

GUEST EDITORIAL

THE 'SOCIAL MODEL OF DISABILITY' MET A NARRATIVE OF (IN) CREDULITY: A REVIEW

M. Miles*

ABSTRACT

The article reviews components and recent discussion of the 'Social Model of Disability', with special focus on two books, Disability Rights and Wrongs by Tom Shakespeare, and The Social Model: Europe and the Majority World edited by Colin Barnes and Geof Mercer. The 'Social Model' calls for close and sceptical scrutiny, as it has become one of the most influential metanarratives in campaigns and publications of the 'Disability Movement', while tending to overlook the complexities experienced by many disabled people and their relatives. Some components of a Social Model appear in historical literature of Asia and the Middle East, lending credibility to its ongoing life as an interesting idea. Yet current anglophone advocacy of the model makes assumptions of universality that are questionable in the socio-economic situations experienced by much of the global population having disabilities. A calmer and better informed discussion of the model's merits and flaws would contribute to greater understanding of global disability.

Key words: Disability, social model

INTRODUCTION

This paper reviews some early history and recent articulation of the so-called 'Social Model of Disability', and some campaigning for and against that model with particular reference to two books, Disability Rights and Wrongs by Tom Shakespeare (1), and *The Social Model of Disability: Europe and the Majority World* edited by Colin Barnes and Geof Mercer (2).

Shakespeare's book (hereafter: *DRW*) collects and organises thoughts and battles in which he has engaged in recent years over a range of topics, most notably the Social Model of Disability (hereafter: *SMOD*). The book seems to land like a wrecking ball amidst the teeth of orthodox believers in the anglophone Disability Movement. On the rebound it threatens to crush the ribs of many a golden calf revered by disciples of Great British Social Modellers such as Colin Barnes, Mike

Oliver, Vic Finkelstein, and the former collective fount of wisdom UPIAS (Union of Physically Impaired Against Segregation), or its descendant British Council of Disabled People. To decorate this analysis with numerical data: in *DRW* those five authors or organisations accrue 79 indexed page references, and 29 cited publications (as first author). Other heavily cited authors of the SMOD camp are Jenny Morris and Jane Campbell (20 page references, 9 cited publications); yet the women's writings are mostly not prodded by Tom's rapier, both because he is a polite man, and because Morris has long taken her own more open-minded and critical view of the Social Model. For comparison, 18 among the Works of Shakespeare are cited in *DRW*, none being by William.

Justification for reviewing this topic is both historical and theoretical, and concerned with maintaining a sceptical research mentality. Two of the 'big ideas' or ideological trends in the disability field during the past 30 years have been the substitution of educational 'integration' by 'inclusion', and promotion of the SMOD. Both trends and notions have had some apparent success, and both may be viewed as having done significant damage to clear thinking, research, and professional skills across the fields of education, rehabilitation and social welfare. Many versions of 'inclusion' and the SMOD share features such as oversimplification, language manipulation, and an idealised vision of society. That 'vision' is often asserted to be a growing and compelling reality, so no further time need be wasted on argument. The glorious future is already dawning, there is no alternative but to leave the sad errors and discredited thinking of the past, and join the march to the Promised Land. Both ideologies have some grounding in observable experience, i.e. small-scale Utopian experiments in which sufficient factors could be controlled, highly facilitative social and educational environments engineered, difficulties overcome by dedicated staff, and positive outcomes reported. Yet efforts to replicate the wonderful vision on a larger scale, in normal situations with ordinary people, have run into scepticism, budgetary constraints, human perverseness, and the tendency of things to fall apart. The receding vision of 20th century Socialism has also reduced the credibility of 'promised land' theories.

Something can be learnt from these ideologies and their problems. Tom Shakespeare has been an activist, has lifelong impairments, and then added professional experience and a researcher's gaze. What he learns, and how he discusses it, can be useful to researchers well beyond his own fields. The second book noticed here, edited by Barnes and Mercer (2) serves to indicate many of

the positions from which Shakespeare has moved on. Shakespeare gives the second half of *DRW* to discussing bioethical matters (pp. 83-132) and issues in the social relations of disability (pp. 135-197). He writes as an experienced communicator, with lively style and chapter summaries. He also trots out the occasional grave heresy, merely because it tells some truth. (Example on p. 175: residential institutions, despite their problems, “were often places of security and friendship for disabled people”, and evidence existed of how “hidden subcultures in institutions emphasise sociability, harmony and self-esteem”, a different matter from having the ‘right’ to die of loneliness and boredom, living independently in one’s own rented room.) However, *DRW*’s second half may not be the part that generates most of the interest in this volume.

EARLIER SMODS

Shakespeare (p. 19) shows some awareness that traces of SMOD-like thinking existed as far back as the 1950s, and hopes that systematic research may one day disclose such gems. In fact they may more easily be found outside the recent anglocentric boundaries of his book. For example, Angus Graham’s expert reconstruction of the philosopher Zhuangzi (and school) offers a plausible SMOD in China of the fourth century B.C. (3). Of a revered wise man with deformed body, presented by Zhuangzi, Graham suggests that,

“The sage is sensitive to and adapts to all pressures from outside. The Power in shaping the body is like the water which, irrespective of its source, has a shape imposed on it by the topography of the place. It seems indeed that it is we ourselves, we ordinary folk, who by crowding round T’o from the day of his birth because the charm of pure spontaneity so attracts us, have forced his superbly sensitive and malleable organism into a shape we judge to be ugly” (p.81).

Of similar antiquity, in South Asia, is *Muga-Pakkha-Jataka*, a story of the Buddha, in infancy, being constrained to simulate deafness and muteness to avoid complicity in the gross cruelty and injustice of his immediate social environment (4).

In Asia Minor around 370 CE, Gregory of Nazianzus wrote a sermon in the context of the construction of several buildings by the Bishop of Caesarea, for care of people with leprosy and other serious disabilities. Gregory detailed the leprosy sufferers’ physical conditions and social exclusion, noting that they were,

“deprived of the opportunity to work and help themselves ... and the fear of their illness ever outweighs any hope in their minds for well-being ... they are afflicted with a second evil, disease, indeed, the most abhorrent and oppressive evil of all and the one that the majority of people are especially ready to label a curse. And third, there is the fact that most people cannot stand to be near them, or even look at them, but avoid them and are nauseated by them, and regard them as abominable, so to speak. It is this that preys on them even more than their ailment: they sense that they are actually hated for their misfortune. ... human beings alive yet dead...” (5).

The worst of the disabling condition was clearly perceived as that part inflicted by negative human attitudes and behaviour.

The use of hurtful and discriminatory terms to label disabled people was identified in the Jaina *Acaranga Sutra*, from India of the 5th century CE, and was forbidden on religious grounds (6). Yet kindness of speech was not always feasible. The celebrated 9th century Muslim writer known as al-Jahiz (‘the pop-eyed’) described the ‘social death’ that a deaf person may suffer among hearing people: “People are bored in his company and he is a burden on them. He is unable to listen to any of the people’s stories and conversations. Though present it is as though he were absent, and though alive it is as if he were dead” (7).

Other parts and aspects of SMODs can be found here and there in ancient and medieval literature and ‘cripple dramas’ of Asia and the Middle East. Baleful ‘influences of society’ on individuals have also been traced by European philosophers from Plato to Locke and JS Mill. In 1762, Rousseau penned his famous picture of avoiding such evils by a Utopian private education (8). The traditional Christian idea of humankind’s Fall from Grace, and the transmission of the fallen state to children (i.e. as ‘Original Sin’), was revised by the theologian Friedrich Schleiermacher (1768-1834), in a kind of Social Model of Moral Disablement, i.e. understanding original sin “not as corruption inherited from Adam and Eve but as the evil social structures into which individuals are born -- even before they make any individual sinful choices” (9). Other interpreters would explain Schleiermacher’s thought in terms of childhood within “God-forgetful” families and societies, offering children banal pleasures and meaningless gratification, with a dearth of the loving relationships that are essential nourishment for soul and spirit (10).

The traveller Thomas Skinner neatly encapsulated SMOD thinking, or perhaps a Social Model of Linguistic Disadvantage, on deaf children he noticed in

Himalayan villages in the 1830s. Their parents considered them “useless idiots”. Yet Skinner, noting their “lively and inquisitive” faces, thought otherwise. If they were useless, he wrote, it was not from imbecility on the children’s side, but arose from “the want of power in the parents to express their wishes in any other way than by speech” (11). Skinner was not particularly ‘modern’; he was merely thoughtful, as some people have been in every age. On a different plane was the crowd of “self-defining lepers”, the numerous 19th century European writers and artists who the historian Roy Porter found embracing mental and physical decay as part of their “revolt against the normal, balanced, pussyfooting philistine mediocrity” of society, which could then be blamed for driving them over the edge (12).

A more immediate precursor of the British SMOD of the 1970s was Lewis Dexter’s “social theory of mental deficiency” which he had been working up between 1947 and 1957 (13). Dexter noted the poor self-image and low sense of worth generated by social disdain for people with weaker intellect. He suggested that, “difficulties are created, derived from the social role of defectives rather than from anything inherent in the bio-psychological nature of defectives” (p.924). Dexter’s ‘defect’ terminology now sounds unpalatable, but his article quite clearly suggests how social structures and educational demands in mid-century North America generated failure, then constructed that failure as a social problem, for which the person of lesser ability was to blame.

RISE AND DECLINE OF THE BRITISH SMOD

After some introductory personal biography in *DRW* (pp.4-6), Shakespeare describes the rise of the British SMOD, from activities in the 1960s, through Fundamental Principles and early definitions in the 1970s, to political campaign slogans in the 1980s. The later period saw increasing rigidity as the universe was simplified into Good and Evil parts; the former being the Disabled People’s Movement under the SMOD banner, the latter being chiefly characterised as the ‘Medical Model’ and all the Damned who sail in her, such as professionals in health and rehabilitation. Like most such black-white dichotomisations of human life, the SMOD is fine for rallying simple-minded followers, but generates contradictions when tried out against the variety and complexity of everyday life. First meeting the SMOD around 1991, Shakespeare initially found it an attractive alternative viewpoint, as many people do at first encounter. In 1997 he was still defending the SMOD, but its problems were becoming more apparent, and by

2001 he was in print suggesting that its time had expired (14). In the present book, Shakespeare discusses a wide variety of flaws in the SMOD, and in its adoption and marketing as a Theory of Everything. Most of the flaws had been noticed up to 20 years earlier, but merely by professionals in the disability field, whose views might be considered partisan. Shakespeare's insider critique cannot so easily be dismissed, and it has aroused anger among some disability activists; yet he reports that others have welcomed his views (15, 16).

It should be recognised that the great majority of rank and file SMOD adherents are ordinary people with disabilities, neither stupider nor brighter than the population average, and having little appetite for academic arguments and sociological theory. The vast majority of the world's people with disabilities do not read English and have never heard of any kind of SMOD, and probably never will. In the Barnes and Mercer book, Tara Flood (p.180) asserts that, "The social model is under attack not just from disabled and non-disabled academics, but also from disabled people around the world who have reached the conclusion that the social model has no relevance to real life" (2). Perhaps they may reach such a verdict after fifty years -- but it will be difficult before they have even heard of the SMOD. Even in UK, where many adherents believe the SMOD is the dominant ideology, "recent research from the Office for Disability issues has shown that only six per cent of disabled people know about the social model of disability", a rise of three per cent since 2003 (17). Something of the broad notion underlying the SMOD has occurred to philosophers, theologians and harmless bystanders through two millennia, and its essential grain of truth may continue to please a minority in future generations; yet the grain has remained insufficient for anything major to grow from it.

WORD GAMES OR 'QUIS HIJACIET HIJACULATOS IPSOS'?

Communication of the British SMOD may have been limited partly by the dubious word games involved. Its launching involved an attempt to hijack an English word ('disability'), then render it to an indoctrination camp, reconstruct it to mean something significantly different from various public meanings it had acquired through five centuries, and finally to reintroduce it, under supervision, as a part of the Politically Correct vocabulary of the day. One may admire the effrontery, while reserving judgement on the efficacy of such games. In this context, it is amusing to find in the Barnes and Mercer book a plaintive note of, 'WHO has hijacked the hijackers themselves'. Rachel Hurst (p.77) mentions the

issue of what the SMOD is and who owns it “which allows policy-makers (for instance WHO) to ignore it and invent their own language” (2).

The World Health Organisation (WHO) did not in fact ‘ignore’ the British SMOD; it was rather a case of SMOD evangelists ignoring several decades of studies on disability terminology. In the late 1970s, WHO had appropriated the stage-wise terminology “Impairment, Disability, Handicap”, formulated as a triad in 1958 by Maya Riviere and colleagues working on the US Rehabilitation Codes Advisory Committee. Riviere’s committee had denounced an earlier US Impairment Code which “reflected current practices of identifying ‘the problem’ and labelling the person who might have it” (18). Riviere’s committee (p.8) wished to “re-orient professional attitudes and services towards individualised evaluation of the person as a human being, rather than the possessor of some detrimental condition.” It is salutary to notice this vigorous rejection of an ‘individual deficit’ model of disability by American rehabilitation professionals already in the 1950s, and their development of terminology that would underpin WHO’s International Classification of Impairments, Disabilities and Handicaps in 1981.

In the Impairment-Disability-Handicap triad, the ‘handicap’ element embraced the idea that impairments (the dysfunctions of body, mind or senses) and disabilities (what one could not do as a result of impairments) became acute at the interface with human society and the environment. Handicaps conflicted with social expectations of what everyone should be able to do (e.g. to hear; to use and understand speech; to see; to walk and climb steps). The three I-D-H words, while later perceived as flawed by a ‘negative’ focus, did embody some analytical subtlety. That subtlety was eliminated when Social Modellers reduced the three terms to an Impairment-Disability dichotomy, and tried to capture ‘disability’ and redefine it as the damage done by society to people having impairments. The SMOD was thus condemned to a lifetime of fighting against what everyone knew ‘disability’ meant, battling with its normal public meanings, and trying to make it mean something else.

SMOD MISSION TO A SMALL WORLD

Barnes and Mercer’s edited collection is not strictly comparable to Shakespeare’s book, as it pulls together a wide variety of chapters, some energetically advocating or defending the SMOD (e.g. those by Tara Flood, Rachel Hurst, A.K.M. Momin, Mark Priestley, Alison Sheldon), while others have only a modest connection with it or treat the SMOD with critical independence of mind (e.g. Bill Albert, Felicity

Armstrong, Susan Berg, Heba Hagrass, Anna Lawson and B. Matthews, Hannah Morgan and Helen Stalford, Enrico Pupulin). Colin Barnes and colleagues at the Centre for Disability Studies, Leeds University, have been among the most active propagators of the British SMOD, with a steady flow of books and campaign articles, but comparatively little research that can obtain traction beyond the world of SMOD adherents. The present book is 'self-published', i.e. produced by The Disability Press at the Centre for Disability Studies, thus avoiding some of the tiresome aspects of commercial publishing but also apparently omitting the discipline of independent peer review, or of constructing a competent index.

While Shakespeare's book is frankly situated in England, Barnes and Mercer's collaborators usefully take a view towards Europe and the 'Majority World'; yet anglocentrism remains insidiously present. The index lists no country under its own name except Britain and the United States, and no continent but Europe. The European Union, Commission, Community, Day of Disabled People, Disability Forum, Parliament, and six other European entities have separate index entries. Yet India and China, home of two fifths of humanity, and Africa with over 50 of the world's economically-dismal nations, are not listed in their own right. Another 38 nations appear in the text (four having chapters situated within their frontiers), yet none has its own index entry. Denmark's Ministry of Foreign Affairs wins a slot. A few countries are indexed under 'education', 'government' or legal cases where they are being sued. Perhaps all the others should be located under 'poverty' or 'foreigners'?

Some competent chapters do appear. For example, Lawson and Matthews (pp. 80-97) take the SMOD thesis that "people with impairments are disabled by barriers", and outline the slow process of "dismantling barriers to transport" across the European Community, by enactment of laws, application of specific regulations on access, and court cases to obtain enforcement. Outcomes are quite patchy, and the available strategies cannot be expected to deliver much more, unless substantial changes appear in government concern and public attitudes, supported by "clear guidance, communication, persuasion and training" (p. 94).

Heba Hagrass (pp. 148-162) gives a reasonable overview of recent disability thinking and policy in Egypt, noting that this is largely based on medical and individual approaches. The SMOD along with some 'rights' rhetoric has appeared, but "in many respects these statements seem little more than an empty reflection of those that appear in documents produced by western policy-makers" (p. 154), without making any real change. As a woman with disability, living in Egypt and

studying various aspects of disability there, Hagrass's appreciation of the social realities has rather more credibility than that of distant western theorists. She points out that in the absence of widespread and well-organised formal services, the 'charitable response' found in many developing countries, and supported by religious teaching, plays a useful role in the care and support of people with disabilities, however problematic this might seem to westerners who mistakenly imagine that basic food, shelter and medical care are a universal provision.

Felicity Armstrong (pp. 49-64) compares SMOD and medical approaches within an educational context, and bravely does this for the French education system, notorious for the fragmentation or disarray of its services for childhood disabilities. The complexities of trying to make sense of French history, plans and strategies in this area are dimly hinted between the lines: "France does seem to be historically burdened with particularly deeply rooted categorical thinking at the different levels of policy making. Paradoxically, this has its roots in progressive thought and the age of the enlightenment in which 'science' was seen as able to address personal and social ills, by processes of assessment, identification and intervention" (p.63). Are science-based francophone medical approaches to disability (le handicap) in schools going to shrivel and disappear in the light of a sociology-based anglophone SMOD? It may be wise not to bet heavily on it.

BIGGER WORLDS TO CRACK

Reflecting on her doctoral studies on disability in China, Emma Stone explained how the SMOD became merely a practical problem and an insurmountable linguistic barrier to working in the real cultural life of China, a significant chunk of the 'majority world' (19). The SMOD is also clearly problematical across much of South and South-East Asia, where attitudes may be strongly influenced by religious thought that links disability with misconduct in the present life or earlier lives. That doctrine seems perfectly reasonable and logical, indeed self-evident, to half a billion adults, some of whom are well educated and 'modern'. It is also compatible with any amount of 'scientific evidence' about impairment causation. Scientific accounts deal with statistical probabilities, whereas individuals with disability or families with a disabled child are usually interested in the 'why me?', 'where did we go wrong?' questions, and can juggle with several parallel or mutually-conflicting theories (20).

These and similar linguistic, cultural and conceptual obstacles across the world, can be expected to wreck any large-scale adoption of the British SMOD as a

functioning theory, though the SMOD's 'grain of truth' will doubtless continue to generate edible shoots indefinitely. Like the abuse of 'inclusion' in India, documented by Singal (21), some SMOD jargon may continue to be redefined and accommodated within the official rhetoric, to warm the hearts of the well-meaning. Meanwhile, outside the box, the world gets on with 'business as usual'.

*Address for correspondence
Email: m99miles@hotmail.com

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