Chronic Illness Inclusion’s Submission to the UNCRPD Shadow Report

For the UNCRPD Shadow Report, Chronic Illness Inclusion has compiled a selection of our research most relevant to the UNCRPD, focusing on Articles 8 (Awareness-raising), 9 (Accessibility), 11 (Situations of risk and humanitarian emergencies), 25 (Health), 27 (Work and employment), 28 (Adequate standard of living and social protection) and 30 (Participation in cultural life, recreation and sport). This submission has five parts. Part I discusses the impact of disbelief and lack of awareness on the everyday lives and employment opportunities of people with energy limiting conditions (ELCs), and the need for an awareness-raising campaign from the UK government to promote understanding of ELCs. Part II reflects on the emergence of remote access and participation during the early stages of the COVID-19 pandemic and makes the case for remote participation in work and recreational activities as an accessibility measure for people with ELCs. Part III reports the experiences of people with ELCs during the COVID-19 pandemic, many of whom suffered from the UK government’s inadequate response. Part IV is the longest section of our submission, focusing on healthcare for people with ELCs, many of whom have uncertain or contested medical diagnoses, and experience harm as a result of inappropriate treatments and institutional disbelief. This section also discusses the difficulties for housebound people accessing healthcare and the impact of COVID-19 on healthcare for people with ELCs. Part V examines the eligibility and assessment criteria for a range of disability-related benefits in the UK, arguing that these criteria do not adequately reflect the lived experiences of people with ELCs, and that they are based on the assumption that ELCs and the testimony of people with ELCs are contentious.

About CII

Chronic Illness Inclusion (CII) was formed after the end of the Chronic Illness Inclusion Project, a DRILL-funded social action research project led by disabled people. CII is a Disabled People’s Organisation. This means we approach chronic illness from a social justice, rather than a medicalised, perspective. Rooted in the social model of disability, we challenge the oppressive attitudes and exclusionary practices that diminish the lives of people with energy limiting chronic illnesses (ELCI), energy impairment and chronic pain over and above their symptoms. We refer to ELCIs, energy impairment and chronic pain collectively as energy limiting conditions (ELCs). CII exists to influence policies and perceptions around chronic illness, and to promote our rights as disabled people. Our vision is a world in which our experience of disability is heard, believed, and understood, our rights as disabled people are upheld, and our lives have equal value.

About energy limiting conditions (ELCs)

We estimate that ELCI, or energy impairment, affects as many as one in three disabled people in the UK.[[1]](#footnote-1) ELC, ELCI and energy impairment are new terms, born out of participatory research by and with disabled people with physical chronic illness. They reflect the lived experience and impact of many chronic illnesses.

Many people living with ELCs identify simply as having ‘*chronic illness*’.

Examples of ELCs include fibromyalgia, Long Covid, ME/CFS, lupus, Ehlers Danlos Syndrome, inflammatory bowel disease, multiple sclerosis, lupus, thyroid problems and POTS, as well as many other neurological, musculoskeletal, endocrinological, respiratory, autonomic and auto-immune conditions. Around 2 in 5 survey respondents with ELCs report a co-morbid mental health condition.[[2]](#footnote-2)

**Key impairment features**
CII research identified the four key work-limiting features of ELCs as:

* **Energy impairment** (an experience more profound and multi-dimensional than ‘tiredness’).
* **Cognitive fatigue and dysfunction**.
* **Fluctuation** in symptoms and severity of impairment.
* **‘Payback’**, which refers to the increase in symptoms and incapacity that typically follows mental or physical activity (sometimes known as ‘post-exertional malaise’ or ‘post-exertional symptom exacerbation’).

*“With ME, you're so limited on energy. And that doesn't only just affect walking and physical things - that's mental ability, that's cognitive, and all of those things.”* (Focus group participant)

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* **Part I**: Disbelief and Lack of Awareness: Articles 8 (Awareness-raising) and 27 (Work and employment)
* **Part II**: Remote Access and Participation: Articles 9 (Accessibility), 27 (Work and employment) and 30 (Participation in cultural life, recreation and sport)
* **Part III**: The Impact of COVID-19: Article 11 (Situations of risk and humanitarian emergencies)
* **Part IV**: ELCs and Experiences of Healthcare: Article 25 (Health)
* **Part V**: Failures of Benefits Assessments: Article 28 (Adequate standard of living and social protection)
* **Conclusion**
1. This is based on the report by the DWP that 1 in 3 of the 14 million disabled people of working age in the UK lives with ‘impairment of stamina breathing or fatigue’. Department for Work and Pensions (2017/18). *Family Resources Survey*. [↑](#footnote-ref-1)
2. Hale, C., Benstead, S., Lyus, J., Odell, E. & Ruddock, A. (2020) *Energy impairment and disability inclusion*. Centre for Welfare Reform. <https://chronicillnessinclusion.org.uk/wp-content/uploads/2021/04/energy-impairment-and-disability-inclusion.pdf>  [↑](#footnote-ref-2)