



CHRONIC ILLNESS INCLUSION PROJECT

Submission to the Work and Pensions Committee's inquiry into the disability employment gap

Chronic Illness Inclusion Project

December 2020

Summary

Our evidence draws on research by the Chronic Illness Inclusion Project (CIIP) into employment and social security among disabled people with energy limiting chronic illness (ELCI) in 2018. Our submission outlines ELCI and energy impairment as a common form of impairment and argues that this significant, but hidden, sub-group of disabled people has been poorly served by government policy. We explain the unique challenges of ELCI in relation to employment, and why these call for a new set of solutions. We share some recommendations from our forthcoming report, including reduction in hours, flexible working, and the creation of niche roles. These recommendations require the development of specialist employment support provision for people with ELCI to supplant the current one-size-fits all approach. Above all, government must acknowledge and account for ELCI as a discrete impairment group and tailor its policies accordingly by engaging with disabled people with ELCI.

Introduction

We are pleased to submit evidence to the Work and Pensions Committee's inquiry into the disability employment gap on behalf of the CIIP. The CIIP represents a large, but hidden, sub-group of disabled people whose needs have not been accounted or provided for by public policy making before now.

Our submission is based upon research carried out in 2018 for the DRILL programme of disability research¹, hosted by the Centre for Welfare Reform. Our research included a survey of over 2,000 disabled people living with energy limiting chronic illness (ELCI) in the UK, as well as an in-depth qualitative research forum on issues with employment and social security with ELCI.

Our research findings form the basis of a report on employment and social security with ELCI, in collaboration with Leeds University Business School and Leeds Social Science Institute (forthcoming,

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

2021). It is the first to consider ELCI as a significant sub-group of disabled people. We are pleased to share findings and recommendations relevant to the WPC inquiry in advance of publication of our report.

About the Chronic Illness Inclusion Project

The CIIP is a voice for disabled people with energy limiting chronic illness, energy impairment and chronic pain. We are currently evolving from a disabled-led research project to an independent user-led organisation. The CIIP 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.² 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.³

ELCI and energy impairment are new terms, born out of participatory research by and with disabled people with physical chronic illness.⁴ 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 (over-)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.

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.

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.

² DWP (2017/18) *Family Resources Survey*

³ Hale, C. et al. (2019) *Energy impairment and disability inclusion*. Centre for Welfare Reform.

⁴ Ibid.

Section One - Progress so far and impact

1.1 What progress has been made, especially since 2015, on closing the disability employment gap?

Progress on increasing employment opportunity and retention for disabled people with ELCI has been limited. Impairment of stamina, breathing and fatigue affects one in three disabled people in the UK, and yet disability employment policy has not considered ELCI and energy impairment as a discrete form of disability, equivalent to mobility impairment, learning difficulties, mental health conditions. Instead, people with ELCI have been shoehorned into measures and services designed for other impairment types, or have received one-size-fits all solutions which have failed them.

Recent policy measures include the Work and Health Programme (WHP) and labour market activation programmes for those with Limited Capability for Work, including the application of conditionality and sanctions.

Work and Health Programme

Recent pilot studies for the Work and Health Programme (WPH) have confirmed the importance of being in a voluntary environment;⁵ the complexity and sensitivity of work capacity;⁶ and the positive correlation between self-assessed work capacity and the severity of disability.⁷ Research into the WHP trials conclude that the support offered by Work Coaches was little more than talk and basic job-search help.⁸ Participants were 'supported', 'encouraged', 'signposted' or 'persuaded' to engage in social or work-related activity. Work Coaches were unable to directly assess what work or work-related activity they might be able to do, assess and provide aids and adaptations, deliver counselling or physiotherapy, or liaise with employers to create or carve out suitable jobs. Yet these are the very measures recommended for increasing employment opportunity and retention for people with ELCI (see below). Overall, Work Coaches from the WHP were found to have little to no impact, with claimants who had secured work attributing this to themselves, their support networks or other organisations.⁹

Sanctions and conditionality have negative effects on sick and disabled people, yet the DWP is expanding the use of mandatory engagement.¹⁰

⁵ Lyne C, Draper M and Whateley J (2017) The 2015 ESA Trials: A Synthesis of Qualitative Research with Work Coaches. Ad Hoc Research Report No. 50. London: DWP.

⁶ Ibid

⁷ Newton B and Sainsbury R (2017) The 2015 ESA Trials: A Synthesis of Qualitative Research with Claimants. Research Report No. 933. London: DWP.

⁸ Lyne et al (2017)

Newton et al (2017)

Moran M (2017) The 2015 ESA Trials: A Synthesis. Ad Hoc Research Report No. 49. London: DWP.

⁹ See Benstead (2019) *Predicting Policy Performance: Can the Work and Health Programme Work for Chronically Sick and Disabled People?* *Critical Social Policy* 39(4):643-662 for more on the problems with the Work and Health Programme and employment support for sick and disabled people.

¹⁰ Hale C (2014) *Fulfilling Potential? ESA and the Fate of the Work-Related Activity Group*. London: Mind.

Low L, Meacher B and Grey-Thompson B (2015) *Halving the Gap? A Review into the Government's Proposed Reduction to Employment and Support Allowance and its Impact on Halving the Disability Employment Gap*. London: Royal Mencap Society.

Dwyer P et al. (2018) *Welfare Conditionality: Sanctions, Support and Behaviour Change. Final Findings: Disabled People*. Economic and Social Research Council.

1.2 Are some disabled people more at risk of unemployment or economic activity than others?

Higher risk of unemployment – health barriers to work for people with ELCI

Evidence suggests that some groups of disabled people, eg those with learning difficulties and severe mental health problems, are more at risk of unemployment than others.¹¹ Our research indicates that disabled people with ELCI also face distinctive and significant challenges in engaging with work. Many cannot work at all, and others can only work part-time. These challenges include:

- a) **The risk of work to health.** The dynamics of energy impairment and ‘payback’ (see forthcoming report) mean that any attempt to ‘push through’ symptoms to engage in work or other activity leads to worsening of symptoms and reduced capacity for activity. In terms of work, this leads to greatly reduced number of working hours in the week. For disabled people with ELCI, work is often not good for health. (See below for further research evidence into work and health.)
- b) **Relative lack of measures to ‘level the playing field’.** Many disabled people can be successfully included in the labour market through the provision of aids, adaptations, personal assistance, accessible transport and environments, and the enforcement of anti-discrimination law, all of which remove socially constructed barriers to work. These measures can improve employment prospects for those with milder forms of ELCI, and must be adopted. However, the global impact of energy impairment, combining both cognitive and physical challenges and a restricted capacity for activity, means that aids, adaptations and barrier removal are less successful in mitigating the effect of impairment on work capability.

Research evidence on work and health.

Health is critical to the employment of sick and disabled people. Repeated research shows that it is an improvement in health that enables returns to work.¹²

In addition, research in the UK has demonstrated that jobs at the bottom of the labour market can cause or exacerbate work-limiting illness. Marmot (2010) concluded that there are many ‘toxic jobs’ in the UK which make people ill, and these ‘toxic jobs’ result in worse health than remaining

¹¹ Powell A (2020) Disabled People in Employment. Briefing Paper No.7540. London: House of Commons

¹² Berthoud R (1998) Disability Benefits: A Review of the Issues and Options for Reform. York: Joseph Rowntree Foundation.

Stafford B (2007) New Deal for Disabled People: Third Synthesis Report – Key Findings from the Evaluation. London: DWP.

Becker E, Hayllar O and Wood M (2010) Pathways to Work: Programme Engagement and Work Patterns. Findings from Follow-up Surveys of New and Repeat and Existing Incapacity Benefits Customers in the Jobcentre Plus Pilot and Expansion Areas. London: DWP.

unemployed.¹³ Bad jobs may have contributed to the rise in work-related disability, especially in the UK.¹⁴

There is, therefore, a major need to address both the quality of the labour market and the funding of the NHS, to ensure that we are not as a country causing or prolonging illness unnecessarily.

1.3 What is the economic impact of low employment and high economic inactivity rates for disabled people with ELCI?

The low employment rates, and low hours of work capability, among disabled people with ELCI have a severe economic impact. For people on Universal Credit in the Limited Capability for Work-Related Activity group, the living allowance of £153.49/wk (excluding the temporary £20/week top-up) is £55.42 below the amount needed for living costs in order for a single working-age adult to participate in society.¹⁵ It is even further below after accounting for the gap between disabled people's extra costs and PIP awards; and still further when this money has also had to top-up housing costs and council tax support. The situation for people assessed as capable of work-related activity is dire: the £74.59 that they receive is only 1/3rd of what they need to live off.

This places disabled people in the WRAG in destitution after accounting for top-ups to rent and council tax benefits.¹⁶ In comparison, the state pension is £175.20 per week and is £56.71 *more* than a pension-age couple needs to live off; and pensioners get full council tax support and are not subject to the benefit cap, bedroom tax or other housing restrictions.

¹³ Marmot M (2010) Fair Society, Healthy Lives. London: Department of Health.

Butterworth P, Leach LS, Strazdins L, Olesen SC, Rodgers B and Broom DH (2011) 'The Psychosocial Quality of Work Determines Whether Employment Has Benefits for Mental Health: Results from a Longitudinal National Household Panel Survey', *Occupational and Environmental Medicine* 68(11): 806–812.

Chandola T and Zhang N (2018) 'Re-employment, Job Quality, Health and Allostatic Load Biomarkers: Prospective Evidence from the UK Household Longitudinal Study', *International Journal of Epidemiology* 47(1): 47–57.

¹⁴ Baumberg B (2014) 'Fit-for-Work – Or Work Fit for Disabled People? The Role of Changing Job Demands and Control in Incapacity Claims', *Journal of Social Policy* 43(2): 289–310.

¹⁵ A Minimum Income Standard for the United Kingdom in 2020. York: Joseph Rowntree Foundation

¹⁶ Fitzpatrick et al (2018) Destitution in the UK 2018. York: Joseph Rowntree Foundation

Section Two - Providing support

2.1 What international evidence is there on “what works” in supporting disabled people into, and in work, and how applicable is this to the UK?

There is no international evidence on disability employment relating specifically to disabled people with ELCI. Our research and forthcoming report are the first to investigate employment and social security for this significant sub-group of disabled people. We offer our recommendations as well as reviews of evidence assessment of existing policy responses.

Our recommendations for employment with ELCI

There is a major need to address both the quality of the labour market and the funding of the NHS, to ensure that we are not as a country causing or prolonging illness unnecessarily.

Provide income security for those able to work part-time only

Some people with ELCI may be able to work part-time, but need stable top-up benefits to compensate for low earnings. This currently does not exist. Under the current WCA, anyone capable of part-time work is typically assessed as fit-for-work and cannot claim Universal Credit without also being required to seek full-time work, as the government has created no medical safe-guard that would allow people to work a limited number of hours. This is a common problem for people with mild-moderate illness who can work 16-30 hours/week but do not have an adequate hourly wage to lift them out of poverty, and are unable to claim any form of in-work benefit.

Employment support

Government should adopt a targeted approach to employment policy for disabled people with ELCI, not maintain the one-size-fits-all approach which has failed people with ELCI. This approach includes:

- Bolster rights to flexible working for disabled people as a reasonable adjustment. Flexible working for people with ELCI includes reduced hours, flexible hours, home working and remote access technology
- Support the development of job brokering and job carving agencies to connect employers with jobseekers with ELCI and work with employers to create tailored roles. A model for this provision is the Individual Placement and Support service for people with mental health conditions. Tailored roles for people with ELCI involve very reduced hours (eg fewer than 16 hours per week), highly flexible working hours and maximum autonomy over pace of work. Currently there is only one employment support and job brokering agency of this kind in the UK (see Astriid).
- Give disabled people a greater choice of provider for employment support in order to develop the ecosystem of specialist disability employment support provision and reward successful providers.
- Increase funding for the Access to Work scheme to cover a greater range of aids, adaptations and assistance; and to do so promptly and up-front in a process that is simple for both employees and employers. Promote knowledge and understanding of the scheme among employers
- Expand the scope of Access to Work to include funding for disability leave for temporary cover to support the employment of disabled people with fluctuating conditions

- Increase funding to social care, with a particular focus on the provision of support for household tasks, to free up capacity for activity from those who want to work
- Support volunteering and informal work as routes to social inclusion and to improving well-being, as well as steps on a journey to employment.

Employers should understand ELCI and energy impairment as a form of disability for which employers have a legal duty to make reasonable adjustments. Strategies for employers to promote employment for people with ELCI include:

- Mainstreaming ELCI as part of broader Equality, Diversity and Inclusion initiatives
- Employers, line managers and co-workers should receive information and training on ELCI and energy impairment. This training should be included within broader disability awareness training, be produced and delivered by disabled people with lived experience of ELCI, challenge negative stereotypes about fatigue and chronic illness and outline key adjustments to support employees with ELCI,
- Foster organisational cultures that support disability disclosure and reasonable adjustments for people with ELCI
- Adopt management practices to support worker-led flexibility. Practices that maximise autonomy, trust and responsibility will empower employees with ELCI to manage their health condition and work within safe energy limits.
- Consider carving out roles tailored to disabled people with ELCI. This could include creating roles below 16 hours per week, removing in-work travel, redesign person specification,
- **Key adjustments to enable people with ELCI to remain in, or take up work include:** Adjustments to working patterns, especially reduced hours, flexible hours, eg annualised hours, home working, remote access provision
- **Workplace adjustments** for those able and preferring to work within workplaces include (but are not limited to) parking spaces, resting spaces, ergonomic seating/reclining, the ability to control light and noise and chemicals (not open plan offices) and the capacity to take breaks during the working day.

2.2 What is the right balance between in and out of work support, and is DWP getting the balance right? What more should the Department look to provide?

Currently the DWP is not providing adequate support for either employment or unemployment. Financial support through the social security system is a key lever for supporting people with ELCI, both in, and out, of work.

Adequate unemployment support would mean benefits at the rate of £208.91/week for those who cannot reasonably be expected to work at least 16 hours/week on a reliable, regular basis in the open (i.e. without Access to Work or other employment support) labour market; and tapered benefits for those who can work part-time but not full-time and therefore need an income top-up. Currently the benefit rate for those assessed as unable to work is inadequate for many and leaves some in destitution; and there is no top-up benefit for those who can only work part-time.

Adequate employment support would include: a secure top-up benefit for those only able to work part-time; long run-on periods of twelve months for those moving into work; full occupational therapy assessments with a commitment from the government to immediately provide the physical aids and any support worker that is needed.

2.3 How can DWP better support employers to take on and retain disabled employees, and to help them progress in work?

Develop and promote training on ELCI and energy impairment in association with user-led organisations for employers to understand ELCI in relation to their duties under the Equality Act 2010. This training should include the kinds of reasonable adjustments that can enable people with ELCI to take up, and remain in, work.

Support the development of job brokering and job carving agencies to connect employers with jobseekers with ELCI and work with employers to create tailored roles.

2.4 What improvements should DWP make to the support it offers to unemployed disabled people via Jobcentre Plus?

The DWP needs to bring in specialist work coaches who have expertise in either a particular disability (e.g. visual impairment or ELCI) or industry; the former may be more important than the latter, although expertise in certain industries may be of additional benefit.

The WHP is inappropriate for disabled people with ELCI and they should not be mandated to it. This should be replaced with funding given up-front for the employment support provider of choice to recipients. By allowing people to choose which employment support provider to go to, money for supporting disabled people will naturally end up going towards those organisations who are most successful and have gained a reputation for being effective and supportive.

The DWP must end conditionality and sanctions.

2.5 How can DWP put this into practice in services such as Access to Work and the Work and Health Programme?

Access to Work support packages should be linked to the individual, not their workplace, to allow efficiency and effectiveness when changing employment.

DWP should expand the scope of Access to Work to include funding for disability leave for temporary cover to support the employment of disabled people with fluctuating conditions

The government should promote knowledge and understanding of the Access to Work scheme among employers.

Section Three - Enforcement and next steps

3.1 Are “reasonable adjustments” for disabled people consistently applied? How might enforcement be improved?

As far as we are aware, reasonable adjustments are not consistently applied, and enforcement is negligible. Many disabled people are unaware of their rights; unable to advocate effectively for themselves against employers, HR or line managers; and unable to bear financially the cost of legal support or physically or mentally the strain of challenging discriminations.

Barriers to disability disclosure and reasonable adjustments with ELCI

For disabled people with ELCI there is an additional barrier to disability equality in work, consisting of barriers to disability identification and disclosure. Our research with over 2,000 disabled people with ELCI suggests that disabled people with ELCI express considerable ambiguity and uncertainty when asked whether they consider themselves to be disabled.¹⁷ A large part of this ambiguity relates to social attitudes and stereotypes about fatigue and chronic illness, in particular the idea that disability is only real if it is visible and fixed or unchanging:

- Over two thirds frequently encountered the attitude that they “don’t look disabled” and 66% agree that “I would risk negative reactions from others” if they refer to themselves as disabled.
- 55% agreed that they encounter the attitude that “fatigue and pain are not real disabilities”.
- More than 4 out of 5 participants agreed that they encounter the attitude that “everyone gets tired”.
- Almost 70% agreed that they encounter the attitude that they “shouldn’t make a fuss” about their difficulties, and 39% frequently, and 44% sometimes, encounter the attitude that they “should try harder to overcome their difficulties”.
- 43% of respondents agreed that “I feel like an imposter” when referring to themselves as disabled.

Many participants only considered that they were entitled to identify as disabled once they had been assessed as eligible for ESA or PIP. This suggests that opportunities for job retention through reasonable adjustments may be missed.

Adoption of the terms ELCI and energy impairment into all areas of government policy making for disabled people would help to challenge stigma and misconceptions about fatigue and chronic illness, and clarify disability identity for people living with ELCI.

This, in turn would empower employees with ELCI to disclose their disability status and therefore increase their chances of obtaining reasonable adjustments in work.

¹⁷ Hale, C. et al. (2019)

3.2 What would you hope to see in the Government's National Strategy for Disabled People?

We would hope to see recognition of ELCI and energy impairment as a discrete impairment group, roughly equivalent in prevalence to mobility impairment and mental health conditions, across all areas of policy relevant to disabled people.

We would hope that all relevant government departments adopt the language of ELCI and energy impairment. In 2019 Government Statistical Services recommended reviewing the term "impairment of stamina/breathing/fatigue," (which is recommended by the Office for National Statistics for use in social surveys on disability) and adapting it to reflect self-identification by disabled people themselves.¹⁸

We wish to see employment policy and employment support provision, as well as social care, education, and social security policy making tailored to the distinct needs of this group.

3.3 How should DWP look to engage disabled people and the organisations that represent them in formulating the Strategy?

DWP should engage regularly with Deaf and Disabled People's user-led organisations, including impairment-specific organisations such as the CIIP. This engagement should be properly resourced and supported.

¹⁸ See CIIP submission to GSS consultation on impairment principles <https://www.centreforwelfare reform.org/uploads/attachment/677/CIIP-GSSconsultation.pdf>