C2 | Disabled people

Disability must first be defined as it is experienced by all disabled people, regardless of age and gender, including those with sensory, physical and intellectual impairment and mental health difficulties. Then, with this shared understanding, an assessment can be made of how well disabled people are being supported within mainstream agendas for health and well-being, the fight against global poverty and the human rights agenda. The chapter then shows how disabled people are taking control over their lives, changing their environments and demanding their right to full participation in society and to equality in freedom and dignity, despite massive violations of their rights and lack of visibility on mainstream development agendas.

Context

Twenty years ago WHO reported that despite some efforts in the areas of rehabilitation and prevention, disabled people were being denied inclusion in their communities and self-determination. Not enough steps were being taken to eliminate the barriers to their full participation in society (WHO 1985). A target was set to be achieved by 2000: 'Disabled people should have the physical and economic opportunities that allow at least for a socially and economically fulfilling and mentally creative life'. This could be achieved if societies 'developed positive attitudes towards disabled people and set up programmes aimed at providing appropriate physical, social and economic opportunities for them to develop their capacities to lead a healthy life'.

Some progress has been made since 1985. A report from the UN Human Rights Commission, on the current use and future potential of UN human rights instruments in the context of disability, says a long overdue and imperfect reform process is under way throughout the world. However, it also notes that the process is slow and uneven, in some places almost non-existent (Quinn and Degener 2003).

Disabled people not only form 20% of the world's poorest people, but poverty also increases the chances of disability – through vitamin A and iodine deficiencies, poor nutrition, bad working conditions, poor sanitation, environmental pollution and lack of health care (Sen and Wolfensohn 2003). Disabled people require higher incomes than non-disabled people to maintain the same living standard because of the social barriers, yet most have lower incomes.

Box C2.1 The facts about disability

Only 2% of disabled children in the developing world receive any education or rehabilitation.

Most public buildings and transport systems throughout the world are inaccessible to the majority of disabled people.

Disabled people of working age in developed and developing countries are three times more like to be unemployed and live in real poverty (65% of disabled people in the UK live below the poverty line).

Disabled people are subjected to appalling abuse. For example:

A family in Spain kept a disabled woman in a stinking six-foot hole for 40 years (1998).

An 18–month-old girl in the UK was refused use of a ventilator or antibiotics because of a legal and medical judgement on the quality of her life (1997).

An 11–year-old boy living at home with his family in Japan was murdered by his brother because 'he was mentally handicapped and had no future' (2000).

Disabled children were starved to death in a Kiev hospital, Ukraine, because staff stole their food (1995).

A man with multiple impairments died in the US after being beaten and stuffed in a dustbin. Authorities called it a 'cruel prank' (1994).

Two people pleading guilty to the killing of disabled family members in the UK were given non-custodial sentences (2000). (*Source*: DAA 2002)

These expenses do not diminish when they are in employment because they are paid disproportionately low wages.

The definition of disability The reasons why progress is so slow and health and well-being systematically denied to disabled people are rooted in the definition of disability. Traditionally, they have been seen as people who are impaired, functionally limited and unable to do things. It was believed that the duty of society was to change the impaired individual to conform to community norms – through cure, treatment or rehabilitation. Disabled people were the commodity of health professionals, and as such a source of power and resources for the professionals, not people in their own right with the same rights to life, participation and personal autonomy as everyone else. Problems that arose around disability could be solved by excluding them in special institutions, by community-based service provision which emphasized them as

recipients of care and special treatment, or simply by neglect because their needs were deemed to be too expensive or not met by mainstream services. To put it bluntly, it was seen as socially unproductive and unsustainable for a developing country to provide resources to support disabled people in their communities. In the developed world, which did not have the excuse of lack of resources, the solutions were to exclude them from the mainstream and to build hierarchical, urban-based systems and services that allocated resources to the professionals rather than the service users.

These social, medical and individual attitudes to disability were embodied in the International Classification of Impairment, Disability and Handicap (ICIDH) formulated in 1980 by WHO as part of the International Classification of Diseases, the international standard diagnostic classification used for all general epidemiological and many health management purposes. The experts brought together to formulate this classification used a causal, linear approach, with its roots in disease and impairment and the outcomes in a person's inability to participate like everyone else in society. The expert group had no members from the disability rights movement – it was not seen as an issue in 1980 that disabled people had rights, including the right to a voice in policies and programmes that directly affected them.

The disability rights movement By that time, however, disabled leaders worldwide had arrived at a clear shared analysis of the situation and a definition of disability. They understood the wide range of social and environmental factors – services, systems, the personal context and environment – that contributed to erecting the disabling barriers that prevented the full and equal participation of disabled people in their societies and communities. This 'social model' of disability proposed that it was not the individual that had to change, but society that should make radical changes through systems, services and attitudes. Above all, disabled people had to be recognized as people – as human beings with equal rights.

This understanding of the social model of disability and the right to protection against exclusion and degrading and inhuman treatment was the catalyst in building a coherent and democratic movement of disabled people. It aimed to ensure that disabled people could be heard in political debate and that future systems and services would mainstream them and acknowledge their humanity. Growing out of a world where disability organizations were either large charitable institutions or single-impairment groups fighting for services, Disabled Peoples' International (DPI) was formed in 1981 to be the international voice of disabled people.

DPI has always included all disabled people regardless of impairment. At its inception, the 44 countries originally involved agreed the principle that all people are equal – and that includes disabled people. 'The principle of equality implies that the needs of each and every individual are of equal importance, that these needs must be made the basis for the planning of our societies and that all available resources must be employed in such a way as to ensure equal participation for each and every individual. Policies of concern to disabled people, therefore, very often involve the distribution of resources in society and as such are political issues' (DPI 1981).

One of its first steps was to apply to the UN for consultative status and to have a substantial input into the UN World Programme of Action Concerning Disabled Persons, agreed by all member states at the 1983 general assembly as the recommendations to support the Decade of Disabled Persons (1983–1992) and to implement the full and equal participation of disabled people in society. This programme of action became a very important lobbying tool for all disabled people's organizations and was elaborated by the UN Standard Rules on the Equalization of Opportunities of People with Disabilities to mark the end of the decade. A panel of experts was set up to advise the UN special rapporteur to monitor these rules, including DPI, Inclusion International (for families and people with intellectual impairments), World Blind Union, World Federation of the Deaf, World Network of Users of the Psychiatric System and Rehabilitation International. With the addition of the World Federation of Deaf/Blind, these organizations have provided a much wider and stronger body of influence, particularly on the formulation of a convention on the rights of disabled people that started in 2002.

Revising the definition and assessing progress

Another important step for the now burgeoning disability rights movement was to call for revision of the ICIDH to reflect the social definition of disability. Using the argument that WHO saw health as a human rights issue, it said disabled people were human beings and therefore disability could no longer be seen as part of the continuum of disease and incapacity. WHO took rather a long time to respond and eventually started the revision process in the early 1990s; the final new International Classification of Functioning, Disability and Health (ICF) was agreed by the WHO general assembly in 2001. WHO has said this relates to all people, that participation is not a consequence of impairment or functioning but a description of components of health, and that the list of environmental factors (including systems, services, policies and attitudes) describes the context in which people live (WHO 2001).
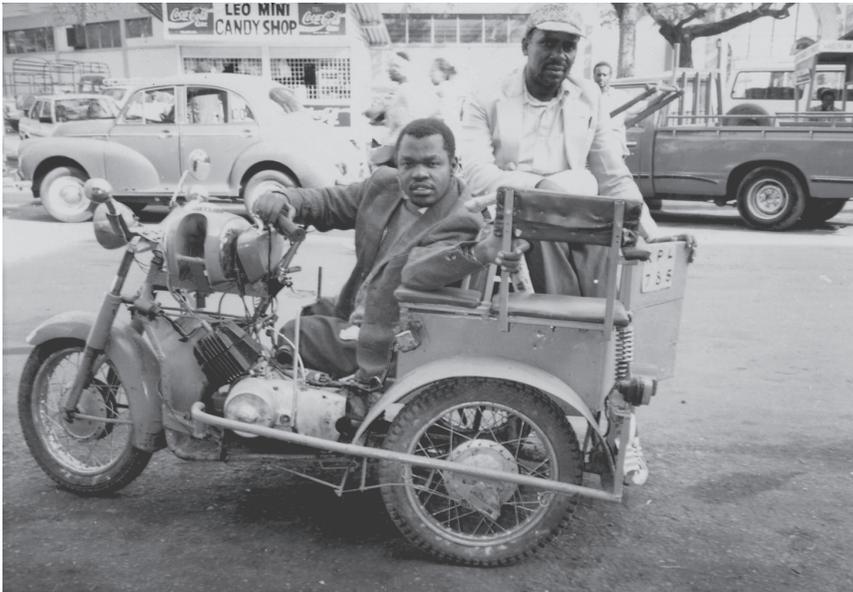
13 A disabled man driving his own home made buggy/taxi with another disabled man as passenger in Nairobi, Kenya

These factors also highlight the disabling effects of poverty, malnutrition, lack of micronutrients, poor sanitation and lack of immunization and show that improved nutrition, food security, access to health care, education, clean water, sanitation and immunization empower people, as do access to transport systems and safer working and living environments. By using the environmental factors in relation to personal factors, the classification can be used to see how wars and armed conflict can cause disabling impairments.

WHO also considers that its family of classifications provides a useful tool to describe and compare population health internationally, going beyond the traditional use of infant and maternal mortality as the key indicator. Unfortunately there is little indication that this is happening. The supporters of QALYs (quality adjusted life years) and DALYs (disability adjusted life years) argue that these relatively similar systems give a better idea of a country's use of its resources and development. The resulting tables seem to suggest, however, that the more disabled people a country has, the lower its status. Using mortality rates as an assessment of a country's development sends out messages ascribing causality to lack of health care, poverty, malnutrition and other factors, but disability-adjusted evidence implies that it is disabled people themselves who are the problem. It is to be hoped that future assessments will shift away from QALYs and DALYs to the more real context of the ICF.

Disabled people

> *Box C2.2 A disabled man from Congo speaks out*
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> 'I am 35 years old now and have never tasted all these facilities I am reading in the Standard Rules. They are a dream! We don't have any rights other that the right of receiving pity words, which we don't need! We cannot make any change to our rights when we are still in the dust asking for cents in the streets, but by improving ourselves through education. There is no encouragement from the government or society.' (*Source*: DAA 2003)

Development According to the man from the Congo (Box C2.2) and many others, you cannot eat rights, nor do international policies and programmes seem relevant at the personal level. Disabled people at the grassroots are systematically ignored in disaster situations and relief aid – if for no other reason than that they cannot get access to that aid – and are rendered particularly vulnerable in times of armed conflict, being deliberately annihilated by warring parties, often hundreds at a time (DAA 2002).

Leaving disabled people off the development agenda has also been a major barrier. It will be impossible to cut poverty in half by 2015 unless disabled people are brought into the development mainstream, says former World Bank president James Wolfensohn. Disabled delegates from 15 developing countries got together in 2003 to discuss why they were left off the agenda and to put forward suggestions for reform. Mainstreaming would mean the expansion of possibilities, establishment of new partners, mutual support and solidarity, said delegate Alexander Phiri, a disabled rights activist from Zimbabwe. 'Instead of proving that we are 10% of any given population and 20% of the world's poorest, we must convince society that we are an irreplaceable part of 100%. If the idea behind mainstreaming is to create a society for all, we need to agree, for example, that no development funds, loans and grants should be spent on projects that are not accessed by all people, including disabled people' (International Service 2003). All agreed that the way forward was through their united, loud and strong voice lobbying governments, policy-makers and funders to recognize the importance and value of that voice and resource it to be mainstreamed at all levels in political and development processes.

Finding solutions

Disabled people's organizations are increasingly realizing that to ensure sustainability, social change based on equality and rights is just as important

as fulfilling individual needs, if not more so. Disabled people may be given the tools to run their own small business – but unless their community accepts them as an equal or the bank gives them a small loan on the same basis as non-disabled entrepreneurs, they will not be able to operate. There is no point in providing a hearing aid if the battery cannot be renewed or charged locally. There is no point in governments announcing 'free education for all' if this does not include disabled children. Disabled people, using their own experience to stimulate strategies and actions, have come up with some fine solutions to ensure their rights to equality and participation.

In the North, 'independent living' was disabled people's solution to freeing themselves from the domination of the medical and charitable professionals and disempowering services. From the late 1970s on, starting in the US and quickly spreading to Canada, the UK, Sweden, Finland and Japan and now to most of Europe and Australia, the principles of self-determination have been implemented by disabled people's organizations through local, non-residential centres of enablement, providing the support and services to lead full and equal lives.

Each organization responded to the principles of independent living in its own way and as appropriate to its local environment. Most have focused on personal support systems, advocacy, housing, transport, access to public facilities, education, employment and working with political and social systems to ensure local, social change. The key is that disabled people must be in control of their own organizations and lives. The result of this activism has been a new generation of disabled people whose expectations of self-determination, inclusion and participation are equal to those of their non-disabled peers – even if those expectations are not actively met. Those organizations also produced a cadre of leaders who, using their experience at the grass roots, were and still are active nationally, regionally and internationally in the struggle for justice. Disabled people in the South have also implemented their own form of independent living in policies and programmes (Box C2.3).

This growth of respect and equality of opportunity has to be enforced through non-discrimination legislation. People's attitudes cannot be changed overnight – legislation is needed to change behaviour. Antidiscrimination legislation for disabled people is increasingly appearing on statute books but is useless without an enforcement procedure. The UN Standard Rules have provided good guidance but have not, in the main, been implemented because there has been no monitoring or exposure of the monitoring mechanisms of the international human rights instruments. Part of disability invisibility is that disabled people are not specifically mentioned in human rights instru-

> ### Box C2.3   The independent living movement in the South – some examples
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> *Self-Help Association of Paraplegics (SHAP) in Soweto, South Africa.* When it started in 1981, disabled people had little chance of survival in such an inaccessible and hostile environment, let alone a decent standard of living (Fletcher and Hurst 1995). It started as a factory employing only disabled people sub-contracted to provide components for industry. It expanded to include transport, education, personal support, sports and a choir. And as with the independent living movement in the North, the leaders of this and other similar initiatives in the developing world became active in building a democratic, political movement of disabled people's organizations.
>
> Another good example of a form of independent living is the *disability component of the Andhra Pradesh rural poverty reduction programme* in which disabled people play a leading role, including initial planning and survey. They set up *sangams* (common interest self-help groups) at village level so that disabled people could work together to improve their situation socially and economically. They define their own needs and barriers and take action collectively. They organize demand for their entitlements and legal certification (many disabled children and adults are never registered). They work to get disabled children into schools and for them to obtain the necessary health care and assistive devices. One of their biggest accomplishments 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).

ments, except the Convention on the Rights of the Child. Nor do the monitoring bodies take disabled people into account when scrutinizing country reports. This is why it is important to have a convention supporting the rights of disabled people – though monitoring it must have appropriate status, not just another report to the UN general assembly that can be agreed and then ignored.

Bioethics and a healthy nation Recognition of disabled people's rights has undoubtedly begun – even though implementation seems a long way off. However, in the last ten years or so a barrier has arisen that is currently unbreachable: the eugenic attitudes underpinning much of the rhetoric and policies around the new genetic sciences (discussed in more detail in part B, chapter 5). Many disabled people are only alive today because of scientific progress generally and new medical techniques in particular, as the DPI Europe position

statement on bioethics says: 'Of course we wish to promote and sustain such advances where these lead to benefits for everyone. But we want to see research directed at improving the quality of our lives, not denying us the opportunity to live. The genetic goal of the prevention of disease and impairment by the prevention of lives judged not to be "normal" is a threat to human diversity. It is a potential Nagasaki for everyone, not just disabled people. The threat is powerful and imminent' (DPI/Europe 2000).

Like everyone else, disabled people want scientific advances that alleviate pain and help them to participate more fully in their lives. What must be contested are scientific advances that ignore the intrinsic humanity of disabled people – that see impaired genes only of use if they can be enhanced. Many modern scientists define eugenics as promoting a healthy nation, and advocate the right of choice. But the whole notion of 'healthy' in this context raises many concerns.

China advocated a healthy nation by enforcing a one-child only families policy. Then, when it discovered that this practice disturbed the balance of the population and endangered sustainability, it introduced a law to guarantee the health of mothers and infants and to improve the quality of born children. It tried to prevent abnormal births by sterilization, banning the marriage of disabled people, and aborting disabled foetuses. It did, however, stop short of euthanasia of children born with disabling impairments (Xinhua 1994). New draft amendments to the Family Code of Albania bar marriage to people with certain mental and physical disabilities (Amnesty International 2004). The Netherlands is discussing extending legal euthanasia to people incapable of deciding for themselves, including disabled children, and such procedures have already been carried out (Sterling 2004).

Until very recently national bioethics committees have mostly been established in developed countries, where the need to make decisions and introduce legislation to control scientific advances has been most necessary. But now such committees are springing up all over the world – the latest in Pakistan – illustrating the seriousness with which they are taking these advances. The influence of the new genetic sciences is becoming increasingly important to everyone, and is also bringing increased power to the transnational pharmaceutical corporations through research and higher profits. Like some non-disabled people, disabled people are often used for research, often without their permission. Global health statistics based on QALYs, and the achievement of a 'healthy' nation through scientific advances to eliminate disabled genes, combine to encourage governments to see genetics as a solution for health for all. The debates do not consider that people born with

disabilities are less than 2% of the disability population and that the majority of disabling impairments are caused by poverty and exclusion. Throughout the world, power and economics prevail in the war against the weak.

Recommendations

- Listen to the voices of the excluded. Promote and support the voice and status of disabled people.
- Understand the nature of exclusion – establish longitudinal data sets based on environmental impacts to monitor disabled people's lives.
- Look for solutions through equality, inclusion and rights. Society has to change, as well as routine daily behaviour.
- Ensure the disability dimension is included in all agendas – especially poverty and development.
- Build alliances to make a difference.
- Include disabled people in the monitoring of all human rights instruments and promote an international convention on the rights of disabled people.
- Above all, recognize the intrinsic humanity of each disabled person, regardless of impairment.

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