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Disability: getting it "right"

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This paper critically engages with Tom Shakespeare's book *Disability rights and wrongs*. It concentrates on his attempt to demolish *the social model of disability*, as well as his sketch of an "alternative" approach to understanding "disability". Shakespeare's critique, it is argued, does British disability studies a "wrong" by presenting it as a meagre discipline that has not been able to engage with disability and impairment effects in an analytically sophisticated fashion. What was required was a measured presentation and evaluation of the rich mix of theoretical and empirically based ideas to be found in the discipline, as the groundwork for forward thinking located within a social oppression paradigm. Shakespeare's undermining of the discipline's credibility in the eyes of outsiders and newcomers represents a diversionary missed opportunity by an influential writer and activist.

Shakespeare's book[1] has certainly stirred up debate, and invited a flurry of angry reviews, in disability studies (DS) in the UK—the social science discipline that has been developing radical ideas about disability and disablism since the 1980s. Peopled by both disabled academics and like-minded non-disabled researchers and writers, the DS community recognises that Shakespeare's book seeks to deliver a fatal wound to what he sees as its sacred cow: the British social model of disability.

Shakespeare explains that what he calls the "strong" version of the social model of disability was formulated by Michael Oliver, a leading DS writer and disability activist, on the basis of the social and political ideas advanced in the 1970s by a group of disabled individuals fighting to free themselves from what they experienced as an oppressive care system that relegated and segregated people with serious impairments to residential institutions and to the category of the unemployable.[2][3] In short, the social model asserts that "disability" is not caused by impairment but by the social barriers (structural and attitudinal) that people with impairments (physical, intellectual and sensory) come up against in every arena. The social model views disabled people as socially oppressed, and it follows that improvements in their lives necessitates the sweeping away of disablist social barriers and the development of social policies and practices that facilitate full social inclusion and citizenship. This "problem and solution" perspective has fuelled the British disabled people's movement's political programme and informed the research agenda in DS for the past three decades. Many would agree that the results have been very impressive, albeit partial and incomplete—for example, anti-discrimination legislation in the form of the Disability Discrimination Act (1995,

2005), "direct payments" arrangements and widespread attitudinal change in favour of inclusion.

AN ATTACK ON PARTISANSHIP

Shakespeare's rejection of the social model of disability generates impassioned controversy because his stance represents a political, and indeed fundamentally ethical, intervention that, at least potentially, strikes at the heart of something more important and valuable than any "this or that" social scientific definitional formulation of disability. His rejection can be read as an attack on an avowedly "standpoint" perspective, one that eschews neutrality, though not objectivity, in theory, research and policy. The social model is partisan; it is "on the side" of disabled people and seeks to further their common sectional and individual interests, their social and political equality and their full civil rights. Whatever the limitations and lacunae of the social model may be, it is its partisanship that is really at issue in the controversy surrounding Shakespeare's book. As we shall see below, his "alternative" idea is that "disability" occurs when there is an interaction of "individual" and "social" factors. Although it may not be Shakespeare's intention, this shifts disability to purportedly neutral epistemological territory. By dislodging "disability" from its moorings in a social oppression paradigm, the book causes deep disquiet among disability activists and DS scholars, because it opens the door to, and begins to hint at, an as yet ill-defined rapprochement with "medical model" and "individual model" thinking. The latter rest upon, or favour, biological reductionist explanations of disability, explanations that view disability as caused entirely, or principally, by bodily impairment. Such explanations are accompanied by an emphasis on "care" services and rehabilitation. This "full circle" overture leaves a very bad taste in the mouths of many in DS and the disabled people's movement.

WHAT ARE THE SOCIAL MODEL'S FAILINGS?

Shakespeare devotes part 1 of his book, the core section that I choose to focus on here, to an inventory of the social model's failings. These boil down to the accusations that the social model

► was the product of Marxist thinking—a now supposedly outmoded theoretical and ideological system (pp10–14);

► made a distinction between "impairment" and "disability" that soon became "ossified and exaggerated into a set of crude dichotomies which were ultimately misleading" (p13) (for example, only social barriers "disable"; impairment effects are irrelevant);

► set up a lasting "mythical dichotomy between "medical" and "social model" thinking" (p26)

(ie, the medical model views disability as caused entirely by impairment, whereas the social model sees it as caused entirely by oppressive social barriers);

► fails to recognise (1) that impairment plays a very significant role in most disabled people's lives (pp38–48), and (2) that ''disability'' would remain if all social barriers were removed—because impairment effects would continue to restrict some people's activity (pp41–48);

► has generated arrogance and stopped British activists and writers recognising, let alone adopting, alternative progressive ways of conceptualising disability that are readily to be found in other disciplines, such as medical sociology, and in other countries, such as the Nordic countries and North America (p10);

► rejects single-impairment organisations and campaigns that are desired by many disabled people and their families in favour of cross-impairment political activism with only minority appeal (p32);

► has ''largely failed to produce good empirical research'' (p9) or defensible theory (pp52–3);

► has ''become fatally undermined by its own contradictions and inadequacies'' (p28).

What is the provenance of these weighty objections? Readers of Shakespeare's book who are new to debates in DS can quickly form the mistaken impression that ''failings'' and points of contestation such as these have just come to light. In fact, the social model has been subject to critical scrutiny and debate within disability politics and DS for many years. The conceptual separation of impairment from disability (the impairment/disability dichotomy), for example, has been heavily lambasted from feminist and poststructualist theoretical quarters.[4] Indeed, the weaknesses that arise from its being a simple *model* of disability for political campaigning purposes, rather than a *social theory* for understanding the social construction and reproduction of disablism, have been exhaustively rehearsed.[4 5]

Especially from the early 1990s, many writers moved on from working with a simplistic model in search of sophisticated theoretical perspectives to use in conceptualising both ''disability'' and ''impairment'',[6 7] and empirical researchers got on with examining the important issues thrown up by the initial ''social barriers'' idea: that is, how to understand the disablist social relationships and forces (individual and collective) that work both to directly socially exclude and to undermine the psychoemotional well-being of adults and children with impairments—for example, in the education system, in employment, in family and personal life, in housing, in healthcare, in the leisure arena and so forth. One only needs to turn the pages of any issue of the international journal *Disability & Society*, based in the UK and founded on the social model perspective, to get a flavour of the rich mix of sophisticated research- and theory-based academic papers *inspired by* the social model and its sister perspectives across the world. (See, for example, the recent special issue on Lessons from History: *Disability & Society* 2006;**21**:383–565.) It is quite astonishing that Shakespeare makes no mention of this tremendously successful peer-reviewed journal. Many journal papers and other publications are devoted to the experiences and social needs of particular groups among disabled people, notably children and adults with learning difficulty. Shakespeare's accusations that the social model of disability did not kick-start high-quality empirical research and theoretical debate and has not encouraged international dialogue and exchange are simply not true. British DS is not the narrow and meagre discipline outlined in

Disability rights and wrongs; rather, it is a vibrant and rapidly expanding multi-disciplinary one in the social and human sciences in the UK's universities. Shakespeare's book unconscionably glosses over the very real theoretical, as well as practical, achievements made under the broad umbrella of the social model. The model's perspective opened up a novel theoretical and research space on the social creation and construction of disability—a space that advocates of the ''medical model'' and of the ''individual model'', including most medical sociologists and psychologists, systematically overlooked, ignored, marginalised or distorted.

WAYS AHEAD: ALTERNATIVE APPROACHES

I was writing my book *Sociologies of disability and illness*[4] at the same time as Tom Shakespeare was penning *Disability rights and wrongs*. Our approaches to the public presentation of DS and its key ideas could not be more contrasting, and I cannot help but see Shakespeare's book—at least part 1—as a diversionary missed opportunity. I, by contrast, was at pains to showcase the richness of the scholarship to be found in the discipline, and to distinguish this corpus from other disciplinary approaches by positioning it within what I chose to call *the social oppression paradigm*. I wanted to inform readers by setting the diverse theoretical perspectives and research traditions in British DS—materialist, feminist, poststructuralist, phenomenological—alongside each other, and to compare these with theories and traditions regarding chronic illness and disability to be found in medical sociology. This could establish the weight and quality of the growing body of knowledge in DS. Put another way, I made a conscious decision to describe the origins and features of the social model of disability and to acknowledge its enormous political significance but thereafter to leave it aside, *because it is not a theory of disability in its own right*. I favoured the notion that it is the social oppression or social exclusion perspective that makes ideas in DS distinct and cutting edge, and I did not wish to lose this when thinking about ways ahead for the discipline. On the other hand, I recognised the fundamental importance of theorising and empirically researching impairment and its effects. The argument that is developed through the chapters of my book, and that retains the partisanship of the 1970s social modellist pioneers, is that DS requires the further development of *a sociology of disablism and impairment effects*. Situated within the social oppression paradigm, this would

> … make use of theories that engage both with social structure (order) and social agency (action), and should therefore accommodate analyses of social relations and social forces that construct, produce, institutionalise, enact and perform disability and disablism. The lived experience of both disablism and impairment should have its place, as should theorisations of impairment *per se*—with chronic illnesses duly represented among categories of impairment (pp181–2).[4]

In his book, Shakespeare opted to rake over the coals of the social model of disability and to set out his epistemologically neutral and thus potentially multi-disciplinary ''alternative'' conceptualisation of disability—one that, in his words, ''neither reduces disability to an individual medical problem, nor neglects the predicament of bodily limitation and difference'' (p2). Shakespeare's key ''holistic'' idea, not itself new, is as follows:

> The experience of a disabled person results from the relationship between factors intrinsic to the individual, and

extrinsic factors arising from the wider context in which she finds herself. Among the intrinsic factors are issues such as: the nature and severity of her impairment, her own attitudes to it, her personal qualities and abilities, and her personality. Among the contextual factors are: the attitudes and reactions of others, the extent to which the environment is enabling or disabling, and wider cultural, social and economic issues relevant to disability in that society'' (pp55–6).[1]

In Shakespeare's view, the adoption of this perspective would enable researchers and writers on DS to leave aside essentialist social oppression ideas and line up alongside those in the other social sciences and medical disciplines who are happy to make use, for example, of the World Health Organization's relatively new ICF (*International classification of functioning, disability and health*).[8]

In the many hours spent hunched over my computer writing *Sociologies*, I considered, but rejected, approaches like Shakespeare's to reformulating the concept ''disability'' and took a different path. Nevertheless, the astute among you may have noticed that Shakespeare's and my own recommendations for the way ahead are not, on the surface of things, a million miles apart: that disabled individuals live lives shaped both by impairment effects and by the effects of disablist social factors.

And it is not accidental that I find myself agreeing with many of the points and arguments that Shakespeare makes on substantive topics in the very interesting later chapters: on bioethics, care, charity, personal relationships and the role of non-disabled people. But, in the final analysis, our books are on different sides of epistemological, political and moral divides, and that will be the cause of many (friendly) inter-personal debates in the years ahead.

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