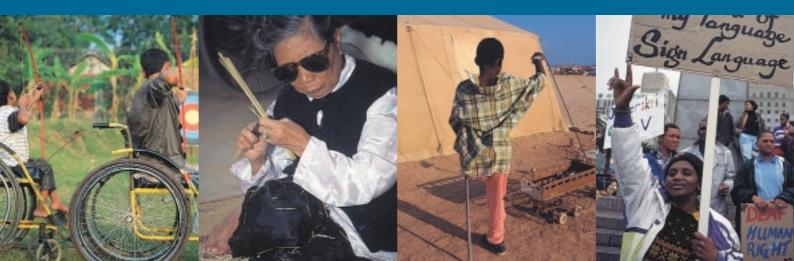


# Disability, poverty and development



### **Department for International Development**

The Department for International Development (DFID) is the British government department responsible for promoting development and the reduction of poverty. The government elected in May 1997 increased its commitment to development by strengthening the department and increasing its budget.

The policy of the government was set out in the White Paper on International Development, published in November 1997. The central focus of the policy is a commitment to the internationally agreed target to halve the proportion of people living in extreme poverty by 2015, together with the associated targets including basic health care provision and universal access to primary education by the same date.

DFID seeks to work in partnership with governments which are committed to the international targets, and seeks to work with business, civil society and the research community to encourage progress which will help reduce poverty. We also work with multilateral institutions including the World Bank, United Nations agencies and the European Commission. The bulk of our assistance is concentrated on the poorest countries in Asia and sub-Saharan Africa.

We are also contributing to poverty elimination and sustainable development in middle income countries, and helping the transition countries in Central and Eastern Europe to try to ensure that the widest number of people benefit from the process of change.

As well as its headquarters in London and East Kilbride, DFID has offices in New Delhi, Bangkok, Dhaka, Kathmandu, Nairobi, Dar-es-Salaam, Kampala, Harare, Pretoria, Suva and Bridgetown. In other parts of the world, DFID works through staff based in British embassies and high commissions.

## Disability, poverty and development

#### Contents

Introduction	1
Disability & poverty	2
What is disability?	
The International Development Targets	
Poverty: a cause & consequence	
The costs of disability	
Rights & social exclusion	
Differential needs	
The international framework	6
Approaches and good practice	7
Prevention	
The 'social model' of disability	
Community-based rehabilitation	
Areas for action and the role of development co-operation	11
The twin-track approach	
Policy	
Economic, social and human development	
Infrastructure	
Conflict and humanitarian assistance	
Empowerment	
Media and communications	
Gaps in knowledge	
Measuring progress	

Annex: United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities 16

Page

Disability is both a cause and consequence of poverty. Eliminating world poverty is unlikely to be achieved unless the rights and needs of people with disabilities are taken into account.

According to the United Nations, one person in 20 has a disability. More than three out of four of these live in a developing country<sup>1</sup>. More often than not they are among the poorest of the poor. Recent World Bank estimates suggest they may account for as many as one in five of the world's poorest<sup>2</sup>. Disability limits access to education and employment, and leads to economic and social exclusion. Poor people with disabilities are caught in a vicious cycle of poverty and disability, each being both a cause and a consequence of the other.

A large proportion of disability is preventable. Achieving the international development targets for economic, social and human development will undoubtedly reduce the levels of disability in many poor countries. However, general improvements in living conditions will not be enough. Specific steps are still required, not only for prevention, but also to ensure that people with disabilities are able to participate fully in the development process, obtain a fair share of the benefits, and claim their rights as full and equal members of society.

An integrated approach is required, linking prevention and rehabilitation with empowerment strategies and changes in attitudes. This paper assesses the significance of disability as a key development issue, and its importance in relation to poverty, human rights, and the achievement of internationally agreed development targets. It also sets out ways in which development co-operation, including DFID's own work, can help incorporate the rights and needs of people with disabilities into the mainstream of poverty reduction work and the achievement of human rights.

<sup>&</sup>lt;sup>1</sup>E. Helander, *Prejudice and Dignity; an introduction to community based rehabilitation*, UNDP, 1992. One in 20 is a conservative estimate, with some sources suggesting that as many as one in ten of the world's population may be defined as having a disability. <sup>2</sup>Ann Elwan, Poverty and Disability; a background paper for the World Development Report, World Bank, October 1999.

#### What is disability?

Defining disability is complex and controversial. Though arising from physical or intellectual impairment, disability has social implications as well as health ones. A full understanding of disability recognises that it has a powerful human rights dimension and is often associated with social exclusion, and increased exposure and vulnerability to poverty. Disability is the outcome of complex interactions between the functional limitations arising from a person's physical, intellectual, or mental condition and the social and physical environment. It has multiple dimensions and is far more than an individual health or medical problem.

On this basis, the working definition of disability adopted in this paper is 'long-term impairment leading to social and economic disadvantages, denial of rights, and limited opportunities to play an equal part in the life of the community'.

#### The International Development Targets

The international community is committed to an agreed set of development targets, aimed at significantly reducing poverty and accelerating the pace of economic, social and human development. These are summarised in Box 1. The international development targets are directly relevant to women, men and children with disabilities in poorer countries. Their needs and rights cannot be fully addressed unless the underlying causes of poverty are tackled, unless they are empowered to gain access to education, health services, a livelihood and participate fully in social life. Given the high proportion of people with disabilities among the poor, it is unlikely that these targets can be properly achieved without specific efforts to tackle disability.

#### Poverty: a cause and consequence

Poverty is both a cause and consequence of disability. Poverty and disability reinforce each other, contributing to increased vulnerability and exclusion.

The majority of people with disabilities find their situation affects their chances of going to school, working for a living, enjoying family life, and participating as equals in social life. It is estimated that only 2% of people with disabilities in developing countries have access to rehabilitation and appropriate basic services<sup>3</sup>.

#### Box 1: The International Development Targets

The UK Government is committed to a set of internationally agreed development targets:

Economic Well-being

• a reduction by one-half in the proportion of people living in extreme poverty by 2015

#### Human and Social Development

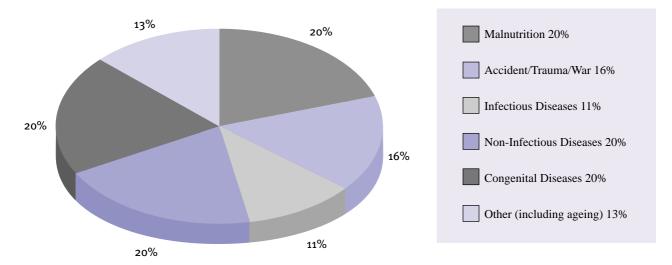
- universal primary education in all countries by 2015
- demonstrated progress towards gender equality and the empowerment of women by eliminating gender disparity in primary and secondary education by 2005
- a reduction by two-thirds in the mortality rates for infants and children under age five by 2015
- a reduction by three-quarters in maternal mortality by 2015
- access through the primary health care system to reproductive health services for all individuals of appropriate ages as soon as possible and no later than the year 2015

#### Environmental Sustainability and Regeneration

• the implementation of national strategies for sustainable development in all countries by 2005, so as to ensure that current trends in the loss of environmental resources are effectively reversed at both global and national levels by 2015

<sup>&</sup>lt;sup>3</sup>Leandro Despouy, 1993, Human Rights and Disabled Persons (Study Series 6), Centre for Human Rights Geneva and UN New York.

#### Figure 1: Causes of impairment



Source: UN Figures in Overcoming Obstacles to the Integration of Disabled People, UNESCO, DAA, March 1995

Poor nutrition, dangerous working and living conditions, limited access to vaccination programmes, and to health and maternity care, poor hygiene, bad sanitation, inadequate information about the causes of impairments, war and conflict, and natural disasters all cause disability (see Figure 1). Many of these causes are preventable. According to estimates by the World Health Organisation (WHO), as many as 20 million women a year suffer disability and long-term complications as a result of pregnancy and childbirth. The most common causes of motor disability are injuries from accidents on the road, at home, or the workplace; war and violence, including landmines; birth trauma; and infectious diseases such as polio and leprosy. Children are often disabled as a result of malnutrition.

In turn, disability exacerbates poverty, by increasing isolation and economic strain, not just for the individual but often for the affected family as well. Children with disabilities are more likely to die young, or be neglected, malnourished and poor. People with disabilities who are denied education are then unable to find employment, driving them more deeply into poverty. Breaking out of the vicious cycle of poverty and disability becomes more and more difficult (see Figure 2).

The result of the cycle of poverty and disability is that people with disabilities are usually amongst the poorest of

the poor and their literacy rates are considerably lower that the rest of the population. Women with disabilities suffer a double discrimination, both on the grounds of gender and of impairment; their literacy rates are lower than their male counterparts. Recent UNESCO studies have suggested that only 1–2% of children with disabilities in developing countries receive an education. Boys with disabilities attend school more frequently than girls with disabilities<sup>4</sup>. Studies show that women with disabilities are twice to three times more likely to be victims of physical and sexual abuse than women with no disabilities. Their access to reproductive health care is minimal and as a result they suffer greater vulnerability to reproductive health problems. There is a lack of awareness regarding women with disabilities and reproductive health needs. More often than not, it is assumed that they do not form part of the target groups because being disabled is associated with being sexless.

As many as 50% of disabilities are preventable and directly linked to poverty. For example, the WHO currently estimates that worldwide there are 1.5 million blind children, mainly in Africa and Asia. In developing countries up to 70% of blindness in children is either preventable or treatable<sup>5</sup>. The WHO also estimates that around 50% of disabling hearing impairment is also preventable. In 1995 this affected a total of 120 million people worldwide (including seven million children).

<sup>&</sup>lt;sup>4</sup>Loud, Proud and Passionate; Including Women with Disabilities in International Development Programmes, C. Lewis and S. Sygall (eds.), MIUSA 1997. <sup>5</sup>The Prevention of Childhood Blindness. WHO, Geneva, 1992. The WHO currently estimates that worldwide there are 110 million people with low vision and 45 million blind people (of whom 1.5 million are children), mainly in Africa and Asia. The main causes of blindness in adults are cataract, infectious diseases (trachoma, onchocerciasis, leprosy), diabetes and degenerative disorders. The main causes in children are corneal scarring (due to vitamin A deficiency, measles, trachoma, neonatal conjunctivitis or harmful traditional eye medicines), cataract, genetic causes, and congenital abnormalities (e.g. rubella).

#### Figure 2: Poverty and disability – a vicious cycle



#### The costs of disability

Disability does not just affect the individual, but impacts on the whole community. The cost of excluding people with disabilities from taking an active part in community life is high and has to be borne by society, particularly those who take on the burden of care. This exclusion often leads to losses in productivity and human potential. The UN estimates that 25% of the entire population is adversely affected in one way or another as a result of disabilities.<sup>6</sup> The cost of disability has three components;<sup>7</sup>

- the direct cost of treatment, including the costs of travel and access;
- the indirect costs to those who are not directly affected ('carers');
- the opportunity costs of income foregone from incapacity.

According to a study of disability in India, 'At least 32 million people were likely to be disabled in 1991, and the lives of their families, those people affected indirectly by

disability amount to perhaps four to five times as many; 130 million. ...These figures are likely to be great underestimates<sup>18</sup>. An earlier study, in 1989, conservatively estimated that the aggregate costs of blindness to the Indian national economy, including a minimal subsistence allowance for blind people, amounted to approximately US\$4.6 billion per year.<sup>9</sup>

Analysis of Tanzanian survey data has revealed that households with a member who has a disability have a mean consumption less than 60% of the average (and a headcount 20% greater than average), leading the author to conclude that disability '... is a hidden face of African poverty'.<sup>10</sup>

Though to be treated with caution, an indicator that is frequently used to quantify the burden of disease in a country or region is the DALY (Disability Adjusted Life Year). This quantification combines estimates of healthy life years lost because of premature mortality with those lost as a result of disability/morbidity. According to World Bank<sup>11</sup> estimates, long-term disabilities were responsible for more than a third (34%) of DALYs lost worldwide in 1990.

<sup>&</sup>lt;sup>6</sup>Leandro Despouy, 1993, Human rights and Disabled Persons (Study Series 6), Centre for Human Rights Geneva and UN New York.

<sup>&</sup>lt;sup>7</sup>S. Erb and B. Hariss-White, Adult Disability, Poverty and Downward Mobility: The Macro and Micro Picture from India; Paper presented to the Development Studies Association Annual Conference, 13th September 1999, University of Bath.

<sup>&</sup>lt;sup>8</sup>ibid.

<sup>&</sup>lt;sup>9</sup>WHO, Fact Sheet No 145, February 1997, WHO Web-site.

<sup>&</sup>lt;sup>10</sup>Howard White, Africa Poverty Status Report, Third Draft, SPQ 1999.

 $<sup>^{11}\</sup>mbox{1993}$  World Development Report; 'Investing in Health'.

The direct cost of disability, is usually unequally shared. The burden of care most often falls on family members, usually mothers or other female relatives. Caring for a child with a severe disability further increases the workload of women living in extreme poverty, and takes valuable time away from the daily struggle to make a living.<sup>12</sup> The burden of care also often falls on other children, usually girls, who may have to miss school to remain at home and care for a sibling or other relative with a disability.

The benefits of reduced disability and morbidity to the economy are numerous and include increased productivity, greater opportunities to obtain better-paying jobs, and longer working lives.

#### **Rights & Social Exclusion**

' Disability [is] a Human Rights issue. So long as people with disabilities are denied the opportunity to participate fully in society, no one can claim that the objectives of the Universal Declaration of Human Rights have been achieved'

Bengt Lindqvist, UN, Special Rapporteur of the Sub-Commission on Prevention of Discrimination and Protection of Minorities.<sup>13</sup>

There is an important and fundamental difference between disability and other forms of disadvantage. People with disabilities can only organise themselves to claim their rights when their additional practical needs, such as for mobility aids, have been met. People with disabilities have a right to be included in all aspects of life. In order to fight for the right to inclusion, people with disabilities need to live in an environment in which they are empowered.

People with disabilities face numerous barriers in realising equal opportunities; environmental and access barriers, legal and institutional barriers, and attitudinal barriers which cause social exclusion. Social exclusion is often the hardest barrier to overcome, and is usually associated with feelings of shame, fear and rejection. Negative stereotypes are commonly attached to disability. People with disabilities are often assigned a low social status and in some cases are considered worthless.

#### **Differential needs**

The needs of people with disabilities differ widely. Children, older people, women, indigenous people, refugees and displaced persons, minorities, and mentally-ill people may all experience disability differently. Some may suffer a multiple disadvantage as a result of their wider social or economic status. Even within these categories needs can differ widely, for example between richer and poorer women.

The consequences are particularly severe for women with disabilities who are also subject to social, cultural and economic disadvantages due to gender discrimination. Moreover, a woman may become disabled due to an abuse of her rights. It is estimated that over 100 million girls and women in more than 28 countries in Africa alone are disabled as a result of female genital mutilation. The physical and psychological consequences of these practices range from mobility difficulties, impaired sexual function and infertility because of infection, to an increased risk of HIV infection.<sup>14</sup>

In many developing countries women are assigned a low status, socially, economically and politically. This is accentuated when disability occurs. Girls and women with disabilities are left marginalised, neglected and are often considered a burden.

Children are another vulnerable group. Mortality for children with disabilities may be as high as 80% in countries where under-five mortality as a whole has decreased to below 20%. In certain cases there seems to be a 'weeding out'<sup>15</sup> of children with disabilities, the 'missing children'.

Mental illness imposes a heavy burden in terms of human suffering, stigmatisation of the mentally ill and their families, and direct and indirect economic costs. The future burden is likely to grow over time as a result of an increasing and ageing global population, and increasing stresses resulting from social problems and unrest, including violence, conflict, and natural and other disasters.

<sup>&</sup>lt;sup>12</sup>S. Miles, Strengthening Disability and Development Work, BOND Discussion Paper, Feb. 1999.

<sup>&</sup>lt;sup>13</sup>World Disability Report, 1999. This quote echoes the Special Rapporteur's predecessor. Leandro Despouy's 1993 report on the connection between Human Rights and Disability clearly made the point that there is a close connection between disability and human rights and that the violations of the human rights of persons with disabilities are extensive and severe.

<sup>14</sup>Overcoming Obstacles to the Integration of Disabled People, UNESCO, DAA, 1995.

<sup>&</sup>lt;sup>15</sup>B. Hariss-White; Presentation to the Development Studies Association Annual Conference, 13th September 1999, University of Bath.

International standards for upholding the rights of people with disabilities are set out in the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (see Annex 1). These were adopted by the UN General Assembly in December 1993. They were developed on the basis of the experience gained during the UN Decade Of Disabled Persons (1983-92). Although the rules are not compulsory, they imply a strong moral and political commitment on behalf of states to take action for the equalisation of opportunities for persons with disabilities.

The 22 rules set out important principles for responsibility, action and co-operation. They point out areas of decisive importance for the quality of life and for the achievement of full participation and equality.

- **Preconditions for equal participation**: awarenessraising, medical care, rehabilitation and support services.
- **Target areas for equal participation**: accessibility, education, employment, income maintenance and social security, family life and personal integrity, culture, recreation and sports, and religion.
- Implementation measures: information and research, policy-making and planning, legislation, economic policies, co-ordination of work, organisations of persons with disabilities, personnel training, national monitoring and evaluation of disability programmes in the implementation of the Standard Rules, technical and economic co-operation, and international co-operation.

The Standard Rules offer an instrument for policy making and action to persons with disabilities and their organisations, and their purpose is to ensure that all people with disabilities may exercise the same rights and responsibilities as other members of society. They draw from other international agreements which constitute the moral and political foundation for them.<sup>16</sup> Many international agreements specifically acknowledge disability as a cause of poverty and disadvantage, and also make the point that the same rights are to be enjoyed by persons with disabilities.

A Special Rapporteur has been appointed by the UN to monitor implementation of the Standard Rules. Regular progress reports are submitted to meetings of the UN Economic and Social Commission. These show that progress is being made, but also suggest that a great deal more could be done. More effort is clearly required by states and the international community to give more prominence to the rights and needs of people with disabilities. The Standard Rules provide a good framework, but need to be delivered with more energy and commitment.

<sup>&</sup>lt;sup>16</sup>These include the International Bill of Human Rights (1948), the International Covenant on Economic, Social and Cultural Rights (1966), the Vocational Rehabilitation and Employment Convention (1983), the Convention on the Rights of the Child (1989), and the Convention on the Elimination of Discrimination against Women (1979).

There has been a long debate within the disability movement and among practitioners about what constitutes good practice. Recently, a shift to a broader framework for action has occurred, with the widespread recognition of the social and human rights dimensions of disability.

Whatever the approach, prevention must be a top priority. This needs to be accompanied with actions which seek to ensure that people with disabilities are supported in their efforts to develop their full potential, and to lead productive and fulfilling lives. As a broad principle, good practice suggests that this means that change must occur within society and in the way it views disability. Rather than people with disabilities having to change to fit society, society must make room for them and uphold their rights.

#### Prevention

A large amount of disability is preventable, often through relatively simple, low cost interventions. The general improvement of living conditions and standards will itself reduce the incidence of disability. General improvements to health services will also bring major benefits, both in reducing the risks of disability and mitigating its effects when it occurs. Programmes specifically aimed at reducing or eliminating specific diseases and conditions can also have a massive impact.

Worldwide, a large number of health initiatives are under way which will have a widespread and significant impact on preventing disability. These include a global commitment, led by the WHO, to eradicate polio, an important cause of disability. DFID has made a major contribution to continuing this work in both Africa and Asia (see Box 2).

This contribution is part of the broader support DFID is giving to numerous UN programmes, all of which will bring benefits in relation to disability. These include programmes to combat leprosy and river blindness, improvements to maternal and child health, and support to family planning services. Work through DFID's direct support to country programmes will also help reduce, and respond to, disability. This work includes efforts to develop health policies and systems which better serve the needs of the poor, to increase access and benefits to sexual and reproductive health services for both women and men, and to promote safer motherhood.

Improved water supply and sanitation, decreased exposure to environmental hazards, better nutrition, conflict prevention, and safer transport are all examples of other areas where support can help prevent disability.

#### The 'social model' of disability

An increasingly common criticism of traditional approaches to disability, particularly from people with disabilities themselves, is that their needs have been marginalised by being categorised as 'special' or 'different' from those of the population at large. Conventional approaches have been criticised for being driven by a perception that people with disabilities need help to adapt to society's demands. This approach runs the risk of favouring technical or medical solutions that emphasise difference rather than promote inclusion<sup>17</sup>.

#### Box 2: Polio eradication in Africa and India

In 1988 the international community set itself the goal of eradicating polio by the year 2000. This objective was enshrined in the Global Polio Eradication Declaration, made at the World Health Assembly. In the year the declaration was made there were an estimated 350,000 cases of the disease around the world. By 1999 this had been reduced to only 5,000.

DFID has been a major supporter of this programme, and in 1999 pledged a contribution of  $\pm 60$  million over a two-year period to help finish the job in Africa and Asia.

The eradication of polio will not only contribute to the achievement of international development targets for poverty reduction and child health, but lessons learnt from polio eradication efforts will positively affect routine immunisation services and help ensure access to these services for all.

<sup>17</sup>S. Miles, Strengthening Disability and Development Work, BOND Discussion Paper, Feb. 1999.

Recently, however, there have been changes in attitude, emphasising what is often termed a 'social model' of disability. This places the emphasis on promoting social change that empowers and incorporates the experiences of people with disabilities, asking society itself to adapt. There is increasing recognition that the term disability does not simply express a medical condition but a complex system of social restrictions emanating from discrimination. Empowerment, participation and equal control become the means of overcoming a disability, rather than medical care alone.

Cross-cultural differences in the interpretation of disability show that the lives of people with disabilities are made more difficult not so much by their specific impairment as by the way society interprets and reacts to disability.

The social model of disability identifies three major types of discrimination:  $^{18}\,$ 

- institutional discrimination;
- environmental discrimination; and
- attitudinal discrimination.

# with a disability can attend school. Environmental discrimination is where a person with a disability is unable to participate due to a physical barrier, such as inaccessible public transport or inappropriately designed buildings. Attitudinal discrimination is often expressed through fear and embarrassment on the part of a non-disabled person when confronted with a person with a disability. Also, low expectations of people with disabilities are discriminatory and undermine the confidence and aspirations of people with disabilities themselves.

Institutional discrimination exists, for example, where no

legal or other provision is made to ensure that children

Good practice is most likely to be ensured through an integrated approach, using best practice in both social and medical terms. The key to ensure the best use of scarce resources is to listen to people with disabilities and to take full account of their views in making decisions, as well as tackling negative attitudes in society as a whole. Examples of the adoption of this approach, in both nongovernmental organisation (NGO) and government policy, are shown in the Box 3.

#### Box 3: Good practice in NGO and government policy

#### NGO policy

**The Swedish Disabled International Aid Association** (SHIA) promotes a rights-based approach to sustainable development for persons with disabilities through an emphasis on satisfying five basic principles:

- 1. *Social Protection:* People with disabilities should have access to basic social protection, defined as housing, health care, rehabilitation services and access devices.<sup>19</sup>
- 2. *Accessibility:* People with disabilities should have access to education, credit, information, and income earning opportunities.
- 3. **Consciousness:** People with disabilities are conscious of their own needs and rights. They are aware of the consequences of neglecting and discriminating attitudes in the society.
- 4. *Influence:* People with disabilities are entitled to have equal opportunities to influence decision and policy making through processes of participation.
- 5. *Control:* People with disabilities are entitled to take initiatives to assert their influence, and promote awareness of their rights. This enables increased control over the distribution of resources and benefits.

SHIA seeks to advance these principles through support to the development and strengthening of organisations of disabled people in developing countries. It prioritises programmes that enable people with disabilities to speak for themselves and which, in turn, strengthen their human rights.

<sup>&</sup>lt;sup>18</sup>Beverly Ashton, A Rights Based Approach to Disability, Development and the Intergenerational Bargain, Paper presented to the DSA Annual Conference, Bath, 13th Sept. 1999.

<sup>&</sup>lt;sup>19</sup>These include artificial limbs, wheelchairs, hearing aids, braille machines, and so on.

#### Government policy

The post-Apartheid government in **South Africa** has published a comprehensive White Paper, putting forward an Integrated National Disability Strategy. This is based on the social model of disability and supports a rights-based approach. Government departments and State bodies have a responsibility to ensure that, in each line function, concrete steps are taken to ensure that people with disabilities are able to access the same fundamental rights and responsibilities as any other South African.

To co-ordinate this activity, the Office on the Status of Disabled Persons has been established in the Office of the Deputy President. This is charged with working together, and in parallel, with the various State bodies and departments and organisations in civil society to further the development of a disability friendly environment.

In **Uganda**<sup>20</sup>, people with disabilities have achieved a greater level of political representation than in any other country. The disability movement has begun to have a real impact on the political scene. The new constitution provides for the representation of the disability movement at all levels of political administration. At parliamentary level five seats are reserved for people with disabilities, representing the four regions of Uganda and the interests of women with disabilities. In each local election, at all levels of government, there must be at least one representative who has a disability.

#### **Community-based Rehabilitation**

Community-based Rehabilitation (CBR) is an approach which has grown out of the debate between the so-called medical and social models of disability. Its supporters believe that it can meet the basic rehabilitation needs of four out of five people with a disability. CBR attempts to combine physical rehabilitation through medical care with empowerment and social inclusion through the participation of both the individual with a disability and the community in the process of rehabilitation.

CBR is often claimed to be the best approach to inclusion and social integration, and an effective means of making the best use of scarce resources. The WHO believes that it promotes and protects human rights while also creating equal opportunities and making the best use of scarce resources.

Advocates of CBR believe that it empowers individuals to take action to improve their own lives. Rehabilitation takes place within the community and is fully participatory. Community members (both with and without disabilities) are the most important resources. CBR depends heavily on the development of positive attitudes and approaches among the people involved. Active community support is vital for its success. Specialist inputs, including appropriate medical and orthopaedic care, remain important parts of the process, but set within a wider context than conventional specialist care. Value is placed on indigenous knowledge and practices, the key being to 'unlock' existing expertise within communities to help them develop their own form of CBR. This way CBR builds on and validates existing indigenous knowledge and information systems, while facilitating access to relevant information and ideas from outside the community.

The concept of CBR has won widespread support, but concerns have also been raised that negative institutional practices and attitudes have, in some cases, simply been relocated to the community. Also, it often takes place on a small geographical scale, and can not provide a solution to all problems.

In a recent paper, the Working Group on Disability and Development of the British Organisation of NGOs for Development (BOND) has suggested that it is essential that people with disabilities exercise choice and control over CBR initiatives. It advises a move to a more inclusive approach, placing disability into a wider community development framework. Community based selfdetermination programmes are particularly favoured, where people with disabilities support each other in rehabilitation, income generation and advocacy<sup>21</sup>. The long-term goal of CBR should be to support people with

<sup>&</sup>lt;sup>20</sup>Beverly Ashton, A Rights-based Approach to Disability, Development and the Intergenerational Bargain, Paper presented to the DSA Annual Conference, Bath, 13th Sept. 1999.

<sup>&</sup>lt;sup>21</sup>S. Miles, Strengthening Disability and Development Work, BOND Discussion Paper, Feb. 1999.

disabilities in their efforts to take control of their own lives and to play a decisive role in any services that are created.<sup>22</sup>

It is estimated that the rehabilitation needs of 80% of people with disabilities could be satisfied at community level. The remaining 20% are likely to require referral to some kind of specialist facility.<sup>23</sup> Abuses need to be prevented, and supervisory committees need to be set up. Standards are also required to regulate admission to, and retention in, mental health care institutions.

<sup>&</sup>lt;sup>22</sup>Susie Miles (SCF); Engaging with the Disability Rights Movement: the Experience of CBR in Southern Africa, Disability and Society, Vol. 11, No. 4, 1996, pp. 515.

<sup>&</sup>lt;sup>23</sup>S. Miles, Strengthening Disability and Development Work, BOND Discussion Paper, Feb. 1999.

## Areas for action and the role of development co-operation

Positive changes in the situation of people with disabilities are dependent on the actions of governments, and the empowerment of people with disabilities themselves. A strong international commitment to uphold the rights of people with disabilities is also an important element, and one which can be supported through development co-operation.

A sharper focus on disability issues, paying attention to the rights of those directly affected and the diversity of their experience, will help achieve greater equality of rights and opportunities for people with disabilities and, in turn, will help ensure that the international development targets are achieved. The UN Standard Rules provide a useful framework for taking this work forward. DFID has been actively involved in disability related work for many years, and will continue to develop its contribution in this area.

#### The twin-track approach

In its pursuit of greater equality for women, DFID has adopted a so-called 'twin-track' approach, combining attempts to take account of women's needs and rights in the mainstream of development co-operation work, as well as supporting specific initiatives aimed at women's empowerment. The analysis set out in this paper suggests that a similar approach may be highly pertinent for work related to disability.

The approach is summarised in Figure 3, and entails the inclusion of an active consideration of disability issues in the mainstream of development co-operation work, and

looking for opportunities to support more focused activities, including direct support to organisations of disabled people and to initiatives aimed specifically at enhancing the empowerment of people with disabilities.

Strengthening disability work through the twin track approach should help provide an enabling environment for people with disabilities to achieve greater livelihood security, greater equality, full participation in the life of the community, and more independence and selfdetermination.

#### Areas for action

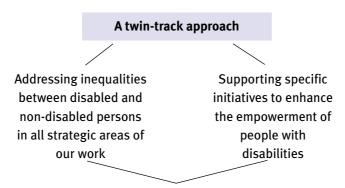
There are many opportunities for action by governments and the international community in support of people with disabilities. Some of these are outlined below.

#### Policy

Good policy is an important starting point, and there is considerable scope for dialogue, both between governments and within the international community to help ensure that policies are developed which seek to uphold the rights of people with disabilities and promote actions consistent with the UN Standard Rules.

Productive policy dialogue could be undertaken, for example, between governments and development agencies in the context of sector programme development, with a view to ensuring that appropriate legal and policy frameworks for the inclusion of persons with disabilities in employment, social service provision and education are developed.

#### Figure 3: A twin-track approach to disability and development



Equality of rights and opportunities for persons with disabilities

The development of better data on persons with disabilities, further broken down by gender, would be helpful both in formulating good policy and also in measuring progress towards the achievement of targets and objectives. It would also help the international community in developing a better understanding of the ways in which the benefits of development are being shared.

Where government commitment is weak, national and international organisations in civil society, particularly Disabled People's Organisations (DPOs), have an important role to play in awareness raising and advocacy.

#### Economic, social and human development

Benefits are likely to be greater when services for people with disabilities are provided within existing social, educational, health and labour structures in society, and where procedures are established to permit effective participation of persons with disabilities in decisionmaking processes.

Inclusive Education $^{24}$  (IE) is an example of an inclusive approach to development. The educational and

developmental needs of children with disabilities are more likely to be fulfilled by their inclusion into mainstream schooling systems (see Box 4). Inclusive education in a developing country implies the equal right of all children to the 'educational package', however basic that package may be. A rights-based approach to education is consistent with providing support to the inclusion rather than to the segregation of children with a disability at school. IE is part of a larger movement towards tackling social exclusion; it seeks to include children on the margins of society, street and working children, excluded minorities.

The development of national policies for education which adopt an inclusive approach is an area where further work is required. International development organisations have a role to play in engaging in policy dialogue with partner countries with a view to ensuring that appropriate legal and policy frameworks for inclusive education are developed.

Similar approaches can be used in relation to health. Good practice suggests that the following principles should be applied:

#### **Box 4: Inclusive Education**

In **India**, the state government of Andhra Pradesh is supporting the inclusion of children with disabilities and special needs in mainstream schools. The integrated education of children with disabilities has been implemented as a pilot project (covering 30–40 schools) under the District Primary Education Programme (DPEP)<sup>25</sup> with DFID support.

Children identified as having difficulties in the areas of gross motor, fine motor, communication and social development are evaluated and assessed both medically and socially, with the help of appropriate specialists. Following these assessments, an individual education programme is prepared by the team for every child with a disability. Teachers are then prepared and sensitised to the needs of the children in question through focused training programmes. Free aids (mobility, hearing etc.) are also provided where required.

Through this pilot project, children with disabilities are given the opportunity of receiving an education. They share their classes with children who have no disabilities, and are therefore included in mainstream school life. Children without disabilities are themselves increasingly aware of the capabilities and potential of their fellow students. The pilot project will therefore have a two-fold benefit; providing an education for children with disabilities while challenging stigma and negative stereotypes too often attached to these children.

**Uganda** has adopted a Universal Primary Education (UPE) policy which illustrates a good way of providing children with access to the 'minimum educational package'. The policy, actively supported by DFID through a major investment programme, provides free primary education to four children per family. It is specified in the policy that at least two of the children should be girls (where there are girls) and any children with a disability. The law states that children with disabilities take priority, on the assumption that parents are less likely to pay for them or for girls than for boys who do not have a disability.

<sup>&</sup>lt;sup>24</sup>Concept emerging strongly from the World Conference on Special Needs Education, Access and Quality, held in Salamanca (Spain) in June 1994. <sup>25</sup>It is worth noting that inclusive education is a feature of DPEP in all 15 states in which it operates.

- consulting people with disabilities and their families in health sector design, monitoring and evaluation;
- ensuring buildings used are accessible to people with disabilities;
- taking account of the transport needs of people with disabilities and their families to give them access to services;
- acknowledging people with disabilities in training materials;
- ensuring people with disabilities and their families and project staff get access to information about disability;
- including in programme evaluation the assessment of impact on people with disabilities and their families as an integral part of the general target group;
- ensure that accessible information regarding reproductive health issues, amongst other health issues, is available, and ensure that extra attention is paid to women with disabilities' needs and rights.

Employment is a key factor in the process of empowerment and inclusion into society of people with disabilities. The development of human resources, through skills development and inclusive training strategies, is crucial in facilitating the inclusion process. Ministries of employment may need encouragement to take into account the training needs of people with disabilities, and to consider formulating legislation and adopting labour standards which respect the rights of people with disabilities to employment and income generation schemes.

Small enterprises can provide employment and income, and have proved particularly useful in helping people lift themselves out of poverty. Many people with disabilities have proven their capability to run businesses on their own account. Much can be done to ensure that small enterprise schemes recognise this potential and actively seek to support its development.

#### Infrastructure

People with disabilities have not always had the opportunity to participate fully and equally in the development and management of basic infrastructure services and shelter.

Where development organisations are involved in infrastructure and shelter projects, local regulations on

disability should be followed as a minimum where these exist, and otherwise, international good practice should guide infrastructure projects. Efforts can also be made to ensure that programmes are developed on the basis of broad-based participation, taking particular steps to ensure that people with disabilities and other marginalised groups are fully included.

#### Conflict and humanitarian assistance

The international community responds to natural and man made disasters with financial, material and technical assistance. This is intended not only to save lives during emergencies, but also to help build capacity to prevent and avoid future disasters.

This broader-based approach requires a wider understanding both of the contexts in which emergencies arise, but also of the impact and consequences of different ways of dealing with them. Wider stakeholder participation, including a more direct involvement of people with disabilities, is a key to developing this understanding.

Differences in vulnerabilities of persons with disabilities must be understood in devising responses. An example would be the importance of considering the needs of deaf people in accessing information. Persons with disabilities should not be seen as victims of conflict and disasters. They have particular capacities which can be built on in responding to and recovering from disasters.

In addition to ensuring that the needs and rights of people with disabilities are broadly considered, targeted programmes may also be needed to respond to the particular needs of people with disabilities. This can include, for example, rehabilitation programmes for landmine survivors.

#### Empowerment

A rights-based approach to disability and development implies a right to self-representation. The rights of people with disabilities are best promoted by people with disabilities themselves. The growth of a democratic, representative disability movement is one way to help ensure that government provision is appropriate to the needs and rights of people with disabilities. It can also help ensure that target groups are involved in the planning, implementation and monitoring of all disability and development work, and to take measures to remove barriers to participation and to combat discriminatory behaviour, practices, policies and environments.

#### Box 5: Empowerment and the Young India Project, Andhra Pradesh

The Young India Project (YIP)<sup>26</sup> provides a successful example of the kinds of empowerment activities required for strengthening the inclusion of people with disabilities in community life. YIP is linked to a federation of trade unions of agricultural and landless labourers (and their families) who advocate for access to existent government schemes, such as employment, income generation, housing, education and health programmes, as well as protest against injustices perpetrated against the rural poor.

YIP, in partnership with Action on Disability and Development (ADD), India, has included people with disabilities in all its work, the aim being to facilitate the access of people with disabilities to the services, equipment and opportunities they need to improve their own lives. Opportunities are created for people with disabilities, through union membership, to form supportive and campaigning self help groups and awareness building groups.

By early 1998, YIP had unions in 209 Mandals (group of 30-50 villages) with a total membership of more than 355,235. Work with people with disabilities makes up 25% of YIP's work. Well over 600 self-help groups of people with disabilities have been formed with a combined membership in 1998 of more than 11,000.

YIP has proved to be successful in linking disability issues into more mainstream debates. People with disabilities are forming their own groups as well as participating in the more general ones. They are increasingly aware of their rights and are able to claim and advocate for their entitlements.

#### Media and communications

Increasingly, media and communications are being used to draw attention to disability issues. Television, radio, the press, networking and lobbying can play an active role in challenging negative stereotypes, pressing for equal rights and raising awareness of disability.

For people with disabilities in many developing countries, being made aware of the range of available support services represents an important first step. In this respect, media and communications initiatives can help people with disabilities feel less isolated and more supported by offering practical information and advice. Various forms of participatory communication such as theatre, poetry and storytelling can also play an important role in reducing the degree to which people with disabilities are stigmatised or discriminated against.

Disability is a rights issue and creative media initiatives such as radio drama can be usefully employed to highlight particularly sensitive socio-cultural issues. Fictional portrayals allow those affected by particular activities/attitudes and those that maintain them, to open a critical social dialogue free from local recrimination.

Using innovative forms of communication can also help to mainstream issues that surround disability. National

initiatives that attain a degree of mass popularity can help promote these issues in contexts where debate did not previously exist or where it had a low profile. This can help to support local and national efforts to network people and organisations that are concerned with raising awareness of disability issues. In turn, clearly defined networks can more successfully lobby law-making bodies to claim, protect and maintain the rights of people with disabilities.

#### Gaps in knowledge

Most research into disability tends to focus predominantly on health or social welfare aspects. There is little coordination or integration between research on disability and research on associated issues in gender, social development, and human sciences. Specific attention needs to be given to both quantitative and participatory components in research methods to ensure that the different dimensions of disability are appreciated.

Research on monitoring and evaluation methods and on topics such as violence against women with disabilities, and the sexual exploitation of children with disabilities, are examples of specific areas requiring greater attention.

This provides opportunities for the international community to seek a better understanding of disability. DFID is planning to further develop knowledge of

<sup>&</sup>lt;sup>26</sup>Partly funded by DFID through the Joint Funding Scheme (JFS), now the Civil Society Challenge Fund, over a three-year period beginning 1994.

disability and development issues, including through applied research and its dissemination<sup>27</sup>.

#### Measuring progress

As with other areas of development, the availability of adequate data for policy making, planning and measuring progress is a challenge in work related to disability. National governments and the international community need to adequately resource statistical and other monitoring systems, and make good use of available information, to obtain more effective means of identifying and replicating good practice.

<sup>&</sup>lt;sup>27</sup>For example, DFID's Knowledge and Research Health Care Technologies Programme has been developed to establish a new inter-disciplinary knowledge programme (Engineering, Health, Social Development) that will support the development and application of appropriate technologies, aiming specifically to improve the health and quality of life for poor people in developing countries. One of the two main themes of the programme is to minimise the detrimental effects of disability on the lives of poor people.

# Annex: United Nations Standard Rules on the equalisation of opportunities for persons with disabilities

#### 1. Preconditions for equal participation

#### • Rule 1. Awareness-raising

' States should take action to raise awareness in society about persons with disabilities, their rights, their needs, their potential and their contribution'

#### Rule 2. Medical care

'States should ensure the provision of effective medical care to persons with disabilities'

#### • Rule 3. Rehabilitation

' States should ensure the provision of rehabilitation services to persons with disabilities in order for them to reach and sustain their optimum level of independence and functioning'

#### • Rule 4. Support services

' States should ensure the development and supply of support services, including assistive devices for persons with disabilities, to assist them to increase their level of independence in their daily living and to exercise their rights'

#### 2. Target areas for equal participation

#### • Rule 5. Accessibility

' States should recognise the overall importance of accessibility in the process of the equalisation of opportunities in all spheres of society. For persons with disabilities of any kind, States should (a) introduce programmes of action to make the physical environment accessible; and (b) undertake measures to provide access to information and communication'

#### • Rule 6. Education

' States should recognise the principle of equal primary, secondary and tertiary educational opportunities for children, youth and adults with disabilities, in integrated settings. They should ensure that the education of persons with disabilities is an integral part of the educational system'

#### • Rule 7. Employment

' States should recognise the principle that persons with disabilities must be empowered to exercise their human rights, particularly in the field of employment. In both rural and urban areas they must have equal opportunities for productive and gainful employment in the labour market'

#### • Rule 8. Income maintenance and social security

*'States are responsible for the provision of social security and income maintenance for persons with disabilities'* 

#### • Rule 9. Family life and personal integrity

' States should promote the full participation of persons with disabilities in family life. They should promote their right to personal integrity, and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood'

#### • Rule 10. Culture

' States will ensure that persons with disabilities are integrated into and can participate in cultural activities on an equal basis'

#### • Rule 11. Recreation and sports

' States will take measures to ensure that persons with disabilities have equal opportunities for recreation and sports'

#### Rule 12. Religion

' States will encourage measures for equal participation by persons with disabilities in the religious life of their communities'

#### 3. Implementation measures

#### • Rule 13. Information and research

' States assume the ultimate responsibility for the collection and dissemination of information on the living conditions of persons with disabilities and promote comprehensive research on all aspects, including obstacles which affect the lives of persons with disabilities.

• Rule 14. Policy-making and planning 'States will ensure that disability aspects are included in all relevant policy-making and national planning'

#### • Rule 15. Legislation

' States have a responsibility to create the legal bases for measures to achieve the objectives of full participation and equality for persons with disabilities'

• Rule 16. Economic policies

' States have the financial responsibility for national programmes and measures to create equal opportunities for persons with disabilities'

• Rule 17. Co-ordination of work

' States are responsible for the establishment and strengthening of national co-ordinating committees, or similar bodies, to serve as a national focal point on disability matters'

Rule 18. Organisations of persons with disabilities

' States should recognise the right of organisations of persons with disabilities to represent persons with disabilities at national, regional and local levels. States should also recognise the advisory role of organisations of persons with disabilities in decision-making on disability matters'

• Rule 19. Personnel training

*•* States are responsible for ensuring the adequate training of personnel, at all levels, involved in the planning and provision of programmes and services concerning persons with disabilities'

• Rule 20. National monitoring and evaluation of disability programmes in the implementation of the Standard Rules

<sup>•</sup> States are responsible for the continuous monitoring and evaluation of the implementation of national programmes and services concerning the equalisation of opportunities for persons with disabilities.

Rule 21. Technical and economic co-operation
States, both industrialised and developing, have the responsibility to co-operate in and undertake measures for the improvement of the living conditions of persons with disabilities in developing countries'

#### • Rule 22. International co-operation

' States will participate actively in international co-operation concerning policies for the equalisation of opportunities for persons with disabilities '

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