CHAPTER 12

'Food' or 'Thought'?
The social model and the majority world

Tara Flood

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. However this clearly demonstrates confusion as to the intention of the social model. People appear to see it as a problem solver and something that will both put food on the table and tarmac on the road – in actual fact it is none of these things. Neither is the social model, as it is often suggested, the only conclusion one should come to when trying to understand disability. Rather, as I understand it, the social model is a way of characterizing or interpreting the relationship between a disablist society and people with impairments.

The social model was and still is a statement of disabled people's exclusion from full participation in a society where the non-disabled majority view impairment as different, inferior, and something, most certainly, to be eliminated. Applying a social model understanding to explain the exclusion of a particular group of individuals is not a new idea. It has been used by many grassroots organisations around the world to explain their experience of poverty, injustice or exclusion from the political agenda. Why it was particularly important to place disability within a 'social model' context was to remove disabled people from the de-humanising effects of the traditional and invalidating medical and charity models.

For centuries disabled people have been seen as everything from the embodiment of sin to super-heroes triumphing over the 'tragedy' of our impaired situations. We have never been seen as equal members of the

human race and more often than not every effort is made to exclude us from social, economic, educational and political opportunities. Society is organised in such a way as to limit our participation and to measure the value and status of each of its members by economic and normalized standards. It is no wonder disabled people are positioned somewhere on the outermost fringes.

Social model thinking was first used to explain the situation of disabled people, by Paul Hunt (1966). His ideas were developed some ten years later by UPIAS (Union of the Physically Impaired Against Segregation) (1976). But it was not until 1983 that the disabled academic, Mike Oliver, described the ideas that lay behind the UPIAS definition as the 'social model of disability'. For disabled people in the UK the social model was the key to our politicisation. It allowed a common space from which to develop politicised actions and theories to explain our experience of exclusion, discrimination and oppression. Even now, for many disabled people, discovering the social model can feel like a liberating factor. I did not find out about the social model until my early thirties, but I remember distinctly that it was like a light switching on – no more accepting society's lies about the tragedy of my life – bring on political activism!

The beginnings of an international movement of disabled people
Internationally, discussions and interpretations about disabled people's experience of exclusion started to take shape during the 1960s and 1970s with the rise of the Independent Living movement in the US and in European countries such as Sweden. Disabled people were tired and frustrated by the 'specialness' of service provision and considered their access to essential services controlled by non-disabled people as the key to their oppression. Service provision, until this point, was deeply medicalised and often institution-based. Disabled people were viewed as passive recipients of state funded care with little or no opportunity for flexibility or influence. The philosophy of independent living was, and is, about the empowerment of the individual through the taking of choice and control in their life. It is about recognising that the disabled individual's rights as a human being are equal to those of the non-disabled majority. Most importantly it is about social action and social change – a recognition of our rights as human beings as the route for the implementation of that social action and social change.

Is the social model international?

Is the social model as relevant to disabled people in the South as it is for those of us who live in the North? Is it imperialistic of those of us living in the North to impose social model thinking on disabled people in the South (Stone 1999) and does the concept of disabilism transfer across countries and continents? The truth is that the social model is as relevant to disabled people in London as it is to disabled people living in Lusaka. Why? Because it focuses on the commonality of our exclusion, rather than the traditional approach of seeing impairment as the problem, or the result of 'sin'. What may be different are the cultural and attitudinal barriers, systems and structures that are designed to keep disabled people out. Some societies are more accepting of disabled individuals, whereas others are deeply repressive and many more are indifferent to their disabled citizens. For many countries in the majority world, cultural influences are much greater than the medical influences of the North. Therefore Disabled People's Organisations (DPOs) must battle against traditional myths that state disabled people are everything from the embodiment of hereditary evil to the cure for HIV/AIDS.

The social model and international agencies

International agencies that do disability-related work, such as the WHO (World Health Organization) have done very little to change the traditional perception of disability which sees disability and impairment as a health and welfare issue. It's only in the last three years, and after ten years of discussion, that the WHO have revised the ICIDH (International Classification on Impairments, Disabilities and Handicaps) to include the disabling impact of the environment on people with impairments. The new ICIDH or ICF (International Classification for Functioning, Disability and Health) is far from perfect, but it is a move in the right direction (Hurst 2000). It will of course take years for the new classification to be implemented at all levels and for a culture shift away from a medicalised approach to disability, to recognition of the negative impact of an inaccessible environment. Unfortunately the situation around an international change in attitude has not been helped by the recent adoption of a health measurement called DALYS (Disability Adjusted Life Years) by bodies such as the World Bank (Russell 2003). DALYS focus on a 'cost benefit' analysis on impairment. Such measurement only serves to reinforce the negative assumptions made about our lives.

Conservative estimates indicate that there are approximately 600 million disabled people, the majority of whom live in countries in the majority world (UN 1990). Taking this into account, it is extremely hard to understand why it is that disabled people are absent from the text of international human rights instruments. In fact the only United Nations (UN) Convention to mention disability at all is the Convention on the Rights of the Child. Disabled people are conspicuous by our absence from the other conventions and indeed the Universal Declaration of Human Rights elaborated in 1948 confines disabled people within the category of 'and others'.

However in 1980, after years of lobbying by disabled people, the UN General Assembly declared 1981 International Year of Disabled Persons. During 1981 a resolution was passed that 1982 to 1993 would be a UN Decade of Disabled Persons that would deliver on the World Programme of Action Concerning Disabled Persons. For the first time the UN demonstrated a commitment to take steps to addressing the worldwide situation of disabled people or the 'silent emergency' as described by UN Secretary General, Perez de Cuellar.

By 1993 *The Standard Rules on Equality of Opportunities for Persons with Disabilities* had been adopted by the UN, in response to calls for a thematic legally binding human rights convention, from the international disabled people's movement. At the time the Standard Rules felt like a real breakthrough because disabled people thought that they were a framework that would create an implicit moral and political commitment from each member state to adopt measures to assure equality of opportunities. Unfortunately some 10 years down the line, the Standard Rules, because they have no basis in international human rights law have resulted in, at best, patchy implementation.

The social model and the international movement of disabled people

The social model is a catalyst – a driver for social action and social change and for disabled people coming together to form their own organisations – working together to identify the barriers to their full and equal participation – and the creation of an action plan for social change.

For disabled people living in countries in the majority world, their first contact with the reality of these new ideas was in 1980 at a Rehabilitation International (RI) conference in Winnipeg, Canada, to formulate an action plan for the 'International Year of the Disabled' in the following year. The 250 disabled people from 40 different countries who were invited, soon

realised that there would be no opportunity to be part of discussions, so chose to boycott the conference and hold their own discussions. Disabled Peoples' International (DPI) was born, in 1981, out of this frustration and its founders sent a clear message to bodies such as RI that never again would it be acceptable for discussions about disabled people to take place without our full and equal participation. Some international organisations of disabled persons already existed at this point, but they had been set up to work on impairment specific issues and were individually campaigning to get disability rights onto the international agenda. None as yet had consultative status with international bodies such as the UN.

At its first congress in 1981, founder members of DPI set out a Manifesto for change which called on:

> disabled people all over the world to unite in organisations of their own and to join DPI in a common struggle for full participation and equality with our fellow citizens (DPI 1981).

DPI's Manifesto set out a set of Basic Rights which included key demands for a right to independent living, a right to economic security and a right to influence. Disabled people were no longer prepared to accept non-disabled experts speaking for them and for the continued exclusion of disabled people from debates and discussions about our lives. DPI through its membership was committed to disabled people being 'where the power is and where important political decisions are made' (Malinga 2002). And so the slogan 'Nothing about us – without us' was born.

This ethos was the message that delegates took back to their own countries. They did not use social model language but the essence was the same – social action and social change. For many countries, particularly those in Africa and Asia, grassroots organisations have been battling, for years, against the ghosts of a colonial past and more recently, the western world agendas of the development agencies. Above all, for disabled people in these countries, the greatest battle has always been about day-to-day survival.

Ironically for many disabled people, in the South one of the greatest barriers to their empowerment, and ultimately their survival is the very aid agencies that secure millions from funders to support development work. Traditionally, development and aid has been seen as the attempt by those who have, to give to those who have not. Aid and development agencies have, historically, given money, time and expertise based on their experience in more 'developed' countries. Although there is now a better

understanding by those involved, that they should bring their expertise to good use in locally appropriate ways, and that development must be led by the people themselves, as far as disability is concerned, it is usually the case that traditional habits die hard.

Disability projects are still, in the main, paternalistic, medically based, exclusive and controlled by non-disabled people. In many cases agencies are still working with organisations that treat disabled people as passive receivers of charitable services, rather than working directly with, and being led by disabled people. As Joshua Malinga (past President of DPI) has said:

> when you (funding agencies) come to us please make sure you consult with us and find out exactly what our needs are and provide permanent solutions and not palliatives (Malinga 1981).

Some development and aid agencies have, in a very cynical move, taken on the language of disability rights and the social model, but continue to consider non-disabled people as experts when it comes to disabled people and our issues. Unfortunately for groups of disabled people based in rural communities in majority world countries, challenging such practices is almost impossible. After all these agencies are often gatekeepers to capacity-building opportunities and vital sources of funding.

There is some good collaborative work being done with the support of development and aid agencies and some are genuinely wanting to work within a social model paradigm – 'mainstreaming' is the new buzz word in development. But for some agencies, such as United Nations' Children's Fund (UNICEF), mainstreaming disability issues has effectively meant that disability issues fall off the international rights agenda. In fact some are more interested in prevention and rehabilitation than human and civil rights. In the case of UNICEF there is no longer anyone who has the sole responsibility for ensuring disabled children remain a priority issue. No surprise then that disabled children continue to remain invisible in policy documents and strategy papers looking at the situation of children generally.

To mainstream disability, development and aid agencies must ensure that they take a holistic approach to issues such as poverty reduction. Agencies must ensure that the monitoring and evaluation of projects are based on an assessment of environmental impacts and the barriers overcome, as well as on individual progress. Without taking a holistic approach to this process, the emphasis will continue to remain on changing individuals rather than changing society as a whole.

The social model in action

The social model of disability, as I have already said, is facing its own battle for survival. Since Oliver (1983) first coined the phrase back in the early eighties the social action to create social change element of the social model has been somewhat overshadowed by circular academic debate about its irrelevance to particular groups of disabled people or debates about the social model's 'failure' to recognise the impact of impairment related issues. As Oliver says:

> we have spent too much time talking about the social model....
> and not devoted enough attention to actually implementing or
> attempting to implement it in practice (Oliver 2004).

Across the world I think there is a very different story going on. The best way to illustrate this is by giving some examples where disabled people living in majority world countries have identified the barriers to their participation and what action they have taken to effectively create social change.

I have recently returned from Mexico where I visited a project called Projimo, a rural Community-based rehabilitation (CBR) programme run by disabled people. The Projimo project was started in the early 1980s, in response to the lack of healthcare support for disabled children in a remote village in the Sierra Madre mountains. Initial support and advice came from David Werner, a disabled American from California, who had been involved in the independent living movement. News of the project soon spread and disabled adults and children began to arrive from every part of Mexico. Many of the disabled people who initially came to Projimo for CBR have ended up staying to help others. Since then Projimo has changed and developed the services and support it provides. They currently make a wide range of mobility devices such as wheelchairs, tricycles, artificial legs and accessible toys and aids for disabled children. It has now moved to a small village called Coyotitan and the disabled people living and working in Projimo are an integral part of village life.

I am delighted to say that my visit to Projimo was everything I expected and more. Its strength is that it is run entirely by disabled people, but more than this, it is a community of about thirty people, disabled and non-disabled, people raising families, people of all ages, visitors staying there for CBR and then sometimes people like me, desperately trying to learn Spanish. The main part of their work is taken up with hand-made cost-effective solutions to the mobility needs of disabled children and adults who arrive on Projimo's proverbial 'doorstep' with nowhere else to go.

The more subtle stuff goes on virtually unnoticed. I met a fantastic young boy, Moises, who has been at Projimo for rehabilitation for about a year. Moises is seven, and attends the village school. He has incredible confidence in his future potential quite clearly gleaned from his time spent with other disabled people. This is also the case for families of disabled children visiting the project and for the local community, whose children play with the disabled children at Projimo because that is where the swings are!

However Projimo is not perfect. How could it be, it is run by human beings. For example the group of disabled people who live and work there are mostly people with physical impairments. Projimo is run by a core of strong and capable disabled women and there is the risk, as has happened elsewhere, that those whose voices are not as strong, or perhaps those who have greater personal assistance needs, are not heard. However, it was incredible to see, in a country were there is very little welfare support or social provision, a group of disabled people getting on and doing it for themselves – working and supporting themselves and others. Projimo gives a clear message that disabled people are our own experts and can and should have choice and control. This has also been the message throughout each of the books published by Projimo's founder, David Werner (1998). When I met David he told me that they did not want people to copy the work being done at Projimo but to use the ethos of 'Nothing About Us Without Us' when thinking about their own situation.

Projimo is in essence the social model in action and in a world where 98% of disabled people living in developing countries have no access to any form of rehabilitation, Projimo is an outstanding example of disabled people taking control. I have no doubt that my suggestion that a rehabilitation programme could ever be considered a good example of the social model in action, will be criticised by some people reading this chapter. I would argue that again those taking this stance are confused about the original intention of defining disability within a social context. In my reading, the social model supports any self-help activity controlled and supported by disabled people which shifts the cause of disability away from the individual and places it within the exclusionary nature of a disablist society. The social model does not deny the need for appropriate medical interventions (Campbell and Oliver 1996) but the key is what constitutes 'appropriate' – for example, who is controlling the intervention? Back in 1981, disabled people, who started Projimo, identified the main barriers to their participation as the lack of healthcare and assistive devices.

They then turned their interpretation of their particular situation into practice by making what was needed themselves and providing the necessary and 'appropriate' services themselves.

Another example of the social model in action is the SHAP (Self-help Association of Paraplegics) in Soweto in South Africa (Fletcher and Hurst 1995). This project was started by Friday Mandla Mavuso, who after becoming disabled during the struggles against apartheid, discovered that the lot of a disabled person was not good, with very little chance of surviving in such an inaccessible and hostile environment. Friday got together with other disabled people and devised a self-help business development project with the aim of creating employment for disabled people. After initial start-up funding, the SHAP project found markets for their products and began building on their original idea of taking action for themselves. Twenty years on SHAP, to all intents and purposes a Centre for Independent Living, still provides employment opportunities and all managerial positions are held by disabled people, but now SHAP is also involved in community initiatives to improve access to health, education, public transport and housing. They have also found the time to set up a choir of local disabled people which has made a number of successful records.

Through DAA's recent 'Rights for Disabled Children' project we have found some good and positive examples where disabled children are using social model understanding to push for their greater inclusion. One such example is the work being done by the Cambodian Disabled Peoples' organisation which supports the inclusion of deaf children into mainstream education. Until CDPO's Deaf Development programme (DDP) (Lansdown 2001), those deaf children who did have the opportunity to go to school were given no support to enable them to follow lessons. Mainstream schools did not recognise sign language and so the children were excluded from learning and often became targets for bullying. Many deaf children and adults were already using their own home-grown sign language but nothing had been done to actively teach signing, or to work on recognising sign language at a national level.

After a number of meetings, set up by CDPO, where deaf people of all ages who did sign met others who didn't, the use of sign language started to spread. The DDP has started to train deaf people as sign language teachers. The CDPO also organised a programme where deaf children met and talked with deaf adults who served as role models. Now the DDP has developed to the point where the deaf children are included in mainstream

education so they are able to learn alongside their non-disabled peers and where sign language is incorporated into the teaching programme.

The last example I am going to give you of what I believe is the social model in action relates again to education. I think that if only 2 per cent of disabled children living in countries in the majority world attend school, then lack of access to education is undoubtedly one of the greatest barriers. The Divine Light Trust, in India, started out, in the 1950s, as a school for visually impaired children. However, after it had been open for a number of years (35 to be precise), the school's Director discovered that only about 5 per cent of visually impaired children throughout India had access to education. It was decided that something radical needed to happen for this to change.

The Divine Light Trust school turned itself into a resource centre training teachers in mainstream education to enable disabled children with visual impairments to be fully included into their neighbourhood schools. The outcome, of course, is not just that now many more children have access to educational opportunities, but also such an approach makes segregated education provision redundant.

At the heart of the social model is the understanding that until disabled people are part of the fabric of society then we will continue to be excluded and treated as 'other'. I have talked about some of the work being done in Mexico, South Africa, India and Cambodia but the fact is groups of disabled people across the majority world are using social model thinking in their daily lives.

Quite exceptionally, two countries, South Africa and Uganda have achieved the social model within their political systems, and in the case of South Africa, have actually articulated it in a White Paper on Disability. (Office of the Deputy President 1997). The South African Government's Integrated National Disability Strategy White Paper 'provides a vision and coherent value structure for driving disability issues in government and society' (Matsebula 2003). It is interesting to note that both these political approaches have arisen as a result of their emergence from apartheid, oppression, violence and conflict and an understanding that disabled people are a specific group which has faced social inequality and injustice.

In South Africa, the Office on the Status of Disabled People is in the President's office, is run by disabled people, has executive powers over other departments, including monitoring their use of the statutory 10 per cent of their budgets on disability. Regional sub-offices also only employ disabled people. Disabled people are appointed to leading political jobs and are members of parliament and regional and local authorities.

In Uganda, the Movement Government, under President Museveni, has assured for disabled people, 5 seats in parliament, one ministerial post and 6,000 local council positions from village to district level. All are elected into their positions by the disabled community. The disabled politicians at all levels have played a significant role in influencing all other public policies, including ensuring that Uganda's recent 'Education for All' legislation stipulates that for the four free places provided by the state for each family, priority must be given to any disabled children. But as Macline Twimyuke, the Executive Director of the National Union of Disabled Persons in Uganda, has rightly said:

> Although Uganda boasts the largest number of political representatives of disabled people in government structures in the world, we (disabled people) cannot afford to be complacent. If there is a change of government these advances could be swept away (Twimyuke 2001).

Inevitably, in both these countries, this high level of status of disabled people has not meant an end to poverty and exclusion, any more than it has for the poor non-disabled people. But the understanding of the social model is both articulated in political agreements and implemented in the political systems. This is a far cry from the status of disabled people in other countries around the world!

Lessons from majority world interpretations of the social model

For me, what is clear from the examples I have given is that disabled people in countries in the majority world are taking *social action for social change*. They are getting on with it themselves, either because no one else can or will, or because disabled people have disengaged from those agencies and charities which have traditionally provided western-driven aid, which is both irrelevant and paternalistic. There are very few countries in the majority world where there is any kind of state or social support. The onus is on individuals to identify self-help solutions – the alternative is starvation. For those of us who live in countries where there is some level of welfare support, we are not going to starve, but welfare is itself a barrier to our participation.

Conclusion

The truth of the matter is that despite the social action examples I have identified in this chapter, for many disabled people around the world, their situation and status whether it be at the grassroots or at a national level

remains at a de-humanising low. Disabled people remain the poorest of the poor whatever the economic state of the country. Disabled people in every country around the world are still being excluded, abused and killed because of the continued lack of value given to our lives and lack of recognition of our humanity. And for many disabled people facing such a fate, a social model explanation for their experience seems irrelevant because it is not the quick fix solution many desperately want. The evidence from Disability Awareness in Action's Human Rights Violations database shows that nearly half a million disabled people have had their human rights violated – 10 per cent of this number have been denied the 'Right to Life' – 31 per cent experienced cruel and degrading treatment (Light 2003). This clearly shows that we are still a long way from a world free of disablism.

The social model has illustrated clearly that solutions to our exclusion, our oppression lie in human rights, equality and justice and the celebration of diversity. The social model is not just an academic tool, it is a lived experience as can be seen from the work being done by the disabled people living in Projimo, Africa, Asia and in many other parts of the majority world. So in conclusion the social model is still absolutely relevant as an explanation of our experience as disabled people whether we live in the developed or majority world. The barriers may be different but the solutions are the same – social action creating social change.

Bibliography

Campbell, J. and Oliver, M. 1996: *Disability Politics: Understanding our Past, Changing our Future*. London: Routledge.

DPI 1981: *Proceedings of the First World Congress*. Sweden: Disabled Peoples' International.

Fletcher, A. and Hurst, R. 1995: *Overcoming Obstacles to the Integration of Disabled People*. London: Disability Awareness in Action.

Hunt, P. 1966: A critical condition. In P. Hunt (ed.), *Stigma: The Experience of Disability*. London: Geoffrey Chapman, 145–59.

Hurst, R. 2000: To Revise or Not to Revise? *Disability & Society*, 15 (7), 1083–1087.

Lansdown, G. 2001: *It is our World Too! – a report on the lives of disabled children*. London: Disability Awareness in Action.

Light, R. 2003: *Review of Evidence contained on the DAA Human Rights Database*. London: Disability Awareness in Action & DAART Centre.

Malinga, J. 1981: Zimbabwe Independence and DPI. ***Proceedings of the First World Congress***. Sweden: Disabled Peoples' International.

Malinga, J. 2002: *The Disability Movement is at a Crossroads*. A speech at the DPI World Congress. Sapporo, Japan.

Matsebula, S. 2003: *Lessons learned from the Office on the Status of Disabled People in the Presidency* – a speech at the 'Left off the Agenda – Mainstreaming Disability in Development' Conference 11/12 November. London.

Office of the Deputy President 1997: ***Integrated National Disability Strategy White Paper***. South Africa: Office of the Deputy President, Government of South Africa.

Oliver, M. 1983: ***Social Work with Disabled People***. Basingstoke: Macmillan.

Oliver, M. 2004: The Social Model in Action: if I had a hammer. Barnes, C. and Mercer, G. (eds), ***Implementing the Social Model of Disability: Theory and Research***. Leeds: The Disability Press.

Russell, M. 2003: ***Nothing About Us Without Us: Human Rights and Disability***. Znet Commentaries. http://www.zmag.org

Stone, E. (ed.) 1999: ***Disability and Development in the Majority World***. Leeds: The Disability Press.

Twimyuke, M. 2001: *The need for a United Nations Convention on Disability* – a speech at the Disability Rights: A Global Concern Conference. 21 June 2001. London

United Nations. 1990: ***Disability Statistics Compendium***. New York: United Nations Statistics Office.

UPIAS 1976: ***Fundamental Principles of Disability***. London: Union of the Physically Impaired Against Segregation.

Werner, D. 1998: ***Nothing About Us Without Us: Developing Innovative Technologies For, By and With Disabled People***. Palo Alto: Healthwrights.