

Policy Briefing: Energy limiting chronic illness (ELCI), social inclusion, employment and social security

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One in three disabled people of working age in the UK has impairment of stamina, breathing or fatigue.¹ Many of them will be living with energy limiting chronic illness (ELCI). This briefing summarises the findings and recommendations from a study into social inclusion, employment and social security for disabled people with ELCI.²

The study forms part of the Chronic Illness Inclusion Project (CIIP), a participatory research project by, and with, the chronic illness community in the UK. This briefing draws on qualitative research on participants' experiences of employment and social security. It is the first research to take account of the lived experience of people with ELCI in order to improve provision for this large, but hidden, cohort of disabled people.

About ELCI and energy impairment

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Previous research by the CIIP found that fatigue or energy limitation is the most restricting feature in many neurological, musculoskeletal, respiratory, autoimmune and other disease groups.³ It also found that fatigue is commonly misunderstood, trivialised and dismissed, by employers and disability assessors as well as healthcare professionals. Consequently, people with ELCI experience the stigma of disbelief and invalidation in addition to their impairment. The CIIP proposes the concept of 'energy impairment', to clarify that fatigue in chronic illness is both qualitatively and biologically different from fatigue experienced by healthy people.

ELCI is multidimensional. Energy impairment involves cognitive fatigue and dysfunction as well as physical fatigue causing restricted mobility. Sometimes sensory sensitivity is also involved. Energy impairment plays out over time through the experience of "payback", as ELCI usually fluctuate both in terms of symptoms and severity of impairment.

The term "energy limiting chronic illness" (ELCI) describes conditions in which energy impairment is a main feature. This includes ME/CFS, fibromyalgia, lupus, chronic obstructive pulmonary disease, as well as many more. Understanding the lived experience of ELCI and energy impairment is crucial to developing policies that meet the needs, and promote the inclusion, of this group of disabled people.

The context of Covid-19

Although the research informing this report pre-dates the COVID-19 pandemic, there is now clear evidence of a new cohort of disabled people living with ELCI due to the emergence of Long Covid.

Over a million people in the UK reported symptoms associated with Long Covid in March 2021, with approximately 200,00 reporting severe disability.⁴ Fatigue, post-exertional malaise and cognitive dysfunction were the most prevalent symptoms of Long Covid in the Zoe Symptom Study at Kings College.⁵ Almost a quarter of patients who took part reported being unable to work at all. This makes it more urgent than ever that policymakers to listen to disabled people with ELCI and respond to their needs and aspirations to participate in society.

ELCI and work

People with ELCI experience a diverse and wide-ranging set of symptoms, which impact on their daily lives. Overall, our research found that energy impairment, especially the cognitive dimension and the fluctuating aspect of ELCI, is the key limiting factor in relation to work.

People with ELCI are excluded from employment by a complex interaction of impairment or illness with social, structural, and systemic barriers.

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The primary limitation for participants with ELCI was the amount, not the type, of work, and the unpredictability of work capability from day to day. Some had no, or few, productive hours of energy left after essential activities of daily living such as washing and dressing. Others were able to allocate a few hours of energy per week to work-related activity but not the quantity or regularity to sustain mainstream employment. These limitations are much less easily mitigated by aids and adaptations, or typical adjustments to the work environment: there are no aids that give someone more energy. More critical to the inclusion of people with ELCI in the labour market are adjustments such as reductions in working hours; working from home; flexibility over hours; and high autonomy.

Work itself can be disabling. Performance-based and rigid human resource policies/practices are barriers to the autonomy needed to manage ELCI. A misplaced focus on time and presenteeism rather than output risks exacerbating illness and can lead to otherwise avoidable exit from employment.

Information and training about ELCI for employers, recruitment managers and line managers is key to increasing employment opportunities. Lack of understanding of ELCI as a type of disability also creates unnecessary barriers to disability disclosure and the provision of necessary adjustments. Misinterpreting energy impairment as lack of willpower or laziness is a major source of conflict at work, with regard to both managers and co-workers. Improved awareness of ELCI and energy impairment in relation to the Equality Act 2010 can aid job retention for individuals with ELCI.

Employment support provision must be reconfigured. In contrast to other impairment groups, employment support intermediaries to specifically broker job opportunities for people with ELCI are almost non-existent. This means that employers are not informed or incentivised to create job roles that maximise the opportunities for people with ELCI. There is a need for job brokers who can create opportunities for people with ELCI by working with employers on job carving and job redesign, to create roles with reduced hours, increased flexibility of time and pace, and remote working practices.

The majority of our participants had previously had employment in high-skilled professional roles but were now largely not engaged in paid work. Their desire to contribute to society was high, as was their aspiration was to lead more meaningful and socially connected lives. But paid work was not the only route, and typically was not the best or even a viable route, to social inclusion. For this reason, the workings of the social security system are a key consideration in the goal of social inclusion for disabled people with ELCI.

Social security

For many people with ELCI, work simply isn't possible. Others can only work part-time and therefore cannot earn a living wage. Employment policy and social security policy must be properly joined up in order to improve the lives of people with ELCI. A robust social security system is key to ensuring social inclusion and participation for people with ELCI who have no or very few hours of capacity for work, as well as being vital to those who can work part-time but cannot earn enough to support themselves.

The main problems identified within the disability benefit system by participants were (1) disability assessments that fail to account for impairment with ELCI and (2) a social security system that disables, rather than enables, pathways into employment.

The Work Capability Assessment (WCA) fails to account for work-limiting disability with ELCI and energy impairment. As the gateway to social security entitlement and employment support, the WCA was a key feature of life for our participants. However, their experiences demonstrated that the WCA does 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 a distressing appeals process. These flaws in the system result in a pervasive insecurity that undermines health and pathways into employment.

The lived experience of energy impairment and ELCI is at odds with the notion of “common health problems” within the field of Disability Assessment Medicine (DAM) which underpins the WCA.⁶ DAM (and by extension the WCA) trivialises fatigue and pain in chronic illness and attributes incapacity for work among people with ELCI to personal failings rather than genuine disability. Our research demonstrates that energy impairment substantially restricts all activity and is not associated with a lack of work ethic. However, DAM construes the testimony of people with ELCI as potentially

deceitful. This has led to a climate of suspicion and distrust between claimants and assessors, which undermines the accuracy of assessments, and produces adversarial relations with DWP staff. The experience of invalidation with disability assessments is traumatic and creates mental distress on top of chronic physical illness.

People with ELCI live in constant fear of suspicion, judgement and hostility from the public, as well as from disability assessors. The implications of suspicion and distrust within DAM have pervaded society through media depictions of ‘skivers’ and ‘cheats’. As a result, people with ELCI are fearful of being seen engaging in any form of activity which could be falsely construed as evidence of capability for work. They fear being reported to DWP, falsely accused of fraud and stripped of the benefits they depend upon. This fear leads to social withdrawal and increased isolation, and is a key barrier to social inclusion, health and wellbeing.

The system as a whole undoubtedly results in people with ELCI moving further away from employment, rather than closer to it.

Summary of recommendations

1. Cross-government departments and agencies should recognise people with ELCI as a discrete sub-group of disabled people, as part of its National Disability Strategy.

2. Employers should promote employment for those with ELCI including through: (i) Adjustments to working patterns (ii) Workplace adjustments (iii) Carving out niche roles tailored to people with ELCI and (iv) The inclusion of ELCI within broader organisational Equality, Diversity and Inclusion (EDI) initiatives.

3. Government should adopt a targeted approach to employment policy and support provision for people with ELCI, including through: (i) Supporting the development of job carving agencies to connect employers with jobseekers with ELCI and work with employers to create tailored roles suited to the skills and capacity of people with ELCI.

4. Government should bolster rights to flexible working for disabled people as a reasonable adjustment, including reduced hours, flexible hours, home working and remote access technology.

5. Government should improve the Access to Work scheme including by: (i) Increasing funding (ii) Speeding up the application process and delivery of support (iii) Promoting knowledge and understanding of the scheme amongst employers (v) Making the scheme more accessible to self-employed workers and (vi) Expanding its scope.

6. Government should increase funding for social care, with a particular focus on the provision of support for household tasks, to free up capacity for those who can and want to work.

7. Government should redesign the Work Capability assessment in partnership with disabled people with ELCI, based on the following principles: (i) Rating the range of work capability according to the number of productive hours that can be repeatedly and

reliably sustained (ii) Exploring how limited energy is allocated across all tasks of daily living, as well as in work (iii) Taking particular account of the impact of cognitive fatigue ('brain fog') and related cognitive dysfunction on work capability and (iv) Training assessors with knowledge and understanding of the lived experience of ELCI.

8. Government should redesign our social security system so it protects health and wellbeing and creates a foundation for social inclusion by: (i) Increasing benefit levels to reflect Minimum Income Standards that support social participation (ii) Increasing income security to enable safe experimentation with work and other forms of social contribution (iii) Compensating for reduced earnings from reduced hours of work, without pressure to increase hours of work (iv) Reducing the unnecessary frequency of reassessments (v) Increasing funding for advice and advocacy services (vi) Simplifying the appeals process and (vii) Making Personal Independence Payment more reflective of the additional costs faced by people with ELCI for social participation.

Notes

1. **Family Resources Survey** (2017/18) *Disability data tables*. London: Department for Work and Pensions
2. **Hale C, Benstead S, Hardy K & Ingold J** (2021) *"I already have a job... getting through the day"*. Sheffield: Centre for Welfare Reform
3. **Hale C, Benstead S, Lyus J, Odell E & Ruddock A** (2020) *Energy Impairment and Disability Inclusion*. Sheffield: Centre for Welfare Reform
4. **Office for National Statistics, 1st April 2021**
5. **Covid Symptom Study** (2020) *How long does covid last?* <https://covid.joinzoe.com/post/covid-long-term>
6. See for example: **Aylward M** (2003) *Origins, practice, and limitations of Disability Assessment Medicine*. In: Halligan P, Bass C and Oakley DA *Malingering and Illness Deception*. Oxford: Oxford University Press, pp.287-300.

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