted that working age adults in Scotland with learning disabilities continue to face a range of difficulties and barriers that often prevent them reaching a good or adequate standard of living. It indicated that these barriers have been exacerbated by the pandemic and stated *“COVID-19 has meant that much of the service infrastructure that was relied on has been taken away, and there are grave (and valid) concerns that their human rights are being curtailed.”*¹

There is also an abundance of evidence that prior to the pandemic people with learning disabilities continued to experience significant barriers to active citizenship, full engagement in civil and public life and a lack of access to education², employment³, relationships⁴, and family lives⁵. SCLD believes that disability assistance can play a huge part in overcoming these socio-economic barriers through promoting equality and fairness and upholding human rights for people with learning disabilities.

¹ Fraser of Allander Institute (2020): *Scotland's Invisible People*

² ENABLE (2016) *#IncludED in the Main?! 22 steps on the journey to inclusion for every pupil who has a learning disability*

³ McTeir et al (2016) *Mapping the Employability Landscape for People with Learning Disabilities in Scotland*

⁴ SCLD (2018) *Safe and Healthy Relationships: Empowering & Supporting People with Learning Disabilities*

⁵ SCLD (2018) *Children's Rights: Consultation on incorporating the UNCRC into our domestic law in Scotland*

The transfer of powers for disability payments from the UK Government to the Scottish Government is the largest with respect to social security to date. This offers Scotland a unique opportunity to create a transformative world-leading rights-based system of disability assistance for Scotland. However, in our view this necessitates more radical change than is provided for within these regulations.

We acknowledge the significant progress in terms of the administrative aspects of ADP. For example, the application process and arrangements for the provision of supporting evidence and consultation with claimants where this is necessary. However, we have considerable concerns that the underlying eligibility criteria, descriptors, and points-based system of the discredited DWP Personal Independence Payment (PIP) remain largely unchanged in this guidance.

While we understand and support the Scottish Government's prioritisation of a safe and secure transition of existing entitlements to Social Security Scotland, we believe Scotland must aim higher and seek to design a more progressive, rights-based approach to disability assistance. One which is less deficit-focused and takes greater accounts of the social and other structural barriers which infringe people with learning disabilities' right to independent living and equal participation in society.

Eligibility – Daily Living Component and Mobility Component – Determination of ability to carry out activities (regulation 6)

Q7: Do you agree the regulations reflect this policy intent?

We agree the regulation reflects the Scottish Government's clearly stated intention not to make any significant changes to the PIP activities, descriptors and supporting eligibility criteria in the ADP regulations. SCLD understand the reasons for this and recognise the need to prioritise of a safe and secure transition of existing entitlements to Social Security Scotland in the immediate term.

However, we have concerns that the continued focus on ability to perform isolated 'activities' may fail to fully capture the experience of living with a learning disability and the multitude of barriers people continue face to equal participation in society and accessing UNCRPD⁶ and other rights.

Our stakeholders have also reported that applying the reliability criteria, which require consideration to be given to the client's ability to complete an activity safely, to an acceptable standard, repeatedly and in a reasonable time, are not always properly applied and may require a very nuanced understanding of the individual challenges people experience in their everyday life⁷.

SCLD believes these are matter which must be given careful consideration moving forward.

Scoring for daily living and mobility activities (regulations 7 and 8)

We agree that it is imperative there is no disruption to the payments individuals rely on and therefore we accept the decision that, in the short-term, this necessitates the retention of the points-based scoring system.

We note that the regulations almost exactly replicate the PIP system. In doing so, they prescribe that eligibility in relation to daily living and mobility activities will be determined by adding together the number of points scored under each activity. To qualify for the standard rate of ADP an individual must be assessed as having 'limited ability' to carry out daily living or mobility activities by scoring at least 8 points. For enhanced rate, an individual must be assessed as having 'severely limited ability' to carry out daily living or mobility activities by scoring at least 12 points.

⁶ UN Convention on Rights of Persons with Disabilities (2006)

⁷ SCLD response to the Social Security Disability Assistance Consultation (2019)

SCLD has significant concerns that activities, descriptors and point-based systems reflect a medical and needs-based model that is predominantly focused on 'impairments' and what people with learning disabilities and other disabled people are *unable* to do. We do not believe this aligns with a human rights based approach to the development of social security focussed on removing the barriers to people's rights to equal participation in society and independent living.

At previous engagement events people with learning disabilities have highlighted the importance of decision makers understanding their learning disability and being able to be open minded, non-judgemental and make person-centred decisions.

A common theme was the importance of being able to describe personal experience more fully. People with learning disabilities told us the process should:

- Build a picture of the whole person e.g. include a personal profile section; provide an opportunity to describe what their worst days look like.
- Be less deficit-focussed e.g. establish what people can do as well as what they need support with
- Be less stressful e.g. offer the option for home assessments
- Be more nuanced e.g. have a less rigid scoring system, more emphasis on non-physical disabilities, consider the experience of stigma and discrimination⁸.

Moving forward, SCLD believes there must be an in-depth examination and comprehensive consultation with people with learning disabilities on the alternative approaches to a points-based system for determining eligibility criteria for disability assistance.

⁸ [SCLD response to the Social Security Disability Assistance Consultation \(2019\)](#)

The Qualifications and Experience Necessary to Carry out Assessments (regulation 38)

Q21: Do you agree the regulations reflect this policy intent.

Yes. We note the provision for consultations to replace PIP assessments where they are necessary and welcome that the regulations provide for the qualifications and experience for undertaking these to be extended to health and social care practitioners including learning disabilities nurses, occupational therapist and social worker, and senior social care workers.

It is unclear from the regulations as to whether provision of 'social care services' includes those who have experience of providing support within the third sector or whether this pertains only to the statutory sector. We seek clarification of this and believe it is critical that those who have experience of delivering health and social care within the non-statutory sectors are included.

It is particularly welcome that some practitioners will be required to have worked with people with learning disabilities and that only those practitioners will be able to undertake consultations with people who have a learning disability.

Schedule 1 – Adult Disability Assistance Determination

Part 1 of the Schedule offers interpretations of the terms relevant to the activities and descriptors.

Q31: If you have any comments on Schedule 1 please provide them here.

The activities and descriptors in the regulations focus on the medical or functional aspects of a person's impairment and what someone is unable to do. In our view, there is potential to design a more nuanced approach which reflect the social and human rights models of disability. Indeed, one of the principles of the Scottish social security system is that 'social security is itself a human right and essential to

the realisation of other human rights⁹. Where we fail to implement this properly, we are at risk of impeding people with learning disabilities realisation of their Article 28 UNCRPD convention rights¹⁰.

It is critical, therefore that that the ADP is rooted in equality and human rights. In our view this must entail a comprehensive review of the activities, descriptors and supporting eligibility criteria for ADP to better reflect the social and human rights models of disability. There is also a need to pay detailed attention to intersectionality and take account of other protected characteristics such as gender and race and how they intersect with learning disability and other disabilities. We believe the ambition should be to design new eligibility and assessment criteria which are less deficit-focused and builds on individuals' assets.

Q33: If you have any comments about the proposed review of Adult Disability Payment please provide them here.

SCLD welcomes the opportunity to comment on the proposed independent review of ADP scheduled for 2023. We believe this represents a critical opportunity for a more holistic interrogation and redesign of ADP in line with the points already made in this submission. We also believe it is important that the review's remit extends to Child Disability Payment (CDP) and Disability Assistance for Older People (DAOP) and that it should also considers Social Security Scotland process and procedures as well as the rules and regulations.

We believe, it is critical that the Independent Review takes a co-produced and rights based approach to:

- Reshaping eligibility criteria
- The role of assessments

⁹ [Social Security \(Scotland\) Act 2018](#)

¹⁰ [Article 28 UN Convention on the Rights of Persons with Disabilities \(2006\)](#)

- Determining adequate levels of payment

We firmly agree with SCoRSS that the ambition should be to design a system of disability assistance with a clear purpose¹¹. That is to compensate people for the extra costs of having an impairment or health condition, enabling them to realise their rights to participate equally in society and to independent living.

In designing a rights based social security system, we also agree that the support provided should be adequate. At present, the rate of disability payments does not adequately reflect the extra costs people with learning disabilities experience. The independent review should examine the merits of using a human rights budgeting approach capable of respecting, protecting and fulfilling the human rights of people with learning disabilities and other disabled people.

Finally, it is critical that the review is co-produced with people with learning disabilities and other disabled people – both those who are currently entitled, and those who are not entitled at present, to disability assistance. It should also include the participation of DPOs, human rights experts, unpaid carers, family members, independent advocates and welfare rights workers.

Q34: If you have any comments about the impact assessments please provide them here.

Impact Assessments are critical to ensuring the social security policy, regulations and delivery match the commitments to the principles enshrined in the Social Security Act. Moving forward, SCLD believes Equalities Impact Assessments (EQIAs) and Human Rights Impact Assessments (HRIA) have a vital role in the continued development of a Social Security System that is compatible with a human rights based approach.

¹¹ Disability Assistance in Scotland – Beyond a Safe and Secure Transition (2020)

SCLD recognises the extensive consultation with stakeholders, engagement through working groups and direct participation of the Experience Panels in providing a strong evidence base for the changes outlined in the impact assessments. We believe many of these will have a positive impact on people with learning disabilities in Scotland. However, we believe it will be essential to ensure that people with learning disabilities are well represented on the Experience Panels moving forward. SCLD would be happy to assist officials in this regard.

The evidence from Experience Panels which suggests that often the most negative part of applying for Personal Independence Payment is attending face-to-face assessments correlates with what people with learning disabilities have told us.¹² For many people this causes high levels of stress and anxiety and impacts negatively on their health and wellbeing. It is welcome, therefore, that existing supporting information will be used to make a determination about ADP for most people and 'consultations' will only be carried out where it is the only way to obtain the information needed to make a decision.

Another issue that reflects what people with learning disabilities and their families and supporters have told us is lack of trust in the assessment process, assessors or the contractors that are responsible for carrying out PIP assessments. We welcome the decision that the new consultations will be undertaken by health and social care practitioners and that some practitioners will need to have experience of working with people with learning disabilities.

Furthermore, we support the multi-channel approach to consultations so that in most cases people will not be required to travel to unfamiliar assessment centres. However, as part of this, SCLD believes it is critical that Social Security Scotland

¹² SCLD response to the Social Security Disability Assistance Consultation (2019)

closely considers the communications needs and preferences of people with learning disabilities as well as the barriers to digital inclusion that many people experience.

SCLD thanks the Scottish Government for the opportunity to respond to this consultation.

Contact us

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