Biopsychosocial Model or Bio-political Ideology?

Medically unexplained symptoms, welfare reform and the implications for Long-COVID

A DISCUSSION PAPER FROM CITIZEN NETWORK RESEARCH

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Summary

The biopsychosocial model as it is applied to myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and so-called ‘medically unexplained symptoms’ has been robustly critiqued for lack of evidential support, additionally being implicated in harms experienced by chronically ill and disabled people within the healthcare arena. However, the political underbelly of this model as it dominates health and social policy in the UK and beyond has received far less attention.

This paper, drawn from a series of the author’s blogposts on the same topic, examines structural (here, socio-political) dimensions of this variant of the biopsychosocial model. The first part of the paper explores how biopsychosocial discourse, as it pertains to ‘medically unexplained symptoms’ and notably to ME/CFS, draws from a politicised variant of the model that has been developed to serve a neoliberal project of retrenchment across welfare and healthcare sectors. This is followed, in the second section, by a closer consideration of the features of this politicised model and how it constitutes deserving and undeserving suffering, where conditions such as ME/CFS are positioned as undeserving. The third section delves into the network of associations between certain academics and actors within the UK government and disability insurance industry, a network that has constructed and continues to reproduce this politicised variant of biopsychosocial discourse. Finally, the fourth section explores the human costs of structural injustices associated with this discourse.

Although focused on historical and current events in the UK, the political and ideological context that has given rise to the marginalisation of ME/CFS and other chronic illness bears relevance far beyond the UK. Importantly, and relatedly, there are indications that actors implicated in the politicised psychosocial framing and marginalisation of ME/CFS have now turned their attention to Long-COVID. The points raised in this paper should therefore be of interest to a wide readership.

1. Origins of a tangled web

[W]herever power is at work, we should be ready to ask who or what is controlling whom, and why.

Fricker M (2007) Epistemic Injustice: Power and the ethics of knowing.
Oxford: Oxford University Press, p.14.

Since the publication of the UK National Institute for Health and Care Excellence (NICE) draft and final guidelines on the diagnosis and management of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) (NICE 2020a; NICE 2021), the provisions of which have not been to the liking of a number of eminent researchers and clinicians, manifestations of epistemic injustice and enacted stigma in this field have become increasingly evident (for examples see Howard, 2020; Garner, 2021; Howard, 2021; Turner-Stokes & Wade, 2020; Newman, 2021).

In this paper, I examine what arguably underpins and explains such stigmatisation, epistemic injustice and broader social injustice to which patients are subjected. Such injustices are not only committed by some researchers and clinicians, but also by policy makers, government, the media and mainstream society more broadly. The paper focuses upon the structural dimensions of the biopsychosocial (BPS) model, that is to say, macro-level phenomena.

Peer-reviewed academic literature has demonstrated how the BPS model in the realm of ME/CFS, and to some extent other chronic illness, manifests and impacts on a micro level (for example, within healthcare encounters) and on a meso level (for example, in terms of healthcare policy) (see Blease et al, 2017; Geraghty & Blease, 2019; Anderson et al, 2012). However, discussion of macro level phenomena – structural or upstream factors such as economic policies, corporate interests, legislation and associated institutions - within the field of ME/CFS and other chronic illness are usually restricted to 'grey literature' such as work by independent researchers for citizen think tanks (see Faulkner, 2016) or the personal blogs of disabled people (see Hunt, 2021 for the academic-activist blogpost series upon which this paper is based). When we consider the power complex that has constructed and reinforces such macro level phenomena, it is not very surprising that mainstream academic journals have historically not wanted to rock the boat – though things may well change with the emergence of Long-COVID.

In writing this, I focus on the situation in the UK, and draw principally from the work of a number of disability activists and scholars (including Rutherford, 2007a; Jolly, 2012; Berger, 2014; Faulkner, 2016; Stewart, 2016, 2018, 2019a, 2019b; Shakespeare et al 2017). More recently, and after many years of trying, I have been able to add to the academic literature on structural injustice and abuse of power as it pertains to ME/CFS and Long-COVID (Hunt, 2022a, 2022b, 2022c, 2022d). Despite the UK-centric flavour of what follows, the political and ideological context that can be argued to have influenced BPS discourse, as examined in this paper, is one that bears relevance far beyond the UK. Retrenchment of welfare and healthcare sectors is a marker of austerity management programmes, notably implemented across member countries of the Organisation for Economic Co-operation and Development (OECD) (see OECD, 2009; Stewart 2019b). Therefore, this paper should be of interest to a wide readership.

Whilst the focus here is largely upon ME/CFS, points raised in this paper apply to other chronic illness and disability, particularly those that can be shoehorned into the 'medically unexplained symptoms' umbrella or 'contested illness' category. Medically unexplained symptoms are sometimes referred to by other names, including functional somatic symptoms and persistent physical symptoms (see Patel et al, 2020). The construct of medically unexplained symptoms, along with its cognate terms, is very pertinent for those sub-groups of patients with Long-COVID without detectable organ impairment, since biomedical conceptualisation and treatment is currently lacking. There are indications that Long-COVID, or at least subgroups thereof, may be subjected to a similar process of politicisation as ME/CFS (Willis and Chalder, 2021; Sharpe, 2021; Verveen et al 2022) and I think it important that people with Long-COVID are aware of the actors and structures underpinning this process.

Beginnings of a politicised model

The BPS model in mainstream healthcare literature is typically associated with the thinking of George Engel (1977), a doctor in internal medicine and psychiatry with training in psychosomatic medicine, who sought to address what he considered to be a reductionist, dualistic biomedical model. The BPS model purportedly encourages a more holistic form of healthcare, ostensibly acknowledging psychological and social factors in health and illness alongside biological considerations.

However, Engel's BPS model has been critiqued on various grounds, chiefly an eclectic freedom and conceptual under-development which means that any pillar can be foregrounded as per the biases of whomever promotes the model (Ghaemi, 2009). This is a crucial point, because it has allowed the BPS model as it dominates UK health and social policy, particularly as it pertains to 'contested' illness, to be manipulated to serve political, economic and corporate interests without any empirical underpinning or theoretical coherency.

As disability studies scholars and disabled people have highlighted, these interests are associated with the work of certain academics within a broader context of government welfare reforms and disability insurance industry profiteering (Rutherford 2007a; Jolly, 2012; Berger, 2014; Stewart, 2016). These reforms, as previously noted, can in turn be located within a global context, that of ableist, neoliberal politics and austerity management (structural adjustment) programmes across the OECD, of which disabled and chronically ill people have borne the brunt (OECD, 2009; Stewart, 2019b). This application of the BPS model has been referred to as the 'Waddell-Aylward BPS model' (Shakespeare et al, 2017) after Professor Sir Mansel Aylward and the late Professor Gordon Waddell, both medics, academics and key architects of the BPS model as it is applied within health and social policy.

I will use the term 'Waddell-Aylward BPS model' to differentiate from Engel's work, whilst also acknowledging that other academics have contributed to its development.

Foundations of the Waddell-Aylward BPS model

The Waddell-Aylward BPS model appears to have its origins in Waddell's thinking on chronic back pain (Waddell, 1987, 1998); Waddell was an orthopaedic surgeon with a particular interest in back pain and related disability. Waddell suggested that back pain should not cause long term disability, that too much rest was harmful, and that a rehabilitative approach (notably with 'controlled exercises') was necessary and sufficient to facilitate recovery and return to work.

Waddell also distinguished between what he considered an illness (a psychosocial entity) and a disease (a biomedical entity), considering back pain to be the former. Parallels to the BPS model of chronic illness and disability (including, significantly, of ME/CFS), can already be observed. However, the model was largely developed through the work of the Centre for Psychosocial and Disability Research at Cardiff University, established in 2004, where both Waddell and Aylward were key academics: Aylward serving as director and Waddell as honorary professor.

The papers produced by the Cardiff centre (e.g. Waddell & Burton, 2004; Waddell and Aylward, 2005; Waddell and Aylward, 2010) provided an academic framework, and therefore purported justification, for the UK government's successive welfare reforms and also helped reinforce a reform of disability insurance policy (Rutherford, 2007a). By reforms, I mean policies of denying disabled and chronically ill people the financial support necessary to live maximally independent, dignified lives whilst those who drive said reforms benefit politically, financially and professionally.

In respect of the above, it is not coincidental that the Cardiff centre was sponsored for some years by US insurance company Unum (then, UnumProvident), whilst benefitting from associations with the UK government and other entities involved in welfare reform. For example, prior to taking up his post as director of the Cardiff centre, Aylward had enjoyed a distinguished career in the UK Department of Work and Pensions (DWP) - or Department of Social Security (DSS) as it was for part of Aylward's office - as Chief Medical Officer, Medical Director and Chief Scientist, whilst some of the Cardiff centre's work (e.g. Burton & Waddell, 2004; Burton & Waddell, 2006) was commissioned by the DWP.

During Aylward's time in the DWP he helped to develop various forms of benefits assessments and training programmes for assessors (including the All-Work Test and Personal Capability Assessment), significantly with input from Unum presence (Aylward & LoCascio, 1995; Aylward & Sawney, 1999; see also Jolly, 2012), and was also involved in various capacities with Atos, a French company whose healthcare division was contracted by the DWP to manage disability and fitness to work assessments (Berger, 2014). The result of successive changes to assessments has been to tighten the eligibility criteria for various disability-related benefits, significantly increasing the refusal rate of new claims and stopping of existing claims. Reform would also make applying for benefits far more stressful, with draconian sanctions befalling anybody who does not – or cannot - 'follow the rules' (see Shakespeare et al, 2017; see also Waddell & Aylward, 2005).

The Work Capability Assessment (WCA), introduced in 2008 to police eligibility for Employment and Support Allowance (ESA) that replaced Incapacity Benefit, has been associated with enormous psychological distress, destitution and increased suicides amongst chronically ill and disabled people (Barr et al, 2016; Stewart, 2018). Atos, which withdrew from its government contract to provide WCA assessors in 2014, has been heavily implicated in these harms (Butler, 2014). Predictably, the DWP has repeatedly attempted to minimise such suffering and loss of life, not least through refusing to publish data around it, before being forced to do so under a number of Freedom of Information requests. In 2015, the media reported that more 80 people per month were dying after being told they were fit to work (Ryan, 2015; Butler, 2015; see also Stewart, 2019b). Mo Stewart, Independent Disability Studies Researcher, has written at length about how the WCA represents a BPS model of disability assessment adopted by US insurance giant Unum for assessing insurance claims (Stewart, 2016, 2018, 2019a, 2019b). Further, Personal Independent Payment (PIP), which gradually replaced Disability Living Allowance (DLA) from 2013, was discussed as being underpinned by 'the' BPS model in the now infamous Lord Freud contribution during the 2012 Welfare Reform debates (Freud, 2012). The more rigid eligibility criteria of PIP have reduced benefits for many disabled people; in some cases, the right to accessible cars and other special equipment that offer disabled folk a degree of independent living has been revoked. Newspaper report and qualitative research has demonstrated the harrowing and profoundly deleterious consequences for disabled people (Ryan, 2016; Saffer et al, 2018).

The UK government's associations with the private disability insurance industry, in particular Unum, date back to at least the 1990s and arise from common interests: both parties were concerned over the rising cost of supporting chronically ill and disabled people in the form of social security benefits and disability insurance pay-outs respectively (Rutherford, 2007a). However, the progressive destruction of the welfare state was already underway at that time-point, having been a key goal under Margaret Thatcher's administrations (Stewart, 2019b). In the early 1990s, under John Major's prime ministership, Peter Lilley (then Secretary of State for Social Security) drafted in Dr John Lo Cascio (then second vice-president at Unum) to provide consultancy on how to reduce welfare spending through increasing restrictions on benefit claims.

A healthcare or social policy model that appeared to provide a scientific basis for reducing welfare expenditure and maximising corporate profits was indubitably a politically and economically attractive prospect. Specifically, conditions that could be positioned as psychological or psychosocial in nature (lacking 'objective' biomarkers), and thus amenable to psychosocial interventions, could be exempted from welfare provision and disability insurance pay-outs, effectuating a retrenchment of the welfare state whilst boosting profits in the private sector. To do this whilst maintaining a façade of ethics, the interventions would have to be demonstrated as being evidence-based (see Faulkner, 2016).

An added bonus for Unum was that, if access to social security was further limited by the UK government, those potential claimants who had the means might be persuaded to take out private income protection insurance, which Unum was keen to sell - and apparently equally keen to renege on, when disabled and chronically ill policy holders tried to claim for the financial support they were paying for.

In fact, Unum has a history of highly ethically questionable conduct on both sides of the Atlantic (Hansard, 1999; Hooper & Williams, 2010): in the US, in 2003, then California Insurance Commissioner John Garamendi stated that Unum (then UnumProvident) had been forcing claimants to accept less than their due, adding that Unum represented an "outlaw company" that "for years has operated in an illegal fashion" (Garamendi cited in Rutherford, 2007a, p.47; see also Rutherford, 2007b). The BPS model has thus been manipulated as a political tool to justify the reduction of welfare expenditure whilst opening up new markets for corporate profiteering.

The Cardiff centre embodies various ethically and morally dubious associations that have been referred to as an 'academic-state-corporate nexus' (Rutherford, 2007b); this nexus will be explored in more detail later in the paper. In the next section, I consider some key constructs of the BPS model, constructs that are largely created for political purposes with a distinct lack of empirical underpinning.

2. Constructs and propaganda

"People go to war for ideas, not for evidence."

Gordon Waddell, cited in: White P (ed) (2005) Biopsychosocial medicine: An integrated approach to understanding illness. Oxford: Oxford University Press, p.218

In this section, I cast an eye on some key constructs or concepts within the BPS model of chronic illness and disability. These concepts have quite literally been constructed, for political purposes, by a network of associations between academics, the UK government and disability insurance industry, with a subsequent attempt to assemble the appearance of an evidence base to fit the policy.

'Common health problems'

The Waddell-Aylward BPS model targets what architects of the model refer to as 'common health problems'. These are constructed as mental health, musculoskeletal and cardio-respiratory conditions that are "characterized more by symptoms and distress than by consistently demonstrable tissue abnormality" and are thus considered "subjective health complaints" (Waddell & Burton, 2004, p.11; Waddell & Aylward, 2010, p.7). The referenced papers, produced by the Cardiff centre, clarify that 'common health problems' is another term for 'medically unexplained symptoms' or 'functional somatic syndromes', citing work by Sir Professor Simon Wessely who, it may be argued, has led the way in extending psychiatric reach over anything that can be framed as psychiatric or psychosocial. Professor Peter White is also cited within the same context, apparently to provide empirical substantiation to the claim that so-called medically unexplained symptoms are subjective, that is, lacking objective pathology. In practice, the label of medically unexplained symptoms often persists even where patients are not biomedically investigated in the first place, making this a clinically meaningless yet politically very useful concept: 'medically under-investigated symptoms' or 'medically under-researched symptoms' might be a more accurate term. It is noteworthy that 'chronic fatigue syndrome' or CFS (the BPS term for ME/CFS, which is frequently further reduced to 'chronic fatigue') is mentioned in the Cardiff centre's work within the context of these common health problems, under the rubric of mental health (Waddell & Burton, 2004).

In an echoing of Peter Lilley (see Rutherford, 2007a), Waddell and Aylward (2010) argue that workers' compensation and social security benefits were originally designed for people with "severe medical conditions and permanent impairment" (p.6), conditions associated with detectable pathology. In contrast, common health problems are considered to be "similar in nature and sometimes even in degree to the bodily and mental symptoms experienced at times by most adults of working age" (Waddell & Aylward, 2010, p.6).

The latter definition deserves some reflection. Such framing means that conditions such as ME/CFS, a condition that has been associated with a lower health-related quality of life and greater functional impairment than (for example) various cancers, multiple sclerosis, chronic renal failure and stroke (see Falk Hvidberg et al, 2015; Kingdon et al, 2018), a condition that can leave people bedbound and tube-fed and from which people have lost their lives, are framed by Waddell and Aylward as similar in nature and degree to symptoms that most working age adults might experience. It could well be argued that this is somewhat akin to comparing HIV/AIDS to a common cold. Moreover, common health problems are positioned as responsible for the majority of cases of sickness absence, long-term work incapacity and ill-health retirement, whilst it is stated that many people with severe medical conditions can and do work (Waddell & Burton, 2004; Waddell & Aylward, 2005). By then locating this within the context of an upward trend in incapacity benefits claims, common health problems are framed as a socio-economic 'problem'. Equally, by downplaying the severity of common health problems, this socio-economic 'problem' is implied to arise from individual deficiency or failure. Through a bio-political lens, this dynamic carries potential implications for long-term clinical and societal positioning of Long-COVID, or at least sub-groups thereof that might be framed as 'common health problems' for policy purposes (see Hunt, 2022c, 2022e).

Deserving and undeserving suffering

According to the Waddell-Aylward BPS model, illness is a mode of behaviour and a social phenomenon, whilst disability (here understood as restricted participation in activity) as it pertains to common health problems is largely conceptualised within a framework of "conscious choice" (Waddell & Aylward, 2010, p.21). Importantly, psychological factors, notably dysfunctional beliefs, attitudes and fear-avoidance, are posited to influence disability (Waddell & Burton, 2004). Effort and motivation are expected to lead to recovery, in particular via compliance with cognitive-behavioural rehabilitation strategies such as graded exercise and cognitive behavioural therapy (Waddell & Burton, 2004). Receipt of benefits and 'decisions' around being unable to work are equally conceptualised as "free choices" (Waddell & Aylward, 2010, p.22). Social factors are acknowledged largely as they fit the individualist and neoliberal narrative of agency and free will. That is to say, reinforcement of illness behaviour through 'colluding' clinicians and family within a culture of entitlement is one of the dominant narratives, yet critically informed social factors such as social disadvantage and discriminatory attitudinal contexts are, conveniently, markedly downplayed. The parallels to the BPS model of ME/CFS as it appears in mainstream literature are clear: the models are one and the same.

According to BPS thinking on ME/CFS, effort and motivation are key in improving health outcomes (Picariello et al, 2017) whilst patients' cognitions and behaviours are framed within the same 'dysfunctional' discourse with attendant recommendations of cognitive-behaviourally inspired interventions (Sharpe et al., 1997; Wessely, Hotopf & Sharpe, 1998; Knoop et al, 2010). ME/CFS is framed as an illness where, once again, 'illness' is considered as a sociocultural phenomenon largely without biological underpinning (Stanley et al, 2002; Sharpe & Greco, 2019). As per the Waddell-Aylward creation, the BPS model of ME/CFS only acknowledges social factors as far they fit an individualist narrative of psychologisation. Receipt of benefits, membership of support groups and 'over-solicitous' significant others have at various points been argued to be associated with poorer health outcomes in ME/CFS (Bentall et al, 2002; Band et al, 2015), thus limiting social influences to purported social reinforcement of 'dysfunctional' psychology. Once again, critically informed social factors are not mentioned. Again, this is very convenient and serves to shift the spotlight of scrutiny from the model itself, and motivations of its creators, onto patients.

It is important to note that the form of psychologisation promoted by this model goes beyond suggesting that patients have a psychological or mental health condition. Rather, in suggesting that patients are motivated by 'secondary gains' (attention, financial benefits, avoidance of work and other obligations) and that conscious choice and free will play a significant role in recovery, the model crosses the line from clinical judgements to moralising and stigmatising rhetoric. Such judgements also appear to be lacking in rationality: why anybody would choose a quality of life lower than cancer, would gain anything from being forced to bear witness to their slow and painful decline into oblivion, all whilst being treated like a social pariah, is never really explained. Secondary gains (along with much thinking in psychiatry) has theoretical roots in Freudian theory and has likely been adopted by eminence-based medicine to serve the financial, professional, and political gains of those who perpetuate it (see Hunt, 2022d). The resistance of many people with ME/CFS to a psychological understanding of their illness has been framed by some BPS proponents as arising from a desire to avoid mental health stigma (Wessely, 1997); whilst this may serve to further misrepresent people with ME/CFS, there is little evidence to support this framing. It is far more likely that people with ME/CFS resist a psychological framing of their illness because it is inaccurate and leads to healthcare interventions with negligible benefit or even harm, whilst risking misdiagnosis or missed diagnoses through lack of thorough biomedical investigation (see Sharpe et al, 1997; RCP 1996 for the suggestion that people with suspected ME/CFS do not require comprehensive medical testing).

It is highly pertinent that the construction of 'serious medical conditions' (worthy of welfare support and biomedical healthcare) and 'common health problems' (unworthy of such), creates a division that has been argued by disability scholars to be evocative of the deserving and undeserving poor narrative (Shakespeare et al, 2017; see also Stone, 1984). According to this delineation, it could well be argued that people with ME/CFS and so-called medically unexplained symptoms are unjustly framed as the undeserving sick – by the very people who claim to want to help them. The UK press has historically done very little to counter such narratives towards chronically ill and disabled people more broadly (Briant et al, 2013) and towards ME/CFS more specifically (Liddle, 2019); denigrating media narratives around disability may be related to increasing rates in police-recorded disability hate crime (see Garthwaite, 2014; Home Office, 2021). In-group out-group dynamics and associated binaries (deserving – undeserving) are a key ingredient in manifestations of social injustice such as stigma, discrimination, victim blaming and scapegoating. Such injustices may serve as a political tool when socially powerful people desire, for their own ends, to commit the most egregious abuses against less socially powerful people – and get away with it.

Eminence-based propaganda

One of the most shocking aspects of this state-sponsored disability denial agenda is the lack of evidential support for this politicised application of BPS model, in particular given the consequences of its application in the realm of health and social policy. Mo Stewart has suggested that UK welfare reforms, in particular through the impact of WCA (remembering that the WCA is derived from a BPS model promoted by Unum), can be considered a form of democide (Stewart, 2019b), pushing thousands of disabled and chronically ill people into early death through neglect and ensuing starvation, untreated disease and destitution, or through suicide. As Stewart (2019a, 2019b) also note, many more have been plunged into constant fear of having no means to survive and into utter despair. In 2016, largely due to the efforts of disabled activists to bring the impact of UK welfare reform to the attention of the United Nations (UN), it was determined by the UN that the UK had violated the human rights of disabled people (see Stewart 2019a, 2019b). Predictably, this was ignored by the UK government. In order to guarantee mainstream society's complicity with such abuses, the UK government needed to present their policies as evidence based. As already outlined, eminent academics have played a key role here, using their privileged positionality to re-frame propaganda as a mix of science and expert opinion. This assertion is more fully substantiated in what follows.

Much has been written on the limitations of the BPS model as it predominates in UK health and social policy, both examining Waddell & Aylward's work (Shakespeare et al, 2017) and the vast literature produced by proponents of a BPS understanding of ME/CFS (Geraghty et al, 2019). A strong theme is that of conflating correlation and causation, with such conflation being employed to make exaggerated claims. The Cardiff academics (for example Waddell & Burton, 2004) pick out reported associations between unemployment and poor physical and mental health, with the conclusion that the former causes the latter (hence justifying all manner of unethical measures to get people back into work, whether they are capable of work or not). It does not seem to occur to these academics that poor physical and mental health might contribute to unemployment, particularly in a society that does not accommodate chronically ill and disabled people in education, healthcare and employment. In the field of ME/CFS, BPS proponents have repeatedly drawn upon observed associations between variables (e.g. 'catastrophic beliefs' and fatigue) such as to infer that one causes the other (e.g. Stahl et al, 2014); predictably, in the direction that fits their theoretical model and supports their favoured interventions. As Shakespeare at al (2017) point out, this has fundamentally changed the BPS model from Engel's largely descriptive framework to one of alleged causal explanations.

Self-referencing, mis-referencing and selective referencing to aid weak arguments is not uncommon amongst BPS proponents. For example, Waddell and Aylward (2010, p.17) refer to "extensive evidence" that financial levels of benefits impact on duration and number of claims, supporting this with one reference co-authored by Waddell and Aylward that is specific to back pain. In the same paper (Waddell & Aylward, 2010), the authors claim to have the knowledge to significantly reduce long-term incapacity and sickness absence relating to 'common health problems' by citing one piece of (partially) self-authored work (Waddell & Burton, 2004). However, as Shakespeare et al (2017) point out, the cited work fails to provide convincing empirical support, with its authors conceding that the evidence is in fact lacking in many respects (Waddell & Burton, 2004, p.50). At one point, the Cardiff academics try to persuade their readers of the potential effectiveness of psychosocial interventions for musculoskeletal issues (one of their 'common health problems'), despite a lack of evidence for their effectiveness, by pointing out that "lack of scientific evidence is not the same as evidence that something is ineffective" (Waddell & Burton, 2004, p.45). Unsurprisingly, authors and kindred academics fail to apply similar logic to their construction of 'medically unexplained symptoms', which are typically positioned as lacking any biopathology on the grounds that pathology is not found; this is a particularly nonsensical construction since, as previously noted, many people with this label are not deemed worthy of thorough biomedical investigations. Precisely how BPS theorising was extrapolated from low back pain (Waddell, 1987, 1998) to almost every other health condition conceivable is not entirely clear; it would appear to be largely achieved by Waddell repeatedly citing himself and like-minded colleagues.

In the field of ME/CFS, internationally criticised BPS research – most significantly the PACE trial (White et al, 2011) - is repeatedly referenced by its authors to purportedly demonstrate robust findings of effectiveness of favoured interventions (Adamson et al, 2020; Chalder et al, 2022). This continues even in the face of NICE concluding that such research is of low and very low quality (NICE, 2020b), and that these favoured interventions (CBT and GET) should not be offered as clinically proven treatments, with GET being repudiated altogether (NICE, 2021). Historically, reports that could be expected to have significant impact on healthcare and social policy have been carefully crafted by selective authoring and selective referencing. One example is the 1996 Joint Report of the Royal Colleges of Physicians, Psychiatrists and General Practitioners on 'CFS' (RCP, 1996) where it would appear at least half of the authors and over half of the references were strongly biased towards a psychological understanding of ME/CFS. The report, predictably, played down biological underpinnings of ME/CFS, advising against all biomedical investigations but the most basic of blood and urine tests and suggesting that GET and CBT were the most 'hopeful' approaches. In *Magical Medicine: How to make a disease disappear*, authors Professor Malcom Hooper and Margaret Williams provide instances of how the authors of this report mis-reference papers to ostensibly strengthen their unsubstantiated position (Hooper & Williams, 2010). The above-mentioned examples of this aspect of eminence-based propaganda only begin to scratch the surface, but hopefully serve to make the point.

Finally, strategic use of language, including theoretical constructs, is apparent both in the writings of the Cardiff academics and academic-clinicians implicated in the psychologisation of ME/CFS. ‘Disability’ takes on a whole new meaning, moving away from both the social and medical models of disability in delineating something that a disabled person allegedly chooses or creates with social and financial reinforcement. However, when key actors in this game want to defend their positions or deflect from criticism, they will profess to believe that patients have a genuinely ‘disabling’ condition (see White et al., 2017; Sharpe, Chalder & White, 2021). Given that many people do not equate disability and derivative terms with individualist, victim-blaming narratives, as per dominant BPS discourse, it is easy to see how such assertions might be construed as coming from a place of benevolence. In a similar vein, ‘illness’, which is typically used in social sciences to describe the lived experience and broader socially situated experience of ill-health - without moralising connotations - is defined in a way that subjectivity becomes synonymous with a problematic lack of verifiable, ‘objective’ pathology, as in “illness-without-disease” (Sharpe & Greco, 2019, p.184) or “an internal, personal experience” (Waddell & Aylward, 2005, p.210). The emphasis on patient subjectivity and alleged lack of disease is then juxtaposed with the assumed objectivity of expert opinion and so-called evidence base (see White, 2005), whereby patient narrative becomes the lowest form of evidence. This mix of self-created, misappropriated, vague and fluid terminology is likely intentionally obfuscating and may raise issues with validity and replicability in research. An example of this in the field of ME/CFS, which will be detailed later, is the political hijacking of the diagnostic entity ME through the creation of ‘CFS’, conflating the two terms through ‘ME/CFS’ (cue numerous conflicting case definitions), then dropping ME (when it suits) to leave CFS or just plain ‘chronic fatigue’. Creating such ambiguity helps to deflect from an underpinning lack of evidence base. As Waddell suggested (in White, 2005, p.218), who needs evidence when you have ideas?

In the next section, I look more closely at the tangled web of professional associations that underpin the state-sanctioned abuse of chronically ill and disabled people. With the emergence of Long-COVID, and a strong possibility of a tidal wave of post-viral chronic illness and disability, the motives and activities of the academic-state-corporate nexus should be of great importance to everybody.

3. Academic-state-corporate nexus

"Oh, what a tangled web we weave, when first we practise to deceive!"

Sir Walter Scott, Marmion: A Tale of Flodden Field (1808)

As has been established, the Waddell-Aylward BPS model and the BPS model of ME/CFS - and any illness that can be shoehorned into a box of 'medically unexplained symptoms' - are one and the same. This is largely because ME/CFS (under the preferred name 'CFS') was used as a blueprint for welfare reform and to serve the interests of the academic-state-corporate nexus.

An exceedingly tangled web of connections exists between the Cardiff academics and key proponents of the BPS conceptualisation of ME/CFS, along with their government and disability insurance industry associations. This power complex is arguably strengthened through biases within the media, research funding bodies and academic publishing – all areas where certain BPS proponents of ME/CFS have influence. Criticism of the BPS model on theoretical and empirical grounds has been covered in various peer-reviewed published papers (Shakespeare et al, 2017; Geraghty et al, 2019; Geraghty & Blease, 2019) and also through patient narrative, though the latter has historically been subject to epistemic injustice. However, the political associations and conflicts of interest that exist within this academic-state-corporate nexus rarely seem to make it through peer-review - I suspect rarely get past editorial screening (but see Rutherford, 2007a; Hunt, 2022a, 2022b, 2022d). These connections can arguably be encapsulated through the oft-named Woodstock conference.

The Woodstock nexus

In 2001, a conference was held in Woodstock (near Oxford in the UK) on the subject of "malingering and illness deception" (see: Rutherford, 2007a; Hooper & Williams, 2010). Significant attendees included Gordon Waddell, Mansel Aylward (Aylward was then medical advisor to the DWP), Professor Peter Halligan (who went on to become associate director at the UnumProvident Centre for Psychosocial and Disability Research), and Professor Derick Wade (formerly of the Oxford Centre for Enablement and author of various papers on the merits of a BPS model, notably with Halligan). Professors Michael Sharpe, Simon Wessely and Peter White - all UK psychiatrists with a special interest in 'CFS' as they like to call it – were also present. Malcolm Wicks (then, Parliamentary Under Secretary of State for Work) and John LoCascio (then, Unum's second vice-president and medical director) also attended, along with 'Wessely School' psychiatrists Professors Christopher Bass and Anthony David. The meeting was funded by the DWP and its purpose has been summed up by Professor Jonathan Rutherford as none other than "the transformation of the welfare system" (Rutherford, 2007a, p.38). In short, this nexus of academic-state-corporate alliances needed to work out how to frame chronically ill and disabled people as morally void scroungers and malingerers with no insight into their own health conditions, so that benefits and insurance pay-outs could be denied, all whilst claiming to be working in best interests of these communities and 'following the science'.

The Woodstock conference is not the only meeting of minds that encapsulates the academic-state-corporate nexus, and it is noteworthy that associations existed between some of the attendees long before 2001, as will be addressed later. Various publications containing multiple contributions from within this nexus, some representing the proceedings of kindred conferences, exist (for example Unum 2002; Atos Origin, 2004; White, 2005; Halligan & Aylward, 2006). Perhaps Woodstock is referred to so frequently within the context of this nexus because the associations – and motivations - are so blatantly obvious. At least some attempt to cover up such iniquitous activities might be expected, but a typical feature of eminence-based healthcare and social policy is that key actors believe themselves to be beyond criticism or question precisely owing to their eminence (see Hughes, 2018). The Woodstock conference also spawned a book, entitled Illness Deception and Malingering (Halligan et al, 2003) after the conference itself, co-edited by Peter Halligan with chapters authored by, amongst others, Michael Sharpe, Simon Wessely, Mansel Aylward and John LoCascio. The publication – which peddles the well-worn narrative of people with 'subjective' health conditions taking advantage of an increasingly generous benefits system through exaggerating their suffering, not understanding their suffering or just plain malingering - also acknowledges the contributions of other Woodstock attendees including Derick Wade, Peter White and Gordon Waddell. The Woodstock connection can also be observed in the previously noted DWP commissioned and Unum sponsored monographs that issued out of the Cardiff centre, including The Scientific and Conceptual Basis of Incapacity Benefits (Waddell & Aylward, 2005) which essentially laid down the protocol for the 2007 welfare reform act. This work draws on the work of a number of the usual suspects, with a foreword of special acknowledgement for, among others, Halligan, Wade, Wessely and White.

ME/CFS as prime target

It is fair to suggest that ME/CFS would have been high on the agenda during the Woodstock conference. Prior to Woodstock, a narrative around ME/CFS as a psychosocial entity amenable to CBT and GET was being constructed by psychiatrists with an interest in ME/CFS, in some cases in collaboration with actors within the DWP (see White 1993; Wessely, 1993). Aylward in particular seemed very impressed with Wessely's position on ME/CFS and gave a talk on 'CFS' (Aylward, 1998) which appeared to draw directly from Wessely's work on the subject matter – conspicuously on purported parallels between CFS and neurasthenia (Wessely, 1990; 1997). Also prior to Woodstock, Unum had singled out ME/CFS as a target for aggressive claims management policy. Unum documentation from 1995 shows that CFS was referred to as "new banner for neurosis" and states:

> *"UNUM stands to lose millions if we do not move quickly to address this increasing problem. The subjective nature of CFS leaves us highly exposed to the self-diagnosis of claimants, some of whom take advantage of doctors and the entire insurance industry"*
>
> Jackson, 1995

In the same Unum policy document, Unum conceptualises CFS as a response to social and economic stressors, combined with 'failure of coping mechanisms' and 'entitlement philosophy', noting that people with CFS tend to understand their illness as a medical condition as opposed to a psychiatric disorder (with the inference that people with ME/CFS lack insight into their health condition). Once again, the propaganda of the academic-state-corporate nexus is evident: Unum's narrative here is strongly reflective of the UK government's stance within the context of welfare reform and implied undeserving illness (see Rutherford, 2007a), of the Cardiff centre's reform documents that informed this stance (Waddell & Burton, 2004; Waddell & Aylward, 2005, 2010), and of eminent academics who favour a (bio) psychosocial understanding of ME/CFS (Wessely, 1994; Wessely, Hotopf & Sharpe, 1998).

It can also be discerned from this Unum document that money lies among the roots of the institutionalised abuses committed against chronically ill and disabled people. Cutting welfare and healthcare expenditure and boosting the profits of the insurance industry is a barely concealed theme in BPS-inspired literature (Waddell & Burton, 2004; Chew-Graham et al, 2017; Sharpe, 2002) and some literature has overinflated costs of 'medically unexplained symptoms' to the UK National Health Service (NHS) (Tuller, 2019). As Waddell once said: "It is all about money. The main thing was to persuade the treasury that there was an opportunity for keeping costs down, particularly over the longer term" (Waddell cited in White, 2005, p.219; see also Faulkner, 2016). This seizing of the opportunity to 'keep costs down' would also prove financially and professionally profitable to those involved in keeping costs down, whilst the means to this end - subjecting chronically ill and disabled people to medical neglect, psychological trauma, destitution and early death – was presumably deemed acceptable. As previously suggested, such a large-scale breach of human rights required mainstream complicity, and such complicity was partly achieved through presenting propaganda as 'following the science'. Complicity was also achieved, as alluded to earlier, through stigmatisation and scapegoating of disabled people, and ME/CFS appears to have been considered a prime target.

In the remainder of this section of the paper, I explore a few further examples of the associations that exist within the academic-state-corporate nexus. This is really the tip of the iceberg, but hopefully will serve to demonstrate the inextricably tangled nature of this web of iniquity.

State - corporate associations

Links between the UK government and Unum have already been touched upon (see also Stewart, 2016, 2019b; Rutherford, 2007a); Aylward might be considered to embody a prime example of these associations. Aylward is also, in my opinion, a prime example of lack of reflexivity vis-à-vis potential conflicts of interest, or lack of moral compass – or both – that appear to be the prerequisite of entry into the academic-state-corporate inner circle. Aylward apparently moved straight from his role as Medical Director at the DWP to directorship of the UnumProvident funded Cardiff research centre; Aylward's account of the dates appear to conflict with that of Unum, and there may have been an overlap with the appointment of directorship in 2004, before leaving the DWP in 2005 (Select Committee on Work and Pensions, 2006; Black Triangle Campaign, 2012). In any case, it might well be asked why Aylward, having been heavily involved in UK welfare reform policy during his time at the DWP, would think it acceptable practice to work for a research centre sponsored by a disability insurance giant that was already developing a reputation for ethically questionable behaviour. Serious issues with Unum's conduct (see Hansard, 1999; Rutherford, 2007a; Stewart, 2019b) were common knowledge before Aylward's move to the Cardiff centre, and Aylward acknowledged that Unum (as UnumProvident) was sponsoring the centre before his taking up office as director (Black Triangle Campaign, 2012). In fact, Aylward seems to have had his fingers in the profitable pies of the disability insurance industry (or associated entities) for quite some time prior to taking the helm at Cardiff.

Aylward was a member of the DSS 'medical evaluation group' (established to develop stricter benefits assessments) from the mid-1990s; LoCascio (then both Unum executive and welfare reform consultant to the UK government) was also a member. The two men certainly seemed to sing from the same song sheets. A paper by Aylward and LoCascio (Aylward & LoCascio, 1995) bears the hallmarks of now dominant BPS discourse pertaining to ME/CFS and so-called 'medically unexplained symptoms'. The authors bemoan the increased claims for benefits on grounds of 'subjective impairment' ('CFS' is mentioned and appears to be framed as a psychiatric disorder), suggesting that such impairment is related to secondary gains and somatisation. Predictably, they conclude that psychiatrists and psychologists can play an important role in assessing purported contributing factors to long-term disability. At the same time, both Aylward and LoCascio support a reduced role for NHS physicians in determining long-term disability, a role that is to be undertaken by 'disability medical analysts', to be trained and examined through a diploma created with DWP and Unum influence (see Dewis, 2002). Aylward's involvement in Mediprobe (Rowe, 1998) - a company set up in the mid-1990s apparently whilst Aylward was on the board of the DSS Benefits Agency Medical Service, with Aylward's wife listed as director - was likely aimed at finding the 'right' practitioners for such a system. According to newspaper report (Rowe, 1998), the company existed to facilitate civil servant doctors in processing disability claims for insurance companies. These associations and influences set the stage for a social security system where claimant testimony is considered less valuable than the opinion of benefits assessors who, in many cases, are not medically trained.

State – academia associations

It is a matter of record that some academics have taken up roles as advisors to the UK government – officially and unofficially. Both Simon Wessely and Peter White are known to have had communication in the 1990s with various facets of the DWP or DSS as it was then - specifically the Disability Living Allowance Advisory Board (DLAAB) and Benefits Agency Medical Services, in which Aylward was involved (see Eliot Smith, 2015, for data from The National Archives). In letters to and from the DSS, both psychiatrists appear to be quite anxious that ME (here, separated from CFS) might be considered a source of severe and permanent impairment in the then forthcoming revised section of the DSS Disability Handbook. The handbook, a guide lead-authored by Aylward for benefits decision-makers with the advent of Disability Living Allowance in 1992, looked set to separate ME from CFS and position ME as a neurological condition. In a letter to Aylward, Wessely (1993) expresses concern over the positioning of ME (which he variously refers to as CFS/ME and CFS) as neurological, suggesting that this "represents the triumph of an effective lobby over scientific evidence" (note the parallels between this response and the backlash from some quarters to the revised NICE guidelines). Wessely suggests that if ME is to be considered neurological in origin, he will campaign for schizophrenia and manic depression (now known as bipolar disorder) to be considered similarly, adding:

> *"The main difference between CFS and the major psychiatric disorders is neither aetiological, nor symptomatic, but the existence of a powerful lobby group that dislikes any association with psychiatry."*
>
> Wessely, 1993

This 'anti-psychiatry' narrative has persisted to some degree in BPS discourse around ME/CFS and has found its way into the media (Wessely, 1990, 1994, 1997; Pemberton, 2011; McKie, 2011). Wessely continues that the DSS is sending out a "most unfortunate message" that "colludes with the erroneous belief that this is a severe disorder of neurological functioning" and goes on to remind Aylward of the costs involved in considering ME as such. This cost is clarified as the "ever increasing stream of claims for permanent benefits in people who might otherwise have had a chance of recovery" (Wessely, 1993). Since this purported recovery would be positioned as a result of interventions Wessely has helped to develop, considering ME (or ME/CFS) as a severe and permanent form of impairment would indubitably also cost Wessely's career dearly.

Wessely also presented his views on ME/CFS to government officials during a plenary session of the DLAAB at Richmond House, London, in November 1993 (Wessely, cited in McGrath, 1993). The plenary was attended by the then Minister of State, DSS, and Minister for Disabled People Rt Hon Nicholas Scott. Wessely was joined by Professor Peter Thomas, who worked at the Royal Free Hospital subsequent to the 1955 viral outbreak of ME, and who is on record as stating that this outbreak was in fact "mass conversion hysteria" (Thomas, cited in McGrath, 1993). Wessely is recorded as stating, among other things, that benefits "can often make patients worse" and that it is important not to position ME/CFS as a progressive or permanent disability (see also Faulkner 2016). During the plenary, both Thomas and Wessely are documented as downplaying biological factors (notably the suggestion of viral persistence) whilst emphasising psychosocial factors (despite lack of evidential support for the latter). Here, the beginnings of now dominant (bio)psychosocial discourse on ME/CFS are evident.

Peter White's documented communications with Aylward involve White's suggestion that the separation of ME and CFS would "enhance disability" and that CFS, his preferred term, has "rehabilitative treatments" available (White, 1993). These 'treatments' are of course CBT and GET, which Peter White has helped to develop. White elaborates on this 'enhancing of disability' by adding that "those who believe in the separate existence of "ME" believe this is a totally physical condition, probably related to immune dysfunction or persistent viral infection, for which no treatment is available" (White, 1993). Here, it can be reasonably suggested that separating ME from CFS and positioning ME as neurological would, from the perspective of White et al, remove ME from the reach of psychiatry and their favoured rehabilitation interventions, which would involve recognising the uneasy juxtaposition of severe impairment with no established treatment. Supporting this move would likely prove costly to White's career, alongside incurring costs to the government and disability insurance industry in terms of benefits and income protection. The subsequent move of power structures to refer to ME as 'CFS/ME' (CFS/ME Working Group 2002; NICE 2007/2018), combined with the disappearance of 'ME' in most BPS literature to leave the term 'CFS' (see Sharpe et al, 1997; Picariello et al, 2017), conveniently amounts to the erasure of ME as a discrete diagnostic entity, contrary to the World Health Organization's (WHO's) recognition of ME as a neurological condition as far back as 1969.

White's associations to the UK government extend beyond the DSS/DWP to include consultancy on ME/CFS for the Department of Health and Social Care (Select Committee on Health, 2007), having been involved in developing national guidelines on ME/CFS for the Department of Health (NHS Plus, 2006). White was also involved in the Chief Medical Officer's Working Group discussions on ME/CFS from 1998 to 2002 (CFS/ME Working Group 2002), but walked out part way through the process (along with Professor Trudie Chalder and other BPS advocates), apparently because the report looked set to stray too far from the BPS line (see Hooper & Williams, 2010). It is also noteworthy that the Chief Medical Officer's Working Group was part-funded by the Linbury trust, well-known for supporting research by Wessely et al, and with established links to the UK government.

Academia – corporate associations

Some BPS academics, notably in the field of ME/CFS and principally psychiatrists, are known for providing consultancy across a vast array of disability insurance companies on the alleged nature of ME/CFS and how it is purportedly amenable to psychosocial interventions developed by said academics (Select Committee on Health, 2007; Hooper & Williams, 2010; Marks, 2017). Prime examples, beyond Aylward's connections which have been touched upon, include Peter White's long-standing association with Swiss Re (reinsurance) and Michael Sharpe's association with Unum and Allied Dunbar. It is increasingly difficult to source first-hand documentation on such associations, not least because many URLs which once navigated to first-hand information now navigate to 'page not found'. It might be asked why webpages would be removed if such associations were not deeply compromising for those involved. However, some remaining sources have been preserved by patients through freeze page software or uploading copies of original documentation online. One particularly interesting source is a UnumProvident brochure (UnumProvident, 2002), to which both Sharpe and Aylward contribute.

In this UnumProvident publication, Sharpe refers to people with 'functional symptoms and syndromes' (yet another term for 'medically unexplained symptoms' which includes people with ME/CFS) as both patients and 'policy holders', whilst reiterating his view on ME/CFS, or CFS as he calls it, as a psychosocial entity to be 'treated' with his favoured interventions of CBT and GET (Sharpe, 2002). Sharpe also highlights the 'problem' that ME/CFS poses to the disability insurance industry and health services and rhetorically asks whether they can afford not to address this issue. (Note the parallels here with Wessely reminding Aylward of the costs involved in recognising ME/CFS as a disability). Sharpe demonstrates the typical BPS crossover from clinical to moralising yet empirically unsubstantiated judgements when he suggests that patients' beliefs may be "driven by anger and the need to explain continuing disability" (Sharpe, 2002 p.19), proposing the benefits system, insurance payments and potential litigation as "potentially major obstacles to effective rehabilitation" (note the inferred 'secondary gains'). Why this dual and conflicting relationship as insurance consultant and scientist-clinician is not considered problematical by Sharpe is unclear. It is somewhat akin to somebody with stakes in the sugar industry being involved in research on nutritional interventions for diabetes, yet there seems to be an almost universal lack of reflexivity within the BPS inner circle, and an apparent assumption that conflicts of interest are not a concern for eminent academics.

Insurance industry-academia links within this nexus were spectacularly played down when Peter White led a research team on the PACE trial (White, et al, 2011) part funded by the DWP with Aylward's assistance, with Wessely and Aylward on the Trial Management Group and Trial Steering Committee respectively. Michael Sharpe was a principal investigator along with Trudie Chalder, who has also done consultancy work for insurance companies (see White et al, 2011). The now infamous trial sought to prove the effectiveness of White et al's favoured 'treatments' of CBT and GET in the management of ME/CFS. Despite the PACE trial being debunked by a large portion of the patient and scientific communities as methodologically and ethically flawed (see Marks 2017, Journal of Health Psychology, Special Issue on the PACE trial; see also Tuller, 2018), and despite NICE (2020b) assessing the quality of evidence for GET and CBT in managing ME/CFS as low and very low, the BPS ideological brigades (to borrow Dr David Tuller's term) are acting like nothing ever happened. This is facilitated by comrades in high places in academic publishing (see ME Association, 2011) and not infrequently biased peer review processes. BPS hegemony persists, now with a threat of Long-COVID being annexed.

In the next and final section, I examine the downstream effects of upstream abuse of power and associated structural injustice.

4. Downstream effects of upstream abuse of power

"The privileged are simply less likely to believe claims about oppression when they come from those who actually experience it".

Nora Berenstain (2016). 'Epistemic Exploitation'. Ergo: An Open Access Journal of Philosophy, 3 (22) 569-590

Macro, meso and micro level phenomena are never fully separable, and pathways of influence may be both top-down and bottom-up. In this section I examine how macro socio-economic policies such as those pertaining to welfare reform, and other structural phenomena such as dominant BPS discourse, influence downstream healthcare and social policy and practice – alongside broader social opinion - through various channels. Again, I focus on ME/CFS as an analogue of broader chronic illness and disability matters.

Academic reach

ME/CFS academics within the academic-state-corporate nexus have worked at macro, meso and micro level within the healthcare system. Beyond their work for the government and disability insurance companies as previously detailed, such academics have also served as clinicians and clinical researchers as well as NHS advisors, contributors to clinical guidelines and clinical handbooks (see Hooper & Williams, 2010; Geraghty & Esmail, 2020). Some of these academics also developed a case definition of ME/CFS (or CFS as they like to call it) – Oxford Criteria (Sharpe et al, 1991) - that is so broad it risks selecting otherwise healthy individuals who present with the symptom of chronic fatigue or people with primary psychological conditions. Despite a good portion of the scientific community suggesting that the Oxford Criteria should be permanently retired, they live on and are typically used in BPS research which then informs practice guidelines. As previously touched upon, these academics have been the driving force in re-framing ME (recognised by the WHO as a neurological condition) into a psychosocial entity, albeit one with moralising overtones about patient character. Many of these academics and associates are prolific publishers in well-respected scientific and professional journals (journals whose editorial boards not infrequently include BPS proponents), including The British Medical Journal (The BMJ), which arguably informs as well as represents medical opinion. The BMJ, international research journal and member magazine of the British Medical Association, has historically appeared content to publish stigmatising pieces about people with ME/CFS (Godlee, 2011; Hawkes, 2011) and, it would appear, any illness that is poorly understood, poorly delineated and poorly treated (Smith, 2002). Finally, BPS proponents were involved in the development of a Royal College of General Practitioners (RCGP) training package on ME/CFS for healthcare professionals (METRiC) which was designed to school clinicians in conceptualising ME/CFS as a psychosocial entity (RCGP, 2012/2018). It would seem very reasonable to suggest that the ideology and interests of academics within the nexus have exerted an influence at every level throughout the healthcare system.

Healthcare, the Unum way

The disability insurance industry's influence (notably that of Unum) can also be understood as pervading all levels of the health system. UnumProvident stated that it promotes a "non-medical, enabling model of rehabilitation" (Select Committee on Work and Pensions, 2006), where 'non-medical' appears to equate to an empirically unsubstantiated psychosocial emphasis and 'enabling' approximates coercing.

Some of the Cardiff Centre's work during its Unum sponsorship was in the field of GP education and revision of sick certification (Waddell & Aylward, 2005; Select Committee on Work and Pensions, 2006; UnumProvident, 2006). Part of the idea was to encourage GPs to push chronically ill and disabled patients back into work with a scheme of GP incentives and sanctions. GPs were to be schooled not to collude with patients to reinforce illness behaviour, to emphasise the importance of work and to acknowledge conditionality - that receipt of benefits would only be a possibility once the patient underwent 'rehabilitative' interventions. At one point, Job Centre staff were stationed in GP surgeries as part of the Pathways to Work scheme that Mansel Aylward helped to develop. In the field of ME/CFS, some of the usual suspects have suggested that patients should try rehabilitative interventions (interventions that are not empirically supported) before they are considered disabled for benefits or insurance purposes (Sharpe et al, 1997).

Patient survey data (Oxcatts, 2019) shows that some people with ME/CFS have felt coerced into undertaking CBT and GET, in some cases resulting in harm, and apparently in some cases associated with such conditionality. This raises questions around freely given informed consent and wider clinical ethics. Such patient experiences should be situated in the wider context of harms associated with psycho-coercion and welfare conditionality in the UK and beyond (see Garthwaite, 2014; Stewart, 2019a, 2019b), where eligibility for benefits is increasingly conditional upon particular conduct, with similar conditionality being written into some income protection insurance policies. Nevertheless, Unum and the Cardiff academics were hopeful that the Unum way would produce a significant shift in health and social policy (UnumProvident, 2005; Rutherford, 2007a). Indeed, Chief Medical Officer at UnumProvident Michael O'Donnell suggested that government policy was largely driven by Unum thinking, and added: "It will not be many years before the rest of medicine follows our lead" (O'Donnell cited in UnumProvident, 2005, p.9).

The influence of Unum's philosophy of 'enablement' - which can also be observed in government discourse (see Faulkner, 2016) and in the Cardiff academics' work (Waddell & Burton, 2004, 2006; Waddell & Aylward, 2010) – is discernible within healthcare in the transition from sick note to 'fit note', more formally known as 'Statement of Fitness for Work'. The 'fit note', which came into force in 2010, was said to reflect the growing evidence that work is good for health, and focuses on what the patient can do as opposed to what they cannot do, allowing GPs and employers to facilitate a quicker return to work, or to obviate the need for sick leave altogether. Whilst ostensibly 'enabling', concerns have been raised regarding its practical application. For example, in 2017 it was reported by the Disability News Service that rules around fit notes and new claims for Universal Credit (rules not announced by the DWP) risked forcing chronically ill and disabled people into work-related activity whilst awaiting benefits decisions, even when issued with a fit note stating they were not fit for work (Pring, 2017).

Enablement philosophy is also evident in the ascendancy of psychosocial interventions (typically CBT and some form of graded exercise or activity) as primary 'treatments' for any chronic illness or disability that can be shoehorned into so-called 'medically unexplained symptoms' or a cognate diagnostic label. The 2007 NICE guidelines for the diagnosis and management of ME/CFS, recommending CBT and GET as 'treatments' (NICE 2007/2018) were underpinned by an implicit narrative of enablement and, perhaps unsurprisingly, were influenced to some degree by the Unum-sponsored Cardiff research centre's work: one of the centre's publications (Waddell & Burton, 2004) is referenced in the RCGP-published version of the 2007 NICE guidelines (Turnbull et al, 2007) in the context of the importance of work for health. A similar narrative is being extended to Long-COVID; for example, Professor Derick Wade (PACE apologist, Woodstock attendee, author of BPS literature and formerly of the Oxford Centre for Enablement) has authored papers and presentations looking at rehabilitation following Covid-19, advocating a BPS formulation of the patient's case and involving use of graduated exercise and psychosocial therapies (Wade, 2020a, 2020b). Further, Professor Kim Burton, co-author of some of the previously outlined DWP-commissioned research produced in collaboration with the Cardiff research centre (Waddell & Burton, 2004; Waddell & Burton, 2006), has been involved in health and social policy development in the realm of Long-COVID, notably promoting 'work-focused healthcare' (see Hunt, 2022e). Finally, BPS proponents in the field of ME/CFS have appeared keen to extend their ideology, where an implicit neoliberal philosophy of enablement can be discerned, into the realm of Long-COVID (Sharpe, 2021; Willis and Chalder, 2021; see also Hunt, 2022b). However, as independent researcher George Faulkner (2016) has pointed out, a narrative of enablement which promulgates an unduly positive conceptualisation of ill-health and associated purported path to recovery can actually have the very opposite effect to enablement, disempowering chronically ill and disabled people.

The fourth estate

As noted earlier, depriving chronically ill and disabled people of the financial support necessary to survive (through refusal of benefits and income protection payouts) requires mainstream complicity, and the same could be said for depriving chronically ill and disabled people of adequate medical care. In the case of ME/CFS, mainstream complicity with what I believe can reasonably be described as the institutionalised abuse of patients has been achieved in part through the UK press, which has historically represented people with ME/CFS very poorly, albeit with a few exceptions (Ryan, 2019). Interestingly, more positive coverage (O'Neill, 2020) of ME/CFS in a few instances has appeared since the emergence of Long-COVID. However, the dominant media narrative of ME/CFS has historically been one of a psychosocial entity with recurrent suggestion of malingering (Liddle, 2019), with ME/CFS advocacy framed as anti-psychiatry (Pemberton, 2011) and extremist (McKie, 2011; see also Blease & Geraghty, 2018).

Some of the academics in the academic-state-corporate nexus have associations with the Science Media Centre, which exists to provide the UK media with science and health-related news briefings and interviews. In *Magical Medicine: How to make a disease disappear* the authors state:

> *"Editors of broadsheet newspapers have confirmed that editorial policy will permit them only to publish items about ME/CFS that come from the SMC"*
>
> Hooper & Williams, 2010, p.73

If this is true, it would certainly explain much of the (mis)representation of people with ME/CFS in the UK press, the highly biased interviews with BPS proponents who are framed as heroic victims of patient abuse (McKie, 2011), and the backlash against journalist George Monbiot's impactful and sympathetic piece on Long-COVID and ME/CFS in The Guardian last year (Monbiot, 2021; see also Sharpe 2021). Given that some research suggests that clinicians may glean some of their 'information' about ME/CFS from the media (Chew-Graham et al, 2009) - presumably in the absence of adequate medical education - it might be asked to what extent clinical practice is influenced by a largely biased and misinformed UK press as opposed to sound clinical judgement.

More broadly, media coverage of chronically ill and disabled people has shifted in a stigmatising and scapegoating direction since the global financial crisis of 2007/2008 and the UK government's austerity measures, with some indications that this has shifted public perception (Briant et al, 2013); such shifts might go some way to explaining rising rates of recorded disability hate crime as previously noted. These are important considerations given the economic costs of the pandemic and the possibility of a new wave of austerity – how will these costs be recuperated, who will bear the brunt, and how will this be justified? I rather suspect that disabled and chronically ill people will again be primary targets, raising implications for how the emerging 'problem' of Long-COVID will be managed politically and clinically. Whilst the media has done little to represent disabled people in a respectful and accurate manner, it has also done little to expose some of the drivers behind the stigmatisation of disabled people. Mo Stewart (2019b) has pointed out that the UK press have been largely silent on Unum's involvement in welfare reform (which has also impacted on healthcare) since Jonathan Rutherford's piece for The Guardian in March 2008 (Rutherford, 2008). It may well be asked whether a publishing prohibition, similar to that inferred by Hooper and Williams (2010) in the context of sourcing for press stories on ME/CFS, also exists for media discussion of academic-state-corporate agendas - in particular given that these subjects are inextricably linked.

The human costs of structural injustice

The impact of an unaccommodating, if not downright hostile, health and social system on chronically ill and disabled people can be observed in patient survey data and qualitative research. In the case of ME/CFS, patients have suggested that fights with the benefits system add to the psychological, physical and financial burden of living with ME/CFS and that the stress of the benefits process can cause relapses (Drachler et al, 2009). Broader disability research indicates that disabled and chronically ill people feel dehumanised through the benefit system and that stresses of navigating this system impacts negatively on their physical, psychological and social functioning (Saffer et al, 2018). Healthcare experiences of people with ME/CFS (both from the perspective of patients and clinicians) have been well-documented (see Anderson et al, 2012): clear cases of negative stereotyping and stigma on the part of clinicians have been demonstrated (Raine et al, 2004; Chew Graham et al, 2009), with concordant felt stigma and associated distress on the side of patients (Dickson et al, 2007).

Most disturbing are cases of suicide amongst chronically ill and disabled people, which may well be related to the inadequacy and hostility of the health and social security system. As previously noted, welfare reform has been associated with rising rates of suicide amongst disabled people, whilst various studies have suggested an increased suicide rate amongst people with ME/CFS compared to the general population (Jason et al, 2006). My experience of working with people with contested and unsupported illness in therapy and clinical settings is that suicidal ideation often arises not from the illness itself, or from underlying depression, but from the distress associated with stigma, marginalisation, unacknowledged losses and dehumanisation, and a recent study by Devendorf et al (2020) appears broadly consistent with these observations. It is as yet unclear how the medical profession and broader scientific and political structures will frame Long-COVID; however, some sub-groups which lack specific and detectable organ impairment are clearly susceptible to psychologisation and politicisation, and as previously indicated there are signs that this is already happening (Willis & Chalder, 2021; Miller et al, 2021; Sharpe, 2021; Verveen et al, 2022).

My own experience, as a marginalised woman who has for decades been point-blank refused neurological investigations past routine bloods (despite my symptoms clearly indicating need for further investigation), suggests that some patients are literally left to rot by the healthcare system, and treated like a social pariah by the benefits system. Now mainly confined to bed, I lose consciousness on a daily basis, experience extreme insomnia, increasing visual impairment and regular episodes of paralysis, stop breathing in my sleep on the occasions I manage to sleep, and am in constant, usually very severe, pain - amongst a plethora of other debilitating symptoms. The NHS is still trying to convince me (or perhaps trying to convince itself) that this is a form of somatisation that can be cured with some psychoeducation and, of course, a spot of CBT. Having worked in the NHS, I am sadly aware that my case is not exceptional. Whilst this may seem literally incredible to those who do not have first-hand experience of the abuses occurring within our health and social systems, I think it can be explained through understanding the socio-political dimensions of the BPS model as it predominates healthcare and social policy, and the incredibly powerful complex of interests that can be defined as the academic-state-corporate nexus.

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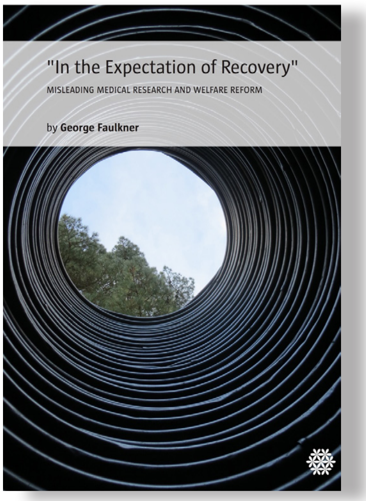

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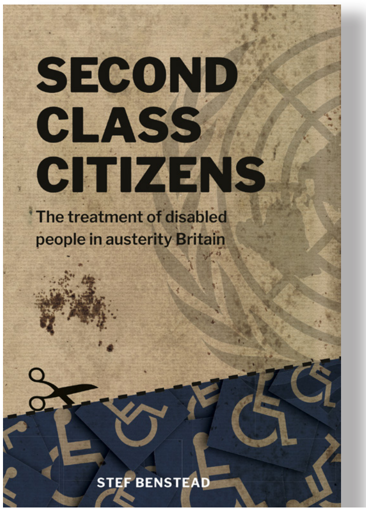

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