

## **Chapter 1**

# **Understanding disability**

“I am a black woman with a disability. Some people make a bad face and don’t include me. People don’t treat me well when they see my face but when I talk to them sometimes it is better. Before anyone makes a decision about someone with a disability they should talk to them.”

**Haydeé**

“Can you imagine that you’re getting up in the morning with such severe pain which disables you from even moving out from your bed? Can you imagine yourself having a pain which even requires you to get an assistance to do the very simple day to day activities? Can you imagine yourself being fired from your job because you are unable to perform simple job requirements? And finally can you imagine your little child is crying for hug and you are unable to hug him due to the pain in your bones and joints?”

**Nael**

“My life revolves around my two beautiful children. They see me as ‘Mummy’, not a person in a wheelchair and do not judge me or our life. This is now changing as my efforts to be part of their life is limited by the physical access of schools, parks and shops; the attitudes of other parents; and the reality of needing 8 hours support a day with my personal care...I cannot get into the houses of my children’s friends and must wait outside for them to finish playing. I cannot get to all the classrooms at school so I have not met many other parents. I can’t get close to the playground in the middle of the park or help out at the sporting events my children want to be part of. Other parents see me as different, and I have had one parent not want my son to play with her son because I could not help with supervision in her inaccessible house.”

**Samantha**

“Near the start of the bus route I climb on. I am one of the first passengers. People continue to embark on the bus. They look for a seat, gaze at my hearing aids, turn their glance quickly and continue walking by. Only when people with disabilities will really be part of the society; will be educated in every kindergarten and any school with personal assistance; live in the community and not in different institutions; work in all places and in any position with accessible means; and will have full accessibility to the public sphere, people may feel comfortable to sit next to us on the bus.”

**Ahiya**

# 1

## Understanding disability

Disability is part of the human condition. Almost everyone will be temporarily or permanently impaired at some point in life, and those who survive to old age will experience increasing difficulties in functioning. Most extended families have a disabled member, and many non-disabled people take responsibility for supporting and caring for their relatives and friends with disabilities (1–3). Every epoch has faced the moral and political issue of how best to include and support people with disabilities. This issue will become more acute as the demographics of societies change and more people live to an old age (4).

Responses to disability have changed since the 1970s, prompted largely by the self-organization of people with disabilities (5, 6), and by the growing tendency to see disability as a human rights issue (7). Historically, people with disabilities have largely been provided for through solutions that segregate them, such as residential institutions and special schools (8). Policy has now shifted towards community and educational inclusion, and medically-focused solutions have given way to more interactive approaches recognizing that people are disabled by environmental factors as well as by their bodies. National and international initiatives – such as the United Nations *Standard Rules on the Equalization of Opportunities of Persons with Disabilities* (9) – have incorporated the human rights of people with disabilities, culminating in 2006 with the adoption of the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD).

This *World report on disability* provides evidence to facilitate implementation of the CRPD. It documents the circumstances of persons with disabilities across the world and explores measures to promote their social participation, ranging from health and rehabilitation to education and employment. This first chapter provides a general orientation about disability, introducing key concepts – such as the human rights approach to disability, the intersection between disability and development, and the *International Classification of Functioning, Disability and Health* (ICF) – and explores the barriers that disadvantage persons with disabilities.

### What is disability?

Disability is complex, dynamic, multidimensional, and contested. Over recent decades, the disabled people's movement (6, 10) – together with

numerous researchers from the social and health sciences (11, 12) – have identified the role of social and physical barriers in disability. The transition from an individual, medical perspective to a structural, social perspective has been described as the shift from a “medical model” to a “social model” in which people are viewed as being disabled by society rather than by their bodies (13).

The medical model and the social model are often presented as dichotomous, but disability should be viewed neither as purely medical nor as purely social: persons with disabilities can often experience problems arising from their health condition (14). A balanced approach is needed, giving appropriate weight to the different aspects of disability (15, 16).

The ICF, adopted as the conceptual framework for this *World report on disability*, understands functioning and disability as a dynamic interaction between health conditions and contextual factors, both personal and environmental (see **Box 1.1**) (17). Promoted as a “bio-psycho-social model”, it represents a workable compromise between medical and social models. Disability is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors) (19).

The Preamble to the CRPD acknowledges that disability is “an evolving concept”, but also stresses that “disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others”. Defining disability as an interaction means that “disability” is not an attribute of the person. Progress on improving social participation can be made by addressing the barriers which hinder persons with disabilities in their day to day lives.

## Environment

A person’s environment has a huge impact on the experience and extent of disability. Inaccessible environments create disability by creating barriers to participation and inclusion. Examples of the possible negative impact of the environment include:

- a Deaf individual without a sign language interpreter
- a wheelchair user in a building without an accessible bathroom or elevator
- a blind person using a computer without screen-reading software.

Health is also affected by environmental factors, such as safe water and sanitation, nutrition, poverty, working conditions, climate, or access to health care. As the World Health Organization (WHO) Commission on Social Determinants of Health has argued, inequality is a major cause of poor health, and hence of disability (20).

The environment may be changed to improve health conditions, prevent impairments, and improve outcomes for persons with disabilities. Such changes can be brought about by legislation, policy changes, capacity building, or technological developments leading to, for instance:

- accessible design of the built environment and transport;
- signage to benefit people with sensory impairments;
- more accessible health, rehabilitation, education, and support services;
- more opportunities for work and employment for persons with disabilities.

Environmental factors include a wider set of issues than simply physical and information access. Policies and service delivery systems, including the rules underlying service provision, can also be obstacles (21). Analysis of public health service financing in Australia, for

### Box 1.1. New emphasis on environmental factors

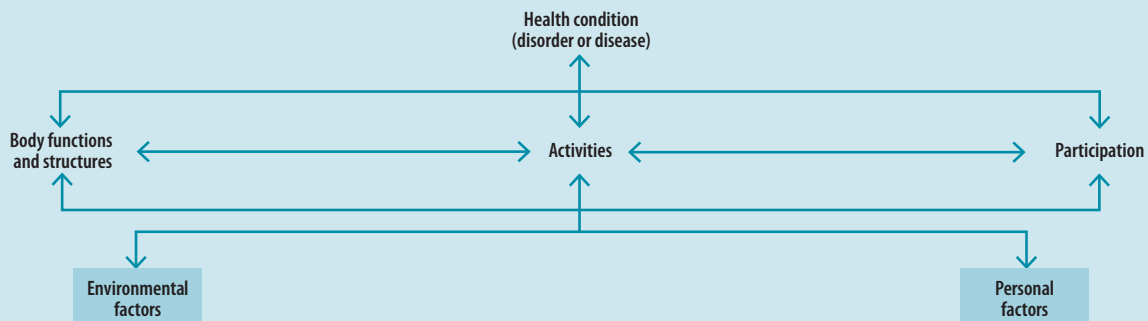
The *International Classification of Functioning, Disability and Health* (ICF) (17) advanced the understanding and measurement of disability. It was developed through a long process involving academics, clinicians, and – importantly – persons with disabilities (18). The ICF emphasizes environmental factors in creating disability, which is the main difference between this new classification and the previous *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH). In the ICF, problems with human functioning are categorized in three interconnected areas:

- **impairments** are problems in body function or alterations in body structure – for example, paralysis or blindness;
- **activity limitations** are difficulties in executing activities – for example, walking or eating;
- **participation restrictions** are problems with involvement in any area of life – for example, facing discrimination in employment or transportation.

**Disability** refers to difficulties encountered in any or all three areas of functioning. The ICF can also be used to understand and measure the positive aspects of functioning such as body functions, activities, participation and environmental facilitation. The ICF adopts neutral language and does not distinguish between the type and cause of disability – for instance, between “physical” and “mental” health. “**Health conditions**” are diseases, injuries, and disorders, while “impairments” are specific decrements in body functions and structures, often identified as symptoms or signs of health conditions.

**Disability** arises from the interaction of health conditions with contextual factors – environmental and personal factors as shown in the figure below.

### Representation of the International Classification of Functioning, Disability and Health



The ICF contains a classification of **environmental factors** describing the world in which people with different levels of functioning must live and act. These factors can be either facilitators or barriers. Environmental factors include: products and technology; the natural and built environment; support and relationships; attitudes; and services, systems, and policies.

The ICF also recognizes **personal factors**, such as motivation and self-esteem, which can influence how much a person participates in society. However, these factors are not yet conceptualized or classified. It further distinguishes between a person’s **capacities** to perform actions and the actual **performance** of those actions in real life, a subtle difference that helps illuminate the effect of environment and how performance might be improved by modifying the environment.

The ICF is universal because it covers all human functioning and treats disability as a continuum rather than categorizing people with disabilities as a separate group: disability is a matter of more or less, not yes or no. However, policy-making and service delivery might require thresholds to be set for impairment severity, activity limitations, or participation restriction.

It is useful for a range of purposes – research, surveillance, and reporting – related to describing and measuring health and disability, including: assessing individual functioning, goal setting, treatment, and monitoring; measuring outcomes and evaluating services; determining eligibility for welfare benefits; and developing health and disability surveys.

instance, found that reimbursement of health providers did not account for the additional time often required to provide services to persons with disabilities; hospitals that treated patients with a disability were thus disadvantaged by a funding system that reimbursed them a fixed amount per patient (22).

Analysis of access to health care services in Europe found organizational barriers – such as waiting lists, lack of a booking system for appointments, and complex referral systems – that are more complicated for persons with disabilities who may find it difficult to arrive early, or wait all day, or who cannot navigate complex systems (23, 24). While discrimination is not intended, the system indirectly excludes persons with disabilities by not taking their needs into account.

Institutions and organizations also need to change – in addition to individuals and environments – to avoid excluding people with disabilities. The 2005 Disability Discrimination Act in the United Kingdom of Great Britain and Northern Ireland directed public sector organizations to promote equality for persons with disability: by instituting a corporate disability equality strategy, for example, and by assessing the potential impact of proposed policies and activities on disabled people (25).

Knowledge and attitudes are important environmental factors, affecting all areas of service provision and social life. Raising awareness and challenging negative attitudes are often first steps towards creating more accessible environments for persons with disabilities. Negative imagery and language, stereotypes, and stigma – with deep historic roots – persist for people with disabilities around the world (26–28). Disability is generally equated with incapacity. A review of health-related stigma found that the impact was remarkably similar in different countries and across health conditions (29). A study in 10 countries found that the general public lacks an understanding of the abilities of people with intellectual impairments (30). Mental health conditions are particularly stigmatized, with commonalities

in different settings (31). People with mental health conditions face discrimination even in health care settings (24, 32).

Negative attitudes towards disability can result in negative treatment of people with disabilities, for example:

- children bullying other children with disabilities in schools
- bus drivers failing to support access needs of passengers with disabilities
- employers discriminating against people with disabilities
- strangers mocking people with disabilities.

Negative attitudes and behaviours have an adverse effect on children and adults with disabilities, leading to negative consequences such as low self-esteem and reduced participation (32). People who feel harassed because of their disability sometimes avoid going to places, changing their routines, or even moving from their homes (33).

Stigma and discrimination can be combated, for example, through direct personal contact and through social marketing (see [Box 1.2](#)) (37–40). World Psychiatric Association campaigns against stigmatizing schizophrenia over 10 years in 18 countries have demonstrated the importance of long-term interventions, broad multisectoral involvement, and of including those who have the condition (41). Evidence from Norway showed that knowledge about psychosis among the general population improved after a year of information campaigns, and that the duration of untreated psychosis fell from 114 weeks in 1997 to 20 weeks in 1999 due to greater recognition and early intervention with patients (42).

Community-based rehabilitation (CBR) programmes can challenge negative attitudes in rural communities, leading to greater visibility and participation by people with disabilities. A three-year project in a disadvantaged community near Allahabad, India, resulted in children with disabilities attending school for the first time, more people with disabilities participating in community forums, and more people

### Box 1.2. Eliminating leprosy, improving lives

The diagnosis and treatment of leprosy is easy and effective. The best way of preventing disabilities associated with it, as well as preventing further transmission, lies in early diagnosis and treatment. Since 1983 the disease has been curable with multidrug therapy, and since 1985 this therapy has been made available by the World Health Organization (WHO) free of charge around the world. WHO estimates that early detection and treatment with multidrug therapy have prevented about 4 million people from being disabled (34).

To eliminate the disease, access to information, diagnosis, and treatment with multidrug therapy are crucial (34). The greatest barriers to eliminating the disease are ignorance and stigma. Information campaigns about leprosy in endemic areas are of supreme importance so that people affected by leprosy and their families – historically ostracized from their communities – come forward and receive treatment. Reducing stigma also improves the quality of life of people affected by leprosy and their families by improving people’s mobility, interpersonal relationships, employment, leisure, and social activities (35).

In India, home to two thirds of the world’s people affected by leprosy, the BBC World Service Trust – in partnership with two Indian broadcasters Doordarshan TV and All-India Radio – launched a 16-month campaign on leprosy in 1999 (36). The campaign stressed that leprosy is curable, that drugs to cure it are available free throughout India, and that people affected by leprosy should not be excluded from society. The central messages of the campaign were:

- leprosy is not hereditary
- leprosy is not caused by bad deeds in a previous life
- leprosy is not spread by touch.

The campaign used 50 television and 213 radio programmes in 20 languages, and 85 000 information posters. More than 1700 live drama shows, 2746 mobile video screenings, and 3670 public events or competitions were performed in remote areas. Independent market surveys conducted before, during, and after the campaign found:

- **Reach of media campaign.** The radio and TV spots were seen by 59% of respondents, or 275 million people.
- **Transmissibility and curability.** The proportion of people who believed leprosy was transmitted by touch fell from 52% to 27%. The proportion believing that people with leprosy who take multidrug therapy are still infectious fell from 25% to 12%. Those who knew that leprosy was curable rose from 84% to 91%.
- **Symptoms.** Awareness that loss of sensation could be a possible symptom of leprosy rose from 65% to 80%. Awareness of pale reddish patches as a possible symptom remained unchanged at 86%. Awareness of non-itchy patches as a possible symptom rose from 37% to 55%.
- **Therapies.** The awareness rate in control villages (not covered in the campaign) that multidrug therapy was a cure for leprosy was only 56%, but in villages that had been shown live drama it was 82%. In rural areas awareness that the treatment was free was 89% among those exposed to the poster campaign, against 20% in those not exposed.
- **Stigma.** The proportion of people saying they would be willing to sit next to a person affected by leprosy was 10% higher in villages where drama shows had been used than in those without. Similarly, the proportion of those claiming they would be willing to eat food served by somebody affected by leprosy was 50% in villages covered by the campaign, against 32% in those not covered.

Sources (34–36).

bringing their children with disabilities for vaccination and rehabilitation (43).

## The diversity of disability

The disability experience resulting from the interaction of health conditions, personal factors, and environmental factors varies greatly.

Persons with disabilities are diverse and heterogeneous, while stereotypical views of disability emphasize wheelchair users and a few other “classic” groups such as blind people and deaf people (44). Disability encompasses the child born with a congenital condition such as cerebral palsy or the young soldier who loses his leg to a land-mine, or the middle-aged woman

with severe arthritis, or the older person with dementia, among many others. Health conditions can be visible or invisible; temporary or long term; static, episodic, or degenerating; painful or inconsequential. Note that many people with disabilities do not consider themselves to be unhealthy (45). For example, 40% of people with severe or profound disability who responded to the 2007–2008 Australian National Health Survey rated their health as good, very good, or excellent (46).

Generalizations about “disability” or “people with disabilities” can mislead. Persons with disabilities have diverse personal factors with differences in gender, age, socioeconomic status, sexuality, ethnicity, or cultural heritage. Each has his or her personal preferences and responses to disability (47). Also while disability correlates with disadvantage, not all people with disabilities are equally disadvantaged. Women with disabilities experience the combined disadvantages associated with gender as well as disability, and may be less likely to marry than non-disabled women (48, 49). People who experience mental health conditions or intellectual impairments appear to be more disadvantaged in many settings than those who experience physical or sensory impairments (50). People with more severe impairments often experience greater disadvantage, as shown by evidence ranging from rural Guatemala (51) to employment data from Europe (52). Conversely, wealth and status can help overcome activity limitations and participation restrictions (52).

### Prevention

Prevention of health conditions associated with disability is a development issue. Attention to environmental factors – including nutrition, preventable diseases, safe water and sanitation, safety on roads and in workplaces – can greatly reduce the incidence of health conditions leading to disability (53).

A public health approach distinguishes:

- **Primary prevention** – actions to avoid or remove the cause of a health problem in an individual or a population before it arises. It includes health promotion and specific protection (for example, HIV education) (54).
- **Secondary prevention** – actions to detect a health problem at an early stage in an individual or a population, facilitating cure, or reducing or preventing spread, or reducing or preventing its long-term effects (for example, supporting women with intellectual disability to access breast cancer screening) (55).
- **Tertiary prevention** – actions to reduce the impact of an already established disease by restoring function and reducing disease-related complications (for example, rehabilitation for children with musculoskeletal impairment) (56).

Article 25 of the CRPD specifies Access to Health as an explicit right for people with disabilities, but primary prevention of health conditions does not come within its scope. Accordingly, this Report considers primary prevention only in so far as people with disabilities require equal access to health promotion and screening opportunities. Primary prevention issues are extensively covered in other WHO and World Bank publications, and both organizations consider primary prevention as crucial to improved overall health of countries’ populations.

Viewing disability as a human rights issue is not incompatible with prevention of health conditions as long as prevention respects the rights and dignity of people with disabilities, for example, in the use of language and imagery (57, 58). Preventing disability should be regarded as a multidimensional strategy that includes prevention of disabling barriers as well as prevention and treatment of underlying health conditions (59).



## Disability and human rights

Disability is a human rights issue (7) because:

- People with disabilities experience inequalities – for example, when they are denied equal access to health care, employment, education, or political participation because of their disability.
- People with disabilities are subject to violations of dignity – for example, when they are subjected to violence, abuse, prejudice, or disrespect because of their disability.
- Some people with disability are denied autonomy – for example, when they are subjected to involuntary sterilization, or when they are confined in institutions against their will, or when they are regarded as legally incompetent because of their disability.

A range of international documents have highlighted that disability is a human rights issue, including the *World Programme of Action Concerning Disabled People* (1982), the *Convention on the Rights of the Child* (1989), and the *Standard Rules on the Equalisation of Opportunities for People with Disabilities* (1993). More than 40 nations adopted disability discrimination legislation during the 1990s (60). The CRPD – the most recent, and the most extensive recognition of the human rights of persons with disabilities – outlines the civil, cultural, political, social, and economic rights of persons with disabilities (61). Its purpose is to “promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by people with disabilities and to promote respect for their inherent dignity”.

The CRPD applies human rights to disability, thus making general human rights specific to persons with disabilities (62), and clarifying existing international law regarding disability. Even if a state does not ratify the CRPD, it helps interpret other human rights conventions to which the state is party.

Article 3 of the CRPD outlines the following general principles:

1. respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;
2. non-discrimination;
3. full and effective participation and inclusion in society;
4. respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
5. equality of opportunity;
6. accessibility;
7. equality between men and women;
8. respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

States ratifying the CRPD have a range of general obligations. Among other things, they undertake to:

- adopt legislation and other appropriate administrative measures where needed;
- modify or repeal laws, customs, or practices that discriminate directly or indirectly;
- include disability in all relevant policies and programmes;
- refrain from any act or practice inconsistent with the CRPD;
- take all appropriate measures to eliminate discrimination against persons with disabilities by any person, organization, or private enterprise.

States must consult with people with disabilities and their representative organizations when developing laws, policies, and programmes to implement the CRPD. The Convention also requires public and private bodies to make “reasonable accommodation” to the situation of people with disabilities. And it is accompanied by an Optional Protocol that, if ratified, provides for a complaints procedure and an inquiry procedure, which can be lodged with the committee monitoring the treaty.

The CRPD advances legal disability reform, directly involving people with disabilities and using a human rights framework. Its core message is that people with disabilities should not be considered “objects” to be managed, but “subjects” deserving of equal respect and enjoyment of human rights.

## Disability and development

Disability is a development issue, because of its bidirectional link to poverty: disability may increase the risk of poverty, and poverty may increase the risk of disability (63). A growing body of empirical evidence from across the world indicates that people with disabilities and their families are more likely to experience economic and social disadvantage than those without disability.

The onset of disability may lead to the worsening of social and economic well-being and poverty through a multitude of channels including the adverse impact on education, employment, earnings, and increased expenditures related to disability (64).

- Children with disabilities are less likely to attend school, thus experiencing limited opportunities for human capital formation and facing reduced employment opportunities and decreased productivity in adulthood (65–67).
- People with disabilities are more likely to be unemployed and generally earn less even when employed (67–72). Both employment and income outcomes appear to worsen with the severity of the disability (52, 73). It is harder for people with disabilities to benefit from development and escape from poverty (74) due to discrimination in employment, limited access to transport, and lack of access to resources to promote self-employment and livelihood activities (71).
- People with disabilities may have extra costs resulting from disability – such as costs associated with medical care or assistive devices, or the need for personal

support and assistance – and thus often require more resources to achieve the same outcomes as non-disabled people. This is what Amartya Sen has called “conversion handicap” (75). Because of higher costs, people with disabilities and their households are likely to be poorer than non-disabled people with similar incomes (75–77).

- Households with a disabled member are more likely to experience material hardship – including food insecurity, poor housing, lack of access to safe water and sanitation, and inadequate access to health care (29, 72, 78–81).

Poverty may increase the risk of disability. A study of 56 developing countries found that the poor experienced worse health than the better off (82). Poverty may lead to the onset of a health conditions associated with disability including through: low birth weight, malnutrition (83, 84), lack of clean water or adequate sanitation, unsafe work and living conditions, and injuries (20, 85–87). Poverty may increase the likelihood that a person with an existing health condition becomes disabled, for example, by an inaccessible environment or lack of access to appropriate health and rehabilitation services (88) (see [Box 1.3](#)).

Amartya Sen’s capabilities approach (91, 92) offers a helpful theoretical underpinning to understanding development, which can be of particular value for the disability human rights field (93) and is compatible with both the ICF (94) and the social model of disability (76). It moves beyond traditional economic measures such as GDP, or concepts of utility, to emphasize human rights and “development as freedom” (91), promoting the understanding that the poverty of people with disabilities – and other disadvantaged peoples – comprises social exclusion and disempowerment, not just lack of material resources. It emphasizes the diversity of aspirations and choices that different people with disabilities might hold in different cultures (95). It also resolves the paradox that many people with disabilities express that they

**Box 1.3. Safety net interventions for people with disabilities**

The United Nations *Convention on the Rights of Persons with Disabilities* (CRPD) states that people with disabilities have an equal right to social protection. Safety nets are a type of social protection intervention that target vulnerability and poverty.

Many countries provide safety nets to poor people with disabilities and their households, either through specific disability-targeted programmes or more commonly through general social assistance programmes.

While systematic evidence is lacking, anecdotal evidence suggests that persons with disabilities may face barriers to accessing safety nets when, for example, information is inadequate or inaccessible, the welfare offices are physically inaccessible, or the programmes' design features do not take into account specific needs of disabled people. Thus, special measures may be needed to ensure that safety nets are inclusive of disabled people. For example:

- information about programmes should be accessible and reach the intended recipients. This may require targeted outreach;
- proxies designated by persons with disabilities should be allowed to conduct many of the transactions in accessing programmes;
- the welfare offices, as well as the transport system, need to be accessible;
- programmes' eligibility criteria may need to specifically include disability;
- means testing mechanisms may need to take into account the extra costs of disability;
- cash transfers might provide higher payments to beneficiaries with disabilities to help with extra costs of living with a disability;
- conditional cash transfers may need to be adjusted to specific circumstances of children with disabilities;
- workfare can introduce quotas and be sensitive to disability;
- labour activation measures should be sensitive to disability.

Some countries, such as Albania, Bangladesh, Brazil, China, Romania, and the Russian Federation also have specific programmes targeted at people with disabilities. The design of these programmes varies. In some cases they cover all disabled people, in other cases they are means tested, or targeted at children with disabilities.

Administration of disability benefits requires assessment of disability. Many formal assessment processes still use predominantly medical criteria, though there has been a move towards adopting a more comprehensive assessment approach focusing on functioning and using the *International Classification of Functioning, Disability and Health* framework. More research is needed to better understand what works with regards to disability assessment and to identify good practice.

Evidence on the impact of safety nets on people with disabilities is limited. While they may improve health and economic status, it is less clear whether access to education also improves. For safety nets to be effective in protecting disabled people, many other public programmes need to be in place, such as health, rehabilitation, education and training and environmental access. More research is needed to better understand what works in providing safety nets to people with disabilities and their households.

Source (89, 90).

have a good quality of life (96), perhaps because they have succeeded in adapting to their situation. As Sen has argued, this does not mean that it is not necessary to address what can be objectively assessed as their unmet needs.

The capabilities approach also helps in understanding the obligations that states owe to individuals to ensure that they flourish, exercise agency, and reach their potential as human beings (97). The CRPD specifies these

obligations to persons with disabilities, emphasizing development and measures to promote the participation and well-being of people with disabilities worldwide. It stresses the need to address disability in all programming rather than as a stand-alone thematic issue. Moreover, its Article 32 is the only international human rights treaty article promoting measures for international cooperation that include, and are accessible to, persons with disabilities.

#### Box 1.4. The Millennium Development Goals and disability

The Millennium Development Goals (MDGs) – agreed on by the international community in 2000 and endorsed by 189 countries – are a unified set of development objectives addressing the needs of the world’s poorest and most marginalized people, and are supposed to be achieved by 2015. The goals are:

1. eradicate extreme poverty and hunger
2. achieve universal primary education
3. promote gender equality and empower women
4. reduce child mortality
5. improve maternal health
6. combat HIV/AIDS, malaria, and other diseases
7. ensure environmental sustainability
8. develop a global partnership for development.

The MDGs are a compact between developing and developed nations. They recognize the efforts that must be taken by developing countries themselves, as well as the contribution that developed countries need to make through trade, development assistance, debt relief, access to essential medicines, and technology transfer.

While some of the background documents explicitly mention people with disabilities, they are not referred to in the MDGs, or in the material generated as part of the process to achieve them.

The 2010 *MDG report* is the first to mention disabilities, noting the limited opportunities facing children with disabilities, and the link between disability and marginalization in education. The Ministerial Declaration of July 2010 recognizes disability as a cross-cutting issue essential for the attainment of the MDGs, emphasizing the need to ensure that women and girls with disabilities are not subject to multiple or aggravated forms of discrimination, or excluded from participation in the implementation of the MDGs (101). The United Nations General Assembly has highlighted the invisibility of persons with disabilities in official statistics (102).

The General Assembly concluded its High Level Meeting on the MDGs in September 2010 by adopting the resolution “Keeping the promise: united to achieve the Millennium Development Goals,” which recognizes that “policies and actions must also focus on persons with disabilities, so that they benefit from progress towards achieving the MDGs” (103).

Despite the widely acknowledged inter-connection between disability and poverty, efforts to promote development and poverty reduction have not always adequately included disability (76, 98–100). Disability is not explicitly mentioned in the eight Millennium Development Goals (MDGs), or the 21 targets, or the 60 indicators for achieving the goals (see Box 1.4).

People with disabilities can benefit from development projects; examples in this Report show that the situation for people with disabilities in low-income countries can be improved. But disability needs to be a higher priority, successful initiatives need to be scaled up, and a more coherent response is needed. In addition, people with disabilities need to be included in development efforts, both as

beneficiaries and in the design, implementation, and monitoring of interventions (104). Despite the role of CBR (see Box 1.5), and many other promising initiatives by national governments or national and international NGOs, systematic removal of barriers and social development has not occurred, and disability still is often considered in the medical component of development (104).

Responses to disability have undergone a radical change in recent decades: the role of environmental barriers and discrimination in contributing to poverty and exclusion is now well understood, and the CRPD outlines the measures needed to remove barriers and promote participation. Disability is a development issue, and it will be hard to improve the lives of the most disadvantaged people in the world

### Box 1.5. Community-based rehabilitation

Since the 1970s community-based rehabilitation (CBR) has been an important strategy to respond to the needs of people with disabilities, particularly in developing countries. CBR was initially promoted to deliver rehabilitation services in countries with limited resources. Field manuals such as *Training in the community for people with disabilities (105)* provided family members and community workers with practical information about how to implement basic rehabilitation interventions.

More than 90 countries around the world continue to develop and strengthen their CBR programmes. Through an ongoing evolutionary process CBR is shifting from a medical-focused, often single-sector approach, to a strategy for rehabilitation, equalization of opportunities, poverty reduction, and social inclusion of people with disabilities (106). Increasingly, CBR is implemented through the combined efforts of people with disabilities, their families, organizations, and communities, and the relevant government and nongovernmental services (106).

In Chamarajnagar, one of the poorest districts of Karnataka, India, many community members did not have access to basic sanitation facilities, putting their health at risk. The Indian government offered grants to families living in these areas to construct toilets. The total cost to construct one toilet was estimated to be US\$ 150. Funding the remaining amount was difficult for most people, particularly people with disabilities. A local nongovernmental organization – Mobility India – assisted people with disabilities and their families to construct accessible toilets. Using existing community-based networks and self-help groups, Mobility India organized street plays and wall paintings to raise awareness about hygiene and the importance of proper sanitation.

As people became interested and motivated, Mobility India – with financial support from MIBLOU, Switzerland, and local contributions – facilitated access to basic sanitation. The group members selected poor households with disabled family members who had the greatest need for a toilet, and they coordinated the construction work in partnership with families and ensured proper use of funds. As a result of the pilot project, 50 accessible toilets were constructed in one year. Many people with disabilities no longer need to crawl or be carried long distances for their toileting needs. They have become independent and, importantly, been able to reclaim their dignity. Their risk of developing health conditions associated with poor sanitation has also been significantly reduced.

Evidence for the effectiveness of CBR varies, but research and evaluation are increasingly being conducted (107–110), and information sharing is increasing through regional networks such as the CBR Africa Network, the CBR Asia-Pacific Network, and the CBR American and Caribbean Network.

The recent publication of the *CBR guidelines (111)* joins the development and human rights aspects of disability. The guidelines:

- promote the need for inclusive development for people with disabilities in the mainstream health, education, social, and employment sectors;
- emphasize the need to promote the empowerment of people with disabilities and their family members;
- through the provision of practical suggestions, position CBR as a tool that countries can use to implement the *Convention on the Rights of Persons with Disabilities*.

without addressing the specific needs of persons with disabilities.

This *World report on disability* provides a guide to improving the health and well-being of persons with disabilities. It seeks to provide clear concepts and the best available evidence, to highlight gaps in knowledge and stress the need for further research and policy. Stories of success are recounted, as are those of failure and neglect. The ultimate goal of the Report and of the CRPD is to enable all people with

disabilities to enjoy the choices and life opportunities currently available to only a minority by minimizing the adverse impacts of impairment and eliminating discrimination and prejudice.

People's capabilities depend on external conditions that can be modified by government action. In line with the CRPD, this Report shows how the capabilities of people with disabilities can be expanded; their well-being, agency, and freedom improved; and their human rights realized.

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