Disability and a Human Rights Approach to Development

“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 KaR programme. In the first 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 and human rights

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.

This social model approach has been used to describe the experience of invalidation, inequality, and injustice for all groups who face discrimination (Kallen 2004).

Essentially, the social model defines difference and disadvantage thereby indicating what social change needs to take place to ensure equality and justice for all.

Human rights are a twentieth century phenomenon in response to the atrocities of World War 2, to 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 single human being can gain justice and equality.
Why disability is a human rights issue and in turn a development issue

As disability describes the barriers faced by people with impairments to 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 for equality and justice outcomes and full implementation and protection of human rights.

As the 24th Special Session of the UN World Summit for Social Development and beyond (1 July 200) said: “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, without discrimination.

As has been repeatedly documented, access to full and equal participation in their societies has been denied disabled people in all countries, putting them amongst the poorest of the poor.

In addition their need for income is greater than that of non-disabled people since they need money and assistance to try to live normal lives (Sen, 2004).

Similarly, lack of development and economic growth creates disabled people through malnutrition, poor sanitation, lack of immunisation, poverty, poor health and safety provisions and pollution.

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

From a human rights perspective, development programmes can no longer make excuses for not addressing disability.

To intentionally exclude disability would be a violation of human rights as expressed in several legal instruments that states have ratified.

Rights are indivisible and universal: leaving disabled people out of mainstream systems of development perpetuates discrimination and exclusion.
A human rights approach to development

To address the problem of poverty many multilateral and bi-lateral agencies have, since the 1990s, 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.

DFID has been one of the leaders in developing this approach, which was set out forcefully in the 1997 and 2000 White Papers (DFID, 1997 and 2000) and in a number of other major documents, including the 2000 Target Strategy Paper (TSP), Realising human rights for poor people.

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

“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, President The World Bank
Disabled People’s Role and Status

Although disabled people are mentioned in DFID’s 2000 TSP on poverty, the way in which their human rights are compromised and the connection between this and poverty is not spelled out.

Only by understanding disability within a social model view, that is as 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 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.

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 many 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”

As one would expect, different local circumstances mean there is considerable variation with respect to how a human rights approach has evolved.

Nonetheless, they share one defining characteristic – they are all controlled by disabled people themselves.

This in turn accords with a key observation made in DFID’s TSP, 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, 10).

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 which can act on their own behalf.
“Nothing about us Without Us” was the slogan promoted by Disabled Peoples’ International at their founding in 1981 and has been used by disability rights activists every since.

It has been particularly effective in ensuring that government the UN process of an elaboration of a convention specifically on protection of the rights of disabled people should 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.*

There are a considerable number of long-term projects developed by disabled people which exhibit implicitly or explicitly a human rights approach as outlined 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 locally run 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 are not just involved in specific income generation or CBR projects but are 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.

We briefly outline two of these projects 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.

**Self-Help Association of Paraplegics (SHAP) in Soweto**

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 onset 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 they have provided a liberating example of other self-help groups in South Africa who are, in differing circumstances, seeking to follow their lead.

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.

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.”

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 original meeting of Rehabilitation International 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 and then on to the world arena of disability rights, creating effective role models for disabled people everywhere.
Andhra Pradesh Rural Poverty Reduction Program (APRPRP)

Disabled people played a leading role in APRPRP, including initial planning and feasibility survey.

They set up disability ‘sangams’ (common interest self-help groups) at the village level so that disabled people could work together to improve their situation, both socially and economically.

They define their own needs and barriers and collectively take action. They organise demand for their legal certification (many disabled children and adults are never registered) and entitlements.

They work to get disabled children into schools and for them all to obtain the necessary medical care, surgery and assistive devices they need.

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 the 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.
References


