

Our voices Our choices

Social Justice & Social Security Committee Call for Evidence: Disability Assistance for Working Age People Regulations

Key issues:

- Length of Awards
- Definition of Terminal Illness
- Qualifications and experience necessary to carry out Assessments
- Equality Impact Assessment
- Schedule 1 Adult Disability Assistance Determination
- Retention of 20 metre walking test
- Retention of 50% rule
- Access to Advocacy

1 Background

- 1.1 Inclusion Scotland is a 'Disabled People's Organisation' (DPO) led by disabled people ourselves. Inclusion Scotland works to achieve positive changes to policy and practice, so that we disabled people are fully included throughout all Scottish society as equal citizens. Inclusion Scotland is part of the disabled people's Independent Living Movement.
- 1.2 Inclusion Scotland welcomes the positive changes that the Scottish Government has made to the original draft ADP regulations. We have therefore restricted our comments on the regulations to those areas where we, and those disabled people we consulted with, continue to have concerns. Unfortunately, we have not had sight of the latest version of the regulations sent to the Committee and therefore some of the concerns we raised earlier with the Scottish Commission on Social Security, that are outlined below, may no longer be pertinent.

2 Key Concerns

- 2.1 **Length of Awards:** The policy paper accompanying the original draft regulations, and the Scottish Government's response to the consultation, stated that 5 or 10 year awards will be made for long term conditions that are unlikely to improve.
- 2.2 The issue of continuing entitlement has now been addressed in the regulations (Regulation 37) however it still does not provide any certainty that 5 or 10 year awards will be the normal length of award for longer term or permanent conditions.

- 2.3 Regulation 37 states that "a determination that an individual is entitled to Adult Disability Payment in respect of a period is to be made on the basis that the individual has an ongoing entitlement to Adult Disability Payment after the end of that period, except where paragraph (2) applies". This is a welcome change as previously entitlement to PIP ended after the fixed period of an award, meaning that those who experienced delays in getting an assessment sometimes lost entitlement whilst they waited for an appointment.
- 2.4 However, Reg. 37, para 3 (a) states that "the individual will continue to be entitled to Adult Disability Payment for a fixed or indefinite period as specified in the notice of determination". Thus, fixed periods of award are envisaged but not who such awards will apply to. This suggests that the issue of the length of awards for long term or permanent conditions is going to be left to guidance rather than set out in regulations. This is problematic in that guidance can be changed at a whim by future Governments with no reference to Parliament and no opportunity for challenge by Disabled People's Organisations and other stakeholders.
- 2.4 We conducted an online survey on the initial draft regulations and received 326 responses to the question on this issue with 76% of respondents stating that they believed that the commitment to 5 and 10 year awards should be set out in regulations and only 9% believing that it should be left to guidance.
- 2.5 Inclusion Scotland believes that regulations which fail to guarantee longer awards for conditions/impairments that will not improve will result in a lack of certainty and thus continuing stress for disabled people who will be fearful of being subjected to frequent assessments.

3 Terminal Illness

- 3.1 A majority (53%) of the 318 people responding to our online survey believed that the Chief Medical Officer's guidance on what constitutes a terminal illness should be enshrined in regulation. Only 12% believed it should be contained in guidance. A substantial minority (35%) were unsure of whether it should be in guidance or regulations.
- 3.2 Inclusion Scotland believes that legislation and regulations should provide certainty for claimants and their advisers but unfortunately neither the legislation nor regulations do so yet on the issue of terminal illness.

4 Qualifications and Experience Necessary to Carry out Assessments

- **4.1** Inclusion Scotland welcomes draft regulations 48 (2) (b) and 48 (2) (c) which provide extra assurance to those disabled people with mental health issues and/or learning difficulties that the impact of their impairments will be assessed by health and social care practitioners with relevant experience.
- 4.2 However, Inclusion Scotland continues to have real concerns that minimally qualified health or social care workers will be able to carry out assessments. Whereas most health professionals will have undergone rigorous training (usually to degree standard) before being allowed to work with patients the same does not apply to all the social care workforce.

- 4.3 Many social care workers have minimal qualifications and work in social care settings where professional development training is minimal. There is a considerable difference between a trained and qualified nurse or occupational therapist with 2 years experience in their field and a minimally qualified (SQA Level 2) trained social care assistant working for 2 years in a care home.
- 4.4 Three hundred and twenty people responded to our online survey question on this issue with 73% disagreeing with the proposition that <u>any</u> health or social care worker with 2 years work experience and minimal qualifications should be able to make a determination on whether someone should, or should not, be awarded disability assistance. Only 8% agreed with that proposition. This reveals considerable disquiet with the notion that 2 years work experience is by itself a substitute for proper qualifications.
- 4.5 The disabled people we consulted also wish to see all staff that are employed to carry out assessments receive training in disability equality from disabled people themselves. They would also like to see a significant proportion of Social Security Agency staff being disabled people as they believe that this would give staff insight into the barriers that disabled people face.

5 The Equality Impact Assessment

- 5.1 The Equality Impact Assessment for the original draft regulations rightly identified that the move from DLA to PIP has, so far, resulted in 603,000 disabled people across the UK losing some or all of their entitlement. The Scottish Government's own estimate is that 25% of those Scottish disabled people reassessed for PIP have lost all entitlement.
- 5.2 Whilst several positive improvements have been made to the draft regulations (e.g. short term assistance) the impact assessment provided no estimate of whether the new Scottish system will reduce this negative impact. It seems unlikely that there will be a substantial improvement in restoring disabled people's eligibility given that the key issues impacting on reduced entitlement (i.e. the 20 metre walking test and the 50% rule) have not been changed. We think that this should have been reflected in the EquIA.

6 Schedule 1 – Adult Disability Assistance Determination:

- **6.1** Inclusion Scotland believe that the "Planning and Following a Journey" descriptors and scoring as set out in Schedule 1 are unfair to people with mental health issues and/or autism.
- **6.2** At present someone who "Cannot undertake any journeys at all because it would cause overwhelming psychological distress.." might only score 10 points meaning that they would not qualify for the Enhanced Mobility rate even though their ability to get around is as, or even more, limited than a person unable to walk. That seems both unfair and unjust to particular impairment groups and we regret that Scottish Government has not addressed this unfairness.

7 The 20 metre Walking Test

- 7.1 Inclusion Scotland and its members continue to disagree with the application of 20 metre walking test. Though disabled people understand the need for a safe and secure transition they also believe that these rules unfairly penalise disabled people and deprive them of benefits to which they should be entitled. Depriving them of entitlement also denies them the support necessary to overcome the barriers to inclusion that disabled people face and thus their human rights. They are also concerned that some of the reasons provided for retaining the status quo would apply equally at the time of any independent review thus constraining the opportunity for a radical change in approach.
- 7.2 The replacement of the previous 50 metre walking test with the 20 metre test has resulted in approximately 50% of DLA claimants in receipt of the Higher Rate Mobility Component losing entitlement to the Enhanced Rate when reassessed for PIP.
- 7.3 Of 326 responses to our online survey question on the walking test over 80% opposed using 20 metres as the distance. At our subsequent webinar on the draft regulations there was unanimous opposition to the use of 20 metres for the walking test. The following comments were made:

"The 20m rule was introduced against every single consultation that was done – from clinical or disability organisations. There is no evidential basis for it".

A double amputee summed up the discussion by saying - "If distance thing stays the same, might as well give it (*the benefit*) back to UK Government".

8 The 50% rule

- 8.1 Although the physical or mental impact of a condition or impairment can vary from day to day those with the condition live with it every day and even on good days it continues to have an impact. This is because it is impossible to predict in advance whether the next day will be a good or a bad one. Thus, planning and going about everyday family, social, community and employment activities becomes extremely difficult.
- 8.2 Only 12% of the 341 respondents to our survey thought that the 50% rule was flexible enough to provide entitlement to people with variable conditions such as Chronic Fatigue Syndrome/ME/Multiple Sclerosis or mental health conditions whilst 72% thought it was not. At our webinar there was a general consensus that the 50% rule did not deal well or fairly with people who had variable conditions. Amongst the comments made were the following -

"I have a variable condition. Under old DLA there was a way of marking on the application form how my condition affected me on different days. Not there with PIP. Worry that variability of my impairment may be missed".

"Similar problem as my condition affects balance – can have a day when fine, and then several days not fine".

9 Access to Advocacy

- 9.1 Inclusion Scotland have concerns that disabled people who require advocacy support in making a claim and dealing with the Scottish Social Security Agency are not currently being referred to advocacy providers. Although the need for advocacy provision will increase when Adult Disability Payments are rolled out the need already exists for claims to Best Start Grants, Child Disability Payment, Scottish Child Payment, etc.
- 9.2 Advocacy support for disabled people is not an optional extra but a right guaranteed in the Social Security Scotland Act. Disabled people should be informed of this right and signposted to local independent advocacy provision. The delay in establishing a dedicated advocacy service is to some extent understandable (given the pandemic) but the need for advocacy support has been known since the Act was passed and should have been addressed earlier.

For Further Information Contact:

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