Disability KAR
Knowledge and Research

BRIEFING PAPER

Disability and a human rights approach to development

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> ‘Disability is a human rights issue! I repeat: disability is a human rights issue.’
>
> Bengt Lindqvist, UN Special Rapporteur on Disability

Introduction

This is the second of two linked briefing notes prepared for the Disability Knowledge and Research (KaR) programme. In the first[1] it was argued that the social model of disability presents a conceptualisation of disability that makes the most sense in terms of an emancipating, participatory, human rights approach to development. In this note we look at what the human rights approach to development means in practice, drawing on both what disabled people have already achieved and highlighting the challenges and opportunities offered by the new aid instruments and structures.

The social model of disability

As set out in more detail in the first briefing note, the social model of disability provides an understanding that is substantially different from the traditional view that disability is essentially about physical or mental deficit or abnormality. Within a social model paradigm impairment is seen as normal for any population. What disadvantages and disables people with impairments is a complex web of discrimination made up of negative social attitudes and cultural assumptions as well as environmental barriers, including policies, laws, structures and services, which result in economic marginalisation and social exclusion.

Of course, this social model analysis is not limited to disability. It has been used to describe the experience of invalidation, inequality and injustice for all groups that face discrimination (Kallen 2004). Essentially, the social model offers an analytical framework for understanding why and how this discrimination occurs.

[1] Bill Albert, 2004. www.disabilitykar.net/pdfs/social_model_briefing.pdf

Why disability is a human rights issue and in turn a development issue

Human rights are a twentieth century phenomenon developed in response to the atrocities of World War II. They set out an internationally accepted moral code by which the intrinsic humanity of every individual is recognised and protected. Human rights are the fundamental, universal and indivisible principles by which every human being can claim justice and equality.

As disability describes the barriers faced by people with impairments to achieving equality and justice, and because disabled people are human beings too, it is axiomatic that disability is a human rights issue. And as with all groups who face discrimination and disadvantage it is the recognition of that intrinsic humanity that is essential to reaching outcomes that result in the full implementation and protection of human rights.

As the 24th Special Session of the UN World Summit for Social Development and Beyond (June 2000) declared, 'The ultimate goals of development are to improve living conditions for people and to empower them to participate fully in the economic, political and social arenas.' This development must be achieved *for all people*.

However, as has been repeatedly documented, access to full and equal participation has been denied to disabled people in almost every country, helping to create conditions that result in them being among the poorest of the poor. At the same time, being poor is not only about being socially excluded but also makes people much more vulnerable to contracting a whole range of disabling impairments. Poverty and disability are in this sense locked in the embrace of a real dance of death. This is made far worse in developing countries in the South, where the failure of economic and social development is characterised by widespread and seemingly intractable poverty associated with wars and civil unrest, malnutrition, poor sanitation, lack of immunisation, inadequate health care, few safety provisions and pollution. Such is the music, which gives the dancers no respite.

Human rights are indivisible and universal. Continuing to leave disabled people out of mainstream systems of development by perpetuating discrimination and exclusion violates these rights. From a human rights perspective, development programmes can, therefore, no longer make excuses for not addressing disability, particularly as many development agencies now claim to be working within an explicit human rights framework.

> 'Overlooking or ignoring the plight of disabled people is not an option that an acceptable theory of justice can have.'
>
> Amartya Sen, 2004

A human rights approach to development

Since the 1990s many multi-lateral and bi-lateral agencies have adopted a human rights approach to development. This approach seeks to ensure that each person is seen as having an equal right to freedom, dignity, non-discrimination and protection from the state against abuse of these rights, together with access to economic, cultural and social rights. It is argued that only by empowering all people to be able to make decisions about their lives will it be possible to reduce poverty and achieve the Millennium Development Goals.

> 'Universality means that all people have the right to claim agreed economic, social and cultural, civil and political entitlements. Universality also means that all people have equal rights. In practice, it is often particular groups of people who cannot claim their rights in different areas of their lives. Policies and practices of governments, civil society and the private sector may discriminate on the basis of class, gender, age, ethnicity, disability or other social status. The consequent inequities in education health, employment, income and political representation perpetuate the powerlessness of the excluded. High levels of inequality generate social division, constrain sustainable development and are a common cause of violent conflict.'
>
> Department for International Development (DFID), *Realising human rights for poor people* (2000)

The UK Department for International Development (DFID) has been one of the leaders in developing this approach, which was set out forcefully in White Papers it produced in 1997 and 2000, and in a number of other major documents, including the 2000 target strategy paper (TSP), *Realising human rights for poor people*. [2] While there are a great many strands to DFID's approach, the main, cross-cutting principles are:

'**Participation**: enabling people to realise their rights to participate in, and access information relating to, the decision-making processes which affect their lives.
Inclusion: building socially inclusive societies, based on the values of equality and non-discrimination, through development which promotes all human rights for all people.
Fulfilling obligations: strengthening institutions and policies which ensure that obligations to protect and promote the realisation of all human rights are fulfilled by states and other duty bearers.'
(DFID, 2000a)

> 'Growth will not, by itself, guarantee that most people in a country have the chance to live lives of dignity and fulfilment. A healthy society is one that takes care of *all* its members, and gives them a chance to participate in decisions that affect their lives.'
>
> Kofi Annan, UN Secretary-General, 2000

Disabled people's role and status

Although disabled people are mentioned in DFID's 2000 target strategy paper on poverty, the way in which their human rights are compromised and the connection between this and poverty is not spelt out. Only by understanding disability from a social model viewpoint, that is with disability being the result of systematic discrimination rather than impairment itself, can the link be made in such a way as to establish a framework for tackling the human rights

[2] For a review of DFID's human rights approach see Laure-Hélène Piron and Francis Watkins, *DFID human rights review. A review of how DFID has integrated human rights into its work*, Overseas Development Institute, July 2004

abuses and poverty which continue to blight the lives of the vast majority of disabled people in the developing world. And, as many prominent commentators have observed, unless this is done it will prove impossible to achieve the poverty reduction targets set out in the Millennium Development Goals.

> 'Unless disabled people are brought into the development mainstream, it will be impossible to cut poverty in half by 2015 or to give every girl and boy the chance to achieve a primary education by the same date – goals agreed to by more than 180 world leaders at the UN Millennium Summit in September 2000'
>
> James Wolfensohn, former President of the World Bank

As will be outlined below, disabled people have been fostering progressive social change by putting a human rights approach to development into practice, often many years before such an approach was adopted by international agencies. While disabled people's organisations (DPOs) are keenly aware of human rights issues and/or have explicitly adopted the social model as their guiding ideal, generally the projects and organisations have developed through a more prosaic route, people simply trying to understand the oppression they experience and struggling against it at a local or national level. As is often the case, it is only through this kind of struggle that a broader and more socially transforming understanding is achieved.

'Nothing about us without us'

It is not surprising that different local circumstances mean there is considerable variation with respect to how a human rights approach has evolved. Nonetheless, there is one defining characteristic: *all such interventions based on this approach have been controlled by disabled people themselves.* This in turn accords with a key observation made in DFID's target strategy paper that: 'Human rights provide a means of empowering all people to make decisions about their own lives rather than being the passive objects of choices made on their behalf' (DFID, 2000a, p10). For disabled people this is of particular significance since traditionally they have been seen as a

group which needs to be looked after by others, not one that can act on their own behalf.

'Nothing about us without us' was the slogan promoted by Disabled Peoples' International at its founding in 1981 and has been used by disability rights activists every since. It has been particularly effective in capturing a key idea of disabled people's struggle for human rights – self determination is essential for achieving equality. This in turn has helped to unite groups from countries throughout the world in common cause. It has, for example, informed their message to governments taking part in the UN process of elaborating a convention on protecting the rights of disabled people: that in doing this they must listen to the voice of disabled people.

Disability and human rights in action

'A rights based approach to disability and development is about levelling the playing field so that people with disabilities can access jobs, education, health and other services. A rights based approach is about the removal of physical and social barriers; it is about attitude adjustments for policy makers, employers, teachers, health care professionals and even family members. A rights based approach is about ensuring universal design, accessible technology, and coordinated public programmes and service. The approach requires government to provide the resources necessary to implement these goals and to enforce penalties for those who refuse to cooperate.'

Disability Dialogue, Issue No. 4, SAFOD (Southern African Federation of the Disabled)

There are a considerable number of long-term projects developed by disabled people which exhibit implicitly or explicitly a human rights approach as outlined in the box above by SAFOD, as well as conforming to the DFID's three principles – participation, inclusion and fulfilling obligations – with regard to disabled people. There are local organisations of disabled people who run income-generating projects such as chicken farms or crafts, operate loan schemes for small businesses, run local community based rehabilitation services and work cooperatively with local elders to raise the status of disabled people in their village and to ensure greater access and self-

determination. These groups are often linked to regional and national organisations who provide them with leadership training, capacity building and the most essential information needed to take action on these rights-based activities. It is crucial that both the local and national organisations or groups do not only take part in specific income generation or CBR projects, but are also involved in:

- ensuring that all policies and programmes that affect disabled people involve disabled people
- raising the status and opportunities for self-determination of disabled people both locally and nationally
- cooperating with the local community and thereby changing attitudes to disability

And last, but by no means least:

- spreading the word – telling other disabled people and the wider community that disability is a human rights issue, how to achieve those rights, giving examples of good practice and how to overcome the obstacles to inclusion and participation.

Below two of these projects are briefly outlined in order to show how a human rights approach grew organically out of struggles against the systemic oppression and denial of basic human rights experienced by disabled people and the transforming power of this approach. We also consider an example of how this same approach has been applied at a higher level by disabled people seeking to build a disability dimension into Poverty Reduction Strategy Papers (PRSPs).

1. Self-Help Association of Paraplegics (SHAP), Soweto, South Africa

In the 1980s black disabled people in South Africa had little chance of survival in such an inaccessible and hostile environment, let alone the chance to achieve a decent standard of living.

In 1981 a group of eight disabled individuals, many of whom had been disabled in the fight against apartheid and unhappy with the prospect of being forced into institutional care, decided to set up a

self help association. They wanted to enjoy the simple dignity of being in control of their own lives but realised this meant having to support themselves. They decided to do this by opening a factory, employing only disabled people, doing sub-contract work for industry. With start-up funding from corporations and trust funds the first SHAP Centre opened in 1983, the second in 1989. From the outset SHAP has been managed by disabled people and after the initial employment initiative, SHAP expanded its programmes to include transport, sport, education, training, advice and peer support. By doing this it has provided a liberating example to other self-help groups in South Africa who are, in differing circumstances, seeking to follow their lead. (Nkeli, 1998)

One of the crucial elements of SHAP was its economic self-sufficiency. After an initial injection of start-up aid funding, SHAP functioned and grew as a non-profit making business. This has also set an example to many disabled people's organisations both in the South and North who, without that economic self-sufficiency, can be constrained in their self-determination by funding criteria and the objectives of aid and development funders. (DuToit, 1989)

Within the context of a human rights approach, the SHAP example is instructive because their initial motivation was about achieving economic independence, not human rights. As Jerry Nkeli, explained:

'In the early 1980s a few of our colleagues in South Africa attended an international conference organized by Rehabilitation International. The few people [from South Africa] who attended that conference were quite privileged and all were from the white community. They came back with a lot of excitement. They had the theory, they knew that it is proper to reject charity and welfare, but they didn't have the numbers. They met the self-help group in Soweto, who did not know how to philosophize, who didn't know how to contextualize their struggle, but who in a very simple way understood that they did not want charity and wanted to run their own life and who had the numbers.' (Nkeli, 1998)

In other words, the founders of SHAP had grasped the importance of self determination, a central element in the current human rights discourse, 20 years before it was taken up by the aid agencies. The

linking of the two groups of disabled people, from Soweto and those with international experience, the example of the black liberation struggle in the US and the continuing battle against apartheid was the heady mixture out of which the South African disability movement was forged.

It is interesting to note that the same meeting of Rehabilitation International, which was to have such a strong impact on SHAP, also prompted the birth of Disabled Peoples' International. In fact, over 200 disabled people returned to their own countries after that conference and set up national organisations of disabled people whose primary demand was for 'full participation and equality in our society with equal rights and responsibilities' (DPI, 1981).The leaders of SHAP went on to the leadership of Disabled Peoples' South Africa (DPSA) and then on to the world arena of disability rights, creating effective role models for disabled people everywhere.

2. Andhra Pradesh Rural Poverty Reduction Program (APRPRP), India

A pilot programme in Andhra Pradesh for reducing poverty, which was funded mostly by the World Bank, contained a 'disability component'. David Werner, one of the founders of the Projimo Project in Mexico[3], was brought in as an advisor. The work done in India bears many of the hallmarks of Projimo's participatory approach, essentially involving disabled people in leadership roles and at all stages of the process, including initial planning and the feasibility survey.

The first part of the project was extremely important, because having disabled people leading the local poverty surveys both encouraged disabled villagers to get involved and offered empowering role models.[4] The survey was designed around a rights-based approach and drew heavily on Paulo Freire's pedagogy of liberation, based on

[3] The Projimo Project, begun in 1981, is a community rehabilitation project run by and for disabled people

[4] A similar process was carried out for the Disability KaR Programme in rural Cambodia and is documented in the report by Steve Harknett et al (2005)

having people describe their world and then through a grounded participatory process arrive at ways to transform it.

One of the outcomes of the survey was the setting up of disability 'sangams' (common interest self-help groups) at village level so that disabled people could work together to improve their situation, both socially and economically. In the sangams disabled people are able to define their own needs, the barriers that exist and collectively take action to overcome them. They also organise demands for legal certification (many disabled children and adults are never registered) and entitlements. Another major goal has been getting disabled children into schools, as well as obtaining the necessary medical care, surgery and assistive devices they need.

Werner writes: 'Within the self-help disability sangams in Mahabubnagar, the interest and potential exist to improve health and rehabilitation services at the village level. Such an empowerment approach could help meet an urgent need for the most vulnerable people. It would also increase respect and opportunities for disabled people. *And reduce poverty*.'

One of the biggest accomplishments the members say they have made is 'to be treated with respect'. 'Now people don't call us "the lame boy" or "the blind girl" but address us by our real names' (Werner, 2002).

The disabled people who initiated this project are not yet fully involved in India's national disability rights agenda, but because of the size of the country and the cultural and political scene, the disability movement has not been able to coordinate nationally with any real coherence. They have, however, had considerable influence on the regional and local environments.

In 2003, the World Bank agreed further to support the APRPRP with a credit of US$150 million. Judith Heumann, the World Bank's Advisor on Disability and Development, said: 'The inclusion of the disability community into this project will enable us to reach a group from the poorest of the poor, who are usually forgotten. The efforts of this project should be duplicated in other states' (World Bank Group 2003).

DPOs engage in formulating Poverty Reduction Strategy Papers: the case of the National Union of Disabled Persons of Uganda (NUDIPU)

Project work on disability and development remains important, but over the last decade or so, an increasing proportion of aid for the poorest countries has been delivered through World Bank/International Monetary Fund (IMF) budget support programmes built around Poverty Reduction Strategy Papers (PRSP) and related aid instruments. On the whole, disability and other cross-cutting issues have fared badly in this new aid regime (Miller and Albert, 2005). On the face of it this may appear somewhat surprising, as a key element in the process of putting together a PRSP is supposed to be consultation with civil society as well as the development of pro-poor growth strategies. With disabled people clearly being both part of civil society and among the poorest of the poor it might be expected that they would be a key constituency. However, a recent World Bank survey (World Bank, 2004) concluded that the coverage of disability within PRSPs was limited and a '…patchwork of fragmented and uncoordinated interventions'. It was also clear that in PRSPs most references that there are to disability are about social protection, not social inclusion.

Because development and spending plans are set out in the PRSPs, if disability fails to get included as a mainstreamed consideration it is likely that the needs of disabled people will continue not to be met. This is why it is so vital that DPOs have a strong voice at every stage of the consultation process. If this was to happen anywhere in the developing world, Uganda was the most likely country, as it has perhaps one of the strongest disability movements and disabled people are integrated at all levels of government. Nonetheless, it was not until the third PRSP that this was to happen and then not without a concerted political effort by disabled people.

The National Union of Disabled Persons of Uganda (NUDIPU) is the national umbrella organisation for Ugandan DPOs. It was set up in 1987 to give a unified voice to disabled people. It now has almost 70 member groups and works closely with national, regional and local

government. The organisation promotes the social model and sees disability as a human rights issue.

> 'NUDIPU perceives the cause of PWDs (people with disabilities) as a human rights issue and aims at liberation and empowerment. The focus of empowerment and liberation is on developing potentials, raising awareness and removal of barriers to integration in society and enjoyment of human rights. Disability is a human rights issue.' (Ndeezi, 2004)

The alleviation of poverty is a principle goal of NUDIPU and this is why they lobbied the government so strenuously to become included in developing the Poverty Eradication Action Plan (PEAP), as the PRSP is known in Uganda (Dube, 2005).

Supported by the Danish Council of Organisations of Disabled People (DSI) and Action on Disability and Development (ADD), NUDIPU developed a detailed submission, the result of research and a broad-based consultation with member groups and disabled people. But, despite having a nominal place at the table, NUDIPU had all kinds of problems. Technical capacity was a major one, as the PRSP process is extraordinarily complex. There was also pressure from donors and government to get the PRSP settled quickly so that the aid would flow. 'As a result, the PEAP process, in which civil society had been meaningfully involved, became constricted into a six month PRSP process from which they found themselves, to some extent, squeezed out' (Dube, 2005). Many people also considered that the government, as well as the World Bank and the IMF, were using DPO involvement as a way of legitimising the PRSP process, rather than out of any genuine interest in the rights or needs of disabled people.

Conclusion

A great many more examples could be given of DPOs involved in innovative, human-rights based projects of empowerment and poverty alleviation. Most of these have undoubtedly made a considerable difference to the disabled people they have touched, the problem is that overall they have not succeeded in touching the vast

majority who continue to be actively and passively excluded from the mainstream of society.

As David Werner (2000, p7) writes of the poverty reduction project in Andhra Pradesh: 'Clearly, to substantially reduce poverty in India – or anywhere else – will require transformation of unjust socioeconomic and political structures that go far beyond the village-based health and rehabilitation measures. But in the meantime, such measures can help the most vulnerable villagers cope a bit more successfully. *By coming together to solve their problems in time a critical mass of "people who care for one another as equals" will be reached so that, collectively, they can begin to demand and work for more far-reaching change*.'

In theory, the PRSP process should be one way to help bring about this 'far-reaching change' as it provides the opportunity for a more democratic formulation of governments' economic policies and a greater opportunity to get disability on the mainstream development agenda. However, as yet this has not happened. The example of Uganda points to the need for more sustained donor capacity-building support for DPOs so they can take part on equal terms, consult and inform their members and hold their governments to account. It also points to a need for donors and governments to take more seriously as well as genuinely value the contribution from civil society organisations. Donors especially must be more assiduous in discovering methods within the new aid paradigm to encourage governments to do this.

Unless this happens, a human rights approach to development will be, as many critics have claimed it is, little more than empty rhetoric to deflect public attention from the resource-draining, poverty-engendering political economy of globalisation.

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