# A TROUBLING TRUTH

## Chronic illness, participation and learning for change

A Discussion Paper from the Centre for Welfare Reform

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# Contents

# 1. Introduction

**To become chronically ill is to enter a reality inconceivable to the healthy, a reality of exclusion, from work, family, friends and the entirety of our previous existence. As someone who enjoyed what would be considered a full and successful life, experiencing chronic, debilitating disease has transformed how I observe the world and how the world seemingly observes me. When living healthy lives we assume, not unreasonably, that we will be looked after and receive adequate healthcare. We also take the Welfare State for granted, expecting it to be there for us when required, that, as I have discovered, is a dangerous assumption.**

Exclusionary practices due to chronic illness, especially in the case of contested diagnoses, are relatively hidden and often remain unchallenged. In this article, I focus on activism, participation and learning in informal settings, from the position of an academic in the field of Education and Lifelong Learning, but also from the position of a chronically sick and disabled middle-class woman who led a life of privilege in terms of access to education, income and relative influence in public life pre-illness.

In this article, I will dedicate thought to the interface of disability, activism and academia. The latter is borne by and infused with traditions dating back hundreds of years and is an institution of considerable power; one example of power is the formation of professions that are, historically, pillars of society. Higher education prepares students for careers in which they, to varying degrees, will contribute towards forming and changing society. What students are taught, how they are taught and who teaches them is significant.

Activism has always been a force for political and social change and whenever activists succeeded in making inroads into higher education they eventually became catalysts for change.

Regrettably, activism carries a negative connotation; even with people who by definition are activists but prefer to be called advocates, perceiving the latter as more pragmatic. Activism is fraught with power relations. There is no hegemony in activism and the struggle for a voice is fierce among activists. It is also disruptive and elites with vested interests in the status quo do not take kindly to disruption from activists. The backlash against action for social and political change can be vicious. These issues are related to questions of learning and participation in many settings, including online social media, in which activism for the sick and disabled often takes place. Such settings are rife with prejudice and misinformation but also energy, creativity and hope for change.

In 2011 I was diagnosed with the debilitating neurological condition myalgic encephalomyelitis (ME). ME has been defined as a neurological disease by the World Health Organisation since 1969 and is accepted as a physiological disease by the British Government. For this narrative to be understood I must provide a brief account of the history and current status of ME, an illness that has been hijacked by proponents of the so-called biopsychosocial (BPS) model. Proponents of this model state that ME does not exist as an organic illness but is instead a result of aberrant thought processes or 'illness beliefs', in a nutshell ME patients imagine their symptoms, which exist only in their minds, not in reality: ME is construed as a mental disorder. When ME sufferers protest against this description they are construed as an uneducated patient population stigmatising mental health (MH).

Thousands of peer-reviewed scientific papers have been published over the past few decades detailing significant physiological abnormalities in ME sufferers, unfortunately this has failed to prevent BPS proponents continuing to promote their belief in ME as a mental disorder. They have not lacked sources of funding, indeed on becoming ill I was greatly surprised to discover how limited funding is for biomedical research into a condition affecting between 100,000-250,000 sufferers in the UK alone, compared to the relative largesse bestowed upon BPS researchers.

Unsurprisingly, ME sufferers protest against the constant misrepresentation of their illness. Chronic illness is difficult enough to endure without the added experience of being disbelieved and stigmatised as unworthy malingerers, with only themselves to blame for their condition.

The failure to acknowledge ME's debilitating symptoms or even its existence, results in neglect and an absence of adequate treatment options for sufferers. The only therapies offered by the NHS are cognitive behavioural therapy (CBT) and graded exercise therapy (GET) neither of which has proved effective, with the latter treatment often causing a marked worsening of symptoms, unsurprising as exercise intolerance is a cardinal indicator of ME.  If you broke your arm and the treatment offered was to have your leg put in plaster, you would probably be unhappy and complain, it is highly unlikely you would express gratitude towards the medical professional placing your leg in plaster. This is effectively what occurs with ME sufferers, patients are denied suitable treatment and often abused when the treatment is ineffective 'you obviously do not want to get well' or considered as ungrateful for querying the usefulness of such therapies. These treatments are predicated on ME being psychological in origin; treatable symptoms therefore often go unnoticed and are left to worsen.

While there is no biomedical treatment available at present (Phase III clinical trials into the immune modulator Rituximab are taking place) there are more effective ways in which to treat patients. Dr Melvin Ramsey, as early as 1956, recognised the importance of rest in preventing the illness increasing in severity. The introduction of the term chronic fatigue syndrome (CFS) in the 1980s, further confused things, encompassing a broader set of symptoms than ME and focussing on fatigue, a symptom of various conditions from cancer to depression, almost to the exclusion of all else. The history of ME is filled with chronic illness and disability denial.

Regarding my personal history, I was diagnosed with malignant gastrointestinal neuroendocrine tumours aged 13 and have experienced repeated episodes of ill health ever since, often requiring hospitalisation. Despite this I managed to achieve a successful career in academia until becoming extremely ill in 2011 and receiving my diagnosis of ME. I was ignorant of ME history and had no opinion concerning psychiatry barring that I had tried certain behavioural therapies for my recurring infections, without result. Like many women (there is a clear prejudice against women in medical practice), I had been told my physical symptoms were a result of behavioural factors. Historically women have often found their illnesses dismissed as 'hysterical' in origin, an obvious example being multiple sclerosis (MS) or 'hysterical paralysis' a disease which, like ME, affects more women than men, reason enough for certain members of the medical profession to determinine it must be a result of the delicate female constitution. The days when MS was treated as an imaginary disease have passed but the same mind-set is responsible for ME's designation as a somatoform (imaginary) disorder. Indeed, the first researchers to suggest it was not a physiological disease, did so following their discovery that more women were affected than men, ergo it must psychological in origin.

I have experienced how the prevalent BPS model preserves the status quo, keeping ill people ill while stigmatising them by claiming they do not wish to get well: this places an enormous burden on individual sufferers and their families. The BPS model harks back to the days of Freud and his teachings about the mind. It is even applied to post-cancer care where patients are told that positivity will contribute towards their healing process, despite there being no scientific evidence to support such a claim.

Against this backdrop, I provide a narrative and analytical account of the years 2011-2016, of informal learning based on personal and interpersonal experiences of being ill and disabled, and of knowledge production as a chronically ill academic. Mine is the voice of an 'inside knower' and as such I make no claim on absolute truths. What I do claim is the right to add perspective to the problematic of social and political exclusion owing to chronic illness and disability. In times of paucity of perspective and lack of knowledge in certain areas of public and personal life, we can attempt to increase the volume of individual voices as bearers of knowledge. The 'I' in my narrative seeks to invite the experiences and perspectives of others so that these can be channelled into future collaborations for social change and justice.

My confidence in the power of collaboration across academia, political spheres and professional fields has led me to many new acquaintances in a variety of academic disciplines. These range from social work to statistics, political science to the natural sciences, charities, advocacy groups and communities of sufferers of chronic disease and disability. I have listened to and discussed issues with influential citizen scientists, activists and a plethora of other voices involved in advocacy for the recognition, treatment, participation and full citizenship of the chronically ill and disabled.

# 2. Transitioning into disability

**Five years ago, I was visible in academia, my physical presence functioning as a guarantor for 'proper' work being done and 'genuine' knowledge being produced.  I have since transitioned from being perceived as healthy to home- and bedbound and have come to regret my failure, pre-severe illness, to address issues of exclusion from the academic, political, social, and public sphere due to illness and disability. The fact is, this is not an issue I had considered or even wanted to consider, as, like most healthy people I was happily engaged in my day-to-day activities, giving little thought to the world I was soon to inhabit.**

In terms of identity, I had placed myself firmly in the world of the able-bodied by deliberately distancing myself from all things to do with illness and disability. This is to accentuate that I am not pointing fingers at academics, let alone ill people, who act as I used to. If there is any finger pointing at all, it includes myself.

The relentless physical pain and crushing isolation that chronic illness and its management bring about were, and are, cruel. The experience of being ill was exacerbated when I realised that few seemed concerned with my altered situation in life. The terror I felt at this moment of realisation was indescribable, that something so severely affecting my life and sense of being meant so little to others.  I was once in a minor earthquake in Tokyo and to feel the shifting of the earth beneath one's feet is an unfathomably disturbing sensation. Losing my grounding due to illness and disability feels like the earth is shifting beneath my feet continually. Feeling ill continually, chronically (many fail to comprehend the meaning of the term) is horrible; feeling ill and being excluded from society and everything that previously gave your life meaning and worth, is much, much worse. This is the situation

I found myself in, and the failure of others to acknowledge, or even observe, my new reality caused me significant anguish.

## 3. Withdrawal and abandonment

**When a member of society fails to present a healthy body and the formerly healthy body is forced to withdraw from visible participation, the life attached to that body ceases to have value. Physical pain, especially chronic physical pain, limits active participation and consequently chances of effecting change. Chronic illness renders people passive and dependent on able-bodied allies to listen, learn and work with them. When that does not happen, life becomes a scary experience. Not only is it crushingly lonely and confusing, it is disempowering to no longer feel a sense of belonging and social cohesion.**

I believe that withdrawal by a friend and colleague is not a private matter of friendships ending and people going their separate ways.  The severely ill have nowhere to go. They run out of options for alternative lifestyles very quickly, and in times of austerity and ideology-driven policies, dehumanising experiences abound without the safe haven of the solidarity and social cohesion friends, family and work can, and normally do, provide. This will sound like a terrible accusation, but it needs to be said: not seeing and not acknowledging the absence of choice for a chronically ill person can be equated to leaving an injured person lying in the street. They become defenceless and vulnerable to attacks from all directions, and they may die of the neglect. This is not a hypothetical supposition, people with chronic illnesses die in considerable numbers from various causes and how often do we hear a friend or relative complaining about the lack of care? Authorities are blamed, justifiably, but friends and relatives often absolve themselves from responsibility towards the chronically ill person, hoping, or assuming, that someone else will look after them. I do not only mean looking after in the sense of a carer but in helping the formerly healthy friend or relative to participate in society and to escape the crushing isolation illness foists upon them.

What if that someone else is a figment of the imagination? There is often no generic, ‘someone else’, and even those who are financially secure can only buy themselves so much care or comfort. Ultimately, we need our fellow human beings to feel a sense of solidarity with or towards us. It is simply a question of human dignity and survival.

# 4. Participation from the margins

**Chronic illness and disability, in their various stages of transition, are chaotic and require people to rethink, redo and reconsider every aspect of their lives, from jobs that they can no longer perform, to children who can no longer be supported to the same extent as pre-illness, to houses that become unaffordable, to friends and colleagues whose expectations we no longer fulfil. If we were not fortunate prior to illness we soon become vulnerable and at risk of impoverishment.**

While this reorganisation of life is proceeding, we have to communicate our situation to family, friends, colleagues, medical doctors, assessors, landlords, banks and many others. Being forced to hear oneself say repeatedly ‘I have fallen ill’ is not only painful, it is humiliating, especially when being forced to explicate in detail without knowing how open we ought to be in order to come across as trustworthy as well as acceptable in terms of social norms. Absurd situations arise where even an adjective such as chronic has to be explained; not understanding the meaning of words, and therefore the very premise for life with a chronic illness, can have serious consequences for the health and safety of the sick and disabled.

# 5. Format and content

**Sometimes, the content, what it is like to be ill and why we need biomedical research, for one, is about the format in which stories can be told, and the format is the content that requires discussion. In other words, being chronically ill requires sufferers to provide the people in their lives with detailed explanations and context, before they can begin to state their actual subject or reason for a conversation.**

I have never contextualised and explained so much as I have in the past five years, which is saying a lot considering I used to teach hundreds of students, and I have often wished my family would do all that on my behalf, simply because I am ill and in pain, which never seems to sink in. No one among my family and friends – and not many of the latter have kept in touch - knows as much as I do about ME and the sorry political state it found itself in long before it became my personal concern. I have educated many and have myself been educated on the history and background of my illness. To learn about this disease without any support from the healthcare system while being stigmatised by members of the medical profession as someone who imagines her illness, which is then reported on by the media with excessive relish, is mortifying and exhausting.

To find and sift through hundreds of research articles on one's own illness, rather than be informed by a medical professional, and to begin to understand the complex science concerning ME, can take months or years. It is a huge undertaking in informal learning. To educate family and friends is exhausting and for many yields little in return.

I feel weighed down by the memory of my attempts to spread education and reason regarding my new situation. Friends and relatives, with whom I have spent hours, days and months in discussion have gone from my life. It seems the more I tried to explain, the more alienating I became to them but I do not know what caused the rupture except that the official discourse or narrative about my illness, that dictates I am supposed to be pitied but not believed, cannot have been conducive to learning. Long since debunked psychosomatic or psychogenic explanations for physical illnesses are alive and well, in fact they appear to celebrate a revival that mirrors the emergence of possible biomarkers for my illness, which is an interesting paradox.

Participation and learning become complex issues in such circumstances. In my experience, friends and family do not wish to be included in the new learning experience that is forced upon the ill, while the ill drift more and more towards exclusion from the world of the able-bodied that comprised their former lives.

## 6. Participation and activism

**Transitioning into chronic disease, and arriving at the insight that not only was I disabled but also that disability could potentially afford me a political tool for change, meant that activism became a choice. I realised there were multiple, serious problems regarding my own, and other chronic diseases, that left people uncared for by the welfare system. Once a diagnosis becomes contested, it becomes difficult to apply for sickness benefits of any kind.**

My use of the term activism is deliberate as it connotes political awareness and recognises the need for fundamental, social change. Unfortunately activism is a term that has been hijacked in neoliberal discourses that seek to smear people who do not comply with perceived norms of good citizenship. In political and some societal circles, helped by certain journalistic styles, activism has become a pejorative term from which many sick and disabled wish to distance themselves. By using the term here, I aim to make it clear that striving for social justice is a matter of logic and applied ethics. I find it logical to want equality and realistic possibilities to participate in society. Activism is not a derogative word. I do not believe that we need more diplomacy to negotiate our way out of a quagmire not of our own making.

Instead, we need more politically driven activism and powerful arguments in favour of full participation and citizenship for chronically ill people.

Discrimination on the basis of an activist's gender is common. The most prevalent forms of discrimination appear to be victim blaming, gas-lighting, and intimidation. I have also noted instances of plagiarism and academic erasure. The question is how much time can and should be expended on people, ill or able-bodied, in an attempt to create common grounds for discussion. While it is of the utmost important to fight discrimination in all its forms, it is time-consuming and detrimental to an ill person's health. Here, again, able-bodied allies would be required to assist those with serious knowledge contributions instead of letting their voices be drowned out by ignorance.

Women are often, almost by default, assigned roles of the lesser. While I have known this all my life (and the statistics in every field of public and private life confirm this) this situation has been made especially clear to me on observing how women activists, often those who have made valuable academic contributions, are treated in the field of ME. History is full with wronged and abused women activists. Those who are perceived as posing a serious threat to power regimes will invariably be vilified. Raising concerns about controversies and issues that are deemed explosive and dangerous is simply not endearing. What the community fails to recognise is that political activism is supposed to push boundaries by speaking truth to power; history provides us with plenty of examples illustrating the necessity to challenge.

To aggravate matters, chronically ill and disabled women activists are condemned to obscurity unlike, for instance, the first and second wave grassroots feminists who were highly visible and clamorous. Unless the former find able-bodied allies willing to help render their precarious existences and knowledge visible to people in positions of power and influence, there is little hope their voices will be heard. Disabled feminists are marginalised within feminist movements but critical feminist theory provides invaluable analytical tools to understand the power hierarchies of informal settings, participation and learning. The more political women activists are in the field of chronic disease and disability, the more marginalised they can become. To lay claim to knowledge from a position on the outer margins is nigh on impossible. Valuable knowledge will therefore become lost and the community is the poorer for it.

# 7. Activism in science

**From my observation of possibilities to participate and learn within the framework of activism there is a paradigmatic battle being waged between certain schools of thought advocating psychogenic explanations for physical illnesses and biomedical research. In a sense it is an uneven playing field, certainly in the UK as serious, peer-reviewed scientific research is often ignored while mere opinion, if it supports the government's aim of reducing the welfare budget, is given undue weight. It is reminiscent of claims made within the discourses about global warming, where climate change deniers' opinions are treated by the media as having equal validity, as the large body of peer-reviewed scientific evidence pertaining to climate change being produced by human activity. This is conveyed as a polarised debate where both sides have equally reasonable and justifiable opinions.**

Concerning ME, sufferers are often constructed as malingerers by sections of the UK media, frequently via articles written by journalists with links to psychiatrists promoting the BPS model, while peer-reviewed biomedical research fails to attract the slightest journalistic curiosity. The media treats BPS proponents as if they make reasonable scientific claims with their mantra 'it is all in people's heads', despite their providing no evidence as to how 'the mind' works to make the body ill, these people lay claim to an absolute truth that is fraught with logical fallacies. In practice, this boils down to stating that the sick and disabled have themselves to blame for their situation. Other scientific paradigms have debunked and rejected the premise of the BPS model, but neoliberal states uphold it, in fact widen its grasp, allowing bureaucrats to declare very ill people healthy and therefore 'fit to work'. The political dimensions of science are often missed or entirely ignored, maybe because many people, including scientists themselves, are unaware of how politically charged their work is.

This has affected me, and other ME sufferers directly through the PACE trial. A DWP funded study by proponents of the BPS model of sickness and disability, which treated ME as a behavioural disorder that could be cured by altered thought processes and increased exercise. It had the unique feature for a scientific study in enabling a participant to finish the trial in a worse state of health than on entry yet still be reported as recovered. Media coverage of the PACE trial, promoted by The Science Media Centre (SMC) several members of which were closely linked with the PACE researchers, was uniformly positive, including headlines such as 'Exercise cures ME'. No critical examination of PACE was undertaken by any media outlet in the UK. In my view the PACE trial is a further example of the historical abuse of the sick and disabled by medical professionals, abuse which is especially prevalent when the majority of those affected are female as pertains in ME. The starkest present day example is the case of Karina Hansen, a seriously ill ME sufferer from Denmark, who has been under effective state detention for over 3 years (detained by followers of the BPS model), during which time her health has deteriorated considerably.

Scientific paradigms have dire consequences outside academia. The situation for the sick and disabled is worsened for many when the loyalty of loved ones, colleagues and friends is tested in light of the type of disability denial that is not only encouraged but rewarded in the public sphere, while the voices of biomedical researchers, are lacking. This allows proponents of the BPS model to lay claim to absolute truths on which they are rarely challenged regarding aetiology, let alone suggestions for effective treatments. Instead, their 'treatments' hold the artificially constructed promise of cost-efficiency for the NHS and other health agencies in Western societies. Of course such cost efficiency is short-lived, as the sick and disabled are denied the adequate research funding and clinical treatments they require, leading to continued illness and exclusion from society. While it would be interesting to calculate how much tax the state loses due to sufferers not being in employment, citizenship ought not to be linked to, or qualified through, participation in the labour market.

To return to the absence of biomedical discourse in the public sphere, this may have to do with the scientific paradigm in which the natural sciences are embedded, and where science communication connotes differently from paradigms that have well-established links to policy makers as well as insurance agencies. It is unsurprising that activists, regardless of their own academic credentials or in other ways impressive backgrounds pre-illness, find themselves condescended to and even vilified by those who work for institutions in whose interest it is to save the state money.

The overlap between theories of participation and learning on the one hand, and practices of participation on the other is fraught with the friction of clashing political agendas and scientific paradigms. But academics' activist voices need to make inroads in academia to influence curricula, syllabi and the way in which content is taught to future generations of members of various professions. I propound that change needs to take place in academia as well, because academia has always had a symbiotic relationship with politics and all other spheres of society. Besides, the BPS model is firmly embedded in syllabi and future generations of medics will learn to ignore the sick and disabled.

# 8. Social media and learning

**Closely linked to issues of formal and informal learning and knowledge production are issues of whose knowledge counts as valuable and whose does not. These issues tie in with gendered notions of knowledge. Sometimes this is explained in terms of embodiment, which means that knowledge attributions depend on who says something rather than what is said. This becomes manifest in scenarios where equally qualified people offer identical suggestions but depending on the sex, race, age, or even perceived sexuality of these people, the suggestions are either deemed noteworthy, ignored or dismissed.**

Finding my normal outlets of expression as an academic closed to me on becoming ill I searched for other areas in which my voice could be heard. One of which was social media. Once hailed as a democratising tool or opportunity, I was dismayed to discover that in reality social media is far from that. Sick and disabled women, historically stigmatised by medicine, have to fight for a voice and recognition on social media just as much as elsewhere in society. Twitter drips with derision the moment even the most respected women courageously challenge the status quo. But, where else can ill people who are housebound go to exchange views, ideas and most importantly, raise awareness of the work they do? To deride Twitter as a joke or at best an amusing pastime is trite. This may be true for those fortunate enough to be able-bodied and capable of participation as visible citizens in the public sphere, but for those imprisoned indoors, it is one of the few available platforms from which to voice their opinions.

Social and political participation and collaboration towards change must be achieved by informal learning and collaborative platforms that are digital, but when the knowledge offered by those living in the margins holds no value or interest for the parties that are required for productive collaboration, that becomes problematic. I have been humoured but not listened to, and am far from being alone in this experience. Some days, intelligent exchanges are impossible on social media. However, participation is required to engage in and encourage informal learning.

# 9. Concluding thoughts

**To confuse intelligent debate and criticism with conflict is not conducive to participation and learning for all. For someone used to vivid intellectual discussion, it is hard to accept the low level of genuine engagement imposed upon me as a chronically sick person. Advancements in science will not save the day for the sick and disabled as long as the BPS model is allowed to thrive unchallenged.**

While I condemn unsafe knowledge claims made in paradigms that have done nothing towards breaking ill people's marginalisation through the provision of adequate treatments, I am also wary of unsafe knowledge claims or limiting and limited approaches to activism from within marginalised groups. The risk for groupthink endangers change projects, and the silencing of significant or vital knowledge favours those who set the agenda at the political level.

The chronically sick and disabled are not entirely disempowered stakeholders and while members of the ME community could do more to learn about the political context of their situation, they should not have to. Adequately trained specialists and GPs should look after them. This is not achieved through the enforcement of draconian measures, ideologically rather than research driven and based on unscientific treatments. Blame for the neglect rests squarely on the shoulders of the proponents of the BPS model, and those neurologists, immunologists and other medical professionals within whose remit it is to muster scientific curiosity and ambition.

Thus we find ourselves in lives and identities constructed for us by others' notions of what the truly deserving sick and disabled look like, how they behave and what they can or cannot do.

If we do not comply with generally held perceptions of the deserving cripple, we soon find ourselves in trouble. Unless the hard work of women and men engaging in political activism is fully recognised as a key component for change, there will be no fundamental, sustainable change. Political activism is necessary whether natural scientists and others, who are disinclined to acknowledge the political context, like it or not.

Transformative change, permeating a diversity of practices can be initiated to an extent but not solely effected by people with debilitating chronic diseases. The transformation of practices in activism and pertinent areas of the public sphere will remain elusive as long as there is a lack of willingness to learn from those whose lives are disrupted by unforeseen events such as disease. The urgent question we need to answer is how learning and participation can occur when political agendas appear to be set in stone by ideologues whose interest in listening to reason is absent. We also need to ask ourselves who the reliable, able-bodied or influential allies are in a political climate in which chronic disease and disability are increasingly constructed as wilful offences to normality and societal order.

I believe the sick and disabled community needs to work together to engage politicians, the media and their own charities in opposing the rise of the BPS model of disease, which has caused so much damage and distress to so many without producing effective treatment for ME or any other condition. The abuse of the sick and disabled, which has risen markedly in recent years, needs to stop and it is only by working together that this can be achieved.

**My vision for an immediate action plan for social and political change includes but is not limited to:**

- Reform of medical education syllabi in conjunction with an overhaul of the NHS guidelines
- Improved patient safety for the chronically ill with fluctuating symptoms
- Scrapping of the WCA, to be replaced with a humane system that is based on facts about the fluctuating nature inherent in many chronic diseases
- Awareness of the consequences of physical absence and reasonable adjustments to this specific type of dis/ability, which is to say provisions by all institutions for the inclusion of the chronically ill in decision making processes and genuine participation (as opposed to the chronically ill having to fight for access and participation individually and being exposed to volatile decisions)
- Science, advocacy groups and politicians collaborating, driven by an explicit agenda for social change for the sick and disabled
- Political accountability on the Council level and collaboration between Councils (to render it possible for the sick and disabled to move to any area of the UK they wish instead of being forced to live wherever they happen to receive healthcare and the support they require)
- Accountability on the part of GP surgeries. It should no longer be lawful for a GP to send away severely ill patients on the basis of personal beliefs as to the existence of a particular disease, which is a common complaint heard from the chronically ill

- Integration of facts and science about chronic diseases in all social policies as well as accountability on the part of the formal education and higher education system in terms of access and full participation
- The establishment of a well considered link between any form of work capability assessment and realistic opportunities at entry point to the labour market. Without there being jobs available commensurate with an applicant's formal qualifications, regardless of their able-bodiedness, it ought to be unlawful to declare such a person fit for work, as the latter is effectively non-existent

Lastly, the sick and disabled need to ask themselves what type of identity politics they think is the best way forward. Are the chronically ill disabled? I say they are and they should join the disability rights movement.

# APPENDIX

- **BPS** – The biopsychosocial model focuses on psychological, behavioural and social aspects of disease rather than physiological mechanisms. In the case of ME, this has led to patients being blamed for their ill health as physiological abnormalities are ignored with a focus instead placed on patients' behaviour or 'illness beliefs', the implication being that illness is the patient's fault. Proponents of this model in the UK include professor Sir Simon Wessely (President of The Royal College of Psychiatrists) and professor Michael Sharpe (Department of Psychiatry, Oxford University).
- **CFS** – chronic fatigue syndrome, a term created in the USA in 1988 for which fatigue is the primary symptom. A significant increase in ME diagnoses occurred in the US in the 1980s causing concern amongst medical insurance companies due to increasing healthcare costs. Along with psychiatrists they created the term CFS, defined as a psychiatric condition, encompassing ME and allowing the latter to be subsumed and reclassified.
- **ME** - myalgic encephalomyelitis, an organic neurological disease recognised by the World Health Organisation since 1969 code G.93.3, named by Drs Melvin Ramsay and John Richardson in 1956 following the Royal Free Hospital outbreak in 1955, though it has probably existed for centuries. Disease onset normally follows a viral infection. Symptoms include post-exertional malaise, swollen lymph nodes, severe pain, digestive problems, orthostatic intolerance, low circulating blood volume, paralysis and cognitive dysfunction. Physiological abnormalities in ME patients include significant mitochondrial defects, aberrant brain function, altered levels of pro- and anti-inflammatory cytokines, persistent viral infection, abnormal natural killer cell function and reduced cardiac activity.[1, 2, 3, 4, 5, 6, 7, 8]
- **WCA** – work capability assessment. Introduced in 2008, the WCA assesses the capacity of a disabled person to work. It utilises the BPS model of sickness, focussing on what the disabled person could manage if their thought processes towards work were altered. This has resulted in numerous cases where severely ill patients have been classed as 'fit to work', with several dying from their conditions during the process of assessment.

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# ABOUT THE AUTHOR

**Claudia Gillberg** is is an affiliated scholar with the Swedish National Centre for Lifelong Learning and a member of several academic as well as professional bodies. Claudia's research interests comprise learning in informal settings, participation, organisational development, ethics and feminist pragmatism. When Claudia relapsed into severe illness a few years ago, she started taking an interest in Disability Studies while struggling with her own identity and issues of exclusion/inclusion and full citizenship. She realised that able-bodiedness is automatically ascribed a positive value, so she is now exploring ways to understand and resolve problems of devaluation and exclusion owing to chronic illness and ensuing disability. Online participation and activism as forms of exercising citizenship for the home and bedbound are of great interest to her. In her pre-severe illness life Claudia had roles on a number of organising committees for gender equality, advised UNICEF on their project Human Rights Respecting Schools, helped organise a World Congress for Action Research in Melbourne in 2010 and supervised Masters and PhD students. She has taught on the history and philosophy of education, gendered knowledge production, teacher education programmes, citizenship and education, as well as feminist pragmatism.

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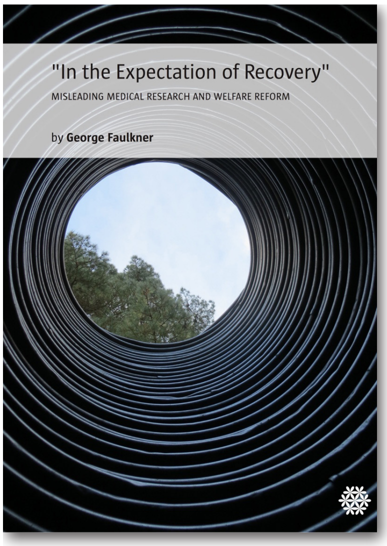
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