Failures of Benefits Assessments: Article 28 (Adequate standard of living and social protection)

Chronic Illness Inclusion (CII) is concerned that disabled people’s rights to social protection and an adequate standard of living have regressed even further since the report by the UN Committee on the Rights of Persons with Disabilities in 2017, as the £20 uplift to Universal Credit during the COVID-19 pandemic was not extended to people on ‘legacy’ benefits, the majority of whom were disabled people on Employment and Support Allowance (ESA).

This follows a broader failure to address the inadequate standard of living and unacceptable rate of poverty and destitution among disabled people. We note that the UK government’s survey of both disabled and non-disabled people found that only 8% believe that the social protection system for disabled people in the UK is adequate.[[1]](#footnote-1)

However, the following shall focus specifically on issues relating to people with energy limiting conditions (ELCs).

Introduction

The Health and Disability Green Paper proposes improvements to assessments for the UK’s social protection and poverty reduction programmes for disabled people: ESA (and its equivalent under Universal Credit) and Personal Independence Payment (PIP). However, the Green Paper does not address the flawed eligibility and assessment criteria used to determine impairment and disability.[[2]](#footnote-2)

Eligibility criteria for these benefits are not in line with a Human Rights model of disability. The so-called ‘functional assessments’ used for Work Capability Assessment (WCA) and PIP are based on a stereotypical and medically reductionist model of disability that disregards lived experience.

In-depth research by CII with people with a variety of ELCs shows that the ‘descriptors’ for WCA and PIP fail to capture the impairment and restriction people with ELCs experience in relation to work, daily living activities and mobility. The features of ELCs that are disregarded by WCA and PIP criteria include the holistic impact of energy impairment on daily life, fluctuation, ‘payback’, and cognitive fatigue and dysfunction.

This failure to account for ELCs seems to be an intentional feature of the functional assessments, rather than an omission, and is linked to an agenda of austerity that aims to narrow the definition of disability by excluding those with ELCs (as well as those with mental health conditions) and thereby reduce the numbers of disabled people receiving support.

Energy impairment, fluctuation and ‘payback’

WCA and PIP assessments consider a range of activities and functions in isolation from each other, which fails to account for the interdependence of daily living activities in everyday life for people with ELCs.[[3]](#footnote-3), [[4]](#footnote-4)

Living with an ELC requires rationing limited units of energy. A person may be able to perform activities A, B or C – for instance, cooking, washing, or dressing – in isolation, but the nature of energy impairment is such that performing activity A may deplete one’s energy for activities B and C on any given day, or on future days. It might be physically possible for a person to perform activities A, B and C in one day, but this could result in severe payback that leaves them unable to do much at all for several days to come. Additionally, a person’s energy levels often fluctuate, which means that they might be able to perform activities A, B, or C on one day but not another.

However, the WCA and PIP descriptors only consider a person’s ability to perform activities in isolation and assume that if a person can sometimes perform activities A, B *or* C, that they can therefore perform A, B *and* C successively, on any given day. This fails to account for the significant negative cumulative impact of performing multiple daily living or work-related activities, and the fluctuating nature of ELCs.

The consideration of whether a single activity can be performed ‘repeatedly’ also addresses only one sort of activity at a time, and not the cumulative impact of distinct activities.

Consequently, the functional limitations of people with ELCs are grossly underestimated, and they are likely to be wrongly found fit for work or denied the substantial extra costs that they need.

This problem cannot be addressed by simply tinkering with the current tick-box system of assessment. The impact of energy impairment can only be captured within the holistic context of everyday life over an extended period of time.

Cognitive fatigue and dysfunction

Our research has shown that many people with ELCs experience cognitive fatigue and dysfunction, including problems with concentration and short-term memory. In a recent survey of disabled people who reported having ‘energy impairment,’ 58% said they had problems with memory, and half noted problems with learning, understanding, or concentrating.[[5]](#footnote-5)

With some conditions like Long Covid, fibromyalgia and ME, cognitive dysfunction and fatigue can be severely disabling, making even a five-minute conversation difficult or impossible. People with ELCs working in desk-based jobs report that cognitive dysfunction and fatigue are one of the key work-limiting features of their condition.

Such difficulties are inherent to many energy-limiting physical conditions, regardless of whether the person has a comorbid mental health condition. However, the DWP’s guidance to assessors states that the mental, cognitive and intellectual descriptors should only be applied to people with certain psychiatric diagnoses, brain injury, autism, or learning disabilities.[[6]](#footnote-6) People with ELCs are thus unable to gain ‘points’ for their disabling cognitive problems, and are given incorrect awards and inadequate levels of support.

Limiting the scope of descriptors in this way is at odds with the principle of a functional assessment that looks not at a person’s diagnosis, but at how that condition affects their function, which is the stated aim of the WCA and PIP assessment method.

A systemic programme of disability denial for ELCs

Assessments for ESA/Universal Credit (Limited Capability for Work and Limited Capability for Work and Work-Related Activity) and PIP are based on the model of health, disability and chronic illness set out within the field of Disability Assessment Medicine (DAM). Chronic illnesses causing energy limitation, fatigue and pain are characterised within the DAM literature as ‘common health problems’ that do not, in themselves, prevent work or cause disability. Waddell and Aylward, the chief proponents of DAM, argue that people with so-called “common health problems” bear personal responsibility for being out of work through their own “attitudes” and “motivation” (2005, p.8).[[7]](#footnote-7) They claim that “many” Incapacity Benefit (IB) recipients experience “incapacity without disease or impairment” and that “one of the main social security problems today is the number of people whose incapacity is based on feeling ill (and therefore limited in their activities), claiming the sick role, legitimised by sick certification, often in the absence of commensurate disease or impairment” (p.30). The principles of DAM are also referred to as the biopsychosocial (BPS) model of disability.

DAM and its model of disability denial has been implicated in the UK government’s austerity agenda since before 2010, as Waddell and Aylward’s 2005 report formed the basis of subsequent reforms that aimed to increase the overall employment rate to 80% and reduce the numbers of people on IB by 1 million,[[8]](#footnote-8) on the assumption that these people were not genuinely disabled.

As a result, a key principle underpinning WCA and PIP assessments is that the experiences of impairment and disability reported by people with ELCs are contentious, and not to be taken at face value.

Dishonest Assessments

Not only are the assessment criteria and ‘descriptors’ for WCA and PIP inadequate in themselves for capturing ELCs, but people with ELCs and other invisible impairments, pain and distress also frequently report that assessors lie and misconstrue their testimony.

Conclusion

The premise of disability assessments must be reconfigured to move the eligibility criteria and assessment descriptors away from this agenda of retrenchment connected with the BPS model of disability. To ensure an adequate standard of living and social protection, and to restore dignity and respect to people with ELCs, assessments must give full weight to disabled people’s lived experience and their testimony about how their conditions impact employment, mobility, and daily living activities.

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2. Gov.uk (2021) *Shaping future support: the health and disability green paper*. Available from: <https://www.gov.uk/government/consultations/shaping-future-support-the-health-and-disability-green-paper/shaping-future-support-the-health-and-disability-green-paper> [↑](#footnote-ref-2)
3. Centre for Health and Disability Assessments (2021) *Revised WCA Handbook*. Available from: <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1039927/wca-handbook.pdf> [↑](#footnote-ref-3)
4. Gov.uk. (2022) *PIP assessment guide part 2: the assessment criteria*. Available from: <https://www.gov.uk/government/publications/personal-independence-payment-assessment-guide-for-assessment-providers/pip-assessment-guide-part-2-the-assessment-criteria> [↑](#footnote-ref-4)
5. Chronic Illness Inclusion. 2021. *Submission to the Department of Health and Social Care’s Inquiry into Women’s Health and Wellbeing in England*, p.5. Available from: <https://chronicillnessinclusion.org.uk/wp-content/uploads/2021/06/CII.DHSC-Womens-Health-England-June-2021.pdf> [↑](#footnote-ref-5)
6. Centre for Health and Disability Assessments. 2020. *Revised WCA Handbook*, pp.123-140. [↑](#footnote-ref-6)
7. Waddell, G. and Aylward, M. (2005) *The Scientific and Conceptual Basis of Incapacity Benefits*. Great Britain: Department for Work and Pensions. [↑](#footnote-ref-7)
8. Department for Work and Pensions. 2006. *A new deal for welfare: Empowering people to work*. Available from: <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/272235/6730.pdf> [↑](#footnote-ref-8)