

PERSPECTIVES

Disability and Gender: Reflections on Theory and Research

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ABSTRACT This paper reviews theory and research on disability and gender from a UK perspective. It reflects upon the theoretical perspectives and debates that are to be found in UK disability studies today, and considers their relevance for research on the gendered nature of disability. Themes in empirical research are noted, as is the representation and treatment of disability in mainstream feminism(s). The paper warns about the danger of exclusion through nominal inclusion.

Disability studies has a particular meaning in the UK. It is a discipline anchored by the social model of disability, though the model and its theorization of disabled people's oppression is endlessly debated. Within disability studies, I am known for conceptual work on the nature of disability as a form of social oppression, and for my writing on the gendered realities of living with disability, both materially and psycho-emotionally. As a feminist writer, I have drawn explicitly on my own and others' personal experiences of living with impairment and disability. In this paper, I share some reflections on current understandings of gender and disability – particularly on women and disability.

Celebrating Gains Made

In recent decades, and on a global scale, disabled people and their allies have achieved a great deal in the struggle for civil rights, equality, and social inclusion – motivated by the growth in understanding that disability is about social exclusion. Gains are reflected in anti-discrimination legislation in many countries – though we know that such legalistic provision varies markedly in its clout and reach that it has. In the UK, the social model of disability has been of tremendous significance in driving change – a model based on the radical social interpretation of disability introduced by disabled activists such as Paul Hunt and Vic Finkelstein in the 1970s. Expressed very simply, the social model suggests that limitations on activity experienced by disabled

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people are *social* in origin (*not* attributable to impairment as the medical or “individual” models would have it) and constitute a form of social oppression – let us call it *disablism* (Thomas 1999, 2004a,b). As a social phenomenon, limits on activity imposed by disablism can be removed through social change.

However, acknowledging the advances made internationally does not disguise the enormous amount that remains to be done if full inclusion and equality is to be achieved – especially in the majority world. The position of most disabled people remains dire in resource-poor countries – they are among the most economically and socially disadvantaged groups in those communities that know only degrees of material deprivation.

The Gendered Nature of Disability

Deprivation is particularly true of disabled women in such circumstances (Abu-Habib 1997, Stone 1999, Priestley 2001). Whether we consider the gains already made by disabled people or the distance that is yet to be travelled toward full social inclusion in any part of the world, then we find that disabled women are in a relatively more disadvantaged position than disabled men. Research in many countries has established that disabled women and girls face additional disadvantages when compared with disabled men and boys in all social arenas: in securing independent living, in employment, education, healthcare, social care, housing, transport, land-ownership, access to cultural domains, and so on. Indeed, the forms and impacts of disablism are invariably refracted in some way through the prism of the gendered locations and gender relations that pertain in spatial and cultural settings.

It is feminist writers and activists in the disability arena who have drawn attention to this: Jenny Morris, Sally French and the late Marian Scott-Hill (mainly published under the name Corker) in the UK, Rannveig Trausta-dóttir, Kristjana Kristiansen and Karin Barron in the Nordic countries, Adrienne Asch, Simi Linton, Rosemary Garland-Thomson, Susan Wendall and Shelley Tremain in North America, and Helen Meekosha in Australia – to name but a few. They have shown that the social forces and processes that construct and give shape to both gender *and* disability are closely intermeshed.

This intermeshing has come through clearly in my own narrative-based research with disabled women (Thomas 1999, 2001). These women tell their stories with reference to the gender norms that make up their social worlds. That is, whether or not disabled women’s own lives follow conventional gender pathways – and they often do – they construct their narratives with explicit or implicit reference to public discourses about “what it means to be a woman” – weaving their narratives around the themes of partnerships, motherhood, family, household responsibilities and caring. Other researchers have found the same to be true of disabled men in relation to masculine gender norms – though less research has been carried out in this area. Indeed, recent interest in masculinity and disability is very much to be encouraged.

Of course, when we add other dimensions of social exclusion and “difference” into the equation – “race” and ethnicity, sexuality, age and class – then the picture becomes more complex. Disablism intersects with racism, homophobia, ageism and socio-economic stratification to generate intricate webs of disadvantage and exclusion. This gives rise to multiple and intertwined strands in our identities, and warns against bracketing disabled women – or men – into undifferentiated or fixed social groupings. This complexity is now reflected in titles such as “feminist disability studies” and “queer disability studies”.

Turning to Theory

Thinking in these areas – as on any theme in disability studies and politics – is assisted by the ongoing development of radical disability theory – to which I now turn. What developments can we observe on the theoretical terrain in disability studies in the UK?

The relatively rapid growth of disability studies in the British academy in the last 15 years, centred on the social model of disability, has been accompanied by the diversification of theoretical perspectives within the discipline. Social interpretations of disability have been taken in contrasting directions by materialist, feminist, post-structuralist and phenomenologically inspired scholars. However, I would suggest that this diversification is underpinned by the crystallization of disagreement along the contour lines of an old philosophical divide: whether one is for or against foundational premises.

Two theoretical approaches dominate. First, materialist perspectives: the founding force in UK disability studies, associated with the work of Mike Oliver (1990, 1996) and Colin Barnes (1991, Barnes, Oliver & Barton, 2002). These perspectives are far from static, and have developed in new directions, for example through my own materialist feminist contributions (Thomas 1999, 2004a,b). Second, post-structuralist perspectives – whose growing influence in disability studies reflects the late 20th century “cultural turn” in sociology, feminism, and cultural studies more generally. Feminist writers, such as Marian Scott-Hill (Corker 1998, Corker & French 1999, Corker & Shakespeare 2002) in the UK and Shelley Tremain (2005) in the USA, have been important champions of post-structuralism within the discipline. Let us briefly review these dominant theoretical perspectives.

Marxist and materialist scholars advance theorizations of disability and disablism as outcomes of the ways in which society organizes its fundamental activities – especially, but not exclusively, activities in the economic domain (Gleeson 1999). The roots of the social marginalization and spatial segregation of men, women and children with impairments are located in the historical development of capitalist commodity production and exchange. These socio-economic developments are seen as giving rise to social relationships between those deemed “normal” and “impaired” that systematically disadvantage and disempower the latter. Key to these social relationships are systems of “treatment and care” that subject disabled

people to professional control, especially medical jurisdiction, and enforce their dependency – through institutional regimes *and* systems of “community care”. Materialists have been sensitive, however, to the charge that their approach ignores or attaches insufficient significance to the role of cultural practices in shaping disablism. They have argued, in response, that attitudes, discourses and ideological representations are of great importance in the construction of disability – though there is an insistence that the cultural dimensions of disablism are themselves materialized through the social practices that are required to meet basic needs. Importantly, the materialist world-view grants disabled people the individual and collective capacity to resist exclusionary practices – to exercise their agency and resist disablism.

In contrast, post-structuralist theorizations focus on the cultural, the discursive and the linguistic. Materialism’s emphasis on the economic is rejected, as is its so-called modernist grand narrative on the distinction between disability and impairment – something I shall return to in a moment. Attention has also been paid to the application of Foucauldian thinking to the historical and contemporary disciplining and regulation of people constructed as “disabled” by systems of bio-power – especially systems associated with medicine and state welfare. Foucauldians have been sensitive, however, to the charge that their approach renders disabled people politically passive in the face of discursive practices and other technologies of bio-power – that is, that disabled people are denied agency. Foucault’s later writings are invoked in an insistence that resistance is possible.

Impairment

The meaning of the category “impairment” is a persistent theme in theoretical debate in UK disability studies. The split between disability (social) and impairment (biological) introduced by early social modellers has been defended as crucial by some and attacked as problematic by others. Discussion is now plentiful and rich on how to theorize impairment *per se* and on the relationship between the impaired body, disability and disablism. Indeed, it would now be inaccurate to say that UK disability studies ignore impairment or “the body”.

Post-structuralist writers who draw on Foucault and Derrida have demanded the reformulation of “impairment” in purely socio-cultural terms (Corker & Shakespeare 2002). The distinction between impairment and disability at the heart of the social model of disability is viewed as an unsustainable version of the out-moded Cartesian nature/society dualism. It is argued that each side of any Cartesian binary divide – “normal” versus “abnormal”, “society” versus “nature” – is socially constituted and can only come into being through explicit or implicit reference to its opposite. This turns the spotlight on the work that dualisms do in constituting and fixing the “impaired” or “disabled” as “other”. The deconstruction, or transcendence, of modernist dualistic thinking has remained at the heart of post-structuralist projects in disability studies (Corker & Shakespeare 2002, see also Tremain 2005).

In contrast, thinkers whose theoretical points of departure are materialist, realist or phenomenological have not been able to accept the post-structuralist proposition (however varied in its presentation) that impaired bodies are nothing other than social or discursive constructions. Rather, bodies are thought to have *real* or mind-independent – “pre-social” – material qualities that are *overlaid* with social meanings and interpretations. My own ongoing work on the concept “impairment effects” represents an attempt to develop a non-reductionist materialist ontology of impairment and “the body”. Taking another path, phenomenologists, such as Bill Hughes and Kevin Paterson (1997), have argued for a focus on the lived experience of both impairment and disability, drawing on the ideas of Merleau-Ponty. And, following Liz Crow (1996), feminist activists continue to demand that the *experience* of living with impairment and disability is fully acknowledged.

However, social scientists, *all* agree that biological reductionism is to be avoided at all costs.

Where is Gender in All of This?

Despite the influential role that feminists have played in these theoretical debates and developments, I would suggest that we have yet to see the full unfolding of the ideas that have been amassed for the theorization of gender and disability *per se*. In other words, while publications on gender and disability stimulated theoretical development and diversification in the 1980s and 1990s, the gendered character of disability and impairment has yet to be revisited – in full – in the light of this new thinking.

For example, much remains to be achieved by materialist feminists in their analyses of the political economy of disability and systems of care. Theorizations are required on the significance of gender in relation to patterns of employment and labour market mechanisms, on standards of living and access to material resources for independent living and personal assistance, on state welfare systems and “care” services, on parenting and the normative character of familial and sexual relationships, on the cultural practices and ideological systems bound up with economic and reproductive systems. Moreover, Foucauldian inspired historical and contemporary studies are needed on the gendered features of the exercise of bio-power – in medicine and the “welfare” and “care” sectors. However, post-structuralist feminists, inspired by Judith Butler and others, have yet to resolve the difficulties that arise when categories such as sex and gender are thoroughly deconstructed. The problem is that it ceases to be legitimate to explore the lives of “disabled women” because this category, like “women” itself, becomes a discredited modernist construct.

These observations are not to suggest that feminist research and writing has been completely in abeyance in recent years. On the contrary, feminist researchers in the UK and elsewhere who have not allowed themselves to be too weighed down by theoretical baggage and deliberation *have* got on with studying and writing about the gendered realities of daily life with disability and impairment. Their work is notable for its “real world” qualities, its focus

on the experiential, and its acute sensitivity to “difference”, diversity and the multiple dimensions of identity.

The book *Gender and Disability Research in the Nordic Countries* edited by Kristjana Kristiansen and Rannveig Traustadóttir (2004) is a good example of this, and is much to be welcomed. It explores gender themes associated with: daily living, education, employment, friendship, “race” and ethnicity, family and parenting, sexuality, mental health, intellectual disability, and violence and abuse. Examples in the UK include Jenny Morris’ empirical and policy-related research projects on the lives of disabled children (1997), and on independent living (1993, 2004). Others have begun to engage with the gender dimensions of the moral challenges of the day: genomics and bioethics, assisted suicide, and abortion (see Asch 2001, Kerr & Shakespeare 2002) – themes of burning interest and concern to disabled women and men.

Psycho-Emotional Dimensions of Disability

One research theme that I introduced some years ago concerns the *psycho-emotional dimensions of disability*. A number of researchers have found this useful and have taken it up. This is a form of disablism that works with and upon gendered realities; it operates along psychological and emotional pathways – and frequently results in disabled people being made to feel worthless, useless, of lesser value, unattractive, a burden. It is present when disabled people find themselves having continuously to manage negative and discriminatory social reactions and behaviours at an interpersonal level, and when they encounter layers of degrading images of themselves in the media, art and other cultural discourses. It is also often present in interaction with parents, teachers, health professionals, social workers or complete strangers – when disabled people confront words and actions that undermine their self-esteem and personal confidence.

In this way, limits are placed on who disabled people *can be* by the shaping of individuals’ inner worlds and social behaviours. This interacts with social barriers that restrict what disabled people *can do* – “out there” – in the “public” arena. Limitations on what we *can be* and what we *can do* fuse together in a toxic disablism mix. If disabled individuals are isolated from one another – as they often are – then mounting *resistance* to this toxic mix is extremely difficult. But resistance has become possible through the self-organization and collective struggle of disabled women and men, and through the winning of allies and supporters among non-disabled people.

Psycho-emotional dimensions of disablism only come to light if we learn from feminism and refuse to allow disability studies to replicate the “public-private” or “personal-political” divide that is so evident in academic and public debate. By reasserting the adage that “the personal *is* political” we are able to recognize the disablism that operates in numerous ways in the realms of “the private” and “the personal”. The research agenda ceases to be focused *solely* on analysing social barriers in the so-called public sphere “out there” – in employment, education, housing, transport, and so on – critically important though these are.

Mainstream Feminism(s)

This brings us, finally, to the relationship between feminist disability studies and mainstream feminism – or, more accurately, *feminisms*. This relationship continues to be an uneasy one. In the 1980s and early 1990s, disabled feminists found themselves “shut out” of the wider sisterhood (Thomas 1999). The 1970s women’s movement – and the feminists who rose to prominence in its wake – tended either to ignore disability completely or actively distance themselves from disabled women. The trouble was that, from their point of view, disabled women’s “weak” and “dependent” status detracted from attempts to present women as strong and independent.

One example of this “shutting out” in the UK was mainstream feminist research on the “community care” developments in health and social care in the 1980s and early 1990s. This produced a body of work that objected strongly to the British Government’s extension of community care “for dependants”, following the closure of long-stay institutions. Mainstream feminists argued that more community care would mean the exacerbation of women’s oppression, because the euphemistically named “care in the community” really meant unpaid care by women in the family: it was women who would have to give up paid work to pick up “the burden” of caring for “the old” and “the disabled”. In approaching the matter in this way, mainstream feminists in the UK identified entirely with the interests of women *as carers*, completely ignoring the interests of disabled and older women – who actually made up the majority of the so-called “cared for”. Feminists did not notice that by so doing they bought into, and reinforced, prejudicial ideas about disabled people being dependent burdens. In response, disabled feminists such as Jenny Morris (1991, 1993, 1996) advanced strong criticisms of these disablist identifications and exclusions. Their criticisms have had an important impact. In response, many mainstream feminists have taken note and rethought their positions on care, and on disability in general.

Of course, this growing recognition and appreciation of disabled women has been greatly assisted by the wider celebration of “difference” within feminism. Disability has, at last, won *something* of a presence on the feminist agenda. If you look at recent feminist textbooks, for example, the likelihood is that you will find some reference to disability in their coverage, and there are other signs that disablism is recognized alongside sexism, racism and homophobia.

However, I would suggest that disabled feminists must be aware of the danger of tokenism here, and of the possibility of a second type of exclusion – what we might call *exclusion by nominal inclusion*. Simply including disability in a list of discursively constructed differences will sell disabled women very short indeed, because much more sustained analyses of the social and gendered character of disability and impairment – both culturally and materially – is required.

Summary

The key points in this paper can be summarized as follows:

- UK disability studies has witnessed theoretical diversification in recent years, a process in which feminists have played a crucial role.
- Materialist and post-structuralist theoretical perspectives now dominate, with feminist thinkers taking a lead role in developing post-structuralist disability studies.
- However, the application of these theoretical perspectives to further developing our understanding of *gender and disability* has not yet caught up – much remains to be done. Post-structuralists face particular difficulties here, because their opposition to dualistic thinking – in this case the men/women, masculine/feminine dualisms – destabilizes the very project of examining gender differences.
- Feminist researchers who are not so weighed down by theoretical baggage *have* got on with researching and writing about the gendered realities of daily living with disability and impairment. Important research has been published in recent years. Nevertheless, the research agenda remains a long and complex one.
- Feminisms in the mainstream are paying more attention to disability as a dimension of difference among women; disability features in feminist texts and conference programmes more frequently. However, we must be wary of a potentially new form of exclusion: *exclusion by nominal inclusion*.

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