



Chronic Illness Inclusion response to the Health and Disability Green Paper

Shaping Future Support – consultation response from Chronic Illness Inclusion

October 2021

Introduction

We are pleased to submit evidence to the Department of Work and Pensions' (DWP) consultation on *Shaping Future Support* on behalf of Chronic Illness Inclusion (CII). CII represents a large, but hidden, sub-group of disabled people with energy-limiting conditions whose needs are poorly understood by society and insufficiently accounted for by government departments.

The failings of the disability benefits system have been widely documented by Disabled People's Organisations and other civil society groups. They include inadequate levels of financial support, flawed decision making, punitive bureaucracy and a climate of stigma and distrust towards claimants. It is right that the *Shaping Future Support* Green Paper addresses at least some of these concerns, although we are very disappointed that the poverty-level rate of benefits is not addressed here.

But disabled people with energy limiting conditions face an even starker barrier to support. **The WCA and PIP assessment systems fail, in many respects, to capture our lived experience of impairment. In too many cases they effectively deny our needs for support.** We would, therefore, particularly draw attention to our responses to Chapter 4: *Re-thinking Future Assessments* to emphasise this issue.

Our submission is based upon user-led research carried out by the Chronic Illness Inclusion Project (CIIP) in 2018 for the DRILL programme of disability research.¹ CIIP was a mixed methods research project, including a survey of

¹ See Disability Research into Independent Living and Learning
<https://www.disabilityrightsuk.org/policy-campaigns/drill-programme/about-drill-programme>

over 2,000 disabled people. Our research findings form the basis of a report and briefing paper on employment and social security with energy-limiting chronic illness (ELCI), in collaboration with Leeds University Business School and Leeds Social Science Institute.² It is the first to consider ELCI as a significant subgroup of disabled people.

About Chronic Illness Inclusion

CII is a Disabled People's Organisation giving a voice to disabled people with energy limiting chronic illness (ELCI), energy impairment and chronic pain. CII exists to influence policies and perceptions around chronic illness, and to promote our rights as disabled people.

What is Energy Limiting Chronic Illness (ELCI)?

ELCI is closely aligned with impairment of stamina, breathing, or fatigue, which is reported by approximately one in three disabled people of working age in the UK.³ According to our research, ELCI includes musculoskeletal, neurological, endocrine, respiratory, autonomic and autoimmune conditions such as fibromyalgia, Ehlers-Danlos Syndrome, multiple sclerosis, COPD, lupus and thyroid problems. Around 2 in 5 survey respondents with ELCI report a co-morbid mental health condition.⁴

ELCI and energy impairment are new terms, born out of participatory research by and with disabled people with physical chronic illness.⁵ They reflect the lived experience and impact of many chronic illnesses.

ELCI is a debilitating mix of physical fatigue, cognitive fatigue and pain alongside other diverse illness symptoms. The main feature of ELCI is energy impairment: a generalised limitation on capacity for activity. Energy impairment can also be a secondary feature of other impairment types. People with ELCI experience 'payback': a disproportionate increase in pain, fatigue and other illness symptoms as a consequence of activity, and as a result of which prolonged rest is required to prevent deterioration in health. The ability to manage activity in accordance with energy limitation is paramount for the health of people with ELCI.

² Hale, C. et al. (2021) "I already have a job... getting through the day: ELCI, social inclusion, employment and social security. <https://chronicillnessinclusion.org.uk/wp-content/uploads/2021/04/CfWR-ELCI-and-Work-b.pdf>

Briefing paper <https://chronicillnessinclusion.org.uk/wp-content/uploads/2021/06/CfWRBriefingELCIWork-final.pdf>

³ DWP (2017/18) *Family Resources Survey*

⁴ Hale, C. et al. (2019) *Energy impairment and disability inclusion*. Centre for Welfare Reform.

⁵ Ibid.

ELCI and work

With regard to work, the primary limitation for people with ELCI is the amount, not the type, of work. The main employment adjustments include reduction in hours, removing travel requirements, flexible hours, and maximum autonomy of pace. Energy impairment is much less easily mitigated by aids, adaptations or adjustments to the work environment than, for example, mobility and sensory impairments. This is because energy impairment is primarily a restriction in capacity for activity.

The relationship between overexertion and increased disability means that **in many cases, work is not good for health** for people with ELCI. In order to have a health-sustaining role, work requirements must not exceed a person's limited energy capacity, and it must be integrated into their health management strategies of pacing, rest and work-life balance.

Social security policy and employment policy are inextricably linked when addressing barriers to work and inclusion for people with ELCI. The primary adjustment for employment is reduced hours. Such part-time work is far less likely to result in a liveable income, and therefore employment is rarely a route to financial independence for people with ELCI.

ELCI and social security

The WCA and PIP assessment systems do not adequately capture the key features of energy impairment, especially cognitive fatigue and dysfunction, fluctuation, and the dynamic nature of disability caused by "payback", or post-exertional malaise. Moreover, the WCA fails to measure the key indicator of employability for this group, which is the number and predictability of productive hours. This results in incorrect decisions, disentanglement to support and unnecessary distress of going through the appeals process for justice. These flaws in the system result in a pervasive insecurity that undermines health and pathways into employment. (See Chapter 4 for further detail and recommendations).

RESPONSES TO KEY THEMES PROPOSED IN THIS CONSULTATION

Chapter 1: Providing the right support

Improvements to forms

All forms should be easily available online and in PDF or similar format so they can be completed on a tablet or computer. The DWP should set up an email system so that claimants and their advocates can easily contact the DWP and get copies of the forms required by email that can be electronically completed.

We acknowledge that it is inevitable, when asking about a wide range of conditions and their impacts on individual people, that forms will be long and ask many questions. Making forms simpler needs to be balanced with making forms thorough.

Testing advocacy support

We welcome the DWP's intention to introduce advocacy support for claimants with additional barriers to accessing the benefit system. This is something that a number of user-led DPOs have been requesting for a while, based on feedback from disabled people.

Rather than attempting to pre-determine which groups will require advocacy support, the DWP should ensure that everyone who needs advocacy support can access it. This will smooth the process for all claimants and is likely to lead to more accurate assessments, and therefore reduced appeals and reassessments, leading to cost savings for the DWP and Tribunal system.

There are multiple potential barriers to accessing the benefit system for people living with health conditions and impairments. Those affecting disabled people with ELCI are some of the least-well recognised. These include:

- 1) Cognitive dysfunction.

Cognitive fatigue and dysfunction in ELCI are not the same as intellectual impairment or learning difficulties, and can be present in the absence of a psychiatric diagnosis. This feature can be extremely debilitating, and is often the key restricting feature in relation to work and other daily living activities. People with ELCI may only be able to concentrate on forms and related

administrative processes for 5-10 mins at a time, and sometimes not at all. Effectively, filling out a claim form, and gathering medical evidence, can take several weeks, during which a person's limited energy for self-care and other essential daily living activities has to be redirected to this activity. The process of making and maintaining claims often has a detrimental effect on health and wellbeing as a result.

Advocacy services are required by people with ELCI to reduce the significant burden on cognitive function and the adverse impact of this on health and wellbeing

2) Lack of support services for ELCI.

There are very few existing organisations providing advocacy support for welfare benefit claims for people with ELCI. This is a result of a vicious circle of under-investment in understanding diseases, lack of timely investigation, diagnosis and treatment, and lack of specialist services.

Significant numbers of people who need healthcare services, mental health support and social care support are unable to get the help they require. It is vital that these difficulties are taken into account and recognised. Just because someone does not get referrals to services doesn't mean that person doesn't need such services.

We have some additional concerns with the proposals for testing advocacy support. 'Value for money' is a nebulous concept that in this instance has to mean far more than whether advocacy services result in cost savings for the DWP. The overall wellbeing of the claimant must be paramount.

It is vital that advocates are properly trained in the lived experience of all impairments and health conditions and the types of barriers commonly faced. This is a particular issue for people with Energy-Limiting Chronic Illness (ELCI) as this umbrella term encompasses a set of poorly understood conditions.

Exploring support for mobility needs

As the DWP was told during the original consultations on the move to PIP, what was needed in regards to mobility was not a tighter threshold for accessing the higher award, but an additional threshold for people who are largely unable to get out of a wheelchair independently; and access to the lower award for people who could mobilise more than 50m, but no more than 200m.

The DWP should look to create three award rates for mobility: a higher award for people who cannot get out of a chair and move more than a few steps;

the current enhanced rate for people who can mobilise up to 50m; and the current standard rate for people who can mobilise no more than 200m.

Chapter 2: Improving employment support

We are concerned that the DWP continues to make statements like “work has a vital role to play in supporting good mental and physical health” (pg 22, para 97) without also saying that work can also have a major role in creating ill-health, and that work which is beyond the capacity of people with ELCI can be damaging to health (see Introduction).

Early Intervention

We are also concerned by statements like “We know that the longer someone is out of work, the greater the risk to their long-term health and wellbeing” (pg 23, para 105; see also pg 25, para 115 and pg 60, para 286). This kind of statement conflates two different reasons why someone might remain out-of-work. Firstly, as the DWP suggests, that being out-of-work itself may contribute to ill-health (this is particularly the case when unemployment means severe poverty and high levels of bureaucracy or conditionality, as in the UK benefits system); and secondly, that having a long-term condition that is not compatible with work necessarily means a person stays out-of-work in the long-term. This latter situation is not a ‘problem’ that needs to be ‘solved’, but merely a circumstance that needs to be recognised and appropriately supported through secure, liveable rates of social security.

The increase in people who need to access food banks and the likely increase of fuel / heating poverty this winter will be another factor in ill health. No one should have to choose between eating and heating.

Working to support employers

We appreciate the introduction of an ‘Access to Work passport’ (pg 24, para 111).

We suggest that an Access to Work passport should be made available to anyone making a request for Access to Work support, regardless of whether this is their first job or not.

Ensuring Jobcentres Are Welcoming, Engaging and Expert

Applying a new approach to conditionality

We agree that removing conditionality for people assessed as having limited capability for work but capability for work-related activity is helpful and important. However, we remain concerned that Jobcentre staff do not have the requisite training to properly help people with ELCI.

There should be suitable toilet facilities at JobCentres that claimants can easily access. It should be recognised that some claimants will need quick access to toilet facilities.

Testing new support through Health Model Offices

We remain concerned that placing Jobcentre or other DWP staff in medical buildings such as GP surgeries will mean that people who need to attend their GP, will be reluctant or refuse to do so. People need to feel safe with their GP and in the GP surgery. It is inappropriate and unethical to continue such placements.

Providing extra support for our staff

We welcome the contribution of health professionals to the conversation between a Jobcentre staff member and a benefit recipient, given that jobcentre staff lack the requisite medical knowledge. We suggest that Occupational Therapists are an important profession to include. However, medical knowledge is often lacking and incomplete in the case of many ELCIs such as Long Covid and fibromyalgia.

It is crucial that any HCP involved in employment support should be trained to understand the lived experience of ELCI, not only the limited medical perspective.

Personalising Employment Support

Providing tailored support

There are a very limited number of specialist organisations with expertise in supporting people with ELCI into work. One such is Astriid. It is very important that DWP learns from Astriid's success in this field. It is also important to note that small, specialist organisations with expert knowledge, like Astriid, are not necessarily locally-based but may take referrals from all over the UK. The DWP should ensure it does not conflate *specialist* organisations with *local* ones.

Greater guidance should be available for employers on the rights of employees so ask for reasonable adjustments and the need to ensure that workplaces are not hostile environments for people with ELCIs. An employment culture that is supportive will help in retaining employment.

Encouraging people in the Support Group or with LCWRA to take up support

Firstly, for people whose health is too poor to allow work, the key factor in returning to work is an improvement in health.

Secondly, people take up offered support when it is recognised that that support is of high quality and that the provider has knowledge and understanding in working with their impairment type. Unfortunately, the reputation of the DWP, Jobcentre and associated work programmes are very poor. They are commonly viewed to offer predominantly generic support, not

tailored specific conditions or impairments, which is experienced as unhelpful and irrelevant.

Improving the support available to people in the Support Group/LCWRA would entail 1) having at least twice as many DEAs placed within Jobcentres, and 2) Having DEAs trained to in awareness and understanding of the lived experience of ELCI 3) Drawing on the knowledge of expertise of specialist employment support services for ELCI.

Exploring digital employment support

If such support were available via the claimant's existing email address, not a digital platform, such as Egress, requiring login, that would be helpful and less stressful than long waits on the phone. It would provide both clarity and an audit trail.

Chapter 3: Improving current services

Exploring different ways to conduct assessments

Making greater use of triaging

We welcome the DWP's increasing use of paper-based assessments where these are adequate to make a decision. We are glad that the government has recognised the value of paper-based assessments. There are often very good reasons why being forced to attend face to face appointments is psychologically damaging for a claimant. This should be clearly flagged on a claimants file. Such claimants should always have paper based assessments.

We believe it should be possible to make at least 75% of all assessments be done as paper only assessments.

Using telephone and video assessments

The DWP should offer a range of formats for all claimants, so that they can choose the one that is most accessible to them. However, the offer of telephone and video formats does not negate the legal duty to ensure that all assessment centres are fully accessible and that all potential claimants are able to travel to an assessment centre.

Claimants should be encouraged and supported to have an advocate or family member present during assessments. Assessors need to recognise that assessments can be very frightening and that claimants will often forget vital information. The advocate or family member can supply missing details or information where needed. There is often a total disconnect in what the claimant says and what the assessor inputs onto the system. A copy of that information should be sent to the claimant with their decision letter. At present the only way to get such information is to make a Subject Access Request. This is a cumbersome process, for both the claimant and the DWP. If this information were automatically supplied, it could be more easily challenged and assessors would be encouraged to be more accurate in their assessments.

Many people will not have adequate internet facilities for a video assessment and some will not have adequate telephone facilities. If these people are to be able to access telephone or video assessments then the DWP will need to provide high-quality technology in locations accessible to the claimants, that are also private and secure, so that claimants can travel to these venues if that is preferred to travelling to an assessment centre (e.g. if an assessment centre is further away).

Reducing repeat assessments

We welcome the proposal to reduce repeat assessments. Many anecdotal reports from supporters of CII show a causal link between undergoing

assessments and a deterioration in health and wellbeing. This is partly due to the anxiety of potentially losing their only source of income, and partly because their very limited energy has to be diverted from self-caring and health-sustaining activity to finding the focus and concentration and fulfilling the administrative requirements of their claim. For this reason, repeat assessments should be avoided wherever possible.

Some people with ELCI do not have a definitive diagnosis, and many do not have a defined prognosis of either a static, permanent condition or a deteriorating condition. Instead, their conditions are quasi-permanent (i.e., highly likely to be lifelong but with a small possibility of improvement) and variable (i.e., the severity of symptoms and balance of symptoms may change over time).

We suggest that for people with ELCI, and other similar conditions that have an uncertain but likely lifelong prognosis, that repeat reassessments gradually reduce in frequency. In the early years of a chronic illness there is more chance of recovery or change, so a reassessment two years after the first assessment can be appropriate. However, as time passes the chronic illness typically becomes less and less likely to attenuate.

We recommend assessing someone with an ELCI every 5 years, after the first 2 years.

Improving decision making

The DWP is right to recognise the need for more evidence, but should focus on increasing this at the very first stage – the assessment – rather than waiting for the decision maker or mandatory reconsideration (MR). If a decision is overturned at MR due to new evidence being supplied, then that evidence should have been made available to the original assessor and decision maker.

The Mandatory Reconsideration process itself is an unnecessary bureaucratic step whose chief effect has been to sharply constrict the number of appeals. Given that the DWP reconsidered any decision automatically when an appeal was lodged, it was unnecessary and inappropriate of the DWP to create an additional bureaucratic burden and psychological barrier for benefit claimants. **The MR stage should be removed, and the DWP should return to simply reconsidering any award when an appeal to the Tribunal system has been lodged.**

The DWP should provide documentation to claimants giving their reasons for opposing any appeal. It is often impossible for Advocates to make contact with Decision Makers and conflicting advice/information is commonplace. Phone calls to claimants trying to 'negotiate down' an award prior to a tribunal hearing are extremely distressing. This practice should stop.

The DWP notes that a 'sizeable minority' have problems with PIP assessments, but it is important to understand the impact that MR has had on appeals, and that a substantially larger number of people would likely go to appeal if MR were removed. This indicates a large but hidden level of dissatisfaction with PIP and ESA assessments. The fact that it is hidden may be misleading the DWP into thinking that satisfaction with PIP and ESA is higher than is in fact the case.

Chapter 4: Re-thinking future assessments to support better outcomes

A New Approach: Proposals for Future Assessments

Making changes to the assessment criteria

The current points-based approach used by PIP and the WCA is fundamentally unsuited to the assessment of people with ELCI. Both systems fail to adequately capture the impact of fluctuating conditions and dynamic disability; both systems fail to account for the impact of cognitive fatigue and dysfunction, and both do not capture the impact of an overall limitation of energy on everyday life.

The impact of energy impairment can only be captured within the holistic context of daily living, and over a period of time. Our analysis of the problems with WCA and PIP assessments includes recommendations for immediate reforms to the existing system, as well as recommendations for a complete redesign of the methods and principles of disability assessment over the longer term.

Problems common to WCA and PIP assessments

Decontextualised activities. Both assessments consider a range of activities or functions in isolation from each other. Current assessment systems do not consider how performance on one activity can affect performance on another, and therefore implicitly assume and assess people as though there is no such effect. The consideration by assessors of whether an activity can be performed 'repeatedly' is irrelevant because it still only addresses activities in isolation from each other and does not address the interdependence of daily living activities in everyday life.

A person with ELCI may, for example, be able on any given day to do two out of a possible three assessed activities (e.g. cooking, washing and dressing). The assessment processes consider each activity separately, and assesses the person as able to do each activity on two out of three days (i.e., more than 50% of days or more than 50% of the time) and therefore not disabled on these activities. The person would be found fit for work or not to have substantial extra costs, when in reality they experience substantial limitations every day because every day they are unable to perform at least one of these activities. Additionally, they may experience significant, negative cumulative impacts from activities.

This limitation cannot be addressed by tinkering with the current tick box system of assessment. In the longer term, a much more holistic assessment method is needed, which we outline below.

The failure to capture the impact of cognitive fatigue and related dysfunction.

Cognitive fatigue and related dysfunction (short-term memory, concentration, communication, and executive function difficulties), sometimes referred to as 'brain fog', is often the most restricting feature of ELCI in terms of work capability and daily living activities (see Introduction). The WCA and PIP assessments effectively exclude ELCIs from the descriptors for Mental, Cognitive and Intellectual Function (WCA) and for Communicating Verbally, Engaging with Other People and Making Budgeting Decisions (PIP). The DWP's guidance to assessors on the scope of descriptors and activities⁶ clarifies that activities are intended for certain diagnoses.

For example, in relation to Activity 13 in the WCA: *Initiating and completing personal action*, guidance to assessors states:

"[This activity] is intended to reflect difficulties that may be encountered by people with conditions such as psychosis, OCD, autism and learning disability. A very severe depressive illness that results in apathy, or abnormal levels of mental fatigue, may result in problems in this area."
Revised WCA Handbook, Centre for Health and Disability Assessments, p131

This is entirely 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. Restricting the application of descriptors to some diagnoses and thereby effectively excluding others is incompatible with a functional assessment.

Assessors must apply the cognitive, mental and intellectual descriptors to ELCIs where cognitive fatigue and dysfunction are key restricting factors in work capability and daily living activities, such as learning tasks, awareness of hazards, initiating and completing personal action, and coping with social engagement. With regard to PIP, assessors must consider the impact of

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https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/925097/wca-handbook.pdf

cognitive fatigue and dysfunction on communicating verbally, engaging with other people and making budgeting decisions.

WCA – no measure of reduced hours of work capability.

The WCA gives no indication of the crucial question of how many hours per week a claimant with ELCl may, or may not, be able to work. This is affected by what proportion of their limited energy is taken up in essential daily living activity, the cumulative impact of activity; the increased symptoms and disability incurred as a result of activity ('payback'); the added time taken up by resting; as well as the unreliability of being able to perform an activity when required to with a fluctuating condition.

Future assessments should include indicators of how many hours per week claimants can work repeatedly, reliably and without damaging their health.

Longer term reform of disability assessment systems and principles

We recommend a fundamental redesign of the WCA and PIP assessments in partnership with disabled people with ELCl, as well as other impairment groups. The principles of disability assessment should be rooted in lived experiences of impairment and the impact on work and daily living. This entails:

Rating the range of work capability according to the number of productive hours that can be repeatedly and reliably sustained in work, as part of a holistic assessment model

An understanding of when paid work is unsafe and causes deterioration due to payback and need for pacing and rest

A relational approach that explores how limited energy is allocated across all tasks of daily living, including self-care, health management and domestic and financial management, as well as in work. A completely new way of assessing people based on their ability to carry out basic tasks such as getting washed and dressed, doing laundry and ironing, cooking regular meals, (not just reheating a microwave meal), doing housework, shopping and travelling to work or hospital appointments and the pay-back involved after carrying out such tasks would be a more realistic way of assessing people.

Taking particular account of the impact of cognitive fatigue ('brain fog') and related cognitive dysfunction on work capability

Training assessors with knowledge and understanding of the lived experience of ELCl, as well as more specialised medical knowledge of the conditions with which claimants present with

Restoring trust between assessors and claimants by allowing for a

longitudinal and holistic assessment of work capability, rather than a 'tick-box' model of assessment.

Supporting evidence for assessments

The role of evidence in WCA and PIP assessments

Currently, the DWP can ask and pay for medical evidence from a claimant's HCPs, but does not routinely do so. Claimants can ask their HCPs to send in evidence, but usually then have to pay themselves; this prevents many from being able to do so, as they lack the finances. HCPs themselves are routinely over-worked and under-funded, so can struggle to send in meaningful evidence even when they are paid because they lack the time or funding to write medical reports for the DWP.

The DWP should ask claimants if they want the DWP to ask an HCP for medical evidence, and if the claimant says yes then the DWP should directly request and pay for such evidence from the relevant HCP. Claimants are best placed to know whether an HCP can help, because claimants know which HCP they see the most or has the most relevant or up-to-date knowledge of the claimant.

The government as a whole needs to fund the NHS adequately, so that HCPs have time to answer requests for information. The government should also provide training to HCPs on what information the government is seeking, so that HCPs don't waste time sending information that is unhelpful, irrelevant or uninformative.

The role of assessors in the process to decide financial support

There is an urgent need for more training of assessors so that they have more medical knowledge of individual health conditions, but also a much better understanding of the lived experience of ELCI and energy impairment. This training should be developed and delivered by experts by experience so that assessors understand both the impact of their decisions and the difficulties faced by claimants.

Testing an employment and health discussion

We welcome the support that Occupational Health Professionals and Occupational Therapists can provide to all areas of an individual's life, not just employment issues. We have been saying for some time that most people in receipt of sickness benefits are likely to need this level of support if they are to be able to engage in some form of work. The government should invest in more OHPs and OTs so that everyone can access support from someone with these levels of training. An OT can additionally help to create the 'Access to Work passport' which should be provided to all sickness benefit recipients.

Chapter 5: Exploring Ways to Improve the Design of the Benefits system

We are concerned with the DWP's focus on controlling spending. This is not the right way to support people with chronic illness and disability. People should receive the level of support that they need, not a fraction of it out of a misguided fear of spending. Proper investment in support can lead to reduced costs further down the line, whereas inadequate support typically results in a decline in a person's health, wellbeing and independence, and therefore results in increased costs compared to supporting a person properly in the first place. This misguided focus on cost is likely to result in higher costs for lower outcomes.

Why Further Change is Needed

How Can We Better Support People into Work and Adjust to Changes?

Some of the biggest concerns about moving into employment include the increased costs for work clothes, commuting and childcare. People who do not get a work allowance can end up poorer in work because the 37p of every £1 they earn is inadequate to cover the extra costs they incur as a result of working.

All costs incurred by working should be offset by a tailored work allowance, so that no-one is effectively made poorer by going to work. The taper should also be reduced to at most 50p in the £1. Currently it is higher than the highest marginal tax rate, and this is unfair.

We strongly recommend France's approach of a 'grace period' as this gives people warning about a change in their income, time to adjust and if appropriate time to appeal the outcome.

Submission led by Stef Benstead for Chronic Illness Inclusion