Chapter 9

The way forward: recommendations
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. Disability is complex and the interventions required to overcome disability disadvantage are multiple, systemic, and will vary depending on context.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD), adopted in 2006, aims to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (1). It reflects the major shift in global understanding and responses towards disability. The World report on disability has assembled the best available scientific information on disability so as to understand and help improve the lives of people with disabilities and facilitate the implementation of the CRPD.

This chapter summarizes the Report’s findings about what is known about disability and makes final recommendations to assist stakeholders in overcoming the barriers that people with disabilities experience.

Disability: a global concern

What do we know about people with disabilities?

Higher estimates of prevalence

More than a billion people are estimated to live with some form of disability, or about 15% of the world’s population (based on 2010 global population estimates). This is higher than previous World Health Organization estimates, which date from the 1970s and suggested a figure of around 10%.

According to the World Health Survey around 785 million (15.6%) persons 15 years and older live with a disability, while the Global Burden of Disease estimates a figure of around 975 million (19.4%) persons. Of these, the World Health Survey estimates that 110 million people (2.2%) have very significant difficulties in functioning, while the Global Burden of Disease estimates that 190 million (3.8%) have “severe disability” – the equivalent of disability inferred for conditions such as quadriplegia, severe depression,
World report on disability

or blindness. Only the Global Burden of Disease measures childhood disability (0–14 years) which is estimated to be 95 million (5.1%) children of which 13 million (0.7%) have “severe disability”.

Growing numbers
The number of people with disabilities is growing. There is a higher risk of disability at older ages, and national populations are growing older at unprecedented rates. There is also a global increase in chronic health conditions, such as diabetes, cardiovascular diseases, and mental disorders, which will influence the nature and prevalence of disability. Patterns of disability in a particular country are influenced by trends in health conditions and trends in environmental and other factors – such as road traffic crashes, natural disasters, conflict, diet, and substance abuse.

Diverse experiences
The disability experience resulting from the interaction of health conditions, personal factors, and environmental factors varies greatly. While disability correlates with disadvantage, not all people with disabilities are equally disadvantaged. Women with disabilities experience gender discrimination as well as disabling barriers. School enrolment rates also differ among impairments, with children with physical impairment generally faring better than those with intellectual or sensory impairments. Those most excluded from the labour market are often those with mental health difficulties or intellectual impairments. People with more severe impairments often experience greater disadvantage.

Vulnerable populations
Disability disproportionately affects vulnerable populations. There is a higher disability prevalence in lower-income countries than in higher-income countries. People from the poorest wealth quintile, women, and older people have a higher prevalence of disability. People who have a low income, are out of work, or have low educational qualifications are at an increased risk of disability. Data from selected countries show that children from poorer households and those in ethnic minority groups are at significantly higher risk of disability than other children.

What are the disabling barriers?

The CRPD and the International Classification of Functioning, Disability and Health (ICF) both highlight the environmental factors that restrict participation for people with disabilities. This Report has documented widespread evidence of barriers, including the following.

- **Inadequate policies and standards.** Policy design does not always take into account the needs of people with disabilities, or existing policies and standards are not enforced. Examples include a lack of clear policy of inclusive education, a lack of enforceable access standards in physical environments, and the low priority accorded to rehabilitation.

- **Negative attitudes.** Beliefs and prejudices constitute barriers when health-care workers cannot see past the disability, teachers do not see the value in teaching children with disabilities, employers discriminate against people with disabilities, and family members have low expectations of their relatives with disabilities.

- **Lack of provision of services.** People with disabilities are particularly vulnerable to deficiencies in services such as health care, rehabilitation, or support and assistance.

- **Problems with service delivery.** Issues such as poor coordination among services, inadequate staffing, staff competencies, and training affect the quality and adequacy of services for persons with disabilities.

- **Inadequate funding.** Resources allocated to implementing policies and plans are often inadequate. Strategy papers on poverty reduction, for instance, may mention disability but without considering funding.
Lack of accessibility. Built environments (including public accommodations) transport systems and information are often inaccessible. Lack of access to transport is a frequent reason for a person with a disability being discouraged from seeking work or prevented from accessing health care. Even in countries with laws on accessibility, compliance in public buildings is often very low. The communication needs of people with disabilities are often unmet. Information is frequently unavailable in accessible formats, and some people with disabilities are unable to access basic information and communication technologies such as telephones and television.

Lack of consultation and involvement. Often people with disabilities are excluded from decision-making in matters directly affecting their lives.

Lack of data and evidence. A lack of rigorous and comparable data on disability and evidence on programmes that work often impedes understanding and action.

How are the lives of people with disabilities affected?

These barriers contribute to the disadvantages experienced by people with disabilities, such as the following.

They have poor health outcomes. Depending on the group and setting, persons with disabilities may experience greater vulnerability to preventable secondary conditions and co-morbidities, untreated mental health conditions, poor oral health, higher rates of HIV infection, higher rates of obesity, and premature mortality.

They cannot always live independently or participate fully in community activities. Reliance on institutional solutions, lack of community living, inaccessible transport and other public facilities, and negative attitudes leave people with disabilities dependent on others and isolated from mainstream social, cultural, and political opportunities.

They are less economically active. People with disabilities have lower employment rates than people without disabilities. Where people with disabilities are employed, they commonly earn less than their counterparts without disabilities.

They experience higher rates of poverty. Households with a person with a disability have higher rates of poverty than households without disabled members. As a group and across settings, people with disabilities have worse living conditions and fewer assets. Poverty may lead to disability, through malnutrition, poor health care, and dangerous working or living conditions. Disability may lead to poverty through lost earnings, due to lack of employment or underemployment, and through the additional costs of living with disability, such as extra medical, housing, and transport costs.

Recommendations

The evidence in this Report suggests that many of the barriers people with disabilities face are avoidable and the disadvantages associated with disability can be overcome. The following nine recommendations for action are cross-cutting and guided by the more specific recommendations at the end of each chapter.

Implementing the recommendations requires involving different sectors – health, education, social protection, labour, transport, housing – and different actors – governments, civil society organizations (including disabled people’s organizations), professionals, the
It is essential that countries tailor their actions to their specific contexts. Where countries are limited by resource constraints, some of the priority actions, particularly those requiring technical assistance and capacity-building, can be included within the framework of international cooperation (see Box 9.1).

**Box 9.1. An example of inclusive international cooperation**

In November 2008 the Australian Government launched its strategy “Development for all: towards a disability-inclusive Australian aid program”. The strategy marks a significant change in the way Australia’s aid is designed and delivered. Development for All is about improving the reach and effectiveness of development assistance by ensuring that people with disabilities are included, contribute and benefit equally from development efforts.

In preparing the strategy AusAID, the Australian government’s development aid agency, conducted consultations in most of the developing countries where AusAID works, involving people with disabilities, their families and caregivers, government representatives, nongovernmental organizations, and service providers. Almost 500 written submissions were received in the process.

During the consultations overseas-based AusAID staff – often with little experience of relating to people with disabilities – were supported to engage with local disabled people’s organizations. The direct involvement of AusAID staff was an important step in commencing the process of building institutional understanding of the importance of disability-inclusive development. Many came away better informed about disability issues and more confident about spending time with people with disabilities.

Two years into implementation, there are strong signs that the strategy is working:

- People with disabilities are more visible and taking a central role in decision-making, ensuring that Australia’s development policies and programmes are shaped to better take account of their requirements.
- Australia’s support is bolstering partner Government’s efforts, such as in Papua New Guinea, Cambodia and Timor-Leste, towards more equitable national development that benefits all citizens, including people with disability.
- Investments in leadership by people with disabilities, together with advocacy by Australian leaders internationally, is helping to increase the priority and resources for inclusive development globally.
- AusAID’s processes, systems and information about the aid programme are more accessible to people with disabilities. Key programme areas such as scholarships have revised guidelines resulting in increased number of scholars with disabilities.

The strategy takes a rights-based approach, is sensitive to the diversity of people with disabilities, gender issues, and focuses on children with disabilities.

Recommendation 1: Enable access to all mainstream policies, systems and services

People with disabilities have ordinary needs – for health and well-being, for economic and social security, to learn and develop skills, and to live in their communities. These needs can and should be met in mainstream programmes and services. Mainstreaming not only fulfils the human rights of persons with disabilities, it is also more effective.

Mainstreaming is the process by which governments and other stakeholders ensure that persons with disabilities participate equally with others in any activity and service intended for the general public, such as education, health, employment, and social services. Barriers to participation need to be identified and removed, possibly requiring changes to laws, policies, institutions, and environments.

Mainstreaming requires a commitment at all levels, and needs to be considered across all sectors and built into new and existing legislation, standards, policies, strategies, and plans. Adopting universal design and implementing reasonable accommodations are two important...
strategies. Mainstreaming also requires effective planning, adequate human resources, and sufficient financial investment – accompanied by specific measures such as targeted programmes and services (see Recommendation 2) to ensure that the diverse needs of people with disabilities are adequately met.

**Recommendation 2: Invest in specific programmes and services for people with disabilities**

In addition to mainstream services, some people with disabilities may require access to specific measures, such as rehabilitation, support services, or training. Rehabilitation – including assistive technologies such as wheelchairs, hearing aids, and white canes – improves functioning and independence. A range of well-regulated assistance and support services in the community can meet needs for care, enabling people to live independently and to participate in the economic, social, and cultural lives of their communities. Vocational rehabilitation and training can open labour market opportunities.

While there is a need for more services, there is also a need for better, more accessible, flexible, integrated, and well-coordinated multidisciplinary services, particularly at times of transition such as between child and adult services. Existing programmes and services need to be reviewed to assess their performance and make changes to improve their coverage, effectiveness, and efficiency. The changes should be based on sound evidence, appropriate in terms of culture and other local contexts, and tested locally.

**Recommendation 3: Adopt a national disability strategy and plan of action**

While disability should be a part of all development strategies and action plans, it is also recommended that a national disability strategy and plan of action be adopted. A national disability strategy sets out a consolidated and comprehensive long-term vision for improving the well-being of persons with disabilities and should cover both mainstream policy and programme areas and specific services for persons with disabilities.

The development, implementation, and monitoring of a national strategy should bring together a broad range of stakeholders including relevant government ministries, nongovernmental organizations, professional groups, disabled people and their representative organizations, the general public, and the private sector.

The strategy and action plan should be informed by a situation analysis, taking into account such factors as the prevalence of disability, needs for services, social and economic status, effectiveness and gaps in current services, and environmental and social barriers. The strategy should establish priorities and have measurable outcomes. The plan of action operationalizes the strategy in short and medium terms by laying out concrete actions and timelines for implementation, defining targets, assigning responsible agencies, and planning and allocating needed resources.

Mechanisms are needed to make it clear where the responsibility lies for coordination, decision-making, regular monitoring and reporting, and control of resources.

**Recommendation 4: Involve people with disabilities**

People with disabilities often have unique insights about their disability and their situation. In formulating and implementing policies, laws, and services, people with disabilities should be consulted and actively involved.

Disabled people’s organizations may need capacity-building and support to empower people with disabilities and advocate for their needs. When suitably developed and funded, they can also play a role in service delivery – for example, in information provision, peer support, and independent living.
At an individual level, persons with disabilities are entitled to control over their lives and therefore need to be consulted on issues that concern them directly – whether in health, education, rehabilitation, or community living. Supported decision-making may be necessary to enable some individuals to communicate their needs and choices.

**Recommendation 5: Improve human resource capacity**

The attitudes and knowledge of people working in, for example, education, health care, rehabilitation, social protection, labour, law enforcement, and the media are particularly important for ensuring non-discrimination and participation.

Human resource capacity can be improved through effective education, training, and recruitment. A review of the knowledge and competencies of staff in relevant areas can provide a starting point for developing appropriate measures to improve them. Relevant training on disability, which incorporates human rights principles, should be integrated into current curricula and accreditation programmes. In-service training should be provided to current practitioners providing and managing services. For example, strengthening the capacity of primary health care workers, and ensuring availability of specialist staff where required, contribute to effective and affordable health care for people with disabilities.

Many countries have too few staff working in fields such as rehabilitation and special education. Developing standards in training for different types and levels of rehabilitation personnel can assist in addressing resource gaps. There are also shortages of care workers and sign language interpreters. Measures to improve staff retention may be relevant in some settings and sectors.

**Recommendation 6: Provide adequate funding and improve affordability**

Existing public services for people with disabilities are often inadequately funded, affecting the availability and quality of such services. Adequate and sustainable funding of publicly provided services is needed to ensure that they reach all targeted beneficiaries and that good quality services are provided. Contracting out service provision, fostering public-private partnerships, notably with not-for profit organizations, and devolving budgets to persons with disabilities for consumer-directed care can contribute to better service provision.

During the development of the national disability strategy and related action plans, the affordability and sustainability of the proposed measures should be considered and adequately funded through relevant budgets. Programme costs and outcomes should be monitored and evaluated, so that more cost-effective solutions are developed and implemented.

Often people with disabilities and their families have excessive out-of-pocket expenses. To improve the affordability of goods and services for people with disabilities and to offset the extra costs associated with disability, particularly for poor and vulnerable persons with disabilities, consideration should be given to expanding health and social insurance coverage, ensuring that people with disabilities have equal access to public social services, ensuring that poor and vulnerable people with disabilities benefit from poverty-targeted safety net programmes, and introducing fee-waivers, reduced transport fares, and reduced import taxes and duties on assistive technologies.
Chapter 9  The way forward: recommendations

**Recommendation 7: Increase public awareness and understanding of disability**

Mutual respect and understanding contribute to an inclusive society. Therefore it is vital to improve public understanding of disability, confront negative perceptions, and represent disability fairly. For example, education authorities should ensure that schools are inclusive and have an ethos of valuing diversity. Employers should be encouraged to accept their responsibilities towards staff with disabilities.

Collecting information on knowledge, beliefs and attitudes about disability can help identify gaps in public understanding that can be bridged through education and public information. Governments, voluntary organizations, and professional associations should consider running social marketing campaigns that change attitudes on stigmatized issues such as HIV, mental illness, and leprosy. Involving the media is vital to the success of these campaigns and to ensuring the dissemination of positive stories about persons with disabilities and their families.

**Recommendation 8: Improve disability data collection**

Internationally, methodologies for collecting data on people with disabilities need to be developed, tested cross-culturally, and applied consistently. Data need to be standardized and internationally comparable for benchmarking and monitoring progress on disability policies, and for the implementation of the CRPD nationally and internationally.

Nationally, disability should be included in data collection. Uniform definitions of disability, based on the ICF, can allow for internationally comparable data. Understanding the numbers of people with disabilities and their circumstances can improve country efforts to remove disabling barriers and provide appropriate services for people with disabilities. As a first step, national population census data can be collected in line with recommendations from the United Nations Washington Group on Disability and the United Nations Statistical Commission. A cost-effective and efficient approach is to include disability questions – or a disability module – in existing sample surveys such as a national household survey, national health survey, general social survey, or labour force survey. Data need to be disaggregated by population features, such as age, sex, race, and socioeconomic status, to uncover patterns, trends, and information about subgroups of persons with disabilities.

Dedicated disability surveys can also gain more comprehensive information on disability characteristics, such as prevalence, health conditions associated with disability, and use of and need for services including rehabilitation. Administrative data collection can be a useful source of information on users and on types, amounts, and cost of services, if standard disability identifiers are included.

**Recommendation 9: Strengthen and support research on disability**

Research is essential for increasing public understanding about disability issues, informing disability policy and programmes, and efficiently allocating resources.

This Report recommends several areas for research on disability including:

- the impact of environmental factors (policies, physical environment, attitudes) on disability and how to measure it;
- the quality of life and well-being of people with disabilities;
- barriers to mainstream and specific services, and what works in overcoming them in different contexts;
- accessibility and universal design programmes appropriate for low-income settings;
- the interactions among environmental factors, health conditions, and disability – and between disability and poverty;
the cost of disability and the cost-effectiveness of public spending on disability programmes.

Research requires focused investments in human and technical capacity, particularly in low-income and middle-income countries. A critical mass of trained researchers on disability needs to be built. Research skills should be strengthened in a range of disciplines, including epidemiology, disability studies, health and rehabilitation, special education, economics, sociology, and public policy. International learning and research opportunities, linking universities in developing countries with those in high-income and middle-income countries, can also be useful.

**Conclusion**

The CRPD established an agenda for change. This *World report on disability* has documented the current situation for people with disabilities. It has highlighted gaps in knowledge and stressed the need for further research and policy development. It has also provided recommendations for action towards achieving a society that is inclusive and enabling, providing equal opportunities for each person with a disability to fulfil their potential.

**Translating recommendations into action**

To implement the recommendations, strong commitment and actions are required from a broad range of stakeholders. While national governments have the most significant role, other players also have important roles. The following highlights some of the actions that the various stakeholders can take.

**Governments** can:

- Review and revise existing legislation and policies for consistency with the CRPD;
- Review and revise compliance and enforcement mechanisms;
- Review mainstream and disability-specific policies, systems, and services to identify gaps and barriers and to plan actions to overcome them;
- Develop a national disability strategy and action plan, establishing clear lines of responsibility and mechanisms for coordination, monitoring and reporting across sectors;
- Regulate service provision by introducing service standards and by monitoring and enforcing compliance;
- Allocate adequate resources to existing publicly-funded services and appropriately fund the implementation of the national disability strategy and plan of action;
- Adopt national accessibility standards and ensure compliance in new buildings, in transport, and in information and communication;
- Introduce measures to ensure that people with disabilities are protected from poverty and benefit adequately from mainstream poverty alleviation programmes;
- Include disability in national data collection systems and provide disability-disaggregated data wherever possible;
- Implement communication campaigns to increase public knowledge and understanding of disability;
- Establish channels for people with disabilities and third parties to lodge complaints on human rights issues and laws that are not implemented or enforced.

**United Nations agencies and development organizations** can:

- Include disability in development aid programmes, using the twin-track approach (mainstreaming and targeted);
- Exchange information and coordinate actions – to agree on priorities for initiatives to learn lessons and to reduce duplication of effort.
Chapter 9  The way forward: recommendations

- Provide technical assistance to countries to build capacity and strengthen existing policies, systems and services – for example, by sharing good and promising practices.
- Contribute to the development of internationally comparable research methodologies for collecting and analysing data relating to people with disabilities.
- Regularly include relevant disability data into statistical publications.

**Disabled people’s organizations** can:
- Support people with disabilities to become aware of their rights, to live independently, and to develop their skills.
- Support children with disabilities and their families to ensure inclusion in education.
- Represent the views of their constituency to international, national, and local decision-makers and service providers, and advocate for their rights.
- Contribute to the evaluation and monitoring of services, and collaborate with researchers to support applied research that can contribute to service development.
- Promote public awareness and understanding by professionals about the rights of persons with disabilities – for example, through campaigning, advocacy, and disability-equality training.
- Conduct audits of environments, transport, and other systems and services to promote barrier removal.

**Service providers** can:
- Carry out access audits, in partnership with local disability groups, to identify physical and information barriers that may exclude persons with disabilities.
- Ensure that staff are adequately trained about disability, implementing training as required and including service users in developing and delivering training.
- Develop individual service plans in consultation with disabled people, and their families where necessary.
- Introduce case management, referral systems, and electronic record-keeping to coordinate and integrate service provision.
- Ensure that people with disabilities are informed of their rights and the mechanisms for complaints.

**Academic institutions** can:
- Remove barriers to the recruitment and participation of students and staff with disabilities.
- Ensure that professional training courses include adequate information about disability, based on human rights principles.
- Conduct research on the lives of persons with disabilities and on disabling barriers, in consultation with disabled people’s organizations.

**The private sector** can:
- Promote diversity and inclusion in working environments.
- Facilitate employment of persons with disabilities, ensuring that recruitment is equitable, that reasonable accommodations are provided, and that employees who become disabled are supported to return to work.
- Remove barriers of access to microfinance, so that persons with disabilities can develop their own businesses.
- Develop a range of quality support services for persons with disabilities and their families at different stages of the life cycle.
- Ensure that construction projects, such as public accommodations, offices and housing include adequate access for persons with disabilities.
- Ensure that ICT products, systems, and services are accessible to persons with disabilities.
Communities can:
- Challenge and improve their own beliefs and attitudes.
- Protect the rights of persons with disabilities.
- Promote the inclusion and participation of disabled people in their community.
- Ensure that community environments are accessible for people with disabilities, including schools, recreational areas and cultural facilities.
- Challenge violence against and bullying of people with disabilities.

People with disabilities and their families can:
- Support other people with disabilities through peer support, training, information, and advice.
- Promote the rights of persons with disabilities within their local communities – for example by conducting access audits, delivering disability equality training, and campaigning for human rights.
- Become involved in awareness-raising and social marketing campaigns.
- Participate in forums (international, national, local) to determine priorities for change, to influence policy, and to shape service delivery.
- Participate in research projects.

References