



Chronic Illness Inclusion

Chronic Illness Inclusion's Submission to the UNCRPD Shadow Report¹

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.

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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 (ELCIs), 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 ELCl, or energy impairment, affects as many as one in three disabled people in the UK.² ELC, ELCl 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, myalgic encephalomyelitis/chronic fatigue syndrome, lupus, Ehlers Danlos Syndrome, inflammatory bowel disease, multiple sclerosis, thyroid problems and postural tachycardia syndrome, 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.³

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.

² 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*.

³ 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>



- **'Payback'**, which refers to the increase in symptoms and incapacity that typically follows mental or physical activity (sometimes called '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)

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.⁴ People with hidden impairments were particularly likely to be portrayed negatively and in association with reports of fraud.⁵

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.⁶

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.⁷

⁴ Hughes, B. (2015). Disabled people as counterfeit citizens: the politics of resentment past and present. *Disability and Society*, 30(7), pp. 991–1004. Available from: <https://doi.org/10.1080/09687599.2015.1066664>

⁵ Briant, E., Watson, N. and Philo, G. (2011) *Bad News for Disabled People: How the newspapers are reporting disability*. Project Report. Strathclyde Centre for Disability Research and Glasgow Media Unit, University of Glasgow. (November).

⁶ 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.

⁷ 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: <https://doi.org/10.1017/jme.2021.60>

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.⁸

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%).⁹ Out of 2000 people with ELCs, over two thirds frequently encountered the attitude that they "don't look disabled".¹⁰

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".¹¹

80% of participants agreed that they encounter the attitude that "everyone gets tired".¹² 55% agreed that they encounter the attitude that "fatigue and pain are not real disabilities".¹³ 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.¹⁴

"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".¹⁵

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.¹⁶ 80% said they feel anxious about being watched or judged in relation to the veracity of their disability in public spaces.¹⁷ 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".¹⁸

⁸ 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>

⁹ CII and Disability Rights UK (Forthcoming).

¹⁰ Hale et al (2020), p.42.

¹¹ Hale et al (2020), p.45.

¹² Hale et al (2020), p.15.

¹³ Hale et al (2020), p.42.

¹⁴ Hale et al (2020), p.42.

¹⁵ Hale et al (2020), p.43.

¹⁶ Hale et al (2020), p.15.

¹⁷ Hale et al (2020), p.46.

¹⁸ Hale et al (2020), p.47.

A focus group participant with respiratory disease, who regularly used a mobility scooter, and was advised by a doctor to 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”.¹⁹

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)

¹⁹ Hale et al (2020), p.46.

Part II. Remote Access and Participation: Articles 9 (Accessibility), 27 (Work and Employment) and 30 (Participation in cultural life, recreation and sport)

During the pandemic, the government and many private businesses adapted to enable remote participation. Many people with energy limiting conditions (ELCs), many of whom are at least partially housebound,^{20, 21} were frustrated that it took such extreme circumstances to facilitate the remote access to work and cultural life that they had been demanding for so long, and were rightly concerned that this access might evaporate as soon as able-bodied people did not need it.²² In this section we discuss the importance of remote participation as an accessibility measure in regard to both employment and recreational activities.

Remote access and work

A survey conducted by the Chronic Illness Inclusion Project before the pandemic found that 72% of respondents who had requested remote access were denied this adjustment.²³ This survey also found that there were three main barriers experienced by people with ELCs when requesting and using remote access: attitudinal barriers, organisational barriers, and technological barriers. Many people with ELCs encountered disbelief about their impairment, leading them to doubt their legal status as disabled people and consequently their right to accessibility. These attitudinal beliefs often seep into organisational barriers, as participants reported that “feeling like a minority makes it harder to be heard or get my points across”.²⁴ Another organisational barrier is the size of meetings, as it is harder to hear and see what is going on over video conferencing in a large meeting. Technological access was also

²⁰ Hale, C., Benstead, S., Lyus, J., Odell, E. & Ruddock, A. (2020) *Energy impairment and disability inclusion*. Centre for Welfare Reform, p.61. <https://chronicillnessinclusion.org.uk/wp-content/uploads/2021/04/energy-impairment-and-disability-inclusion.pdf>

²¹ Hale, C., Brough, J., Allam, A., Lydiard, S., Springfield, F., Fixter, A., Wright, N., Clutton, V. and Bole, K. (2021) *Submission to the Department of Health and Social Care's Inquiry into Women's Health and Wellbeing in England*. Chronic Illness Inclusion, p.8. Available from: <https://chronicillnessinclusion.org.uk/wp-content/uploads/2021/06/CII.DHSC-Womens-Health-England-June-2021.pdf>

²² Hale, C. with Allam, A., Clutton, V. and Gunn, L. (2020) 'What does Covid-19 mean for the chronic illness community?' *Disability Wales*. Available from: https://www.disabilitywales.org/coronavirus-and-chronic-illness/?fbclid=IwAR27SZ8O2-td8fRQ99wJ0_S37A6pTNaqVc_XURQFcJYFV14SFT9KMQ5dX20

²³ Hale, C., Allam, A., Meyer, P., and Springfield, F. (2020). *Turning the Remote Access Revolution into Reasonable Adjustments*, p.8. <https://chronicillnessinclusion.org.uk/wp-content/uploads/2021/04/remote-revolution-to-reasonable-adjustments.pdf>

²⁴ Hale, Allam et al (2020), p.11.



a major issue, with participants regularly having their requests dismissed due to vague bureaucratic reasons, poor internet connections at venues, and an unwillingness from organisers to make an event accessible, with one participant being told “it’s too disruptive to have mixed methods” of both remote and face to face participation.²⁵

The widespread rollout of remote participation in both the public and private sector demonstrates that these adjustments could have been put in place all along. Rather than pushing to return to life as ‘normal’ with work in the office, remote access in the workplace should be understood as an issue of accessibility for people with ELCs.

Remote access and participation in culture, recreation and sport

As part of their ratification of the UNCPRD and its National Disability Strategy, the UK Government promised to widen disabled people’s participation in arts, culture and sport, recognising that, “[d]isability is one of the main barriers people give for not attending art and cultural events, and disabled people are nearly twice as likely to be physically inactive.”²⁶ However, this has not been reflected in any commitment to remote participation in culture, recreation or sport. Although remote access to leisure activities emerged during the lockdown, much of this disappeared when lockdown was lifted. For instance, while “56% of publicly subsidised theatres had at least one online performance during the first 18 months of the pandemic,” the same theatres had no online performances scheduled for the autumn season of 2021, offering in-person shows only.²⁷ This is especially egregious considering the number of theatres that are publicly subsidised by Arts Council England.²⁸

Access to leisure is just as important to people with ELCs as access to work, because “disabled people deserve the right to have a life like everyone else.”²⁹ It may even be more important, given that many people with ELCs would be unable to work even if remote participation were a widely recognised reasonable accommodation.³⁰ While remote access is not, and should never be, an alternative to

²⁵ Hale, Allam, et al (2020), p.9.

²⁶ Disability Unit, UK Government. (2021) *Leisure: National Disability Strategy explained*. Available from: <https://disabilityunit.blog.gov.uk/2021/07/28/leisure-national-disability-strategy-explained/>

²⁷ Sherwood, H. (2021) ‘50% of UK theatres streaming shows online during Covid revert to in-person only’. *The Guardian*. 10 October 2021. Available from: <https://www.theguardian.com/stage/2021/oct/10/50-of-uk-theatres-streaming-shows-online-during-covid-revert-to-in-person-only>

²⁸ Statistica.com. (2021) *Leading subsidized theatres ranked by amount of funding received from Arts Council England from 2018/19 to 2021/22** Available from: <https://www.statista.com/statistics/510623/most-subsidized-theaters-by-funding-amount-in-england-uk/>

²⁹ Ryan, F. (2021) ‘Remote working has been life-changing for disabled people, don’t take it away now’. *The Guardian*. 2 June 2021. Available from: <https://www.theguardian.com/commentisfree/2021/jun/02/remote-working-disabled-people-back-to-normal-disability-inclusion>

³⁰ Hale, C., Benstead, S., Hardy, K. and Ingold, J. (2021) *I already have a job... getting through the day: Energy Limiting Chronic Illness (ELCI), Social Inclusion, Employment and Social Security*. Centre

accessible venues, remote access provisions should be continued so that people who are housebound are not entirely cut off from recreation and cultural life.

A note about terminology: what we mean by ‘housebound’

Chronic Illness Inclusion (CII) recognises that ‘housebound’ is a contentious term in disability activism because it has been used to naturalise the confinement of people with impairments to their homes or to institutions, when these people can in fact leave their homes if provided with appropriate, self-directed support. However, this is a term that many people with ELCs feel describes their lived experience, as there are often not support or accommodations that can enable people with energy impairment to leave their homes safely.

In our survey on women’s health, CII defined being ‘housebound’ as:

“either 1) being always or sometimes unable to leave the home to get to a medical appointment even with support or assistance, or 2) the exertion from leaving the home to attend a medical appointment would result in significant worsening of symptoms, flareup, relapse, or setback as a consequence, e.g., for days or weeks.”³¹

Remote access thus allows many people to engage in aspects of work and social life from which they will otherwise be barred, either because it is not physically possible for them to leave their homes, or because the cost of doing so in pain and fatigue is intolerable.

for Welfare Reform. Available from: <https://chronicillnessinclusion.org.uk/wp-content/uploads/2021/04/CfWR-ELCI-and-Work-b.pdf>

³¹ Hale, C., Brough, J., Allam, A., Lydiard, S., Springfield, F., Fixter, A., Wright, N., Clutton, V. and Bole, K. (2021) *Submission to the Department of Health and Social Care’s Inquiry into Women’s Health and Wellbeing in England*. Chronic Illness Inclusion, p.8. Available from: <https://chronicillnessinclusion.org.uk/wp-content/uploads/2021/06/CII.DHSC-Womens-Health-England-June-2021.pdf>



Part III. The Impact of COVID-19: Article 11 (Situations of risk and humanitarian emergencies)

Introduction

Chronic Illness Inclusion (CII) understands the COVID-19 pandemic as a clear instance of a situation of risk and humanitarian emergency, thus falling under the remit of Article 11. This section draws on evidence gathered in April 2020 through a survey conducted by CII about the impact of the COVID-19 pandemic on people with energy limiting conditions (ELCs), in response to a call for evidence by the Women and Equalities Parliamentary Committee. 776 people responded, of whom 85% were women.³²

We have highlighted where the evidence also has implications for other Articles of the UNCRPD.

Evidence summary

Our survey results showed a population at increased risk from COVID-19 due to underlying chronic conditions but excluded from the government's policy response. These people's needs were being ignored and their health and wellbeing was deteriorating. 82% of respondents reported that the pandemic had had a negative impact on their overall wellbeing. The overwhelming majority of our respondents were disabled women, who were already at greater risk of marginalisation and exclusion (**Article 6: Women with disabilities**).

28% of our survey respondents did not know if their chronic condition placed them at higher risk according to government guidance. This showed the need for clearer guidance, both for people living with chronic conditions and the shops and services expected to respond to their needs (**Article 21: Freedom of expression and opinion, and access to information**).

“When I asked if I could check with the GP if I was in the vulnerable group I was told to look online.” – **Woman in Yorkshire and the Humber, living with fibromyalgia.**

86% of respondents reported that the pandemic had had a negative impact on their ability to access food and essential supplies. Many of these people were largely housebound and reliant on supermarket deliveries. They were denied access

³² Ruddock, A. and Gkiouleka, A. (2020) “*I feel forgotten.*”: A Submission by the Chronic Illness Inclusion Project to the Women and Equalities Committee inquiry into the impact of coronavirus (covid-19) on people with protected characteristics. Centre for Welfare Reform. Available from: <https://citizen-network.org/library/i-feel-forgotten.html>



because of overwhelming demand and unclear guidance. The policy deprived disabled people of access to the essentials for survival (**Article 9: Accessibility, Article 28: Adequate standard of living and social protection**).

“I seem to be in a category where I'm not vulnerable enough to get help with essentials like food shopping, but too vulnerable to catch Covid and survive.” – **Woman in Wales, living with fibromyalgia and stenosis of the spine.**

“I'm on the 'vulnerable' list but not the 'extremely vulnerable' list - I am concerned about the possible effects of coronavirus on me but there is no support available with things like shopping. As a younger person with no visible disability I fear I wouldn't be allowed to use shopping hours dedicated to vulnerable people.” – **Woman in London, living with ME.**

“We have lost both our incomes, and we were already using foodbanks before the lockdown. We can't access them now, and nobody has been in touch from the various services that were in contact with us. I am very concerned about accessing food as I cannot stand for long at all and queuing would be out of the question at supermarkets.” – **Woman in Scotland, living with fibromyalgia.**

“I am housebound and one of the forgotten ones. I feel very isolated, frightened, anxious, lonely, hungry, very tired, hopeless. I am hungry due to the fact I need home delivery groceries and it's a three-week wait. I am nearly down to my last scrap of food from my freezer and I don't know what I am going to do. I sleep a lot lately, very tired probably because of my high dose of medications and very little food.” – **Woman in Northern Ireland, living with arthritis, complex regional pain syndrome (CRPS), dystonia, fibromyalgia, degenerative disc disease (DDD), heart condition.**

“When I told the supermarkets how I rely on delivery to get basics, they responded with a script about the government's ridiculously limited list of vulnerable groups each time. I was completely brushed aside.” – **Woman in East Midlands, living with ME, polycystic ovary syndrome (PCOS), IBS.**

Of the respondents under the regular care of a GP or specialist for chronic conditions, 66% reported disruption to care during the pandemic. This has long-term implications for people's health and will place increased pressure on the NHS and social care once the current crisis has passed (**Article 25: Health**).

“The lack of access to medical help for anything other than coronavirus is very scary. Plus, if I get the virus will they decide I'm not worth saving because of my conditions?” – **Woman in North West England, living with Graves' disease, thyroid eye disease, anxiety disorder, depression.**

“There has been a major impact on the ability of people with severe chronic illnesses to access support and healthcare. I am extremely concerned about the backlog this is going to cause down the line, as there are already significant waiting times for specialists. The NHS has been underfunded for so

long that I am terrified I won't have any access to this specialist care when the pandemic subsides. Our conditions are not going away and I think the lack of care during this time will cause irreversible damage to many of us and make our conditions even worse. I think policy makers have to understand that many people with chronic and rare diseases already feel like we are forgotten, but there are millions of us and this could cause a tsunami of healthcare problems after the pandemic earthquake." – **Woman in East Midlands, living with asthma, fibrous dysplasia, hypermobility syndrome.**

"Diabetes nurse appointment cancelled, diabetes annual review cancelled including eye screening, endoscopy for Crohn's cancelled, asthma annual review cancelled. I used to have monthly GP review - cancelled, but I can contact by phone for emergency." – **Woman in East England, living with diabetes, Crohn's disease, asthma, endometriosis, post-traumatic stress disorder (PTSD).**

"Hospital appointments for pain injections, neurologist, infusions have all been cancelled." – **Woman in London living with spinal cord injury, chronic pain, neurogenic bladder and bowel, osteoporosis.**

"Appointments I have fought for and waited almost a year for have been cancelled."
– **Woman in South West England, living with myalgic encephalomyelitis (ME), postural orthostatic tachycardia syndrome (POTS), irritable bowel syndrome (IBS), ulcerative proctitis.**

"The doctors are unable to grasp 'don't phone me, I can't hear'. It's all so much harder."
– **Woman in South West England, living with ME, rheumatoid arthritis (RA), hearing impairment.**

"I have mental health therapy twice a week; this has been cancelled and nothing has been put in place. All specialist appointments that I've been waiting 9 months for have been cancelled or even discharged." – **Woman in South East England, living with ME, fibromyalgia, POTS, anxiety, depression, costochondritis, asthma, IBS, interstitial cystitis, non-alcoholic fatty liver disease (NAFLD).**

"I have sought medical support for infections but been unable to make contact with my medical surgery as my only way I can communicate is via email (I am too weak and disabled to use the telephone) and the surgery now only replies to telephone calls. I have no support and no one to telephone for me."
– **Woman in South West England, living with severe sweating disorder, severe ME, multiple chemical sensitivity (MCS), spinal nerve disorder, complex PTSD.**

"I had a text saying not to contact them unless it's an emergency." – **Woman in Scotland, living with ME.**

56% of respondents reported that their health had declined since the pandemic began, with a significant number reporting the detrimental impact of increased stress and anxiety (**Article 25: Health**).

Many respondents reported experiences of discrimination in shops, the NHS, the media and public conversation. People reported feeling unseen, unheard and unvalued (**Article 5: Equality and non-discrimination**).

“I was very upset to see that because I need a carer, the NHS considers me too frail for ventilation and my life not worth saving. Hard to live with this hideous, soul-crushing disease knowing the NHS doesn’t consider me worth saving. Not sure I’ll ever trust the NHS again.” – **Woman in London, living with ME.**

“I feel the whole 'management' of the pandemic by central & local governments has been discriminatory as we have been completely overlooked.” – **Woman in East Midlands, living with fibromyalgia, Sjogren’s syndrome, osteoarthritis, spondylitis, sleep apnoea, depression, disassociation disorder, PTSD.**

“It has been incredibly difficult to prove you are disabled because people apply old-fashioned criteria of what is a disability to police access to things like supermarkets.” – **Woman in East Midlands, living with asthma, fibrous dysplasia, hypermobility syndrome.**

“I stopped in the park for a rest and was shouted at for stopping. It made me anxious to go out again.” – **Woman in East Midlands, living with ADHD, dyspraxia, PTSD, IBS, chronic pain.**

“I feel a bit like the experiences of disabled and chronically ill people have been at once co-opted and erased. We are experts in isolation yet we’ve been ignored/told we are expendable.” – **Woman in Scotland, living with fibromyalgia, c-PTSD, PCOS, Hashimoto's disease.**

“Politicians not talking to, but talking about, disabled people (when they remember us) has been quite painful to experience. The 'oh, it only kills people with a pre-existing condition,' as though that doesn't include anyone they think is listening. It's never 'your life is valuable and we're doing all we can to support you' - it's often in the third person.” – **Woman in East England, living with a thyroid condition.**

“The marginalisation of people whose disabilities makes them literally the most vulnerable to a novel virus is richly ironic. I have particularly experienced this in work/educational settings: for instance where concern is expressed 'for those whose loved ones and family may be more vulnerable', rather than those who may be more vulnerable themselves.” – **Woman in London, living with Behçet’s disease.**

Part IV. ELCs and Experiences of Healthcare: Article 25 (Health)

In this section we discuss the difficulties faced by people with uncertain or contested medical diagnoses in accessing healthcare, and the harm sustained as a result of inappropriate treatments and institutional disbelief. We also discuss the difficulties housebound people experience accessing healthcare, and finally the impact of COVID-19 on the access to healthcare of people with energy limiting conditions (ELCs).

Medically Unexplained Symptoms, Disbelief and Harm

Disabled people with uncertain or contested medical diagnoses have unequal access to general healthcare, poorer experiences of healthcare services and often report iatrogenic harm (harm caused by medical treatment) as a result of inappropriate and unevidenced psychosomatic frameworks and treatment services. This affects many people with energy limiting conditions (ELCs). Chronic Illness Inclusion (CII) believes that this results from imbalances in the production of medical knowledge, as knowledge about disease is generated exclusively by doctors, without input from patients. This means that lived experiences of impairment and disability which do not align with existing medical knowledge about diseases are systematically invalidated.

Medically Unexplained Symptoms

ELCs are strongly associated within the UK healthcare system with the label 'Medically Unexplained Symptoms' (MUS). This is typically the case either because a particular condition, such as lupus, Ehlers-Danlos syndrome, or multiple sclerosis, is difficult to diagnose and thus remains 'medically unexplained' for years, or because the condition itself, such as ME/CFS, fibromyalgia and Long Covid, is poorly understood by medical science and labelled 'medically unexplained'. The pathology of fatigue states in many chronic diseases is especially poorly understood.

MUS are typically taken as evidence not of genuine physical illness, but of cognitive or behavioural dysfunction,³³ frequently resulting in psychological therapies, in particular CBT, being used to 'treat' MUS, in spite of the lack of evidence that this is

³³ Deary V, Chalder T and Sharpe M. (2007) 'The cognitive behavioural model of medically unexplained symptoms: A theoretical and empirical review.' *Clinical Psychology Review* 27(7), pp.781–797.

effective.³⁴ In fact, there is considerable evidence that such treatments are harmful to patients.

Evidence of harm

CII's recent survey into women's healthcare found that:

- A third of respondents waited more than 10 years for a diagnosis.
- Before receiving their diagnosis, four in five respondents had their physical symptoms attributed to psychosocial causes such as stress, anxiety, or being overweight, and half received psychological therapy for their undiagnosed physical symptoms, with 81% finding this therapy unhelpful.
- Receiving psychological therapy could further diagnostic delays as all a patient's reported symptoms were then treated as manifestations of psychological distress.
- Many respondents described the experience of having their physical symptoms attributed to psychosocial factors, which did not align with their lived experience, as 'gaslighting'.
- Some respondents' health deteriorated either from the exertion of attending psychological therapies, or as a direct result of interventions such as graded exercise therapy for ME/CFS or Long Covid.³⁵

This latter finding has been widely substantiated.³⁶ A significant proportion of people with myalgic encephalomyelitis or chronic fatigue syndrome (ME/CFS) have reported iatrogenic and treatment harms following graded exercise therapy (GET), cognitive behavioural therapy (CBT), and physiotherapy. Of a sample of 60 patients with severe ME, a third reported feeling worse after GET, a sixth felt worse after CBT and 13% felt worse after physiotherapy.³⁷

NICE reported that:

³⁴ Tolin D.F., McKay D., Forman EM, et al. (2015) 'Empirically supported treatment: Recommendations for a new model.' *Clinical Psychology Science and Practice*. **22**(4), pp.317–338.

³⁵ Hale, C., Brough, J., Allam, A., Lydiard, S., Springfield, F., Fixter, A., Wright, N., Clutton, V. and Bole, K. (2021) *Submission to the Department of Health and Social Care's Inquiry into Women's Health and Wellbeing in England*. Chronic Illness Inclusion, pp.2-4. Available from: <https://chronicillnessinclusion.org.uk/wp-content/uploads/2021/06/CII.DHSC-Womens-Health-England-June-2021.pdf>

³⁶ Twisk F.N. and Maes M. (2009) 'A review on cognitive behavioral therapy (CBT) and graded exercise therapy (GET) in myalgic encephalomyelitis (ME)/chronic fatigue syndrome (CFS): CBT/GET is not only ineffective and not evidence-based, but also potentially harmful for many patients with ME/CFS'. *Neuro Endocrinology Letters* **30**(3): 284–299.

³⁷ Scott, M.J., Crawford, J.S., Geraghty, K.J. and Marks, D.F. (2021) 'The 'medically unexplained symptoms' syndrome concept and the cognitive-behavioural treatment model'. *Journal of Health Psychology*, p.5. Available from: <https://journals.sagepub.com/doi/10.1177/13591053211038042>



“Many people with severe ME/CFS report anger and frustration engaging with the medical profession, a significant proportion find getting a diagnosis an arduous task and are reporting that doctors have little knowledge of the illness. ... GET ranked highest for negative responses, followed by CBT and physiotherapy... Participants report that pushing beyond limits, often via participating in graded exercise therapy or physiotherapy, results in some type of negative symptom response that can last from days to months and many report associated psychological distress with such relapses.”³⁸

Patients’ beliefs and behaviours are often blamed by health care providers for the failure of CBT and other psychological therapies to improve their conditions, leaving patients with MUS feeling worse than when treatment began.³⁹

Disbelief and psychological harm

People labelled with MUS report being systematically discredited and disbelieved. In CII’s women’s healthcare survey, half of the respondents said they felt they were not listened to by health or care professionals ‘very often’, with a further 23% saying they felt this way ‘often’.⁴⁰

Many experience this disbelief as traumatic and are more likely to disengage from healthcare services as a result.

Respondents to CII surveys have said that:

- “With medical care I assume I will be disbelieved especially regarding ME & so keep my interactions to a minimum, this means my health care is not adequate.”
- “I am distrustful and anxious when dealing with medical professionals. It is common to be disbelieved and it puts me off seeking medical treatment in a timely fashion because I can’t bear to go through all that again every time, as I find it exhausting, stressful and triggering to my PTSD. At times I have been treated like a liar and a malingerer purely because I am well educated in my conditions.”
- “I don’t trust health and care providers. My health - both mental and physical - have deteriorated and I have refused to seek help.”
- “I don’t trust medical people any more. I try to be optimistic and friendly (or at least to seem to be), but every time I need to see or speak to a GP, I get really nervous and depressed because the normal scenario is that I have

³⁸ NICE (2020) Guideline Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: Diagnosis and management. Draft for consultation, November 2020, quoted in Scott et al (2021), p.5.

³⁹ Scott et al (2021), p.4.

⁴⁰ Hale et al (2021), p.5.

asked for help in vain.”

- “I do not believe my GP has my best interests at heart. As a result of how I am treated I do not trust my doctors.”
- “I hate speaking to the doctor now, I'm always nervous before I call. I expect not to be believed or listened to.”
- “Now when I have concerning symptoms, I don't know if I should seek medical care as I don't know if I'll be believed. So I don't listen to my body or see doctors, even when I have new and significant chest pain, for example. So I am concerned that as I get older, I might end up seriously ill or dead because I've been taught that my symptoms will not be taken seriously when I see a doctor.”
- “I have been traumatised by medical gaslighting to the extent that I [am] frightened to go to the doctor now. When I do go, it takes me days to recover. I have anxiety attacks and become suicidal.”

This disbelief can have a detrimental impact of people's self-esteem and psychological wellbeing. Respondents to CII surveys have also said that:

- “I feel like it makes me less valid as a person as people see me as dishonest and a liar even though it's not me. I don't feel I can be fully open about my conditions [and] health care professionals see me and think I'm making it up even though I know I'm not, and so I feel like I'm never fully myself and this effects my self esteem as I don't feel like I can just be me and the other people can understand who I am. [I] feel like less of a person.”
- “I have developed anxiety about being believed & taken seriously especially with professionals, I struggle with a sense that I am seen as worthless by society in general. I have become apologetic & unassertive.”
- “When you are constantly disbelieved you start to query yourself and over long period of times this wears you down.”
- “Am I making this up? Is it not that bad? I don't deserve care since it's being withheld.”
- “Being treated as untrustworthy and an unreliable witness to one's own experiences is damaging. Being called a hypochondriac, treated as a time waster, or considered unworthy of help makes one feel worthless.”
- “I don't believe myself any anymore. I can't trust myself and I'm constantly questioning. I feel worthless. It's like a mantra in my head now: "Who are you? No one. What are you? Nothing. You are nothing. Shut up." Stop whinging. Stop focusing on yourself. Stop thinking about yourself. Who are you? No-



one. What are you? Nothing. Shut up.”

This experience of disbelief is deeply gendered, with women being at a much greater risk of medical disbelief than men. Additionally, most of the conditions labelled ‘medically unexplained’ are more often experienced by women than men, and the lack of knowledge about them stems from a gendered imbalance in biomedical investigations, where women’s illnesses are vastly under-researched.⁴¹ This should be a particular concern for the committee, given the commitment in Article 6 to recognising the multiple discrimination against women and girls.

It is very difficult for patients to address this gap in medical knowledge because of the imbalance of power between them and their doctors: doctors are regarded as the experts and patients’ opinions or experiences of their own bodies are less valid. Where there is a disagreement between the two, doctors are always presumed to be in the right.

No mechanism for reporting harms to MUS patients

This pattern of medical neglect has become pervasive in part because UK agencies tasked with monitoring harms to patients, such as the Yellow Card scheme operated by The Medicines and Healthcare products Regulatory Agency (MHRA), and the new proposed Patient Safety Commissioner and Redress Agency, only look at harms from “medicines and medical devices”,⁴² and do not consider potential harms to patients from psychosocial and behavioural interventions.

MUS framework as a healthcare spending reduction strategy

Patients with MUS are often made to feel like a drain on NHS resources, such as one focus group participant who said that they had been called “a burden on NHS care”.

There is evidence that this is how the NHS itself views MUS patients. The IAPT manual for treating MUS with CBT explains: “chronic repeat attenders account for 45% of primary care consultations and 8% of all emergency department attendances; the most common cause of frequent attendance is an untreated mental health problem or MUS”.⁴³ This treats the frequent attendance of these patients as the problem, rather than the patients’ poor health.

It appears that part of the motivation for ‘treating’ MUS with psychological therapies may be to reduce spending. NHS England states that the strategy of including MUS under the IAPT programme “is more cost effective and can reduce a person’s use of

⁴¹ Dusenbery, M. (2018) *Doing Harm: The Truth About How Bad Medicine and Lazy Science Leave Women Dismissed, Misdiagnosed and Sick*. New York: HarperCollins.

⁴² Gov.uk. *Report a problem with a medicine or medical device*. Available from: <https://www.gov.uk/report-problem-medicine-medical-device>

⁴³ NHS. (2021) *The Improving Access to Psychological Therapies Manual*, p.12. Available from: <https://www.england.nhs.uk/wp-content/uploads/2018/06/the-iapt-manual-v5.pdf>

physical health services: this can reduce the annual expenditure per person by £1,760,⁴⁴ and that it should “address problematic beliefs and behaviours that may increase the impact of LTCs [long term conditions] on people and their families and carers”.⁴⁵

Recommendations

- Knowledge production in medical science and healthcare must involve and engage patients and the public, not only to ensure co-production of knowledge, but also to avoid top-down hierarchical service provision and iatrogenic harm.
- More biomedical research should be carried out into conditions that predominantly affect women. Spending on MUS services under IAPT must be redirected to investment in biomedical research on ELCs.
- Healthcare professionals should receive extensive training on the (often unconscious) impact of gender biases on the credibility afforded to a patient’s report of their symptoms.
- The MUS concept can no longer be accepted as a viable diagnostic term. Use of MUS as a quasi-diagnostic category should be stopped because it obstructs access to needed medical diagnosis and care. Every time a doctor uses an MUS label to explain physical symptoms as psychosomatic, a patient in need of medical care may be denied access to it.
- A mechanism for reporting harm from cognitive behavioural treatments must be implemented. It is vital that the safety and effectiveness (or lack of effectiveness) of psychological and behavioural interventions is also covered by the Yellow Card scheme and a future Patient Safety Commissioner and Redress Agency. This agency must also be prepared to look seriously at the potential for conflicts of interest in those conducting any such research.
- Any commitment to listen to patients and protect them from harm must extend to behavioural and psychological treatments. The merit and safety of these interventions is often backed up by poor science which escapes the greater scrutiny given to research on drugs and medical devices.

⁴⁴ NHS. (2018) *The Improving Access to Psychological Therapies (IAPT) Pathway for People with Long-term Physical Health Conditions and Medically Unexplained Symptoms*, p.7. Available from: <https://www.england.nhs.uk/wp-content/uploads/2018/03/improving-access-to-psychological-therapies-long-term-conditions-pathway.pdf>

⁴⁵ NHS. (2018), p.11.

Access to healthcare for housebound⁴⁶ people

People who are frequently unable to leave their homes because they have ELCs that fluctuate unpredictably can struggle to access healthcare, including not only doctors' appointments, but also health prevention and screening services.

In a recent survey by CII, only 12% of respondents had ever received a home visit by their GP, fewer than 2% had ever received a domiciliary or sexual health screening service, and only 5% had accessed domiciliary dental care. Respondents were often refused not only home visits but even telephone appointments, and many were unaware that they could request domiciliary services as a reasonable adjustment. Many felt too afraid, ashamed, or hopeless to request domiciliary services, and many were denied such services because their testimony about the impact of their symptoms was not believed by service providers. One respondent had "gone without treatment for weeks or months until I have a period of improved symptoms and can go out to get care".⁴⁷

Access to healthcare and COVID-19

The COVID-19 pandemic has had a detrimental impact on people's access to healthcare. Nearly 6 million people in England, which amounts to 9% of the population, are currently waiting for surgery.⁴⁸ 42,430 patients were waiting more than two weeks to see a cancer specialist after being urgently referred by a GP in October, the highest figure in 12 years, and only 67.8% of cancer patients received their first treatment within two months of urgent referral.⁴⁹ In October the average ambulance response time was 53 minutes and 54 seconds, three times the target of 18 minutes.⁵⁰ 121,000 people waited at least four hours for A&E services, with 7,059 people waiting more than 12 hours.⁵¹ The Royal College of Emergency Medicine estimated that over 6,000 patients were dying every year because of the overcrowding of A&E.⁵² A record 5.8 million patients were waiting to start routine hospital treatment at the end of September 2021.⁵³

People with ELCs have been badly affected by these delays to accessing healthcare. In a recent CII survey, 66% of respondents under the regular care of a

⁴⁶ Please see Part II of this submission for a note about CII's use of the term 'housebound'.

⁴⁷ Hale et al (2021), pp.8-9.

⁴⁸ Campbell, D. and Duncan, P. (2021) 'Almost 6 million people on waiting lists for hospital treatment in England'. *The Guardian*. 9 December 2021. Available from:

<https://www.theguardian.com/society/2021/dec/09/almost-6-million-people-on-waiting-lists-for-nhs-surgery-in-england>

⁴⁹ Campbell and Duncan (2021).

⁵⁰ ITV News (2021) 'Ambulance and A&E wait times and waiting list for NHS hospital treatments reach record high'. 11 November 2021. Available from: <https://www.itv.com/news/2021-11-11/ambulance-delays-reach-record-levels-with-longest-response-times-in-three-years>

⁵¹ ITV News (2021).

⁵² Campbell, D. (2021) 'A&E overcrowding in UK 'killing thousands a year', say doctors'. *The Guardian*. 18 November 2021. Available from: <https://www.theguardian.com/society/2021/nov/18/a-and-e-overcrowding-uk-deaths-year-doctors-treatment>

⁵³ ITV News (2021).

GP or specialist reported disrupted access to care since the pandemic began, and 56% reported a decline in their health.⁵⁴ Responses to this survey regarding access to healthcare have been outlined in Part III of this submission.

⁵⁴ Ruddock, A. and Gkiouleka, A. (2021) *I Feel Forgotten: The Impact of COVID-19 on People with Chronic Illness*, p.2. Available from: <https://www.centreforwelfareform.org/library/i-feel-forgotten.html>



Part V. 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.⁵⁵

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.⁵⁶

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

⁵⁵ Gov.uk (2021) *UK Disability Survey Research report, June 2021*. Available from: <https://www.gov.uk/government/publications/uk-disability-survey-research-report-june-2021/uk-disability-survey-research-report-june-2021>

⁵⁶ 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>

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.^{57, 58}

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.

⁵⁷ 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

⁵⁸ 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>

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 people who reported having ‘energy impairment,’ 58% said they had problems with memory, and half noted problems with learning, understanding, or concentrating.⁵⁹

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.⁶⁰ 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).⁶¹ 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”

⁵⁹ 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>

⁶⁰ Centre for Health and Disability Assessments (2020) *Revised WCA Handbook*, pp.123-140.

⁶¹ Waddell, G. and Aylward, M. (2005) *The Scientific and Conceptual Basis of Incapacity Benefits*. Great Britain: Department for Work and Pensions.

(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,⁶² 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.

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.

⁶² 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

Conclusion

Energy limiting conditions (ELCs), a category that includes ME/CFS, Long Covid, fibromyalgia, multiple sclerosis, POTS, Ehlers Danlos Syndrome, inflammatory bowel disease, thyroid problems and lupus, are often poorly understood by the UK government's social protection and poverty reduction programmes, healthcare professionals and the medical establishment, and the general public, leading to a range of adverse experiences for people with ELCs that contravene their human rights as outlined in the UNCRPD. This ignorance about ELCs means that the particular needs of people with ELCs, such as remote access to work and recreational activities, and access to domiciliary healthcare services, are also poorly understood and rarely met. People with ELCs were greatly disadvantaged by the UK government's inadequate response to the COVID-19 pandemic, and many suffered in particular from a lack of access of healthcare.

ELCs should be recognised as a real and frequently debilitating form of impairment, and people with ELCs must be afforded the same rights and protections as other disabled people. There needs to be more and better research into ELCs and other conditions that predominantly affect women. This research should respect the lived experiences of people with ELCs and regard people with ELCs as genuine sources of knowledge about their own bodies. 'Medically Unexplained Symptoms' must be abandoned as a diagnostic category. Better mechanisms must be developed for reporting harms resulting from behavioural and psychological treatments. Remote participation should be recognised as an accessibility need and made available for accessing employment and recreational activities. Access to domiciliary healthcare services, including screening and prevention services, should be made available to people who are housebound.

Rather than perpetuating stereotypes about disability 'fakers' and 'scroungers', the UK government should lead by example, changing their approach to disability-related benefits assessments to better reflect the lived experiences of people with ELCs, and raising awareness of ELCs and the needs of people with ELCs among the general public. Better preparations should be made by the government for the future for protecting people with ELCs in the ongoing COVID-19 pandemic and for future humanitarian emergencies. Our lives, basic needs, wellbeing and human rights should never be disregarded.