

Disability KaR Research Project Enabling disabled people to reduce poverty

Briefing Note: The social model of disability, human rights and development

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"In the last few decades, disabled people's organisations around the world have promoted a human rights approach and an environmental approach to disability issues. These approaches are both based on a social model of disability. The focus is on disabled people's rights and on the need to change society to be inclusive of everybody. Within these models, it is the way that society is organised to exclude people with impairments that is considered disabling, not the individual impairment. Organisations of disabled people have been coming together increasingly to fight for their rights on this basis." European Union Guidance Note¹

Introduction

There has been and continues to be a wide-ranging and fiercely contested debate about how disability should be understood. For those unfamiliar with this subject it might seem surprising that something apparently as obvious as the definition of disability should excite controversy. The objective of this briefing note is to outline why this has happened, why the apparently obvious is not so obvious, and why the arguments are of such importance for policies and practices concerned with disability and poverty in the developing world.

Understanding disability

Individual/medical model of disability

The traditional understanding of disability is that it is what 'is wrong' with disabled people – how their health is compromised. This view equates disability with impairment. So, 'disabilities' would include blindness, deafness, the various conditions that make it difficult or impossible to walk or to speak, mental illnesses and such conditions as Downs Syndrome and epilepsy. This is a medicalised view of disability and is often called the medical model of disability.

In general, by conceptualising disability as an individual health issue disabled people are socially imagined and may imagine themselves as, among other things, damaged, abnormal, as patients and/or as the dependent objects for a variety of medical or rehabilitative interventions. While those who view disability through a medical lens may concede that there are unfortunate social consequences that arise from having a disability, within this paradigm social exclusion is seen essentially as the result of limitations imposed by 'disabilities'. As the problem is primarily a medical one the solution tends to be cure and/or rehabilitation, the latter, in some cases, requiring segregation into special institutions. This is carried out, usually by health service professionals of one sort or another, with the intention of caring for and protecting the disabled person, as in the case of institutionalisation, or to restore 'normal functioning'.

¹ Guidance note on disability and development for EU delegations and services, EC DEV/RELEX/AIDCO and Delegations Staff Briefing Note. March 2003 www.iddc.org.uk/dis_dev/mainstreaming/guidance_note.pdf

Social model of disability

"It is society that disables us, not our impairments."

The critique of the traditional interpretation of disability, which eventually was transformed into the social model of disability, was developed from the 1970s within the disability movement in the UK. It offered a radical alternative to the individualised medical conception of disability by asserting that disabled people were disadvantaged not because of their impairments, but as a result of the limitations imposed on them by social, cultural, economic, and environmental barriers. Disability according to this formulation is not about health or pathology but about discrimination and social exclusion. From a social-model perspective disability is a socio-political issue. This in turn leads to fundamentally different policy priorities and choices, mainly around the removal of disabiling barriers, as well as a strong emphasis on human and civil rights.

Unlike medical model assumptions of individual abnormality and the primacy of cure, the social model, while not rejecting medical intervention, implicitly acknowledges the normality of impairment. Furthermore, it is recognised that medical advances far from reducing the number of disabled people have led to an increase, as people not only live longer but are also better able to survive illness and injury. It might be said that the proportion of disabled people in a population is a good indicator of an economy's prosperity.²

Fierce academic and political debates continue, both within the disability movement and from outside, about the nature of the social model, its relevance, as well as how and if it can be applied in any given situation.³ It is beyond the scope of this note even to outline these debates. Instead, after a brief account of some benefits of applying the social model in development, specific questions that have been raised about the social model in this context will be considered.⁴

² There is a lack of comparable statistical data, but it appears in general that the proportion of disabled people in the developed world is many times that in the developing world. For example, in the 1980s the UK reported 14.2% of the population over 16 as disabled, while in Nepal and the Philippines it was (for all ages) 3% and 4.4% respectively. However, this is based on unreliable, outdated data. See United Nations, Department of International Economic and Social Affairs, Statistical Office, *Disability statistics compendium*, 1990.

http://unstats.un.org/unsd/pubs/gesgrid.asp?mysearch=disability

³ See, for example, Barnes, C. and Mercer, G. (eds.), *Implementing the social model of disability: theory and research,* Leeds, 2004, and articles on this topic in the journal *Disability and Society*. An excellent web-based resource is the <u>Disability Archive</u> hosted by Centre for Disability Studies at the University of Leeds. <u>www.leeds.ac.uk/disability-studies/archiveuk/</u>

⁴ For a discussion of the influence of the social model of disability on development policy and practice see Albert, B. and Turner, M. <u>Is disability really on the development agenda? A review of official</u> <u>disability policies of the major governmental and international development agencies</u>, Disability KaR programme report, 2004

"In the broadest sense, the social model of disability is about nothing more complicated than a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment – whether physical, sensory or intellectual." Mike Oliver⁵

Nothing about us without us!

By seeing impairment as an ordinary part of life, and disability as the result of discrimination and exclusion, the social model has underpinned efforts to extract disability from the medicalised, 'special needs' ghetto and push for the mainstreaming of disability concerns in all development policies and practices. Although this is yet to happen, there have been numerous positive statements of intent by both government and international agencies about the need to mainstream disability in development work.⁶

The social model has also provided a powerful framework for bringing disabled people together in a common struggle for equality and rights. By doing this the social model has promoted the idea that disabled people should be actors in their own lives, rather than passive recipients of care. This equates almost exactly to current thinking on a rights-based approach to development, adopted by government development agencies throughout the world. For example, a key DFID paper about planning to meet the UN's International Development Targets (latterly the Millennium Development Goals) states that: "The central message [...] is that the International Development Targets can only be achieved with the engagement of poor people in the decisions and processes which affect their lives. Human rights are a central part of work to achieve the International Development Targets because they provide a means of empowering all people to make effective decisions about their own lives."⁷

By projecting disabled people into a leading role in defining and controlling their lives, the social model offers a powerful device for the liberation of those who remain the poorest of the poor in all countries, both developed and developing⁸. The model is so powerful because it illuminates the fact that the roots of poverty and powerlessness do not to reside in biology but in society. The former is, for most disabled people, immutable; the latter, through purposeful collective action, can be transformed. A human rights approach offers both the platform for such societal transformation and a way for disabled people to transform their sense of who they are – from stigmatised objects of care to valued subjects of their own lives. For people who are

www.dfid.gov.uk/pubs/files/tsphuman.pdf

⁵ Mike Oliver, 'The social model in action: If I had a hammer', in Barnes, C. and Mercer, G. (eds.), *Implementing the social model of disability: Theory and research*, Leeds, 2004, p.21.

⁶ See Albert and Turner, *Is disability really on the development agenda?* (ibid.) for examples.

⁷ DFID, <u>Realising human rights for poor people.</u> October 2000, p.10.

⁸ It is widely recognised that disabled people make up a substantial proportion of the poorest in the developing world. See Elwan, A. <u>Poverty and disability. A survey of the literature</u>, a background paper for the World Development Report, World Bank, December 18, 1999.

poor and oppressed this is a key starting point of any meaningful process of social and economic development.

"Disability is a human rights issue! I repeat: disability is a human rights issue. Those of us who happen to have a disability are fed up being treated by the society and our fellow citizens as if we did not exist or as if we were aliens from outer space. We are human beings with equal value, claiming equal rights...If asked, most people, including politicians and other decision makers, agree with us. The problem is that they do not realize the consequences of this principle and they are not ready to take action accordingly."⁹ Begnt Lindqvist, UN Special Rapporteur on Disability

Relevance of the social model in developing countries

Is the social model relevant for poor disabled people in developing countries? A number of questions have been raised about the efficacy of both the human rights approach to development and the use of the social model of disability in helping to frame that approach. Some of these questions, and comments on them, are briefly outlined below.

Ignoring impairment?

Perhaps the most common issue raised by critics of the social model is that it ignores the reality of what impairment means for disabled people. This, they say, is problematic in the North, but when applied to the South it is catastrophic. At one level this claim could be dismissed as it is most frequently made by non-disabled people, while the social model has been embraced by disabled people, in both the North and South, who clearly *do* know what impairment means on a daily basis.

But more to the point, advocating the social model does not mean ignoring the causes of impairment or the health care needs of anyone, including disabled people. Proper health care is a basic human right and provision of clean water, disease prevention, ending conflicts, eradicating poverty, and getting rid of landmines, all of which would remove major causes of illness and injury, are important for all. Finally, it should be stressed that the social model critique of the medical model of disability is, at least in part, about rejecting the medicalisation of disabled people, not rejecting medical intervention.

⁹ Speech by Bengt Lindqvist, Special Rapporteur on Disability of the United Nations Commission for Social Development, at the 19th Congress of Rehabilitation International, Rio de Janeiro, 25–30 August 2000 (quoted in Quinn, G., Degener, T., (eds.), *Human rights and disability: The current use and future potential of United Nations human rights instruments in the context of disability*, UN, Geneva, March 2002, p.13) www.unhchr.ch/disability/report.htm

Ignoring assistive technology?

An objection related to the above has been raised by David Werner, one of the founders of the Projimo Project¹⁰ in Mexico. He has written that disability activists in the North "...already have the essential personal aids they need. So their top priority is the struggle for their social rights. They have tended to project their own priorities onto the poor disabled people of the Third World, whose lack of assistive equipment (braces, wheelchairs, etc.) may be their biggest limitation."¹¹

The issue of disability rights, far from being a Northern project, has found some of its most vocal and innovative proponents in the South.¹² Furthermore, as the practice at Projimo indicates, access to the proper technology, far from being antithetical to a rights-based approach to disability, can be immensely liberating if developed within a framework that prioritises the real needs of disabled people as well as their genuine participation at all levels. In fact, access to a wheelchair or a hearing aid is a basic human right for someone who would otherwise be unable to take part in any social activity.

Ignoring cultural difference?

Another criticism is that the social model as been developed in the North where the cultural context, particularly the emphasis on individual rights, differs greatly from the more family-based and/or communal situation found in many developing countries.¹³ Similar culturally-relativist arguments have been made about the international human rights agenda in general. Such criticisms raise the question of whether any practice – slavery, female circumcision, infanticide and so on – can be defended on the grounds that it is part of local culture.

More significantly, by stressing the commonality of disability discrimination, the social model, rather then promoting an individualist agenda, has helped foster cross-impairment-based collective action on issues of concern to all disabled people, i.e. transport, access to education and employment. Finally, it is up to disabled people in the South, if they find the social model useful, to interpret it in ways appropriate to their own circumstances. Such cultural adaptation is precisely what has happened in many developing countries.¹⁴

¹² Disabled People's International, a human rights organisation of disabled people, has national assemblies in 160 countries, most of which are in the South. <u>www.dpi.org/en/start.htm</u>
¹³ Raymond Lang, 'A critique of the disability movement', guest editorial in Asia Pacific Disability Rehabilitation Journal, Vol.9, No.1, 1998.

www.dinf.ne.jp/doc/english/asia/resource/apdrj/z13jo0100/z13jo0103.htm

¹⁰ The Projimo Project, started in 1981, is a community-based education and rehabilitation project run by and for disabled people. See <u>www.healthwrights.org/projects/projimo/projimo.htm</u>

¹¹ David Werner, <u>Nothing about us, without us: Developing innovative technologies for, by and with</u> <u>disabled people</u>, p.6.

¹⁴ A briefing note on the social model in practice is being prepared by the author for the Disability KaR Programme.

Ignoring difference?

It has been claimed that the social model of disability ignores the differences among disabled people with respect to their impairments, and that there is an impairment, class and gender hierarchy (wheelchair-using, middle-class men being dominant) within the disability movement.¹⁵

Leaving aside the latter point, which is factually incorrect¹⁶, the criticism about a lack of homogeneity is rather curious as no one has ever made such an argument or even implied that differences do not exist or are not significant. Individually, disabled people, even those with the same impairment, have a vast range of life experiences, as do any other oppressed group such as women or ethnic minorities. What brings them together in a movement is the shared experience of discrimination and exclusion. This is precisely the focus given by the social model and one reason that it has been so important for, and embraced so avidly by, disabled people.

Ignoring poverty?

Why, in conditions of extreme poverty in which most disabled people in the developing world live, should they care about the social model or a rights-based approach to disability? Surely 'you cannot eat rights'. Just as surely, people without rights often can't eat. As indicated above, this latter idea firmly underpins current thinking on the poverty reduction in the developing world, with its emphasis on a human rights approach. It must be stressed, however, that this approach can only yield results for disabled people if they are able to organise and lobby effectively as equal members of civil society. Otherwise the mantra of human rights will remain little more than a public relations exercise to cover the failure of globalisation to meet the needs of the worlds' poor.

"A rights perspective means incorporating the empowerment of poor people into our approach to tackling poverty. It means ensuring that poor people's voices are heard when decisions which affect their lives are made. It means recognising that equality matters. Addressing discrimination in legislation, policies and society contributes to an environment in which excluded people have more control over their lives. A rights approach also means making sure that citizens can hold governments to account for their human rights obligations." DFID, *Realising human rights for poor people*¹⁷

www.ee.umanitoba.ca/~kinsner/sds2001/program/sessions/sat/sa.html

¹⁵ David Seddon and Raymond Lang with Victoria Danes, *Mainstreaming disability issues into development studies – In theory and practice*. Paper given at the Society for Disability Studies 14th Annual Conference, 2001.

¹⁶ "...most of the leaders of the international disability organisations are from the developing world, at least 40% are women and many were born in poverty and illiteracy...", Rachel Hurst, 'To revise or not to revise?', in *Disability and Society*, vol.15, no.7, 2000, p.1086.

¹⁷ DFID, Realising human rights for poor people, (ibid.) p.8.

Conclusion

The social model of disability represents a protean challenge to traditional thinking about disability. If applied in the development context it has the potential to transform policies and practice as well as the lives of disabled people. However, neither it nor a human rights approach are magic wands. While many people may find the social model a helpful way to conceptualise disability and have even begun using disability rights language in reports and policy documents, this is not enough to make a real difference. A too-easy acceptance of the new disability paradigm may even be counterproductive: by being so easy it runs the risk of ignoring how negative assumptions and attitudes about disability (held by both disabled and non-disabled people) are so deeply ingrained and continually reinforced.

Furthermore, understanding the strength and social authority of these attitudes demands a genuine awareness of the unequal power relationships that define the reality of disability. This applies equally to gender and ethnicity. For example, you cannot challenge sexism and racism in a 'white man's world' by using non-sexist, non-racist language while accepting the power relationships in that world. Until this problem is addressed and the insidious layers of institutionalised disablism¹⁸ are exposed and stripped away it will be impossible to develop and implement effective policies to address the poverty and disadvantage so endemic among the hundreds of millions of disabled people in the developing world.

¹⁸ Institutionalised disablism, like institutionalised racism, refers not only to policies and practices that directly and indirectly discriminate against disabled people, but, as importantly, to the unrecognised and unacknowledged prejudicial attitudes that inform these policies and practices. See Miller, P., Parker, S. and Gillinson, S., *Disabilism. How to tackle the last prejudice*, DEMOS, 2004. www.demos.co.uk/uploadstore/docs/disablism.htm