Disbelief and Lack of Awareness: Articles 8 (Awareness-raising) and 27 (Work and employment)

One of the most common barriers that people with energy-limiting conditions (ELCs) experience is a lack of awareness and understanding of their illnesses, and disbelief that they are ill. This greatly impacts their everyday lives, employment opportunities, and experiences of healthcare. This section focuses on the impact on everyday life and employment opportunities, and the responsibility of the UK government to undertake awareness-raising campaigns to address this issue. The impact of disbelief on the experiences of healthcare for people with ELCs is discussed in Part IV.

Awareness-raising

Before the Committee on the Rights of Persons with Disabilities published its recommendations for the UK Government in 2017, a strong link had already been identified between austerity programmes and the increasingly negative media portrayal of disabled people in the UK, with stories of disability benefit fraud being used to morally justify welfare reform.[[1]](#footnote-1) People with hidden impairments were particularly likely to be portrayed negatively and in association with reports of fraud.[[2]](#footnote-2)

In 2017 the Committee recommended that the State Party, in close collaboration with organizations of persons with disabilities, strengthen its awareness-raising campaigns aimed at eliminating negative stereotypes and prejudice towards persons with disabilities.[[3]](#footnote-3)

However, the UK government has not undertaken awareness-raising campaigns aimed at eliminating negative stereotypes and prejudice towards disabled people, and the belief that non-disabled people are abusing legal protections and privileges meant for the disabled remains prevalent, often preventing disabled people from accessing their rights.[[4]](#footnote-4)

Research by Chronic Illness Inclusion (CII) shows that there is a pervasive lack of awareness or understanding of energy limiting conditions (ELCs), and that stereotypes of people with hidden impairments as fakers and benefits cheats are widespread. Whereas many disabled people face stereotypes and prejudice because they are perceived as disabled, negative stereotypes and prejudice towards disabled people with ELCs are grounded in disbelief and invalidation of their disability.[[5]](#footnote-5)

The most frequently reported barriers encountered by people with ELCs are ‘lack of understanding of energy limiting chronic illness’ (85%), followed by ‘disbelief in my illness or disability’ (65%).[[6]](#footnote-6) Out of 2000 people with ELCs, over two thirds frequently encountered the attitude that they “don’t look disabled”.[[7]](#footnote-7)

Focus group participants shared experiences of overt hostility when positioning themselves as disabled by using accessible facilities, mobility aids or claiming disability benefits. These experiences generally involved accusations of exaggerating or feigning impairment to obtain privileges.

“The first time I used a shop mobility scooter, the person in the store when collecting said loudly 'You don't need this!'. I've never hired one again”.[[8]](#footnote-8)

80% of participants agreed that they encounter the attitude that “everyone gets tired”.[[9]](#footnote-9) 55% agreed that they encounter the attitude that “fatigue and pain are not real disabilities”.[[10]](#footnote-10) 83% encountered the attitude that they “should try harder to overcome their difficulties,” indicating that ELCs are frequently attributed to moral weakness and personal failing.[[11]](#footnote-11)

“There's a lot of stigma to putting yourself in the disabled category if the person you're talking to disagrees with you being there. I've had a lot of experiences of others being hostile or patronising because they believe I'm not trying hard enough to be well or am exaggerating my limitations”.[[12]](#footnote-12)

In a survey by the Chronic Illness Inclusion Project in 2018, 66% of respondents agreed that they risk negative reactions from others when referring to themselves as disabled.[[13]](#footnote-13) 80% said they feel anxious about being watched or judged in relation to the veracity of their disability in public spaces.[[14]](#footnote-14) Half of respondents said they frequently or sometimes restrict activities like walking or recreational activities in public “in case I appear less disabled than I am”.[[15]](#footnote-15)

A focus group participant with respiratory disease, who regularly used a mobility scooter, and was advised by a doctor to do undertake some therapeutic walking to maintain lung function said:

“If I did that you can guarantee that someone will see me and think I'm lying, I'm faking, I'm making a false claim for disability mobility allowance”.[[16]](#footnote-16)

The government’s commitment to improving public awareness of disability in the National Disability Strategy must include a campaign to change perceptions and improve public understanding of ELCs, alongside other hidden and invisible impairments. In particular, the government’s awareness-raising campaign must challenge the harmful stereotype of attributing energy impairment to moral weakness, lack of effort or a strategy to game or cheat systems of disability support. The government must lead a change in the UK media to promote positive images of disabled people with ELCs by increasing understanding of their lived experiences, and an attitude of respect and belief.

Work

Attitudes of disbelief are also frequently the root of disability discrimination for people with ELCs through the refusal of reasonable adjustments in the workplace.

“I know the occupational health doctor at my work doesn't believe in ME/CFS and said my colleague should be given a parking space further away to encourage her to do more exercise.”(Focus group participant)

“I wasn’t able to advocate for the accommodations that I needed. I worked in a quite old school medical related charity, so [...] because I didn’t have ‘hard’ medical evidence, that they didn’t know what to do with me. I felt like a burden and an inconvenience. It completely destroyed a dream job.” (Focus group participant)

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3. Committee on the Rights of Persons with Disabilities (2017) *Concluding Observations on the initial report of the United Kingdom of Great Britain and Northern Ireland*. United Nations. [↑](#footnote-ref-3)
4. Dorfman, D. (2021) Pandemic “Disability Cons” *Journal of Law, Medicine & Ethics*, Volume 49, Issue 3: Malingering & Health Policy, Fall 2021, pp. 401 – 409. Available from:

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6. CII and Disability Rights UK (Forthcoming). [↑](#footnote-ref-6)
7. Hale et al (2020), p.42. [↑](#footnote-ref-7)
8. Hale et al (2020), p.45. [↑](#footnote-ref-8)
9. Hale et al (2020), p.15. [↑](#footnote-ref-9)
10. Hale et al (2020), p.42. [↑](#footnote-ref-10)
11. Hale et al (2020), p.42. [↑](#footnote-ref-11)
12. Hale et al (2020), p.43. [↑](#footnote-ref-12)
13. Hale et al (2020), p.15. [↑](#footnote-ref-13)
14. Hale et al (2020), p.46. [↑](#footnote-ref-14)
15. Hale et al (2020), p.47. [↑](#footnote-ref-15)
16. Hale et al (2020), p.46. [↑](#footnote-ref-16)