Energy Impairment and Disability Inclusion

TOWARDS AN ADVOCACY MOVEMENT FOR ENERGY LIMITING CHRONIC ILLNESS

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Executive Summary

About the Project

The Chronic Illness Inclusion Project (CIIP) ran from 2017 to 2019 as part of the DRILL programme of research led by disabled people, for disabled people. We looked at the experience of chronic illness as a type of disability or, in the language of the UK Disabled People s Movement (DPM), as an impairment group .

The CIIP was a programme of emancipatory research, aiming both to produce knowledge about people with chronic illness, and to begin to transform that knowledge from an individual experience into a collective struggle for change. Our research agenda evolved from the researchers lived experience of chronic illness, and their involvement in internet-based peer support networks and communities for chronic illness. It culminates in a manifesto for equality and inclusion, to be launched alongside this report.

We found compelling evidence that there is common experience and shared knowledge among people with chronic illness that is not heard or represented beyond our online networks, despite being a large subsection of the disabled population. The aim of this report is to bring the knowledge of the 2,300 people living with chronic illness who took part in our research closer to those who make decisions about our lives. Just as importantly, we propose strategies for amplifying our voice going forward.

Aims and methodology

The CIIP was different from other patient-led initiatives whose focus is to advocate for improved medical care. As insider researchers, we believe that experience of living with chronic illness can, and must, be transformed by changing the way society responds to us as disabled people, as well as through advances in medical treatment for particular diseases. For this reason, we aimed to follow the principles of emancipatory disability research.

Emancipatory disability research has been underpinned by a social model of disability. The social model has many strands but at its core is a distinction between impairment and disability . Impairment is the restriction caused by malfunction of body or mind, while disability is restriction caused by factors external to the body/mind; barriers within the material environment, cultural attitudes and social organisation.

It can be difficult to disentangle the biological from the social causes of disadvantage and exclusion in any given case. However, we believed that exploring this distinction between impairment and disability in the experience of chronic illness would help us identify, and thus, challenge, the forms of social oppression that restrict and diminish

our lives over and above our illnesses and diseases themselves. Therefore, the impairment/disability distinction framed our research questions, and it informs the structure of this report.

> ***Chapter One*** deals with experiences of impairment with chronic illness: what is it about our conditions that restricts activity and wellbeing in and of itself; and who do we include under the chronic illness label?

> ***Chapter Two*** looks at experiences of disability, or what is more commonly referred to as ableism , with chronic illness. What are the barriers , whether material or cultural attitudes, that restrict or oppress us as disabled people?

> ***Chapter Three*** discusses the implications of this knowledge for taking collective action. We explore how communication strategies could support a more effective advocacy movement for chronic illness. We ask what participants' priorities are, in terms of social issues and public policy, for improving our lives.

We heard from hundreds of people in the online chronic illness community, in a programme of research designed to capture the breadth, as well as depth, of their knowledge. An extended qualitative research forum, or focus group , made up of 20 people and lasting eight weeks, allowed in-depth exploration of individual experiences. It took place on a tailor-made online platform, enabling us to reach people who would have been excluded from traditional face-to-face focus groups. A follow up survey designed to test and validate this experiential knowledge yielded 2,300 responses.

Chronic illness and the DPM

Investigating a social model of disability in relation to the experience of chronic illness lays bare certain tensions and challenges. The concept of chronic illness is largely absent from both Disability Studies and disability activism in the UK. This occurred as chronic illness became associated with an oppressive, medical model of disability. Indeed, many feel that chronic illness and the social model of disability are conceptually incompatible. On the one hand, some in the DPM think people with chronic illness focus too much on impairment – on restriction, suffering and the pursuit of medical intervention – and see this as a betrayal of the social model of disability. On the other hand, people with chronic illness think the social model does not apply to them because addressing external barriers and discriminatory attitudes doesn t mitigate the impact of chronic illness enough to allow for social participation and inclusion. Thus, chronic illness and disability have been conceived of as different states.

We feel that these conceptual tensions create an impasse that prevents people with chronic illness from identifying and challenging the social and structural causes of our disadvantage. This makes it harder to claim our rights as disabled people. The aim of the CIIP was to explore whether and how the social model could be harnessed productively to support our own emancipation as disabled people.

Chapter One - A hidden impairment group

This chapter explores a) what it is like to live with chronic illness, and b) who we mean by the chronic illness community . It presents first-hand accounts from our focus group participants, followed by quantitative data on impairment type, disability status and medical diagnoses and classification from survey respondents.

We explored the lived experience of impairment among people who identify as having chronic illness, as distinct from medicalised accounts of their illnesses and diseases. Despite their diverse symptom clusters, a surprising consensus emerged among focus group participants (who were selected for their broad range of diagnoses). Limited energy and fatigue were by and large the most debilitating and restricting feature of their chronic illness. This finding was corroborated by the survey, where almost three quarters of respondents selected the category stamina, breathing fatigue , to describe their impairment, and where fatigue or energy limitation, followed by pain, were rated as the most restricting symptoms.

Our focus group participants found common ground in their experiences of day-to-day life and the difficulty of conveying these experiences to others. They agreed that pathological fatigue is very different to the universal experience of tiredness . Living with chronic illness, they reported, means carefully rationing scarce units of energy to get through each day.

Compared to many other forms of impairment, pathological fatigue is fluid in nature. Its impact on activity can t be isolated to one bodily or mental function because fatigue impacts on all functions, physical, cognitive and sensory. As a result, participants felt that the pathological fatigue they experienced did not meet the socially constructed definition of, and expectations around, disability as a fixed state of incapacity.

Nearly three-quarters of our survey respondents described their impairment type using the category of stamina/breathing/fatigue (SBF). According to government disability data, impairment of SBF is the second largest group among disabled people in the UK. Yet, in many ways SBF is a hidden impairment group. This is not only because fatigue is invisible. It is hidden because government departments formulating policies for disabled people, such as social security, employment and social care do not capture, or account for the needs of, people with SBF difficulties. It is hidden because organisations of, and for, disabled people have no equivalent term

to SBF in their lexicon of impairment types. It is hidden because medical authorities on impairment and disability only acknowledge fatigue in relation to cardiorespiratory disease. Lastly, it is hidden because, unlike with other impairment groups, there are no organisations representing and advocating for people with SBF difficulties broader than disease specific organisations.

The consequences of the misunderstandings, under-reporting and lack of accounting for fatigue and stamina issues are far reaching. They are deeply intertwined with the oppression we face as a group of disabled people.

Chapter Two - Chronic illness and ableism

In this chapter we look at participants feelings about, and experiences of, identifying as a disabled person. These accounts reveal a form of oppression shared by many people with chronic illness. We explore how this experience of oppression fits into the social model framework of barriers to participation, as well as more recent ideas around ableism. Finally, we discuss how participants responded to the social model of disability as a way of thinking about their circumstances.

Focus group participants evoked a deep paradox in their situation. While energy limitation and fatigue were the most disabling aspect of their health condition, it was the thing that least conferred the status of disability in the eyes of others. When discussing whether or not participants considered themselves to be disabled, it emerged that access to the social status of disabled person is not only socially constructed but powerfully controlled, even policed, by society generally. Nearly all participants felt they were not allowed , or deserving enough to identify as disabled.

They described hostile encounters when referring to themselves as disabled, using accessible facilities or claiming concessions, where their status was contested. This was partly in response to having a largely invisible form of impairment, but also because of the wide-spread perception that fatigue is not associated with disability but is, rather, a universal experience that must be overcome by personal effort and willpower. Everyone gets tired”, you don t look disabled” and just try harder” were the most commonly encountered attitudes reported by survey respondents.

Sometimes the hostility was subtle but pervasive expressions of disbelief of their impairment experience. Other times it took the form of direct accusations of faking, exaggerating or cheating the system to obtain unfair advantages. The potential for disbelief coloured almost every aspect of social encounters and relationships, with loved ones as well as acquaintances and figures of authority. The fear of surveillance and suspicion of fake disabled people profoundly affected how our focus group participants went about their life. It resulted in activity avoidance, in non-disclosure of disability, and failure to access support, adjustments and accommodations that could facilitate inclusion and participation.

It was powerfully clear that the fundamental oppression discussed by our participants was not environmental barriers but negative attitudes, essentially based on the attitude that fatigue is not a disability. We therefore suggest that much of the oppression reported by people with chronic illness takes the form of invalidation and disbelief of their impairment.

Our focus group research found that, although incidences of disbelief and hostility were frequently mentioned, they were rarely framed as structural barriers. Instead they were expressed as personal feelings, e.g. feeling like a fraud". This suggests that oppression of people with chronic illness is strongly internalised. It also appears to result in shocking levels of emotional isolation: over three quarters of survey respondents agreed that they felt isolated by people s lack of understanding of how their health condition affects them.

Participants who did, over time, learn to challenge this oppression all agreed that identifying as disabled was liberating. People with chronic illness would therefore be likely to benefit from peer support and encouragement to challenge internalised oppression.

Disbelief and invalidation form disabling barriers to living as fully as possible with chronic illness. We suggest that developing a social model of chronic illness means understanding this oppression as a form of ableism. This is challenging and involves turning accepted ideas about ableism inside out. For example, in relation to disability discrimination, people with chronic illness experience hostile treatment on the basis of a denial of their disability, rather than directly because of it.

We begin, therefore, to interrogate and expand understandings of ableism so that they include the forms of oppression experienced by people with chronic illness.

Chapter Three – Towards advocacy

In this chapter we consider how to take action to challenge our oppression as a hidden impairment group. We consider strategies for mobilising a movement based on our identity as an impairment group, so that we can influence decisions made about our lives. We explore what are the most pressing social and political issues we need to address as an impairment group.

Our participants strongly expressed the desire to come together beyond the focus group period to have their voice heard as a constituency broader than their diagnoses. They felt that government departments do not acknowledge the existence of chronic illness as a type of disability, and most of them felt that existing organisations of, and for, disabled people did not adequately give voice to their experiences or represent their needs.

Language is an important aspect of the gap in representation and self-advocacy for people with chronic illness. Many participants felt that fatigue is not an adequate term. Survey respondents also confirmed that neither the term long-term health conditions nor the concept of fluctuating conditions adequately describes their impairment experience and its impact to policy makers. Most participants agreed that a more effective framework for self-definition and self-identity is crucial if people with chronic illness are to have their voice heard.

Our research suggests that the terms energy limiting chronic illness (ELCI) and energy impairment are broadly acceptable within the chronic illness community as descriptions for the lived experience of their condition. We accept that not everyone with chronic illness experiences significant energy limitation, and that these terms cannot capture every individual constellation of symptoms. However, given that impairment of stamina and fatigue is so common among disabled people, we stand a much greater chance of having our voice heard and our needs met if we adopt a language that clearly conveys this experience.

Oppressive attitudes towards people with ELCI were most acutely felt by survey respondents when interacting with both the social security system and the healthcare system. Both of these areas were policy priorities for people with ELCI, rating much more highly than other policy areas affecting disabled people such as employment or social care policy.

Conclusions

What did we learn from exploring chronic illness through a social model of disability?

Both our focus group discussions and survey responses demonstrate that socially-created barriers are a major issue for people with ELCI in terms of social security and healthcare. While survey respondents wished for better medical treatment above all else, they also overwhelmingly agreed that their lives would be better if there were greater understanding and acceptance of chronic illness, and if society believed and respected people with chronic illness. Therefore, in some ways, we believe that the medical vs social model of disability for people with ELCI is a false and unhelpful dichotomy, not least because medical research and treatment is strongly influenced and shaped by social and political interests.

The CIIP has provided a way for incorporating ELCI into the social model of disability, including the impact of disbelief and denial as an attitudinal barrier experienced by people with ELCI. The social model helps us understand that our feelings of undeservingness, of shame, of feeling like a fraud, come not from our own flaws or weaknesses but from deeply negative social attitudes around disability. It helps us to realise the extent to which we internalise these attitudes in ways that further disable us.

Participants welcomed the impairment/disability binary as a tool for thinking about socially-produced disadvantage. But the idea that disability is located entirely outside the body was strongly resisted. The social model provides the chronic illness community with a transformative understanding of our experience, and a way of thinking that supports collective action but it should not form a straitjacket for language and thought.

Lastly, we conclude that paying attention to experiences of chronic illness is not in conflict with the emancipatory aims of the social model of disability. Talking about our illness or impairment is crucial to challenging powerful knowledge systems and validating our marginalised experience. Affirming our embodied knowledge is part and parcel of resisting our oppression. There can be no emancipatory framework for ELCI unless we allow discussion of illness and impairment into the frame.

We were overawed by the sheer numbers of people who took part in, or engaged with, the CIIP. We conclude that the CIIP addressed a gap in the landscape of representation for disabled people with chronic illness in the UK. This research has provided us with a framework, in the concepts of ELCI and energy impairment, to build a platform for more effective advocacy alongside and within the DPM. We must now find a way to deepen this dialogue and continue this work.

Key Findings

1. Fatigue and energy limitation were the most debilitating features of chronic illness, followed by pain, for focus group participants and for 43% of survey respondents. The latter reported significant restriction with physical activity (walking 200m) as well as cognitive function (using a computer).

2. The most common impairment type among survey respondents, at 73%, was stamina/ breathing/ fatigue (SBF). Respondents reporting impairment of SBF were spread across multiple categories of disease type, the largest being nervous system diseases, and musculoskeletal and connective tissue diseases.

3. People with chronic illness experience many of the same disabling barriers as people with other forms of impairments. However, the main form of oppression reported by participants was invalidation of their experiences of impairment.

4. More than 80% of respondents felt that people think everyone gets tired". Participants experienced this as a denial and disbelief of their experience of impairment and disability.

5. 66% of respondents felt that they risk hostility if they identify as disabled. Participants described a range of responses, from implied disbelief to direct accusations of faking or cheating.

6. About a half of survey respondents felt that legal obligations to make adjustments for disabled people do not apply to them. When they did disclose impairment, participants often found that systems of disability support are not designed for their impairment experience.

7. Half of respondents said I feel like an imposter", suggesting that invalidation is often internalised. Focus group participants spoke of distress and self-doubt which sometimes compelled them to behave in ways that reinforced their oppression.

8. 85% of respondents reported feeling isolated by society s failure to understand the impact of their condition. This emotional isolation clearly compounds the isolation that results from reduced face to face contact with ELCI.

9. When polled over possible alternative language for self-advocacy, the term energy impairment was accepted by 72%, and sometimes" by a further 15% as an alternative to the term fatigue . The term energy limiting chronic illness" (ELCI) as a descriptive label of their identity as disabled people was strongly preferred over the existing categories of long term health condition and fluctuating condition .

10. Respondents' policy priorities were healthcare and social security, with Personal Independence Payments (PIP) a particularly strong priority. Interactions with DWP staff and healthcare professionals were perceived to be the main source of oppressive attitudes towards people with chronic illness.

11. Issues of independent living such as social care provision, and choice and control over support, are near the bottom in terms of policy priorities, notwithstanding strong evidence of need for care and support in daily living.

12. Nearly two-thirds of survey respondents said that improved medical treatment was the main thing that could significantly improve their quality of life. At the same time, more than four in five agreed that better understanding of and accounting for chronic illness would significantly improve their quality of life.

Key Recommendations

Our manifesto for equality and inclusion for chronic illness sets out our full programme of demands. Some of our important recommendations to key bodies are listed here:

World Health Organisation (WHO) and other health authorities should:

Review the International Classification of Functioning, Disability and Health, considering the reality that problems of fatigue and stamina apply much more widely than just the domain of cardio-respiratory medicine.

The UK Government and other public bodies should:

Recognise people living with impairment of stamina/breathing/fatigue as a discrete impairment group. Disability support systems should be expanded to account for our specific needs and experiences.

Incorporate an understanding of the lived experience of ELCI and its impact on function into all disability assessment systems for government programmes of disability support, benefits and concessions.

Devote specific funding for biomedical (*not* biopsychosocial) research into pathological fatigue, including its impact on cognitive function, given its centrality in chronic illness experience. The development of biomarkers for fatigue states is crucial for demonstrating eligibility for social support.

Government Statistical Services should review the language for the category of stamina, breathing, fatigue for use in social surveys on disability, and consider replacing it with energy impairment reflecting participants preferred language for self-identity.

The disability sector (organisations of, and for disabled people) should:

Engage with the knowledge and experiences of people with chronic illness, and support our language of self-identification.

Include and represent people with ELCI and energy impairment in education and training on access and inclusion.

Challenge ableist attitudes and practices in all their forms and manifestations, including invalidation and disbelief.

Foundations, funders and charitable organisations should:

Support the establishment and sustainability of a user-led organisation for people with energy limiting chronic illness (ELCI). Its aims and purposes would be:

- Capturing our lived experience and knowledge, and amplifying our voice;

- Involving us in the design of policies and services;

- Encouraging take up of the terms ELCI and energy impairment as strategies for self-advocacy in claiming our rights as disabled people;

- The development of information and training on ELCI and energy impairment to increase our access, inclusion and entitlements as disabled people.