

British disability studies: Moving on and with the social model*

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Introduction

This paper draws and explores some key contemporary debates in British disability studies. First, we will explore models of research in disability studies. Second, we will consider the place of impairment. Third, we will ask questions about the potential for disability studies to include and represent all disabled people. Fourth, we will conclude by thinking about disability studies as a trans-disciplinary arena.

(1) Researching disability

Individualising moral and medical models of disability have historically dominated the lives of disabled people:

Goodley (2010) Figure 1.1. Two dominant perspectives of disability (as) impairment

adapted from Olkin (2001, 2002, 2009), Barnes and Mercer (2003), Oliver (1996) and Goodley (2000)

	DISABILITY AS A MORAL CONDITION	DISABILITY AS A MEDICAL CONDITION
Meaning	<i>Disability is a defect caused by moral lapse or sins. The reification of sin or evil, failure or a test of faith. Includes myth that as one sense is impaired by disability another is heightened, i.e., the blind seer.</i>	<i>Disability is a medical problem that resides in the individual – a defect in or a failure of a bodily system that is inherently abnormal and pathological. Impairment and disability are conflated. i.e., the Down Syndrome child.</i>
Moral Implications	Shame to the person with the disability and their family. The family must address their immoral nature as evidenced through the presence of a disabled family member.	Repudiates the view of disability as a lesion on the soul but may blame person or family for health care habits (e.g., Type A personality leads to heart attack) and promulgates view of disability as a personal tragedy.
Sample Idea	God gives us only what we can bear. Example: Gaelic plaque: “May those who love us, love us. And those who don’t love us, may God turn their hearts; and if he doesn’t turn their hearts may he turn their ankles so we’ll know them by their limping.”	Patients are described clinically (e.g. ‘patient suffers from Trisomy 21 / Down syndrome’ or ‘there is an incomplete lesion at the C4 level’). Isolation of body parts and view of PWD as atypical, abnormal and pathological.
Origins	Oldest of all disability models but, arguably, still the most prevalent world-wide.	Mid-1800s onwards. Underlies most rehabilitation facilities and most rehabilitation journals in rich countries.
Goals of Intervention	Spiritual or divine or acceptance. Increased faith and forbearance. Finding meaning and purpose in affliction.	Patients or clients are expected to avail themselves of services offered by trained professionals with the promise of cure (the amelioration of the physical condition to the greatest extent possible); rehabilitation (the adjustment of the person to their condition) or adjustment (adjust to live as a PWD).
Benefits of Model	Acceptance of being ‘selected’ to have a disability, feeling a relationship with God, having a sense of greater purpose. Some impairments understood as evidence of spiritual embodiment (e.g. pure simple child).	Promotes faith in medical intervention, a defined patient role and offers a label as explanation. Medical and technological advances in key services of the welfare state have improved the lives of PWD.
Negative Effects	Being ostracized from family and community, feeling profound shame, having to hide disability symptoms or the person with a disability. Disability exposes sinful (past and present) lives of family.	Paternalism, pathologisation and the promotion of benevolence. Interventions <i>on</i> PWD rather than <i>with</i> . Promotes research by outsiders and services for but not by disabled people.

These ideas have also influenced research *on* disabled people, often carried out *by* non-disabled people, which have contributed to deficient understandings. Linton (1998a: 531) argues that:

The overwhelming majority of scholarship on disability either utilises or implies the third person plural: ‘they’ do this, ‘they’ are like that, ‘they’ need such and such. This contributes to the objectification of disabled people and contributes to their experience of alienation.

Alternative models of disability, posed by disability studies, have brought with them contrasting approaches to research:

Goodley (2010) Figure 1.2: The minority and social barrier approach (incorporating the affirmation model) to disability studies adapted from Olkin (2001, 2002, 2009), Oliver (1996), Gabel (2006), Brandon (2008)

	DISABILITY AS MINORITY POLITICS (STATES AND CANADA)	DISABILITY AS SOCIAL BARRIERS (UK)
Meaning	<i>People with Disabilities (PWD) constitute a minority position in society, like people of colour, who are devalued, stigmatised, discredited and discounted. ‘PWD’ comprise a minority group that has been denied its civil rights, equal access and protection.</i>	<i>Disability is a social construct. People with impairments are oppressed/disabled by society: they are disabled people (DP). Primary impediments are discrimination, social isolation, economic dependence, high unemployment, inaccessible housing, and institutionalization.</i>
Moral Implications	Society has devalued and marginalised disabled people to confer minority status. PWD are only offered peripheral membership of society.	Society has failed DP and oppressed them through barriers that prevent access, integration and inclusion to all walks of life including work, education and leisure.
Sample Idea	The politics of PWD. ‘Nothing about us without us’, ‘Not Dead Yet’, ‘Access Now’, ‘You gave us your dimes, now give us our rights’, campaigning for anti-discriminatory legislation. ‘PWD and proud’.	The politics of DP. ‘Nothing about us without us’, ‘Piss on Pity’ ‘Civil rights, not charity’, campaigning for anti-discriminatory legislation. ‘DP and proud’.
Origins	Early 1900s, disappeared until 1975 protests in Washington DC and San Francisco, demanding that the 1973 Rehabilitation Act was signed. Intellectuals with disabilities (e.g. Hahn, 1988a; Charlton, 1988) followed impact of Goffman (1963) and Black civil rights movement.	Post 2 nd World War, DP’s organisations. Disabled intellectuals (e.g. Hunt, 1966; UPIAS, 1976; BCODP and DPI, 1982; Oliver, 1990; Barnes, 1991; Morris, 1993a) with strong adherence to (Neo-Marxist) materialist accounts of disability.
Goals of Intervention	Political, policy, economic, educational and social systems; increased accessibility of places and services; broad systemic change; development of Centres for Independent Living; disability arts. Promote positive sense of disabled self.	Political, policy, economic, educational and social systems; increased accessibility of places and services; broad systemic change; development of Centres for Independent Living; disability arts. Promote positive sense of disabled self.
Benefits of Model	Promotes integration of disability into self. Focus on how world disadvantages PWD. Sense of belonging and involvement in a disability community. Disability pride.	Promotes integration of disability into self. Focus on how world disadvantages DP. Sense of belonging and involvement in a disability community; disability pride. Clear distinction between social barriers (which can be changed) and impairment (which cannot).
Negative Effects	Feeling powerless in the face of political and economic odds. Need for strong self-advocacy skills. Blurring of impairment and disability.	Feeling powerless in the face of political and economic odds. Need for strong self-advocacy skills. Lack of acknowledgement of the effect of impairment on everyday life.

Goodley (2010) Figure 1.3: The cultural and relational models of disability adapted from Davis (1995, 1997, 2002, 2006b), Garland Thomson (1997), Mitchell and Snyder (1995); Snyder and Mitchell, (2006); Tøssebro (2002, 2004); Traustadóttir (2004a, 2006a).

	DISABILITY AS CULTURAL CONSTRUCTION (STATES AND CANADA)	DISABILITY AS RELATIONAL (NORDIC)
Meaning	<i>Disability is a construction of culture and modes of production, in ways that provide metaphorical crutch for the constitution of 'abled'. Disability can only be understood in relation to 'the normate', normalcy and ableism.</i>	<i>People with disabilities are disabled through dynamics relationships of body/mind and the environment. Disability is created through three relational processes (i) the person-environment mis/match (relationship/relational); (ii) Disability is a situational or contextual phenomenon and (iii) Disability is a relative construct.</i>
Moral Implications	Cultural re/production constitutes disabled people as mere carriers of information and passive recipients of hegemony that is founded on the ambitions of 'able' people.	Disabled people are excluded from communities, services and professional practices because of a mismatch of expectations, biological needs and environmental opportunities.
Sample Idea	Deconstruction and ideology critique of film, novel and media. Reconstructing disability histories, identifying disability fantasies and offering 'crip' alternatives.	Slogans, services and practices associated with 'Empowerment now', 'Label Jars not People', 'Community-based workplaces not segregated employment'.
Origins	1960s onwards, emerging out of minority group and social models through dialogue with cultural and literary critiques and the areas of feminism, queer and postcolonial critique. Key writers include Davis (1995), Garland Thomson (1997), Mitchell and Snyder (1995)	1960s roots in normalisation principles - the community resettlement of disabled people outside of institutions and the development of expansive, responsive forms of welfare. Open minded to pan-national models of disability studies. (e.g. <i>Scandinavian Journal of Disability Research</i> , 6, (1), 2004).
Goals of Intervention	Destabilise cultural performances of dis/ability and ab/normality; promotion of disability arts and subculture; subvert liberal arts agenda which often excludes disabled people. Disability is renamed as a site of resistance that critiques 'the normate' and 'the abled'.	Political, policy, economic, and social systems; increased accessibility of places and services; broad systemic change; development of Centres for Independent Living; normalisation and inclusive community living; an ordinary life.
Benefits of Model	Sense of belonging and involvement in a disability community; disability pride; promotion of critical faculties in relation to the normate culture. Disability is a site of phenomenological value not purely synonymous with the process of social disablement.	Sense of belonging and involvement in a disability community; disability pride. Promotion of empowering professionals and self-advocacy informed services.
Negative Effects	Feeling powerless in the face of cultural hegemony. Lack of explicit engagement with disability activism, professional practice and service delivery. Over-emphasis on cultural construction rather than political marginalisation.	Lack of distinction between impairment and disability might re-insert a medicalised view of the disabled body and mind. Over-emphasis on professional practice and service delivery and lack of engagement with disabled people's organisations.

Theorists from a relational model, for example, study the complex fit between impairment and environment. Cultural theorists ask questions about ideology in the

constitution of disabling society. Social model thinkers demand changes to the structural exclusion of disabled people. In this section, I want to ask questions about the meaning of social scientific research. Following a close reading of the literature, in our introduction, Goodley and Lawthom (2005b) teased out a number of common questions asked by disability studies researchers:

Inclusion – to what extent does research include disabled people?

Accountability – who are disability studies researchers accountable to?

Praxis – does disability research make a positive difference in the lives of disabled people?

Dialectics – how is disability research impacting upon, and is influenced by, the social conditions in which it is carried out?

Ontology – whose knowledge and experiences count?

Disablism/ impairment – does disability studies research focus on understanding disabling society or the meaning of impairment?

Partisanship – whose side is the disability researcher on?

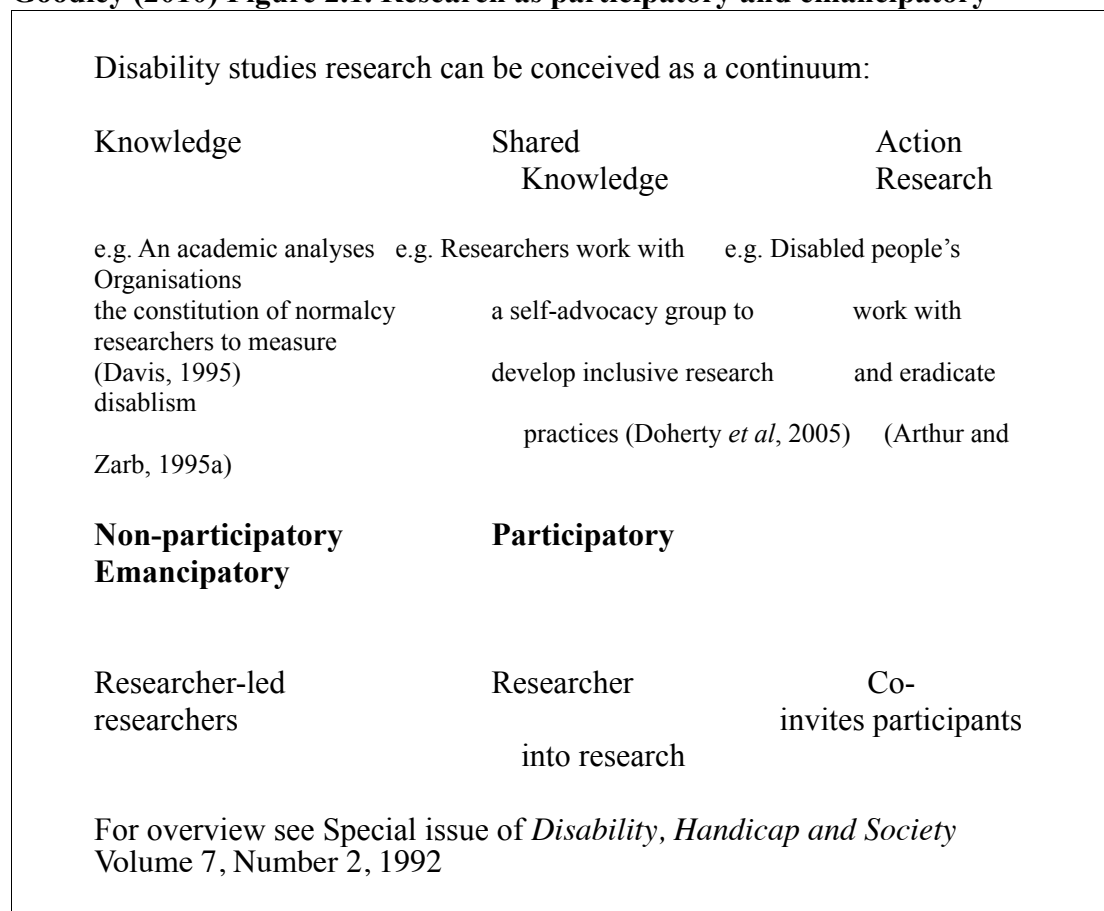
Analytical levels – does research investigate politics, culture, society, relationships or the individual?

Clearly there is not enough space here to visit all of these debates and not all disability researchers will have these questions in mind (see instead Taylor and Bogdan, 1984; Skrtic, 1995; Atkinson and Williams, 1990; Morris, 1992; Zarb, 1992; Stone and Priestley, 1996; Oliver and Barnes, 1997; Barnes and Mercer, 1997; Moore *et al*, 1998; Barton and Clough, 1998; Priestley, 1998; Goodley *et al*, 2004; Kristiansen and Traustadóttir, 2004; Van Hove *et al*, 2008). We will, though, consider three areas of contention.

Research by whom, with whom and for whom?

As disability studies developed alongside the growing politicization of disabled people then this raised questions about ownership, involvement and applications of research, depicted by figure 2.1:

Goodley (2010) Figure 2.1. Research as participatory and emancipatory



Each of these three positions is captured well in the exchanges of Barnes (1996), Shakespeare (1997b) and Oliver (1998). Barnes's position is one aligned to the right of the continuum. He argues that researchers must work with disability organisations and develop user-led research with and for disabled people. Social model research aims to contribute to the politics of disability: by unearthing and challenging the structural exclusion of disabled people, thus enhancing the 'catalytic validity' of research (Law, 2007). Shakespeare (1997b) provides an alternative account. He argues that while he remains personally accountable to many of the aims of disabled people (and their organisations), research can be academic; developing theory that can be used for those with emancipatory visions. He argues that researchers should, of course, be mindful of the application of their ideas but should not be apologetic about developing new theories. For Shakespeare, the researcher can lead research as long as s/he keeps in mind that the aim of disability studies is theorising and tackling disabling society. Shakespeare is open to any theory that has utility. Oliver (1998) intervenes in an interesting way. While aligned with the position of Barnes, he worries about the exploitative tendencies of researchers who, led by an interest in capturing the experiences of disabled people, develop their own academic careers rather than the ambitions of disabled people. He argues, 'this raises the uncomfortable question of whether disability researchers are 'shitting' disabled people when they write about

experiences that they have no access to, save through their own research techniques' (Ibid: 187). Instead, Oliver proposes, disability researchers need to change the social and material relations of research production in order to make research worthwhile. Yet, perhaps akin to the position of Shakespeare, Oliver himself concludes that his own attempts to promote emancipation in research have failed (while his own career has blossomed). While it has been argued that many disabled people are unwilling to actually contribute to emancipatory projects (Kitchin, 2001: 67), Oliver asserts that unless research works with disabled people towards their goals and ambitions then it will fail to be nothing more than an academic endeavor; a time of waste and a waste of time (Oliver, 1992). Oliver (1998: 188) argues that a new epistemology for research practice must reject the discourse that sustains investigatory research and replace it with a discourse of emancipation.

(2) Impairment and diversity in disability studies

As you will have picked up on, splitting impairment and disability allowed many scholars – especially those in the British social model camp - to turn their attentions away from the personal tragedy model of impairment to the public problems of disablism. The distinction severed the link between the body and disablism. However, for some researchers and activists, there are real dilemmas in ignoring the importance of impairment.

The 'reality' of impairment

Some disabled scholars responded to the severed link by publicly reflecting on their personal experiences of impairment. Disabled feminists such as French (1993), Crow (1996) and Morris (1992) were heretical in their attempts to articulate their experiences of impairment. Of course society was disabling, they argued, but impairment effects such as pain, inability and tiredness were also a disabling in their own right. These views sparked outrage:

Writers like Jenny Morris have elevated the importance of personal psychological experience in understanding disability. Such work encouraged a shift away from thinking about the real world. Finding insight in the experiences of discrimination is just a return to the old case file approach to oppression, dressed up in social model jargon (Finkelstein, 1996: 11)

Similarly, Barnes (1998) dismissed impairment talk as 'sentimental biography', which was preoccupied with the medical details of a particular condition. Impairment talk creates conflict. This word symbolises social death, inertia, lack, limitation, deficit and tragedy. It references an individualised phenomenon, the currency of medics and other rehabilitation related practitioners, hardly the focus of critical researchers engaged with the socio-cultural conditions of disablism. The 'absent presence' of impairment in (British) disability studies has been a key focus for Shakespeare and Watson (e.g. Shakespeare and Watson, 1997, 2001a, 2001b; Watson, 2002; Shakespeare, 2000; 2006). In one of these pieces Shakespeare and Watson (2001a) argue against the policing of debates by some disability studies academics, such as Barnes, who now use the social model as a rigid shibboleth. This strong social model, they argue, has outlived its usefulness and therefore should put to one side so disability studies can start again. The social model has bracketed impairment in similar ways to the denial of biological difference by feminists in the 1970s. They argue that impairments are important because some are static, others episodic, some

degenerative and others terminal. They conclude that a social model can only explain so much before we need to return to the experiential realities of ‘impairment’ as object(s) independent of knowledge (Shakespeare, 2006a: 54). Impairment *is* a predicament and *can* be tragic. Meanwhile, back in the rest of the (minority) world, impairment talk is less fraught. As we saw in chapter 1 (Goodley, 2010), Nordic relational theorists share interactionist views of the impairment and disability dynamic. Yet, how impairment is conceptualised has huge implications for questions about quality of life, reproductive decisions and debates around the right to die (chapter 7, Goodley, 2010).

Impairment and culture

The severed link has also been criticised for casting a simplistic understanding of impairment as natural and biological. Critics suggest that impairment is far from being natural and more an embodied experience shaped by culture (Jung, 2002; Hughes and Paterson, 1997, 2000; Hughes, 1999, 2000, 2002a, 2002b, 2004; Paterson and Hughes, 1999; Hughes and Paterson, 2000). Abberley (1987), for example, was an early critical voice about the atheoretical impairment label that had been left by UPIAS (1976). His solution? To call for a sociology of impairment alongside a sociology of disability: ‘a theory of disability as oppression [that] recognises and, *in the present context, emphasises the social origins of impairment*’ (Abberley, 1987, in Barton and Oliver, 1997, p176, my italics). Donaldson (2002), Thomas (2004) and Gabel (2004) all challenge what Meekosha (1998: 175) describes as the dangerous problem of leaving the impaired body as untouched and unchallenged: a taken for granted fixed corporeality. Marks (1999b: 611) goes further to suggest that the social model’s marginalisation of the personal experiences of impairment actually contributes to the maintenance of the individual model of disability. By excluding a discussion of impairment from an analysis of disability, a theoretical vacuum is left, which is filled by those who adopt an individualistic and decontextualised perspective (such as medics):

‘**IMPAIRMENT:** is the functional limitation within the individual caused by physical, mental or sensory impairment (DPI, 1982) definition:

There is something inherently medicalised and individualised about this definition. Instead, Marks (1999a) adds (following Abberley, 1987), we need to consider impairment on a number of levels including when and where an impairment was first discovered; perception of and the in/visibility of the impairment; the severity of the impairment and the standards against which that severity is judged; whether or not having an impairment provides a base for the development of positive identity formation and social group membership; the relative stability and fluidity of impairment. As soon as we start thinking through the meaning, experience, treatment and enactment of the impaired body or mind we begin peeling away the socio-cultural layers of these phenomena. Impairment is understood by the words we use to describe it. And the words or discourses we use are socially mediated. It might be possible to say there is no body or mind outside of discourse (chapter 7, Goodley, 2010). Moreover, the very ‘fact’ of impairment cuts to the flesh and bones of what it feels to be in our bodies and heads. As we consider in chapter 6 (Goodley, 2010) our bodies are felt in relation to others: what Marks (1999a: 129) defines as the phenomenology of the body. Impairment evokes deep psychological feelings about minds and bodies. The psyche is made through the cultures in which we develop. Impairment, we could

argue, is made by institutions, such as schools, which define children through the use of a growing array of scholastic labels. The concept of impairment is predicated on the notion that some bodies/minds are flawed and others are not. And those that are not are deemed to be autonomous, able and capable. We can only know impairment in relation to that which is upheld. The meaning of impairment is culturally constructed because bodies/minds have histories, are experienced, performed and institutionally located. Finally, minds/bodies can only be understood as raced, gendered and sexed which intersect to further complicate the ‘fact’ of impairment.

Impairment effects

Thomas’s (1999) notion of ‘impairment effects’ has been highly influential in British disability studies. Thomas (2008: 16) argues that disability studies need to further develop social theories of disablism and impairment inspired by the social relational ideas of founding fathers such as Finkelstein (1981) and Abberley (1987). In any real social setting impairment and disablism are thoroughly intermeshed with the social conditions that bring them into being (Thomas, 2007). The ways we feel the ‘realness’ of our bodies – the materiality – are felt in the dynamic interplay of self and the social world. While Shakespeare and Watson (2001a) appeal to the biological realities of body, Thomas calls for a more dialectical analysis of impairment and disablism, well captured in Ghai’s (2006: 129) definition that ‘impairment like disability should be a signifier of not just society’s response to impaired bodies but also to illustrate how these bodies are shaped materially and culturally’. Thomas (1999) suggests that the pain of impairment is often only felt during times when ‘restrictions of activity’ (UPIAS’s definition of disability) are imposed on people with impairments. Hence impairment is felt at the same time as disablism. These impairment effects capture impairment as a ‘socially embedded and embodied phenomenon’ (Ghai, 2006: 149). A realisation of the embeddedness of disability in impairment adds to an understanding of the complexities of a disabled person’s identity (Ibid: 52). For as Ghai asserts, ‘to negate ontological reality would imply that every issue connected with disabled existence could be resolved with a change in social conditions’ (Ibid: 53).

Divisions and differences

Watson (2002) asks an important question: if disabled people do not see themselves as disabled then do disability studies have anything of relevance to say to them? The vast majority of disabled people are ‘non-politicised, marinated in a disabling culture and identify themselves with repressive individual models of disability’ (Finkelstein and Stuart, 1996: 176). Watson’s question raises three related queries. First, is the question of identification. Clearly, people will differ in the marks of identity that they prioritise. Gender, ethnicity, age, class and sexuality might be as, or more important than, disability and we will address the issue of diversity in chapter 3 (Goodley, 2010). Who is to say that disability is the ‘master signifier’ of one’s identity (Shakespeare, 2006b)? Identity work is often more complex than the essential binary difference of disabled/non-disabled (Sherry, 2006). Second, is the question of why people do/not identify as disabled? This requires us to interrogate culture, society and politics for possible answers. Third, is the question of representation, can disability studies address the ambitions of all disabled people? While disability can be a source of pride it also recalls a history of shame. People with the label of intellectual disabilities, for example, set disability studies a number of challenges including making research more inclusive; theoretical ideas more accessible and fully

representing their activism as it is enacted in the international self-advocacy movement (e.g. Chappell, 1992; 1998; Chappell *et al*, 2000; Boxall, 2002a, 2002b; Boxall *et al*, 2004; Doherty *et al*, 2005). Questions remain about how scholars understand ‘intellectual disabilities’. Goodley (2001) argues that historically British social model writing has risked viewing intellectual disabilities in terms of deficit – as an organic impairment of intellectual functioning, social incompetence and maladaptive functioning – because of the uncomplicated essentialist notion of impairment left by the original UPIAS (1976) distinction. This is acknowledged by Aspis:

People with learning difficulties face discrimination in the disability movement. People without learning difficulties use the medical model when dealing with us. *We are always asked to talk about advocacy and our impairments as though our barriers aren't disabling in the same way as disabled people without learning difficulties.* We want concentration on our access needs in the mainstream disability movement (Quoted in Campbell and Oliver 1996: 97, my italics).

Pat Worth, a Canadian self-advocate, expresses similar misgivings; ‘People see our disability only, they don't see our ability. We may have a handicap but *we're* not the handicap (Quoted in Yarmol 1987, p28, italics in original)’. This explains the self-advocacy movement’s preference for People First language: emphasising their humanity over the pathological labels that they have acquired (Gillman *et al*, 1997). If, by contrast, their ‘intrinsic handicaps’ were tacitly assumed then one would expect disability studies to remain unconnected to their lives. Similarly, as Beresford and colleagues have argued, disability studies (at least in Britain) have been largely unresponsive to the activism of survivors of mental health systems (Beresford and Wilson, 2002a, 2002b; Beresford *et al*, 2002). Survivors have been involved in different fights to those of other disabled comrades. Following Chamberlin (1990) and Sayce (2000), the survivors’ movement can be characterised by three main historical projects. Firstly, the rejection of dehumanising ‘mental illness’ labels assigned through arbitrary, unsystematic and oppressive forms of ‘scientific diagnosis’. Their fight for humanity shares similarities with comrades from the self-advocacy movement. Secondly, survivors have challenged the practice of, what Rose (1989) calls, the *psy-complex*: those human service and welfare institutions and assemblages of knowledge that have contributed to practices and treatments associated with ‘the abnormal’ (see chapter 5, Goodley 2010 and Parker *et al*, 1995). Thirdly, the multiple positions of ‘madness’ suggest an ever more complicated relationship with impairment that that nominally described in some of the disability studies literature. Madness can be a positive identity, a state of rebellion, a call for help and /or a manifestation of cultural impotence and political constraint (Donaldson, 2002). The extent to which disability studies respond to diverse requests and ambitions remains an ongoing debate.

(3) Conclusions: Disability studies as a trans-disciplinary space

Tackling the debates raised above requires us to think across the social sciences. It is possible to view disability studies as a *transdisciplinary* space which breaks boundaries between disciplines (Thomas, 2007) and creates in-roads into disciplines that have historically marginalised disabled people such as medical sociology

(Thomas, 2007), philosophy (Kristiansen *et al*, 2009) and psychology (Nagi, 1976; Olkin and Pledger 2003). Disability studies might be seen as *paradigm busting*: subverting the normative tendencies of academic disciplines, testing respected research encounters and challenging theoretical formations. Disability studies continue to theoretically develop in ways that can and should encompass the ambitions of all disabled people. The social, cultural, minority and affirmation models provide philosophical and political resources from which a whole host of social theories and forms of activism can be developed. Disability studies populate an arena in which social theories of disability and impairment can be developed to promote the inclusion of all disabled people in mainstream life.

Reference

All references can be found in Goodley, D. (2010). *Disability studies: An interdisciplinary introduction*. London: Sage.