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# Gender, feminism and the project of critical disability studies (CDS)

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# Gender, feminism and the project of critical disability studies (CDS)

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#### ABSTRACT

In an era where basic 'rights' have been eroded on all fronts (e.g. income, employment, access, health and social care), we argue that acknowledgement of the contributions of disabled women, and collaborative action to improve the positions of disabled people in the academy is crucial. We highlight the need to understand how disabled women's contributions to the development of theory were pivotal to the development of theories of disability, not least in a synthesis of experiential approaches with those which focus on social barriers. We show how disabled women's contributions were fundamental to the specific development of Critical Disability Studies (CDS), but that they are increasingly excluded in current academic contexts. We discuss intersectional examples of disablism, and assess the value and inter-relationships of various feminist and Disability Studies/ CDS approaches, raising questions about how they could be harnessed in alternative ways, in service of campaigns for disabled people's rights.

#### **ARTICLE HISTORY**

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#### **KEYWORDS**

Critical disability studies; disabled women: scholarship; theory

# **Points of Interest**

- This article discusses the changing nature of disability scholarship. .
- We argue that disabled people should occupy greater places in • Disability Studies and Critical Disability Studies.
- We outline the importance to take a more critical approach to the everyday realities disabled people face.
- We argue that disabled women's contributions are being adopted but increasingly overlooked more and more by Disability Studies writers.
- We think that some current debates distract attention from the important issues currently faced by disabled people.

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• We are not seeking a return to 'nothing about us without us', an impossibility in both real and philosophical terms; we are advocating changes so that disabled people occupy more central places in research and scholarship on disability, impairment and disablism.

# Introduction

This article is rooted in the topic of gender, focussing particularly on the roles which feminism and disabled women have played in the development of Disability Studies and Critical Disability Studies (henceforth C/DS when used to denote both). When we look back over the history of Disability Studies (DS), it is clear that feminist critiques of disablement and the social model of disability have played a pivotal role in the evolution of C/DS, as Meekosha and Shuttleworth (2009), and Finkelstein (1996) have explained. Indeed, as Meekosha and Shuttleworth show, disabled women, feminists and disability studies scholars grappling with the dilemmas of intersectional approaches to disability and impairment, and particularly with gendered, embodied experiences of disablement, have been a major driver of theoretical, political and practical change, not least in the ways in which academics began to synthesise experiential approaches with social model concerns. Thus, disabled women can be seen to have played a crucial role in orientating us towards new directions for theory, much of which critiques the 'rather insular' nature of DS (Flynn, 2021, 11) and are attributed to the burgeoning body of work found under the aegis of Critical Disability Studies (CDS):

Feminist disability studies addressed questions of representation and difference and engaged with issues of identity, subjectivity, the body, sexuality and language. For example, stereotypical representation of disabled women in public imagery and the media contributes to their second-class status. (Meekosha and Shuttleworth, 2009, 59)

However, at this juncture, it seems to be something of a paradox that some of the forces (such as exclusion) which drove women's critiques of the social model (see Meekosha and Shuttleworth for example, 2009) are re-emerging in the current era, with little attention paid to the ways in which disabled women are marginalised within academia. Indeed, we are concerned that disabled women are becoming overlooked within C/DS, being something of an 'absent presence', in much the same way that Witz (2000) describes gendered bodies (specifically the excluded female body) within sociology. We examine the considerable risks of the disappearance of disabled women's voices from C/DS agendas, showing how the evolution of CDS, the changing character of Higher Education, and the continuing social marginalisation of disabled people pose considerable dangers to the access of disabled women to Higher Education. We believe that this will have profound implications for epistemologies of disability. In so doing, we discuss intersectional examples of disablism, and assess the value and inter-relationships of various feminist and Disability Studies/CDS approaches, raising questions about how they can both be harnessed in service of campaigns for disabled people's rights.

We begin our discussion with recent criticisms of CDS and its relationship to DS and the social model of disability, before using this as a basis to understand and recuperate the roles of disabled women within it, outlining the implications for C/DS knowledge in the future. However, we begin here by acknowledging and supporting ideas that Critical Disability Studies/Disability Studies, should be as intersectional as possible, engaging with axes of race, class, nationalism, colonialism, imperialism, age, and sexuality; indeed, a central concern is how to make it so. We also acknowledge that these strands of CDS were essential correctives to the 'normalising tendency' of social model accounts which predominated until the end of the 1990s (e.g. see Meekosha and Shuttleworth, 2009, 62). However, like Meekosha and Shuttleworth, we are wary of the ways these commitments can be used to subordinate one dimension of inequality to another and create further hierarchies and divisions, reinforcing the place of disabled people as the lowest priority on the social justice agenda. Although there has been work on DS/CDS which emphasises intersectionality, and blends both to excellent effect (e.g., see Flynn's 2021 synthesis of CDS with the affirmative model of disability), research and scholarship on intersectionality has often neglected disability, with Frederick and Shifrer (2019, 201) describing disability as 'the form of inequality that has received the least attention from sociologists'. Indeed, there is even a danger that the embedding of C/DS within a wider social justice agenda will continue to demote disability issues to the bottom. Despite disabled people's efforts to the contrary, and the expansion of work on disability to many academic disciplines, disability has never been perceived as a 'sexy' subject in academic fields. It is often the 'Cinderella' topic in the social sciences and humanities, and frequently approached in an individualistic manner rather than as a social concern (Wilde, 2018). We will suggest that the field of CDS is dominated by what Finkelstein (1996, 3) originally referred to as a 'passive' model (rather than an 'active social model') which militates against practical use in the promotion of disabled people's rights. As Finkelstein stated, 'actions following from this viewpoint are secondary to our experiences of discrimination' (ibid, 3).

There are a range of issues at stake (most of which are beyond the remit of this article), at a time where disabled people are bearing the brunt of austerity policies and the brutal inequalities of the pandemic. For us, these include: the potential re-emergence or strengthening of a personal tragedy model of disability; the disproportionate effects of poverty and disempowerment on disabled women; the relegation of disabled people to a fetishized academic gaze which effectively excludes them further; and the return of a

parasitic model of disability research (Oliver, 2017), which marginalises current and future disabled academics. It is the latter of these which concerns us here. As Meekosha and Shuttleworth (2009, 47) claim, 'The politics of knowledge creation is a critical dimension in the success of any social movement', underlining the centrality of academia in this movement.

This is at the heart of our concerns and is the starting point for this exploration of C/DS. We will go on to explore the role of disabled women in the development of CDS theory, and we will argue that there is a crucial need to remind ourselves of disabled people's roles in C/DS, raising questions about the perceived divisions between DS and CDS and how both can work together for change, a strategy also suggested by Flynn (2021).

### Critical disability studies, and disability studies: exploring the divide

Hall (2019), following Goodley, Liddiard, and Runswick-Cole (2018), and Meekosha and Shuttleworth (2009), argued that CDS 'responds to the traditional disability studies project by pointing to its limits, including exclusions and framing' (Hall 2019, para 29). It is suggested that chief amongst these gaps and constraints are the 'psychological, cultural, discursive and carnal' areas of existence (Hall 2019, para 28, citing Meekosha and Shuttleworth (2009, 50). But, as the following discussions show, these areas of investigation have been fundamental to DS itself, especially in scholarship by disabled women.

Objections to CDS are conceptualised along the lines mapped out by Vehmas and Watson (2014, 2016) and Sheldon (2014). They raise questions about the relevance of CDS work to the ethical and political issues facing disabled people during times of austerity. Vehmas and Watson's analysis of the deployment of concepts of normativity in 'postconventional disability studies' (2016) demonstrates how CDS tends to 'prescribe empirical description' in ways that exercise and support normative judgements, often in favour of the 'positive'<sup>1</sup> or 'productive potential' of disability (ibid, 13), despite simultaneously calling for 'non-normative and anti-establishment ways of living life' (e.g. Goodley, Lawthom, and Runswick-Cole 2014, 348). They show how this can also be 'negative' in prescribing a 'deprivation of possibilities' e.g. in the case of Harris (2001). Indeed, Vehmas and Watson argue that 'the concept 'normative' is often used confusingly and has become a synonym for 'normal', 'normate' or 'standard' in disability studies' (ibid, 3). Arguing against any ensuing ideas of empirical neutrality, they asked for a consideration of all aspects of disability and, in agreement with this, we argue that C/DS should consider less palatable experiences of disability, and re-centre disabled people's voices, without betraying celebrations of 'difference' (ibid, 14).

CDS has undertaken valuable work to deconstruct the binary distinctions that are used to 'create difference and hierarchies and obscure connections between disabled and nondisabled people' (Vehmas and Watson, 2014, 639). Doing so serves to emphasise similarities between people yet this may erode the cultural narratives of disabled people, representing them as 'bare life' (Reeve 2009). Unfortunately, this is also a move that can be used to deprive us of the identities which served as a foundation stone for collective resistance. Sheldon (2014) has raised significant questions along these lines, pertaining to the future of Disability Studies and its suitability for meeting disabled people's needs and concerns, including the impacts of growing epistemological tensions, the pressure from the academy for people to use CDS to build careers, and the disconcerting re-emergence of fascination with the disabled body.

In a similar vein, we contend that there is a series of significant difficulties with CDS which have become particularly urgent in the troubled times of 2023-4. We hope to initiate dialogue about building a useful framework for change, as Sheldon (2014) suggested. We can only skim the surface of these tensions, and we believe this should begin by acknowledging and planning for remedial action to reinstate disabled people within meaningful positions within C/DS, whilst recognising the need for discussion of gender and disabled women's experiences within the wider project of C/DS, Alongside a more critical intersectional approach to recruitment and inclusion in Higher Education (Wilde, 2022), perhaps the best starting point is an honest guestioning of the need for a divided Disability Studies. Here, we are referring to the division between Disability Studies and Critical Disability Studies, though at the time of writing this could also be extended to include Crip Theory and Cultural Disability Studies, and an emerging alternative proposed by David Bolt's 'autocritical disability studies' (Bolt 2020). Although this is positioned as a 'departure', it is founded upon a melding of CDS with autoethnography, predicated on contributors having 'direct or at least intimate individual experience of disability' (para 7). Indeed, Bolt states that 'the individual experience of disability is recognised and positioned as both start and finish' (para 9) of this enterprise. Similarly, we believe that his claim for the 'epistemological importance of disability experience' should be at the heart of all forms of C/DS and clearly visible in our academic community.

The division between DS and CDS is unclear at best. There are many scholars who align themselves with DS and the social model who use critical and poststructuralist theory, and intersectional approaches without dualistic thinking, whilst retaining their commitment to the production of knowledge that is useful for the betterment of disabled people's lives. Perhaps the only difference here lies in the ways in which DS scholars retain the commitment to the idea of a community of disabled people as a prerequisite for political and social actions. Certainly, there are many examples of feminist, and other, scholars using the approaches claimed by CDS for their own work whilst aligning themselves with Disability Studies and the social model, although there are many differences here in biases for and against different variants,

e.g. the relational model proposed by Thomas (1999), and early variants such as that proposed by Mike Oliver. Recent examples include St Pierre's brief exploration of the possible limits of critical phenomenological accounts which asserts that

Neoliberalism (but not only neoliberalism) constructs disabled people as buffers that suffer for the good of society. The subject of abeyance is made to endure and suffer privately like, to quote Tolkien, butter scraped over too much bread,

before going on to recommend more attention to the 'unravelings of lived experience in order to bear witness to the vectors of our becoming' (St. Pierre 2020, 32).

Similarly, Wilde's discussion of disability, comedy, and film (2018) is interdisciplinary and intersectional. This draws on poststructuralist and phenomenological theory, and theorists such as Deleuze and Bakhtin, fusing Disability Studies with Film and Cultural Studies approaches, emphasising the cultural value of disabled people as a central concern. Early disabled feminist commitments to disabled women's lived experiences of oppressive systems also informs Fish's (2018) ethnography of locked wards exploring the intersectional oppression experienced by women labelled as learning disabled who have been segregated from society.

Significantly, all these publications and practices 'hang onto more economically informed interpretations of disabled people's oppression in order to effectively draw links between disability and the capitalist mode of production' (Sheldon, 2009, 669-70). As such they advance theory, and question binary constitutions of difference, whilst retaining the capacity to inform strategies for change. They have the 'normative commitment' to disabled people's concerns and the production of useful knowledge at their centre. Just as St Pierre envisages disabled people as 'patients-in-waiting' (St. Pierre, 2020, 31) embedding personal pain/issues within wider structural/political contexts, our intention is to place the, oft-invisible, lived experiences of potential/disabled academics within wider academic contexts, all too often as 'academics-in-waiting', not to mention those who have simply turned away from a fight they feel they can't win. Just like the people who informed Gill's (2009) study of the 'hidden injuries of academia' our analysis has been informed by disabled people, women in particular, who have shared their pain over the years, especially in private places where there is less risk to their complaints. It would be deeply unethical to reveal such identities, and these narratives cannot be 'proven' of course: a vexed, if seldom acknowledged, problem for social research.

As Sheldon highlighted in 2014, 'there are possibly as many versions of disability studies as there are academics working in the field' (328). Sheldon was particularly concerned to emphasise the growing schism between those in CDS and scholars who they see as less academic, or anti-theoretical,

in their desire for politically informed resources for change. These might include those aligned more closely with the social model and critical realism, and their espousal of more overt aims to provide tools to benefit disabled people and the disabled people's movement. Like Shakespeare (2012), Sheldon was unconvinced of the political efficacy of CDS. In agreement with her view, here, we take up the calls discussed so far and extend them, asking for an urgent reconsideration of the 'ideological divide' and the mismatch between the theorising of disability in universities and the 'worsening conditions in which many disabled people are forced to live' (Sheldon, 2014, 331).

The deterioration of disabled people's experiences in austerity was a compelling enough reason to return to the positioning of disabled people's lives in DS/CDS, but the impact of the pandemic provided incontrovertible reasons to so do (Wilde et al., 2020a). While we would want close attention to be paid to all forms of intersectionality, as mentioned, the fundamental connections of class can easily be forgotten in the 'development' of theory that moves away from materialist analysis. Issues of income, access to work and welfare remain fundamental to those who bear the brunt of ableism/disablism. Indeed, despite some recent attention paid to austerity in the burgeoning corpus of CDS work, many of the biggest changes in many people's lives, before and during the pandemic, have ensued from policies such as (in the UK) the move from Disability Living Allowance to Personal Independence Payment, a topic which is seldom considered in CDS. There are noticeable exceptions here, such as the work of Mills (2018). Amongst a wider range of action-orientated work on disability and poverty, her article 'Dead people don't claim' delivers a blunt and crucial message which places disabled people's lives and deaths, and the need for welfare reform, as central. However, Dodd argues that the CDS analysis can be 'almost exclusively limited to the rhetorical or discursive aspects of the problem' (Dodd 2016, 158), and that this neglect of class and social structural issues can lead to 'misunderstandings and the tacit acceptance of pervasive myths' including those pertaining to individual blame. As scholars whose primary affiliation is to Disability Studies, this all-important issue of the immiseration of disabled lives plays the main part in our rallying call for change; and such analysis would need to place intersectional analysis at its core to understand the complex dynamics of the social relations of disability.

Chief amongst our concerns here are the effects on disabled women – which have been compounded by austerity and the pandemic (Day, 2020). Disabled women are amongst the poorest of the poor worldwide (which even women's magazine *Marie Claire* has reported (Seven, 2017)). Disabled women also face disproportionate disadvantage in the majority world, (Barnes and Sheldon, 2010) as well as occupying the lowest rungs of the economic ladder both in the United States (Bleiweis et al. 2020), and in the UK (Women's

Budget Group, 2018), where there has been an exacerbation of poverty for the high numbers of women claimants and carers, disabled women already having much lower rates of employment (Kim et al. 2019).

The remainder of this article sets such themes within the ongoing marginalisation of disabled people within Higher Education - C/DS in particular, and the contributions they make to a body of knowledge, posing questions about the direct relevance to disabled people's lives, and contending that disabled women are particularly at risk of losing their place within the production of disability knowledge. We begin by citing Garland-Thomson's statement on the value of Feminist Disability Studies and the experiences of disabled women, which has never been truer:

Because prevailing narratives constrict disability's complexities, they not only restrict the lives and govern the bodies of people we think of as disabled, but they limit the imaginations of those who think of themselves as nondisabled. Stereotypical, often unexamined narratives ultimately undergird exclusionary environments, employment discrimination, and social marginalization. Women with disabilities, even more intensely than women in general, have been cast in the collective cultural imagination as inferior, lacking, excessive, incapable, unfit, and useless (2005, 1567).

With these points in mind, we now reconsider the place of disabled academics in disability research - especially women, outlining some of the potential epistemological implications.

# Deaf and disabled women, and the development of disability studies

The acknowledgement of the crucial role of disabled people in past debates contrasts sharply with the place of disabled people in the C/DS contemporary landscape. In 2017 Mike Oliver invoked, for the second time, Paul Hunt's concept of 'parasite people' for the second time (he had previously presented a paper on parasite people at a University of Leeds conference in 1996) with the term denoting those who build 'their own careers on the backs of the struggles of disabled people to lead ordinary lives', this time used to refer to organisers from the Centre for Disability Studies. He was berating them for using the late Vic Finkelstein's name for the title of a lecture series without his family's permission, criticising what he felt to be their inappropriate choice of speaker. As part of this statement Oliver argued, 'not only must we make our own history, we must record it for ourselves as well otherwise it will not be ours' (Oliver, 2017, para 25). Significantly, Oliver equated the Centre with a non-disabled viewpoint at that time, despite its long history of disabled leadership and the continuing membership of disabled academics. One might easily deduce that the inclusion of disabled people is becoming less important in C/DS. This is a far cry from the principle embedded in the disabled people's movement when the Centre was established. At this point the Centre took its cues from disabled people's organisations (DPOs), i.e. those consisting OF disabled people (rather than being FOR them) which insisted on at least 51% membership of disabled people as an operating principle; this is still a principle upheld by many internationally (see Grills et al. 2020; People with disability Australia, 2018, for example). Here, and elsewhere, disabled people have been pioneers in the development of C/DS as a field, upholding similar values to DPOs (notable examples include Education at Syracuse University in the United States). Moreover, it has often been disabled women whose contributions have served to advance and improve the theory and scope of Disability Studies, partly because there was discontent about their marginalisation within activist circles and in the emerging field of Disability Studies.

Broadly speaking, most of the body of work which has focused upon gender, impairment and disability has, understandably, been undertaken in order to highlight disabled women's concerns, particularly those which are perceived to lie outside the ambit of the social model of disability and feminism. This body of work can be characterised by its emphasis on private worlds, e.g. interdependencies, ethics of care, relationships and psycho-emotional topics. Following such tendencies, a range of feminist perspectives were used to shift the emphasis away from the importance of the public, masculine, 'rational' world, towards the private, domestic, emotional sphere - common issues featuring in publications from disabled women after 1981. This influenced feminist activism (Fraser, 2008; Gillberg, 2020), and scholarship within gender studies and feminist pedagogy (Piepmeier et al. 2014; Rummery, 2020).

Edited collections of writing from disabled and Deaf women were common, such as those compiled by Campling, 1981, Fine and Asch (1988), Brown et al. (1985) and Saxton and Howe (1987). Morris (1996) drew attention to distinctly gendered experiences of impairment, such as highly gendered constructions of 'madness', and intersectional forms of racial prejudice (e.g. MacNamara, 1996; Vernon, 1996). Significant sole-authored publications include the work of Wendell (1996), Garland-Thomson (1996) and Thomas (1999). Alongside disabled men such as Abberley (1987), Shakespeare (1994) and Hughes and Paterson (1997), disabled women and feminists were at the forefront of those raising impairment orientated issues and concerns, arguing for the need to re-examine the social model.

However, these associations with the private and individual domains were often seen as cause for concern by those following early variants of the social model. There were fears about returning to the traditional association of disabled people with medical sociology and the 'medical model' (Finkelstein, 1996; Rae, 1996) which would weaken the more collective basis for organisation. Nonetheless, disabled scholars and activists were questioning the social

model's positioning of the binary between impairment and disability, which was seen to be similarly problematic as feminist conceptions of sex and gender (e.g. Shakespeare's discussion in Shakespeare [2006, 217]). This paved the way for disabled women (Thomas, 1999); and Reeve (2014) to develop theory on impairment effects, a relational model of disability, and the psycho-emotional aspects of disability, informing much that followed.

As suggested Marian Corker's (later Marian Scott Hill) work also played a significant role, especially her work on discourse, Deafness, and the diversity and complexity of disabled identities. She argued beyond/against the more simplistic idea of double discrimination for a more sophisticated, gendered analysis of disability and impairment. Corker also warned against the 'dys-appearance' of disabled bodies in academic work on disability, where 'disability in the collective sense disappears' (Corker, 1999, 77). Likewise, Simi Linton's (1998) contestation of epistemologies that relegate disability to the margins of knowledge also proposes that insights and models from disabled people and disability studies should be key to most curricula. This provided a key perspective on the disablism of academia.

In 2005 Garland-Thomson discussed a large body of selected 'representative' work undertaken by disabled women in her article on feminism and DS. Contemporary scholars will recognise many of the contributors she documented, such as Kittay, Thomas, Fine, Tremain, and Asch. Garland-Thomson called for a Feminist Disability Studies that rejects impairment-specific categories and instead examines the 'patterns of meaning' that imagine and construct us as 'defective and excluded from an equal place in the social order' (Garland-Thomson 2005, 1558). As an article which summarises the corpus of work from the mid-1990s to 2005, this remains valuable in tracing some of the origins of our current period of C/DS and including the contribution of feminist scholarship.

The work of Deaf and disabled women was significant within parallel developments in the 'sociology of the body'. Early post-structuralist and phenomenological accounts, including by scholars such as Shildrick and Price (1996), Corker, (1998), and Iwakuma (2002), have served, to some extent, to align women with 'experiential' perspectives, and to the sharpening of gender divisions along a political continuum within disability studies. By 1999 Carol Thomas had demonstrated an important consequence of this division - that disability and 'the personal' were effectively mutually excluded from one another. This has changed over time with the masculine/feminine, political/personal division transmuting from a gendered binary to one conceptualised along lines of a political/theoretical dualism. Whilst this can be seen as a form of progressive change in the evolution of knowledge, it has created a spurious political/theoretic division whilst serving to obscure gendered relations from our view, especially the contributions made by disabled women.

The role of disabled women and feminism in Disability Studies was always troubled, as Sheldon argued (Sheldon 1999), but there is little doubt that disabled

women's contributions to contemporary work on disability, sexuality, and gender was pivotal in the development of all models of disability. It is, for example, impossible to imagine the work of McCruer (2006) without this bedrock of disabled women's work. But again, caution should be exercised in what this means for C/DS paradigms. Bone, for example, argues that Crip Theory spurns the personal experiential roots of disabled scholars' lives. She claims that this serves to 'fracture' the disabled people's community, and 'silence [...] actual disabled experience' (Bone 2017, 1297) creating hierarchies based on 'crip visibility' (Bone 2017, 1309). She contends that Crip Theory has depoliticised theory further - rejecting Shalk's (2013) call for coalitional theory – and showing how Crip is used as a term of disidentification where a non-disabled person can claim a disabled identity. Bone also critiques Kafer's idea that claiming 'an identity that is not one's own, can be an effective tool in creating coalitions with other minority identities' particularly for those who want to resist 'normative ideas of personhood' (1303). Such moves to include all people in the disabled people's community raise concerns of where those with accredited impairments facing disablement fit: in resistance movements; within the social relations of research production; throughout the creation and dissemination of knowledge, and throughout the academy. Indeed, borrowing from Critical Race Theory, such a position can be interpreted as a form of 'interest convergence' (Bell, 1980) whereby people align themselves to a cause and declare common interests whilst benefiting more from such alliances (e.g. in the development of their own agendas or their careers), while the significant issues of the subordinate group recede from view. Shakespeare, like Sheldon, gets to the heart of the matter for many disabled people. In his criticisms of this vein of work, commenting on McRuer and Mollow's (2012) edited collection Sex and Disability (and anticipating the predominance of non-disabled authors in the collection) he said the book presented,

a confusing collage of ideas and concepts and readings, which seems unlikely to have even an indirect impact on the lived experience of disabled people (Shakespeare, 2012, 894).

Regardless of the issues which complicate the relationship of feminism and disability studies, or personal opinions on the value of work, it is becoming increasingly clear that the marginalisation of disabled people within C/DS is contributing to a body of knowledge which has less direct relevance to disabled people's lives, and women in particular.

# Disabled people in disability studies, contemporary disablement and disabled women

It is apparent that growing epistemological tensions, theoretic differences and political debates usually work to exclude or marginalise disabled women in Higher Education (however unintentional this may be), especially given

their wider social positions and the normativity of higher education institutions and funders (see Gill, 2009; Wilde et al. 2020b; Aspis, 2022, and the following pages). The propensity for the latter can be clearly seen in the case of the UK government's appropriation of recent theorisations of disabled people's identities and perceptions of their capacities for independent living and decision-making, e.g. studies of increased choice and control in personalisation policies since 2007. These have been easily shaped to fit within the harsher conditions of economic austerity and a severe rationing of services since the 2010 Coalition government exacerbated by Brexit and the pandemic (Rosken et al, 2021). Further, psycho-emotional theorisations of impairment and disability continue to be misappropriated in the UK, where the development of the bio-psychosocial model is still used to support the targeting of 'austerity' cuts on disabled people. An example is Jeremy Hunt's message that 'anyone choosing to coast on the hard work of taxpayers will lose their benefits', placing the blame for deeply disabling benefits and employment systems firmly on disabled people's attitudes (Disability Rights UK, 2023, para 8). As Debbie Jolly argued, extending the work of the psycho-emotional theory of Thomas (1999) and Reeve (2014), the government's regime of cuts needed to be understood in terms of their development of the bio-psychosocial model as a destructive new paradigm, which has to be opposed (Jolly, 2012).

In 2012, speaking of the attacks on disabled people, Jolly said that resistance to the new regime of welfare cuts imposed on disabled people is

... about recognising the imposition of a bio-psycho social model - a model that the Government and its partner companies use to provide a bizarre focus on denying disability, impairment and ill-health, each of which are being reconstructed as individual failings brought about by individuals adopting the wrong attitude - thinking yourself 'well'[14] is cheap - it's also impossible (Jolly 2012, para 3).

Since she wrote this, the erosion of disabled people's rights has continued apace. To use Jolly's words, we are now in a bizarre situation where C/DS is flourishing with interpretations of disabled people's lives, yet 'rights' have been eroded on all fronts. Neoliberal regimes have much to be gained from the misappropriation of disability theory, for example, dissolving the binary categories of disabled/non-disabled (and sick/non-sick) into a far more lucrative and controllable group of everyone. As St. Pierre has explained:

When standards of health and well-being are free-floating, are no longer indexed to social codes, the body becomes a site of ongoing biomedical improvement and optimization. And, as Sunder Rajan states, within the neoliberal age of Big Pharma, Big Data, and therapeutic dominance, we are 'patients-in-waiting' inevitably transformed into 'consumers-in-waiting' (2006, 144). Far more value and utility can be extracted from a body never-fully-well than from one normalized by the categories of ability and its pathological other. (2020, 31)

We need to be particularly alert to the ways in which C/DS discourses of disability and illness are easily appropriated or usurped by the regimes which oppress us, simultaneously robbing disabled people of the group identities which have been crucial to the fight for equality. This is an ethical concern for all of us in C/DS.

We are now perilously close to a complete re-emergence of a 'tragedy model' (foreseen in Corker's theorisation of the dys-appearance of the disabled body), one of the prime obstacles that Jolly and many other disabled activists and academics sought to vanquish. The pandemic ushered in a sense of urgency in dealing with the multiple and manifest impacts of the bio-psycho social model, accompanied with a deep sense of frustration that COVID-19 thwarted most of the scant opportunities we had for getting out and making our voices heard (literally). Put bluntly, the chances for activism were much reduced. With many disabled people shielding themselves from COVID-19 (a fifth were reluctant to leave their homes according to Young, 2020), and the continuing descent of disabled people into deeper forms of poverty and isolation in the aftermath of the pandemic (Joseph Rowntree Foundation, 2021), their cultural status is lowlier than we previously thought possible.

Many disabled people are fearful about their uncertain futures (Wilde et al. 2020b) and rightly so. Alongside the threats to their health and lives, the shriveling job market of 2020 provided an additional push in forcing people into precarious economic activity, with disabled people being the first to go in such a bleak economic climate. For example, a million disabled people had lost their jobs in the US by August 2020 (Allen Smith, 2020), and disabled people were twice as likely to lose their employment in the UK (Hill, 2020). Whilst this is not always the case in times of crisis (e.g. WWII), the increased risks of infection for many, plus the fears of a denial of life-saving treatments or resuscitation should they become ill, sits alongside clear perceptions of disabled workers as a bad risk for employers in an era where there are far fewer jobs (Jolly 2012). The management of risk and (economic and future) uncertainty are likely to play a significant role in the caution of larger employers, including universities, who are amongst the sectors where jobs have diminished (ONS 2020).

Gaining employment within the field of C/DS ought to be a realistic aspiration for disabled scholars, particularly as many other options have been closed down for those with 'underlying conditions'. However, there are currently few C/DS programmes in the UK, US or globally, and the competition for academic roles is intense (Anonymous Academic, 2018) with disabled people no more likely to gain a post in C/DS than any other discipline. There are no statistics available on this; however, this is a topic of great concern between disabled people in informal conversations and autoethnographic reflections (Griffiths, 2020; Rummery, 2020; Leigh and Brown, 2020). In 2020, Olsen, Griffiths, Soorienen and Porter used their own experiences to highlight these barriers, stating that 'current truth regimes in institutional arrangements

have gone unchallenged on an international level within academia' (Olsen et al. 2020, 272).

In addition, given the institutional norms of HE the number of disabled academics in C/DS is likely to decline further. Olsen et al showed how disabled academics are framed as 'costers' by HE institutions (Olsen et al. 2020) where a failure to allow potential disabled academics to fully demonstrate their knowledge and capabilities excludes them, blocking advancement. This point is also made by Shah (2018), who argues that

...as part of an accepted structure, these approaches often block our non-disabled colleagues from recognising the social injustices we face. Instead they are led to believe our lack of advancement is a natural and inevitable delineation between the capable and the incapable.

Academics might easily point towards the few exceptions of success for disabled academics who have 'made it' or might be flagged as being 'rising stars', but there are other 'hidden injuries' (Gill, 2009) to consider. These might include the pressures on disabled academics to conform to the meritocratic 'disability-blind' cultures and processes of HE, to accept any forms of tokenism extended to them to enhance others' reputations (Niemann, 2016), and therefore to adjust to the expectations of their patrons. There is also the danger of returning the majority of us to tragic or charity status, as Olsen et al. (2020) point out, a move which reinforces the super-cripple status of those 'wheeled-out' to show that disabled people can succeed, further obscuring the ableism/disablism of the academy (Dolmage, 2017).

Indeed, one could argue that the spectre of non-disabled academics dominating the field of C/DS is, somewhat ironically, a prime example of the kind of unacknowledged 'compulsory ablebodiedness' which McRuer theorised; further it might easily be argued that scholars such as himself are the epitome of the 'tolerant subject'. McRuer argued that liberation movements,

throw the successful heterosexual, able-bodied subject into crisis, but he or she must perform as though they did not; the subject must demonstrate instead a dutiful (and flexible) tolerance toward the minority groups constituted through these movements. (McCruer 2006, 18)

The position of individual academics as tolerant, even anti-oppressive, subjects doing good in the world of academic thought does little to change the demographics of C/DS, in a mediascape where performance of credible allegiances is likely to be seen as more important than institutional change. Further, the need for collective forms of resistance to intersectional forms of discrimination in HE is clear in the accounts of disabled academics, including Olsen et al.'s narratives (Olsen et al. 2020) and Shah's account of her experiences (Shah 2018), e.g. in showing considerable barriers to entry and how easily disabled people are 'knocked off' the career ladder when they begin to ascend. The situation many prospective disabled academics will find themselves in is one of lifelong delays in gaining qualifications and jobs, meaning that many will enter their careers much later, patterns which are complicated further by those who have fluctuating impairments and those with caring responsibilities (with women remaining as the major providers of care), combined with the ageism of the academy (Whitbourne and Montepare, 2017).

As Shah suggests, 'successful' academic careers are ended early in HE for most disabled academics, supported by the perpetuation of unfavourable contracts and meritocratic ideologies; e.g. the 'upward curve' as primary measure of value, and research award systems that reproduce structural advantage, those who fit the academic ideals (measured in normative stages of early or mid-career, and so on). If disabled staff manage to cling on despite this, there is still the threat of the annual redundancy practices that many universities now take as an institutional norm (Bhattacharyya, 2019); disabled and older people are the most likely to be seen as the preferred wastage in the name of the academic game of restructuring and lowering operating costs (Shaw, 2020). Again, women are affected disproportionately; recent research has shown that women are one of the primary groups who have borne the brunt of pandemic troubles in the UK and US (University of Cambridge, 2020).

When Gill (2009) 'broke the silence' about the 'hidden injuries' of academia, and the disproportionate effects of these harms on women, this was without any specific reference to the experiences of disabled women, or how institutional barriers and impairments/impairment effects (Thomas, 1999) intertwine with academic norms and obstacles to entry, inclusion and progress. As Gill has suggested of women in general – disabled women remain 'secret and silenced in the public spaces of the academy' (Gill 2009, 229), a position exacerbated further for women who face other aspects of discrimination, such as racism or ageism (see Shaw, 2020 for example). But disabled women are far from reticent when they speak of their exclusion in private; these conversations include the common complaints expressed informally within academic interstices, e.g. in confidence at conferences and in social media conversations, discussing barriers to recruitment, subordinate or exploitative involvement, and the domination and gatekeeping of non-disabled people in HE. As invisible as this discontent may be to non-disabled academics in C/DS (in a climate where speaking out on oppression would put the nail in the coffin of a career in HE), Brown and Leigh's article (Brown and Leigh 2018) shows a clear hunger for support for disabled women in academia, in describing how a support group opened and 60 women joined in less than twenty-four hours.

This issue of disabled women's employment is seldom covered in CDS, reflected in the lack of attention in academia overall. Like Disability Studies alongside it, disabled women are ready and willing to contribute to C/DS,

but experience far more barriers in doing so. Barriers include the usual cultural bias towards white male academics (Reid and Curry, 2019), a lifetime of acculturation as subordinate, as women, as disabled, some as potential mothers, and as disabled women. As suggested, they are a group within the academy who have pitifully low levels of employment (HESA, 2020); this is not to speak about the multiplicity of restrictions that most women (disabled and non-disabled, and any who identify as neither) face by dint of their gender roles (designated, perceived, inculcated, enacted, performed, even refused) if they are fortunate enough to gain entry. For many disabled women this is likely to be exacerbated by difficulties of combining an academic career with motherhood or parenting with intersectional barriers to mobility due to 'the perception that academic life precludes personal preferences about where to work and how to live one's life' (Wolf-Wendel and Ward 2006, 516).

Shaping Our Lives, an organisation of disabled people, has often spoken of the need for the 'ownership' of Disability Studies by disabled people, echoing common debates from the past about the role of non-disabled people as allies. Although this is often interpreted as co-production and 'user-led' research, little critical discussion has taken place on how a greater number of disabled academics play in creating the 'ownership of Disability Studies' by disabled people. Whilst many would argue that this goal of 'ownership' is likely to promote false dichotomies of non-disabled and disabled people, Branfield's hotly contested call (Branfield 1998) for the recognition of a group identity and a central position for disabled people (as a political statement based on collective resistance to oppression) seems especially urgent in an era where disability studies has burgeoned yet most disabled people are likely to remain on the peripheries.

Given the discussions so far, it is clear that the position of disabled women in HE is precarious and invisible at best; and there is little evidence for us to estimate the impacts and potential effects on disabled women. Not only is this a matter of concern for those who are marginalised, excluded and exploited, including the disabled students who would like to follow them, it also begs questions about epistemology in terms of acknowledging the marginalisation of disabled women and keeping these issues on the agenda.

# Conclusion

As identity politics and the struggles for recognition evolve, we have argued that the relationship of theories of disability to the improvement of disabled people's lives has become fraught. Growing epistemological tensions, theoretic differences and political debates have shifted away from direct political usage towards the prioritisation of theoretical concerns. There are a range of issues at stake, such as the re-emergence of a personal tragedy model, the return of a parasitic model of disability research, and the relegation of disabled people to a fetishized academic gaze which effectively excludes or marginalises current and future academics.

We have shown how the contributions of disabled feminist scholars to C/ DS have been overtaken in the pursuance of CDS theory, how this has worked to de-personalise and de-politicise the field as well as reducing opportunities for collectivisation. Consequently, we have grave concerns about the dys/appearance of disabled bodies in CDS. We believe that without a critical examination of the roles that disabled people play within the academy and, most significantly, in the epistemological development of CDS, the use of the term Disability Studies becomes a misnomer, threatening us with the spectre of a return to the dominance of 'parasite people' (Oliver, 2017). We need to ask critical questions about how and where disabled people, especially women, occupy and move through this terrain and what the future implications are of a discipline which has abandoned any guarantee of the inclusion of disabled people at the level of research and analysis (especially beyond fixed-term contracts and co-production), including how this will affect future disability scholars. We also need to ask about how this will inform the specific area of work on gender and where disabled feminist critique might fit within future theoretical developments. We urge C/DS to examine what is at stake in the development of our discipline, who it is populated by, how disabled people can reterritorialize (Deleuze and Guatarri 1987) within the discipline they founded, and how we can take a more meaningful role within disability research and teaching. Crucially, we need to ask how our scholarship can be used to combat ableism, and ultimately improve disabled people's lives.

# **Disclosure statement**

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