

Views of the Lived Experience Leadership Group on the Scottish Government's consultation on the Adult Disability Payment (ADP) Regulations

About the Group

The Lived Experience Leadership Group (LELG) is a group of people with direct experience of poverty from across Scotland. The LELG is supported by the Scottish Human Rights Commission and is committed to advocating for the enjoyment of economic, social and cultural rights for everyone in Scotland.ⁱ

Most members of the group have experience of applying for, receiving or supporting others in applications for DLA/PIP as carers, friends or advocates.

The group notes that the UN General Comment on the right to social security sets out that governments must provide 'adequate income support to persons with disabilities who, owing to disability or disability-related factors, have temporarily lost, or received a reduction in, their income, have been denied employment opportunities or have a permanent disability. Such support should be provided in a dignified manner and reflect the special needs for assistance and other expenses often associated with disability.'ⁱⁱ

Governments have legal duties to respect, protect and fulfil the right to social security without discrimination. The Scottish Government, as the duty bearer, must take steps to progressively realise the right to the maximum of available resources.

Question 6 – On maintaining the current eligibility criteria

The group recognises the importance of ensuring a smooth transition between reserved and devolved benefits, as set out in the Scottish Government's 2019 Position Paper,ⁱⁱⁱ but are concerned that maintaining the current system fails to address many of the significant concerns disabled people have about the eligibility criteria, which are acknowledged in Annex A of the consultation paper. The group notes that the principles set out in Part 1 of the Social Security (Scotland) Act include that 'respect for the dignity of individuals is to be at the heart of the Scottish social security system.' We are concerned that ADP continuing the current model of PIP, albeit with the proposed modifications, will not do enough to ensure the dignity of disabled people in Scotland. While we recognise that work is being done to make improvements, we are particularly concerned that a values based competency is not in place for the recruitment of assessors under the draft regulations. We think the removal of Motability cars where a person's eligibility for the mobility component ceases because of a hospital stay, removes their dignity and potential to live independently at a stroke.

Broadly speaking, despite misgivings on maintaining the criteria developed at UK level, the group welcomes the suggestions to adapt the application and assessment process. Particularly welcome are the longer periods between review and the proposals in favour of gathering existing evidence in preference to reassessment. However, while the group welcomes the move away from undignified assessments and towards using available records, it will be important to consider health inequalities in access to primary care which may affect the quality and availability of information about the person for the purposes of making a decision on an award. For example, where specific communities such as Gypsy/Traveller communities may struggle to access primary care services, and in some cases, where communities may even at times experience discrimination from healthcare providers.

We would like to see greater accountability for the Ministerial commitment to review Adult Disability Payment in 2023, since this will be a key opportunity to ensure that the new ADP is rights compliant. The group also notes that the National Taskforce on Human Rights

Leadership has now reported on its findings in relation to the incorporation of additional rights instruments including the International Covenant on Economic, Social and Cultural Rights and the Convention on the Rights of Persons with Disabilities into Scots law.^{iv} These include the recommendation that the right to social security be incorporated directly into Scots law.^v It will therefore be critical that devolved social security payments meet the standards set out in international human rights law.

In addition, the group notes that the entire process of qualifying for Adult Disability Payment is predicated on a deficit model. A human rights compliant system is one which recognises that disability is not inherent to impairment but rather arises as a result of the interaction of the impairment with various barriers, which may hinder a person's full and effective participation in society on an equal basis with others.^{vi} As they stand, the current regulations demonstrate a medical model approach in which the following definition is not compliant with a human rights based approach: 'ability to carry out the daily living and/or mobility activities is limited by their physical or mental health condition or conditions.' This definition requires to be redrawn to something like 'support may be required to overcome barriers to carrying out daily living or mobility activities.' This would also have the benefit of recognising that people often experience multiple barriers at the same time. One member of the group gave the example of the fact that they had not been awarded any points on the 'Preparing Food' criterion of Daily Living as they were able to prepare a sandwich. However, the same person is not currently able to access physically their kitchen. The group would welcome a commitment to including consideration of this definition within the 2023 Review; in any case it will be an important feature of any consideration of how Scots law is compliant with the CRPD, should the latter be incorporated into Scots law at a later date.

The group would also advocate for the Terms of Reference of the proposed Review to include an explicit assessment of Adult Disability Payment's compliance with the accessibility and adequacy elements of the right to social security, set out in Section II A of the General Comment.^{vii} These include:

- Qualifying conditions for benefits must be reasonable, proportionate and transparent;
- Benefits, whether in cash or in kind, must be adequate in amount and duration in order that everyone may realize his or her rights to family protection and assistance, an adequate standard of living and adequate access to health care;
- The adequacy criteria should be monitored regularly to ensure that beneficiaries are able to afford the goods and services they require to realize their Covenant rights.

Question 8 – On reliability

The group notes that the regulations in Part 3, regulation 7 attempt to address some of the significant concerns which disabled people have about the eligibility criteria, through the inclusion of ‘reliability.’ This is welcome. However, the group would note that reliability criteria are to some extent already incorporated into PIP assessment processes; the issue has been how to ensure that these are recorded and taken into account when allocating points. We would like to see the regulations include a duty **to take into account and record** the extent to which a person can undertake a specific task reliably.

Question 16 - On regulations relating to terminal illness

The group broadly welcomes the change to the definition and verification of terminal illness set out in Part 7, regulation 26.

Question 18 – On the ceasing of elements of ADP where a person is resident in hospital

The group disagrees with the policy rationale behind stopping daily living and mobility components of ADP after a person has been in hospital for 28 days. This decision fails to recognise the reality of many disabled people’s lives, since even in hospital there are extra costs associated with being disabled. In fact, one thing we know is that hospital care does not always meet the specific needs of disabled people, which could be

facilitated through the maintenance of ADP through these periods. One example is the experience of people who require special diets whose needs are often not catered for in hospital; people with food allergies who are hospital inpatients, especially where anaphylaxis is a risk, have to carry on buying their own food and having it prepared and brought in, which for some people will cost more. It is important to recognise that the removal of PIP often has difficult adverse consequences on disabled people in hospital, ranging from stress and worry over finances to increasing levels of poverty. As advocates for others, we have witnessed at first hand the distress which is caused to individuals in mental health hospital at the prospect of PIP being stopped. We would recommend that this part of the regulations does not go forward, or that the time limit before which ADP is ceased is increased significantly.

We are very concerned at the continuation of the policy whereby the mobility component of a person's ADP would be ceased if they were to be a hospital in-patient for longer than 28 days. This puts their access to a Motability vehicle at risk. Motability vehicles are often a key facilitator of the enjoyment of rights for disabled people, as they are specifically adapted for the person in question, and enable people to enjoy their right to live independently in the community, as set out in Article 19 of the Convention on the Rights of Persons with Disabilities. The negative social consequences of being without a vehicle are enormous. To remove a person's Motability vehicle is to remove their dignity at a stroke. This goes against principle 1(d) set out in Part 1 of the Social Security (Scotland) Act 2018.

While it is relatively easy to have DLA / PIP reinstated after being released from hospital, finding another vehicle to replace the one removed can take several months to organise and this is even longer if there are any modifications to the vehicle needed before the recipient can make use of it. Therefore, if we could find a way to ensure that recipients will continue to keep their vehicles while on an extended stay in hospital that would remove many of the concerns that they have about going into hospital.

Question 20 – on the rates of daily living and mobility components

The group recognises that during this transition period, it is important that both components remain at current levels. However, in line with our previous recommendation, the adequacy of social security payments should be ensured through regular monitoring and review and this should be a key questions for the 2023 review.

Questions 21 and 22 – on qualifications for assessments

The group welcomes the intention of ensuring that people who will deliver in-person assessments should have expertise in mental health or learning disability where the person applying experiences these issues. We have all experienced the highly scripted and insensitive nature of PIP assessments and witnessed occasions when the views of clinical experts in specific conditions have been overturned by less well-qualified staff.

However, we are not convinced that the criteria set out of two years' cumulative experience in health or social care is sufficiently robust or lengthy to ensure that assessors will have enough understanding of the range of individuals and conditions which they may be presented with. We suggest that changing the criteria within Part 11, r38 (a) from 'cumulative' to 'continuous' may be advantageous or alternatively specifying a cap on the period of time over which cumulative experience could have been gained. We would also suggest that there be some inclusion of values based criteria for assessors, such as an understanding of the social model of disability and of the right to independent living as set out in the UNCRPD. We have seen at first hand the impact of the attitude of assessors towards the person undergoing assessment, and how this can have an extremely debilitating effect on their well-being. This again relates to the Scottish Government's previously made commitments on ensuring that applicants for social security payments are treated with respect and dignity as a minimum and are not traumatised by their experiences, as many of us have been and have witnessed.

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- ⁱ For more information about the group, please see [Lived Experience \(scottishhumanrights.com\)](https://www.scottishhumanrights.com)
- ⁱⁱ UN Committee on Economic, Social and Cultural Rights, 2008, General Comment 19 'The Right to Social Security' available at [Treaty bodies Download \(ohchr.org\)](https://www.ohchr.org/Treaty_bodies_Download)
- ⁱⁱⁱ Scottish Government, 2019,
- ^{iv} National Task Force for Human Rights Leadership, 2021, National Task Force for Human Rights Leadership Report, Scottish Government, available at [National Taskforce for Human Rights Leadership Report \(www.gov.scot\)](https://www.gov.scot/National-Taskforce-for-Human-Rights-Leadership-Report)
- ^v As above, see Recommendation 1b, page 12/13
- ^{vi} Article 1, Convention on the Rights of Persons with Disabilities [OHCHR | Convention on the Rights of Persons with Disabilities](https://www.ohchr.org/Convention-on-the-Rights-of-Persons-with-Disabilities)
- ^{vii} See ii