SUMMARY

WORLD REPORT ON DISABILITY

World Health Organization

THE WORLD BANK
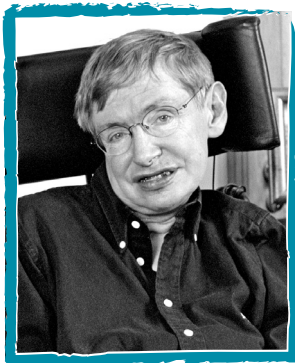
Foreword

Disability need not be an obstacle to success. I have had motor neurone disease for practically all my adult life. Yet it has not prevented me from having a prominent career in astrophysics and a happy family life.

Reading the *World report on disability*, I find much of relevance to my own experience. I have benefitted from access to first class medical care. I rely on a team of personal assistants who make it possible for me to live and work in comfort and dignity. My house and my workplace have been made accessible for me. Computer experts have supported me with an assisted communication system and a speech synthesizer which allow me to compose lectures and papers, and to communicate with different audiences.

But I realize that I am very lucky, in many ways. My success in theoretical physics has ensured that I am supported to live a worthwhile life. It is very clear that the majority of people with disabilities in the world have an extremely difficult time with everyday survival, let alone productive employment and personal fulfilment.

I welcome this first *World report on disability*. This report makes a major contribution to our understanding of disability and its impact on individuals and society. It highlights the different barriers that people with disabilities face – attitudinal, physical, and financial. Addressing these barriers is within our reach.

In fact we have a moral duty to remove the barriers to participation, and to invest sufficient funding and expertise to unlock the vast potential of people with disabilities. Governments throughout the world can no longer overlook the hundreds of millions of people with disabilities who are denied access to health, rehabilitation, support, education and employment, and never get the chance to shine.

The report makes recommendations for action at the local, national and international levels. It will thus be an invaluable tool for policy-makers, researchers, practitioners, advocates and volunteers involved in disability. It is my hope that, beginning with the *Convention on the Rights of Persons with Disabilities*, and now with the publication of the *World report on disability*, this century will mark a turning point for inclusion of people with disabilities in the lives of their societies.

Professor Stephen W Hawking
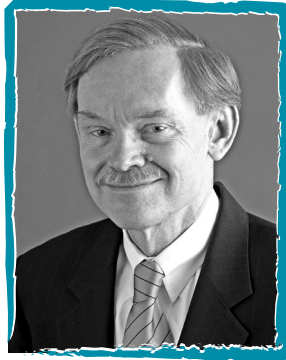
Preface

More than one billion people in the world live with some form of disability, of whom nearly 200 million experience considerable difficulties in functioning. In the years ahead, disability will be an even greater concern because its prevalence is on the rise. This is due to ageing populations and the higher risk of disability in older people as well as the global increase in chronic health conditions such as diabetes, cardiovascular disease, cancer and mental health disorders.

Across the world, people with disabilities have poorer health outcomes, lower education achievements, less economic participation and higher rates of poverty than people without disabilities. This is partly because people with disabilities experience barriers in accessing services that many of us have long taken for granted, including health, education, employment, and transport as well as information. These difficulties are exacerbated in less advantaged communities.

To achieve the long-lasting, vastly better development prospects that lie at the heart of the 2015 Millennium Development Goals and beyond, we must empower people living with disabilities and remove the barriers which prevent them participating in their communities; getting a quality education, finding decent work, and having their voices heard.

As a result, the World Health Organization and the World Bank Group have jointly produced this *World Report on Disability* to provide the evidence for progressive policies and programmes that can improve the lives of people with disabilities, and facilitate implementation of the United Nations Convention on the Rights of Persons with Disabilities, which came into force in May 2008. This landmark international treaty reinforced our understanding of disability as a human rights and development priority.

The *World Report on Disability* suggests steps for all stakeholders – including governments, civil society organizations and disabled people's organizations – to create enabling environments, develop rehabilitation and support services, ensure adequate social protection, create inclusive policies and programmes, and enforce new and existing standards and legislation, to the benefit of people with disabilities and the wider community. People with disabilities should be central to these endeavors.

Our driving vision is of an inclusive world in which we are all able to live a life of health, comfort, and dignity. We invite you to use the evidence in this report to help this vision become a reality.

Dr Margaret Chan   Mr Robert B Zoellick
Director-General   President
World Health Organization World Bank Group

Summary

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 to overcome the disadvantages associated with disability are multiple and systemic – varying with the 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". It reflects the major shift in global understanding and responses towards disability.

The *World report on disability* assembles the best available scientific information on disability to improve the lives of people with disabilities and facilitate implementation of the CRPD. It aims to:

- Provide governments and civil society with a comprehensive analysis of the importance of disability and the responses provided, based on the best available evidence.
- Recommend national and international action.

The *International Classification of Functioning, Disability and Health* (ICF), adopted as the conceptual framework for this Report, defines disability as an umbrella term for impairments, activity limitations, and participation restrictions. Disability refers to the negative aspects of the interaction between individuals with a health condition (such as cerebral palsy, Down syndrome, depression) and personal and environmental factors (such as negative attitudes, inaccessible transportation and public buildings, and limited social supports).

What do we know about disability?

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

Growing numbers

The number of people with disabilities is growing. This is because populations are ageing – older people have a higher risk of disability – and because of the global increase in chronic health conditions associated with disability, such as diabetes, cardiovascular diseases, and mental illness. Chronic diseases are estimated to account for 66.5% of all years lived with disability in low-income and middle-income countries (*1*). 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

Stereotypical views of disability emphasize wheelchair users and a few other "classic" groups such as blind people and deaf people. However, 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 differ among impairments, with children with physical impairments 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, as shown by evidence ranging from rural Guatemala (*2*) to Europe (*3*).

Vulnerable populations

Disability disproportionately affects vulnerable populations. Results from the *World Health Survey* indicate a higher disability prevalence in lower income countries than in higher income countries. People from the poorest wealth quintile, women, and older people also have a higher prevalence of disability (*4*). People who have a low income, are out of work, or have low educational qualifications are at an increased risk of disability. Data from the *Multiple Indicator Cluster Surveys* in selected countries show that children from poorer households and those in ethnic minority groups are at significantly higher risk of disability than other children (*5*).

What are the disabling barriers?

The CRPD and the ICF both highlight the role of the environment in facilitating or restricting participation for people with disabilities. This Report documents 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. For example, for inclusive education policies, a review of 28 countries participating in the Education for All Fast Track Initiative Partnership found that 18 countries either provided very little detail of their proposed strategies to include children with disabilities in schools or did not refer to disability or inclusion at all (*6*). The common gaps in education policy include a lack of financial and other targeted incentives for children with disabilities to attend school as well as a lack of social protection and support services for children with disabilities and their families.
- **Negative attitudes.** Beliefs and prejudices constitute barriers to education, employment, health care, and social participation. For example, the attitudes of teachers, school administrators, other children, and even family members affect the inclusion of children with disabilities in mainstream schools. Misconceptions by employers that people with disabilities are less productive than their non-disabled counterparts, and ignorance about available adjustments to work arrangements limits employment opportunities.
- **Lack of provision of services.** People with disabilities are particularly vulnerable to deficiencies in services such as health care, rehabilitation, and support and assistance. Data from four Southern African countries found that only 26–55% of people received the medical rehabilitation they needed; 17–37% received the assistive devices they needed; 5–23% received the vocational training they needed; and 5–24% received the welfare services they needed (*7–10*). Research in Uttar Pradesh and Tamil Nadu states of India found that after cost, the lack of services in the area was the second most frequent reason for people with disabilities not using health facilities (*11*).
- **Problems with service delivery**. Poor coordination of services, inadequate staffing, and weak staff competencies can affect the quality, accessibility, and adequacy of services for persons with disabilities. *World Health Survey* data from 51 countries revealed that people with disabilities were more than twice as likely to report finding health care provider skills inadequate to meet their needs, four times more likely to be treated badly and nearly three times more likely to be denied needed health care. Many personal support workers are poorly paid and have inadequate training. A study in the United States of America found that 80% of social care workers had no formal qualifications or training (*12*).
- **Inadequate funding**. Resources allocated to implementing policies and plans are often inadequate. The lack of effective financing is a major obstacle to sustainable services across all income settings. For example, in high-income countries, between 20% and 40% of people with disabilities generally do not

have their needs met for assistance with everyday activities (*13–18*). In many low-income and middle-income countries governments cannot provide adequate services and commercial service providers are unavailable or not affordable for most households. Analysis from the 2002–04 *World Health Survey* across 51 countries showed that people with disabilities had more difficulties than people without disabilities in obtaining exemptions from or reductions in health care costs.

- **Lack of accessibility**. Many built environments (including public accommodations) , transport systems and information are not accessible to all. Lack of access to transportation is a frequent reason for a person with disability being discouraged from seeking work or prevented from accessing health care. Reports from countries with laws on accessibility, even those dating from 20 to 40 years ago, confirm a low level of compliance (*19–22*). Little information is available in accessible formats, and many communication needs of people with disabilities are unmet. Deaf people often have trouble accessing sign language interpretation: a survey of 93 countries found that 31 countries had no interpreting service, while 30 countries had 20 or fewer qualified interpreters (*23*). People with disabilities have significantly lower rates of information and communication technology use than non-disabled people, and in some cases they may be unable to access even basic products and services such as telephones, television, and the Internet.
- **Lack of consultation and involvement.** Many people with disabilities are excluded from decision-making in matters directly affecting their lives, for example, where people with disabilities lack choice and control over how support is provided to them in their homes.
- **Lack of data and evidence.** A lack of rigorous and comparable data on disability and evidence on programmes that work can impede understanding and action. Understanding the numbers of people with disabilities and their circumstances can improve efforts to remove disabling barriers and provide services to allow people with disabilities to participate. For example, better measures of the environment and its impacts on the different aspects of disability need to be developed to facilitate the identification of cost-effective environmental interventions.

How are the lives of people with disabilities affected?

The disabling barriers contribute to the disadvantages experienced by people with disabilities.

Poorer health outcomes

Increasing evidence suggests that people with disabilities experience poorer levels of health than the general population. Depending on the group and setting, persons with disabilities may experience greater vulnerability to preventable secondary conditions, co-morbidities, and age-related conditions. Some studies have also indicated that people with disabilities have higher rates of risky behaviours such as smoking, poor diet and physical inactivity. People with disabilities also have a higher risk of being exposed to violence.

Unmet needs for rehabilitation services (including assistive devices) can result in poor outcomes for people with disabilities including deterioration in general health status, activity limitations, participation restrictions and reduced quality of life.

Lower educational achievements

Children with disabilities are less likely to start school than their peers without disabilities, and have lower rates of staying and being promoted in schools. Education completion gaps are found across all age groups in both low-income and high-income countries, with the pattern more pronounced in poorer countries. The difference between the percentage of disabled children and the percentage of non-disabled children attending primary school ranges from 10% in India to 60% in Indonesia. In secondary education the difference in attendance ranges from 15% in Cambodia to 58% in Indonesia (*24*). Even in countries with high primary school enrolment rates, such as those in eastern Europe, many children with disabilities do not attend school.

Less economic participation

People with disabilities are more likely to be unemployed and generally earn less even when employed. Global data from the *World Health Survey* show that employment rates are lower for disabled men (53%) and disabled women (20%) than for non-disabled men (65%) and women (30%). A recent study from the Organization for Economic Co-operation and Development (OECD) (*25*) showed that in 27 countries working-age persons with disabilities experienced significant labour market disadvantage and worse labour market outcomes than working-age persons without disabilities. On average, their employment rate, at 44%, was over half that for persons without disability (75%). The inactivity rate was about 2.5 times higher among persons without disability (49% and 20%, respectively).

Higher rates of poverty

People with disabilities thus experience higher rates of poverty than non-disabled people. On average, persons with disabilities and households with a disabled member experience higher rates of deprivations – including food insecurity, poor housing, lack of access to safe water and sanitation, and inadequate access to health care – and fewer assets than persons and households without a disability.

People with disabilities may have extra costs for personal support or for medical care or assistive devices. Because of these higher costs, people with disabilities and their households are likely to be poorer than non-disabled people with similar income. Disabled people in low-income countries are 50% more likely to experience catastrophic health expenditure than non-disabled people (*4*).

Increased dependency and restricted participation

Reliance on institutional solutions, lack of community living and inadequate services leave people with disabilities isolated and dependent on others. A survey of 1505 non-elderly adults with disability in the United States found that 42% reported having failed to move in or out of a bed or a chair because no one was available to help (*26*). Residential institutions are reported to be responsible for

a lack of autonomy, segregation of people with disabilities from the wider community, and other human rights violations.

Most support comes from family members or social networks. But exclusive reliance on informal support can have adverse consequences for caregivers, including stress, isolation, and lost socioeconomic opportunities. These difficulties increase as family members age. In the United States members of families of children with developmental disabilities work fewer hours than those in other families, are more likely to have left their employment, have more severe financial problems, and are less likely to take on a new job.

Addressing barriers and inequalities

This Report synthesizes the best available scientific evidence on how to overcome the barriers which people with disabilities face in health, rehabilitation, support and assistance, environments, education, and employment. While detailed information can be found in the chapters of the Report, the review here provides direction for improving the lives of persons with disabilities in line with the CRPD.

Addressing barriers to health care

Making all levels of existing health care systems more inclusive and making public health care programmes accessible to people with disabilities will reduce health disparities and unmet need. A variety of approaches have been used in mainstream health care settings to overcome physical, communication and information barriers such as structural modifications to facilities, using equipment with universal design features, communicating information in appropriate formats, making adjustments to appointment systems and using alternative models of service delivery. Community-based rehabilitation has been successful in less-resourced settings at facilitating access for disabled people to existing services and in screening and promoting preventive health care services. In high-income countries disability access and quality standards have been incorporated into contracts with public, private, and voluntary service providers. Such measures as targeting services, developing individual care plans, and identifying a care coordinator can reach people with complex health needs and hard-to-reach groups. People with disabilities should receive services from primary care teams, but specialist services, organizations, and institutions should be available when needed to ensure comprehensive health care.

To improve health service provider attitudes, knowledge, and skills, education for health-care professionals needs to contain relevant disability information. Involving people with disabilities as providers of education and training can improve knowledge and attitudes. The empowerment of people with disabilities to better manage their own health through self-management courses, peer support, and information provision has been effective in improving health outcomes and can reduce health care costs.

A range of financing options has the potential to improve coverage and affordability of health care services. These include ensuring that insurance and

copayments for health services are affordable for people with disabilities. For people with disabilities who do not have other means of financing health care services, reducing out-of-pocket payments, and providing income support to meet the indirect costs can improve the use of health care services. Financial incentives can encourage health care providers to improve services. In developing countries with effective primary care and disbursement mechanisms, targeted conditional cash transfers linked to the use of health care may improve use of services.

Addressing barriers to rehabilitation

Rehabilitation is a good investment because it builds human capacity. It should be incorporated into general legislation on health, employment, education, and social services and into specific legislation for people with disabilities. Policy responses should emphasize early intervention, the benefits of rehabilitation to promote functioning in people with a broad range of health conditions, and the provision of services as close as possible to where people live.

For established services the focus should be on improving efficiency and effectiveness, by expanding coverage and improving quality and affordability. In less-resourced settings the focus should be on accelerating the supply of services through community-based rehabilitation, complemented by referrals to secondary services. Integrating rehabilitation into primary and secondary health care settings can improve availability. Referral systems between different modes of service delivery (inpatient, outpatient, home-based care) and levels of health service provision (primary, secondary, and tertiary care facilities) can improve access. Rehabilitation interventions delivered in communities are an important part of the continuum of care.

Increasing access to assistive technology increases independence, improves participation, and may reduce care and support costs. To ensure that assistive devices are appropriate, they need to suit both environment and user and be accompanied by adequate follow-up. Access to assistive technologies can be improved by pursuing economies of scale, manufacturing and assembling products locally, and reducing import taxes.

Given the global lack of rehabilitation professionals, more training capacity is needed. Mixed or graded levels of training may be required. The complexity of working in resource-poor contexts demands university or strong technical diploma education. Mid-level training programmes can be a first step to address gaps in rehabilitation personnel in developing countries or to compensate for difficulties in recruiting higher level professionals in developed countries. Training community-based workers can address geographical access and respond to workforce shortages and geographical dispersion. Using mechanisms and incentives to retain personnel can provide continuity of service.

Financing strategies, in addition to those for overcoming barriers in health care, include the redistribution or reorganization of existing services (for example, from hospital to community-based services, international cooperation (including rehabilitation in aid for humanitarian crises), public-private partnerships, and targeted funding for poor people with disabilities.

Addressing barriers to support and assistance services

Transitioning to community living, providing a range of support and assistance services, and supporting informal caregivers will promote independence and enable people with disabilities and their family members to participate in economic and social activities.

Enabling people with disabilities to live in the community requires that they be moved out of institutions and supported by a range of support and assistance services in their communities – including day care, foster care, and home support. Countries need to plan adequately for the transition to a community-based service model, with sufficient funding and human resources. Community services, if well planned and resourced, have better outcomes but may not be cheaper. Government can consider a variety of financing measures including contracting out services to private providers, offering tax incentives, and devolving budgets to people with disabilities and their families for direct purchases of services.

Promising government strategies include developing fair disability assessment procedures and clear eligibility criteria; regulating service provision - including setting standards and enforcing them; funding services for people with disabilities who cannot afford to purchase services; and, where needed, providing services directly. Coordination between the health, social and housing sectors can ensure adequate support and reduce vulnerability. Service outcomes can improve when providers are accountable to consumers and their relationship is regulated through a formal service arrangement; when consumers are involved in decisions on the type of support; and when services are individualized rather than "one size fits all" agency-based controlled services. Training for support workers and users can improve service quality and user experience.

In low-income and middle-income countries, supporting service provision through civil society organizations can expand the coverage and range of services. Community-based rehabilitation programmes have been effective in delivering services to very poor and underserved areas. Information provision, financial support, and respite care will benefit informal carers, who provide most of the support for people with disabilities worldwide.

Creating enabling environments

Removing barriers in public accommodations, transport, information, and communication will enable people with disabilities to participate in education, employment, and social life, reducing their isolation and dependency. Across domains, key requirements for addressing accessibility and reducing negative attitudes are access standards; cooperation between the public and private sector; a lead agency responsible for coordinating implementation; training in accessibility; universal design for planners, architects, and designers; user participation; and public education.

Experience shows that mandatory minimum standards, enforced through legislation, are required to remove barriers in buildings. A systematic evidence-based approach to standards is needed, relevant to different settings and including participation from people with disabilities. Accessibility audits by disabled

people's organizations can encourage compliance. A strategic plan with priorities and increasingly ambitious goals can make the most of limited resources. For example, initially targeting accessibility in new public buildings – the 1% extra cost of access compliance in new buildings is cheaper than adapting existing buildings, then expanding the coverage of laws and standards to include access improvements in existing public buildings.

In transport the goal of continuity of accessibility throughout the travel chain can be achieved by determining initial priorities through consultations with people with disabilities and service providers; introducing accessibility features into regular maintenance and improvement projects; and developing low-cost universal design improvements that result in demonstrable benefits to a wide range of passengers. Accessible bus rapid transit systems are increasingly being adopted in developing countries. Accessible taxis are an important part of an integrated accessible transportation system because they are demand-responsive. Training for transport staff is also required, together with government funding of reduced or free fares for people with disabilities. Pavements, curb cuts (ramps), and pedestrian crossings improve safety and ensure accessibility.

Ways forward in information and communication technology include raising awareness, adopting legislation and regulations, developing standards, and offering training. Services such as telephone relay, captioned broadcasting, sign language interpreting, and accessible formats for information will facilitate participation by people with disabilities. Improved information and communication technology accessibility can be achieved by bringing together market regulation and antidiscrimination approaches, along with relevant perspectives on consumer protection and public procurement. Countries with strong legislation and follow-up mechanisms tend to achieve higher levels of information and communication technology access, but regulation needs to keep pace with technological innovation.

Addressing barriers to education

The inclusion of children with disabilities in mainstream schools promotes universal primary completion, is cost-effective and contributes to the elimination of discrimination.

Including children with disabilities in education requires changes to systems and schools. The success of inclusive systems of education depends largely on a country's commitment to adopt appropriate legislation; provide clear policy direction; develop a national plan of action; establish infrastructure and capacity for implementation; and benefit from long-term funding. Ensuring that children with disabilities can have the same standard of education as their peers often requires increased financing.

Creating an inclusive learning environment will assist all children in learning and achieving their potential. Education systems need to adopt more learner-centred approaches with changes in curricula, teaching methods and materials, and assessment and examination systems. Many countries have adopted individual education plans as a tool to support the inclusion of children with disabilities in educational settings. Many of the physical barriers that children with disabilities

face in education can easily be overcome with simple measures such as changing the layout of classrooms. Some children will require access to additional support services including specialist education teachers, classroom assistants, and therapy services.

Appropriate training of mainstream teachers can improve teacher confidence and skills in educating children with disabilities. The principles of inclusion should be built into teacher training programmes and accompanied by other initiatives that provide teachers with opportunities to share expertise and experiences about inclusive education.

Addressing barriers to employment

Antidiscrimination laws provide a starting point for promoting the inclusion of people with disabilities in employment. Where employers are required by law to make reasonable accommodations – such as making recruitment and selection procedures accessible, adapting the working environment, modifying working times, and providing assistive technologies – these can reduce employment discrimination, increase access to the workplace, and change perceptions about the ability of people with disabilities to be productive workers. A range of financial measures, such as tax incentives and funding for reasonable accommodations, can be considered to reduce additional costs that would otherwise be incurred by employers and employees.

In addition to mainstream vocational training, peer training, mentoring, and early intervention show promise in improving disabled people's skills. Community-based rehabilitation can also improve skills and attitudes, support on-the-job training, and provide guidance to employers. User-controlled disability employment services have promoted training and employment in several countries.

For people who develop a disability when employed, disability management programmes – case management, education of supervisors, workplace accommodation, early return to work with appropriate supports – have improved the rates of return to work. For some people with disabilities, including those with significant difficulties in functioning, supported employment programmes can facilitate skill development and employment. These programmes may include employment coaching, specialized job training, individually tailored supervision, transportation, and assistive technology. Where the informal economy predominates, it is important to promote self-employment for people with disabilities and facilitate access to microcredit through better outreach, accessible information and customized credit conditions.

Mainstream social protection programmes should include people with disabilities, while supporting their return to work. Policy options include separating the income support element from the one to compensate for the extra costs incurred by people with disabilities such as the cost of travel to work and of equipment; using time-limited benefits; and making sure it pays to work.

Recommendations

While many countries have started taking action to improve the lives of people with disabilities much remains to be done. The evidence in this Report suggests that many of the barriers people with disabilities face are avoidable and that the disadvantages associated with disability can be overcome. The following nine recommendations for action are cross-cutting, guided by the more specific recommendations at the end of each chapter.

Implementing them requires involving different *sectors* – health, education, social protection, labour, transport, housing – and different *actors* – governments, civil society organizations (including disabled persons organizations), professionals, the private sector, disabled individuals and their families, the general public, the private sector, and media.

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.

Recommendation 1: enable access to all mainstream systems and services

People with disabilities have ordinary needs – for health and well-being, for economic and social security, to learn and develop skills. These needs can and should be met through mainstream programmes and services.

Mainstreaming is the process by which governments and other stakeholders address the barriers that exclude persons with disabilities from participating equally with others in any activity and service intended for the general public, such as education, health, employment, and social services. To achieve it, changes to laws, policies, institutions, and environments may be indicated. Mainstreaming not only fulfils the human rights of persons with disabilities, it also can be more cost-effective.

Mainstreaming requires a commitment at all levels – 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 approaches. 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 or hearing aids – improves functioning and independence. A range of well-regulated assistance and support services in the community can meet needs for care, enable people to live independently and 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 to the culture and other local contexts, and tested locally.

Recommendation 3: adopt a national disability strategy and plan of action

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 the full range of sectors and stakeholders.

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

People 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

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 personnel can assist in addressing resource gaps. Measures to improve staff retention may be relevant in some settings and sectors.

Recommendation 6: provide adequate funding and improve affordability

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, 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.

To improve the affordability of goods and services for people with disabilities and to offset the extra costs associated with disability, consideration should be given to expanding health and social insurance coverage, ensuring that poor and vulnerable people with disabilities benefit from poverty-targeted safety net programmes, and introducing fee-wavers, reduced transport fares, and reduced import taxes and duties on durable medical goods and assistive technologies.

Recommendation 7: increase public awareness and understanding

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. 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 to benchmark and monitor progress on disability policies and on 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. 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. Data also need to be disaggregated by population features 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, use of and need for services, quality of life, opportunities, and rehabilitation needs.

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 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; what works in overcoming barriers in different contexts; and the effectiveness and outcomes of services and programmes for persons with disabilities.

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, 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.

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.
- Exchange information and coordinate actions – to agree on priorities for initiatives, to learn lessons and to reduce duplication of effort.
- 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.
- 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 about the rights of persons with disabilities – for example, through campaigning 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 in 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:
- 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 information and communication technology products, systems, and services are accessible to persons with disabilities.

Communities can:
- Challenge and improve their own beliefs and attitudes.
- 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.
- 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.

Conclusion

The CRPD established an agenda for change. This *World report on disability* documents the current situation for people with disabilities. It highlights gaps in knowledge and stresses the need for further research and policy development. The recommendations here can contribute towards establishing an inclusive and enabling society in which people with disabilities can flourish.

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