

Back to the future: The World Health Organisation's 2011 'World Report on Disability'

Colin Barnes and Mike Oliver: Centre for Disability Studies; School of Sociology and Social Policy, University of Leeds.

(This is a penultimate draft of an article that appeared in *DisabilityWorld and Society*, 2012).

The World Health Report on Disability (2011) produced by the World Health Organisation (WHO) and World Bank was launched recently and was followed by Panel Discussion at the United Nations in New York attended by many of the great and the good of the disability world.

We read Jerome Bickenback's recent endorsement of this document in this Journal (2011) with a growing sense of amazement. He claims that the report is an astonishing achievement because it does three things; it single-handedly shifts paradigms, it makes 'utterly novel recommendations' and it raises 'issues never before considered by people with disabilities' (p. 654).

If these assertions are correct then the Report will give us a greater understanding of the disabling world in which we live, rapidly increase the inclusion of disabled people all over the globe, and give

added stimulation and direction to a stagnating disability studies. In what follows we examine the question of whether Bickenbach can justify the claims in his review and indeed whether the Report justifies such plaudits.

To begin with let's deal with the notion of a paradigm shift. He states:

“Disability, it argues, is a complex, dynamic, multidimensional concept that engages both intrinsic features of human physiology and functioning – the domain of health – and features of the physical, human-built, social and attitudinal environment” (Bickenbach, 2011: 656).

If this view represents a paradigm shift, and we would agree that it does, it was Vic Finkelstein who facilitated it in a presentation he made to a similar audience at an international two-day conference: ‘Changing attitudes and the disabled: issues at stake’, funded by the World Rehabilitation Fund in September 1979, and published in 1980.

Following the ground breaking work of the UK's Union of the Physically Impaired Against Segregation (U.P.I.A.S.), of which he was a member, in it he states:

‘If disability is viewed as a paradoxical situation involving the state of the individual (his or her impairment) and the state of society (the social

restrictions that are imposed on an individual) then attitudes may be directed towards either or both, of these aspects. Attitudes may be toward the individual who is impaired, or toward the social barriers' (Finkelstein, 1980: 6).

In order to avoid any confusion over the meanings attached to the word 'disability', Finkelstein reaffirms the significance of the conceptual distinction between the biological (impairment) and the social (disability) as conceived by U.P.I.A.S. in 1976 (p.14); a distinction which will be familiar to many *Disability and Society* readers. This was necessary to direct attention away from the general tendency to view disability as an individual problem rather than a socio/political issue – a tendency which allows policy makers to focus on 'people fixing' rather than disabling barriers.

Moreover, given that over the last half century disability policy, both nationally and internationally, has and remains dominated by 'a bias in favour of changing the person rather than changing the world' (Bickenbach, 2009: 110), surely the questions Bickenbach should be asking are: a/ why the WHO and World Bank have taken so long to acknowledge this paradigm shift and b/ why do they continue to use terms which allow politicians and policy makers to ignore the social forces that shape disabled people's lives?

Perhaps Bickenbach meant that the paradigm shift applies to the methodology used in producing the

report which again, he suggests, has three aspects; the participation of disabled people; the need for solid evidence based upon good science and sound scholarship; and on a more limited role for political rhetoric.

On the issue of the participation of disabled people, the WHO has been criticised for its failure to involve those with impairments in its attempts to collect evidence about disability since it began work on its first attempt to provide a universal definition of disablement in the 'International Classification of Impairment, Disability and Handicap' (ICIDH) (WHO, 1980) in the late 1970s.

These criticisms have involved not just political sloganeering and actions, but also detailed debates and discussions with disability activists, researchers and policy analysts (see for example, DHS. 1992; Barnes and Mercer, 1996; 1997). The merits of participatory and emancipatory approaches have been aired along with debates about the data collection strategies appropriate to both methodologies. Hence beyond the endorsement of participation there is little that is new or novel in this Report.

In fact, the endorsement of 'sound science' sounds like a return to the bad old days of academic imperialism, when disabled people were told that they could not be involved in disability research as they were not objective about their own lived experiences, or that they did not have the

necessary scientific training and skills. The historical reality of this kind of research is that it failed to deliver any significant improvements in the material circumstances of disabled people though it has, of course, been of great benefit to 'disability researchers' (Oliver, 1992; 1997).

Indeed, we have gone further and argued that the only way ahead for disability research is through a rejection of both the methodological individualism and investigatory foundationalism upon which 'scientific' research is based (Oliver, 2009; Oliver and Barnes 2012).

On the suggestion of a more limited role for political rhetoric, we should point out that it is not just ageing activists like ourselves that have cast doubt upon the validity of the scientific approach to disability research, but Bickenbach himself as the following quote from an earlier paper illustrates:

'So, how do we answer questions about who is disabled or the prevalence of disability in a country or region? As a multi-domain, multi-dimensional, interactive and continuous phenomenon (as it is characterised in the ICF), we must specify which impairment domains qualify, to which degree of severity. Different prevalence rates flow from different decisions. If we are interested in any impairment domain, to any degree of severity, then prevalence is roughly universal - *a conclusion of no use to policy makers*

whatsoever. If we restrict our scope to specific domains and severity levels, then our prevalence levels will differ accordingly. *But these decisions cannot be made conceptually or scientifically, they are political. The scientific approach in a word, does not solve the problem the policy analyst needs to solve'* (Bickenbach 2009: p. 120) (Emphasis added).

It seems to us that both the Report and Bickenbach want to have it both ways in terms of what they are arguing about and in discussions about the approach being used. The reality of the great leap forward in recent times in our understandings and actions in respect of disability, have almost all been produced by political struggle and not scientific research so the Report and Bickenbach cannot and should not ignore this in their quest for a sound evidential basis for action.

If the Report does not represent a paradigm shift then what about the claim that it makes 'utterly novel recommendations'. As readers of this Journal will be aware there is now a growing literature providing evidence and policy insights on health, disability and rehabilitation, and particularly with reference to the poor or 'low or medium resourced countries of the world' (sic) (Bickenbach, 2011: 655). One important example which both the WHO and Bickenbach have apparently overlooked is the WHO's own 'Rethinking Care from the Perspective of Disabled People' (2001) project.

The Rethinking Care project was a 16 month initiative that involved disabled people from start to finish, adopted a holistic, social/political analysis of disability rooted in the writings of disabled people, and which generated several recommendations which in many ways are more 'novel' than those in the WHO, World Bank Report.

It was initiated by the WHO's *Disability and Rehabilitation* (DAR) Team under the direction of Dr. Enrico Populin who commissioned a paper in 1998 by Finkelstein entitled 'Rethinking care in a society providing equal opportunities for all' (Finkelstein, 1998). This prompted the development of the DAR initiative which began in January 2000 with funding from the Norwegian Government and hosted by the Norwegian Ministry of Social Affairs which culminated in a four day international conference in Oslo in April 2001.

The project's organising committee comprised representatives from the Norwegian Federation of Organisations of Disabled People, the Norwegian Association of Disabled People, The Norwegian Ministry of Health and Social Affairs, experts on disability issues as well as representatives of the DAR Team. The project began with a call by the DAR Team for testimonials from disabled people, their families and 'carers' throughout the world on their experience of disability and rehabilitation.

Over 3500 responses were received, almost 80 per cent from disabled individuals. These responses

drew attention to the 'alarming degree of deprivation: economic, political and social', experienced by disabled people and their families; a situation which was attributed to the 'inadequacy and or ineffectiveness' of the then 'current care services' in both 'high income (developed) and low income (developing) countries' (WHOa, 2001: unpagged). A selection of these testimonials is available at WHO, 2001b}.

The Rethinking Care Conference brought together 108 stakeholders from all over the world including disabled people, their personal assistants (PAs), professionals and representatives of disability organisations; the majority were disabled themselves. The general aim was to give participants the space to reflect on and discuss current policies within the context of the first four standard rules of the United Nations 'Standard Rules on the Equalisation of Opportunities for Persons with Disabilities' (UN. 1993) and in so doing provide new insights and knowledge for the formulation of appropriate recommendations for WHO member states' (WHO. 2001a; unpagged).

The conference agenda included presentations by participants, question and answer sessions, focus and discussion groups. These discussions generated 37 policy recommendations which centred around the assertion that:

'health and rehabilitation can no longer be understood solely in term of orthodox medical

interventions and orthodox notions of “care”. These centre almost exclusively on the perceived limitations of individuals rather than on society’s failure to accommodate the needs of people with disabilities. Thus there is an urgent need for an approach that cares not only about disabled people but also about society and its structures’ (2001a: unpagged).

Among the recommendations were calls for states to invest in the eradication of poverty and the development of fully accessible community based services and facilities, and that disabled people should be fully involved in these developments. Also, that where funding was unavailable, as with the majority of so called ‘developing’ nations, this should be provided by rich countries and transnational funding agencies.

Other recommendations required all states to introduce comprehensive mandatory anti disability discrimination legislation and ensure that access to high quality medical services should be available to all regardless of the ability pay. In addition wealthy states should compensate poor countries for poaching their doctors and healthcare professionals with the lure of higher wages and better working conditions.

The report of the entire initiative including summaries of responses to the initial request for testimonials and conference report with appendices documenting participants, agenda and

presentations was submitted to the WHO in June 2001. Because of the WHO's promotion of the ICF (International Classification of Functioning, Disability and Health), referred to in the Bickenbach quote above, the only published output from this project was an edited Conference report of 28 pages. This document does not include appendices: participants, agenda and presentations.

Further in concert with the WHO's language policy the phrase 'disabled people' was replaced by 'people with disabilities', a phrase which reifies disability as an individual problem, in much of the narrative. Thankfully due to the insistence of Dr. Populin and the then DAR team penultimate drafts of documents chronicling the entire Rethinking Care initiative are freely available electronically on the Disability Archive UK, hosted by the Centre of Disability Studies at the University of Leeds *.

In conclusion it should be clear that we reject all the claims Bickenbach has made for the Report. But that does not mean a rejection of the Report's findings or the opportunity it offers for disabled people to use to bolster their collective struggle for a fairer and equitable society. But we must clearly recognise that all social research is political and, perhaps more importantly, consider the political role of the WHO and the World Bank in sponsoring the Report. Both are structurally positioned to facilitate the ongoing development of global capitalism which is based upon the twin evils of domination and exploitation. The inevitable consequences of these

evils are poverty and war, and all researchers, whatever their particular standpoint, would agree that the two main causes of impairment throughout the world are war and poverty. Need we say more?

References

Barnes, C. and Mercer, G. (eds.) 1996: ***Exploring the Divide: Illness and Disability***. Leeds: The Disability Press. *

Barnes, C. and Mercer, G. (eds.) 1997: ***Doing Disability Research***. Leeds: The Disability Press. *

Bickenbach, J. E. 2009: Disability, non-talent, and distributive justice. In Kristiansen, K., Velmas, S. Shakespeare, T. (eds.), ***Arguing About Disability: philosophical perspectives***, London: Routledge, 105 - 123.

Bickenbach, J. E. 2011: The World Report on Disability, ***Disability and Society***, 26 (5) 655-658.

DHS. 1992: ***Special Issue: Researching Disability***, *Disability Handicap and Society*, 7 (2).

Finkelstein, V. 1980: ***Attitudes and Disabled People: Issues for Discussion***. New York: World Rehabilitation Fund. *

Finkelstein, V. 1998: ***Rethinking Care in a Society Providing Equal Opportunities for All***. A Discussion Paper Prepared for the World Health

Organisation's Disability and Rehabilitation Team. *

Oliver, M. 1990: ***The Politics of Disablement***.
Basingstoke: Macmillan. *

Oliver, M. 1992: Changing the Social Relations of
Research Production? ***Disability, Handicap and
Society***, 7 (2), 101- 14.

Oliver, M. 1997: Emancipatory disability research:
Realistic goal or impossible dream. In C. Barnes
and G. Mercer (eds.), ***Doing Disability Research***,
Leeds: The Disability Press, 15-31.*

Oliver, M. 2009: ***Understanding Disability: From
Theory to Practice 2nd Edition***, Tavistock:
Palgrave.

Oliver, M. and Barnes, C. 2012: ***The New Politics
of Disablement***, Tavistock: Palgrave.

UN, 1993: ***The Standard Rules on the
Equalization of Opportunities for Persons with
Disabilities***. New York: United Nations.

WHO, 1980: ***International Classification of
Impairments, Disabilities and Handicaps***.
Geneva: World Health Organization.

WHO, 2001a: ***Rethinking Care from the
Perspective of Disabled People***, Geneva: World
Health Organisations Disability and Rehabilitation
Team. *

WHO, 2001b: ***Rethinking Care from the Perspective of Disabled People: Voices***, Geneva: World Health Organisation's Disability and Rehabilitation Team.*

<http://www.leeds.ac.uk/disability-studies/archiveuk/index.html>

Note: all items marked * are freely available electronically on the ***Disability Archive UK*** at:

<http://www.leeds.ac.uk/disability-studies/archiveuk/index.html>