

## **Chapter 2**

# **Disability – a global picture**

“I lost my leg by landmine when I was 5 years old, at that time I went to the rice field with my mother to get firewood. Unfortunately I stepped on a mine. After the accident I was very sad when I saw the other children playing or swimming in the river because I have no leg. I used to stand with my crutch made of wood and I wish I could play freely like the other children too. And when I walked to school some children they called me *kombot*, meaning disabled person, and [the discrimination] make me feel shy and cry and disappointed. So I want all people to have equal rights and not discriminate against each other.”

### **Song**

“At the age of 9, I became deaf as a result of a bout with meningitis. In 2002, I went for Voluntary Counseling and Testing (VCT). The results showed that I was HIV+. I become devastated and lost hope to live because I thought that being HIV+ was the end of world for me. Later, I met a disabled person who spiritually encouraged me to accept my status. Now I have confidence to be able to speak out on HIV/AIDS openly. I have been interviewed widely by print and electronic media and I have been invited to speak in public meetings. I am creating awareness on the importance of VCT and encouraging people to know their status. My work is limited by lack of money. Deaf people living in rural areas have no information on HIV/AIDS. I would like to break the barriers by going to visit them right where they live.”

### **Susan**

“What makes me to feel not included in this school is because my parents are poor, they can't provide me with enough books. This makes my life difficult in the school. They also can't buy me everything which I am supposed to have, like clothes. Being in school without books and pens also makes me feel not included, because teachers used to send me out because I don't have books to write in.”

### **Jackline**

# 2

## Disability – a global picture

Robust evidence helps to make well informed decisions about disability policies and programmes. 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. Collecting appropriate statistical and research data at national and international levels will help parties to the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD) formulate and implement policies to achieve internationally agreed development goals (1).

This chapter offers a picture of disability that succeeding chapters build on. It presents estimates of the prevalence of disability; factors affecting trends in disability (demographic, health, environmental); the socio-economic circumstances of people with disabilities, need and unmet needs, and the costs of disability. It proposes steps for improving data at national and international levels.

The evidence here is based on national (such as the census, population surveys and administrative data registries) and international data sets and a large number of recent studies. Each source has its purposes, strengths, and weaknesses. The data here are, to varying degrees, in accord with the definition of disability outlined in Chapter 1. Additional data and methodological explanations are in the Technical appendices (A, B, C, and D).

### Measuring disability

Disability, a complex multidimensional experience (see Chapter 1), poses several challenges for measurement. Approaches to measuring disability vary across countries and influence the results. Operational measures of disability vary according to the purpose and application of the data, the conception of disability, the aspects of disability examined – impairments, activity limitations, participation restrictions, related health conditions, environmental factors – the definitions, question design, reporting sources, data collection methods, and expectations of functioning.

Impairment data are not an adequate proxy for disability information. Broad “groupings” of different “types of disability” have become part of the language of disability, with some surveys seeking to determine the prevalence of different “types of disability” based directly or indirectly on

assessments and classifications. Often, “types of disability” are defined using only one aspect of disability, such as impairments – sensory, physical, mental, intellectual – and at other times they conflate health conditions with disability. People with chronic health conditions, communication difficulties, and other impairments may not be included in these estimates, despite encountering difficulties in everyday life.

There is an implicit assumption that each “type of disability” has specific health, educational, rehabilitation, social, and support needs. However, diverse responses may be required – for example, two individuals with the same impairment may have very different experiences and needs. While countries may need information on impairments – for instance, to help design specific services or to detect or prevent discrimination – the usefulness of such data is limited, because the resulting prevalence rates are not indicative of the entire extent of disability.

Data on all aspects of disability and contextual factors are important for constructing a complete picture of disability and functioning. Without information on how particular health conditions in interaction with environmental barriers and facilitators affect people in their everyday lives, it is hard to determine the scope of disability. People with the same impairment can experience very different types and degrees of restriction, depending on the context. Environmental barriers to participation can differ considerably between countries and communities. For example, many children drop out of school in Brazil because of a lack of reading glasses, widely available in most high-income countries (2). Stigma attached to impairments as diverse as missing limbs and anxiety, can result in similar limits on a person’s participation in work. This was shown in a recent comparison between two surveys in the United States of America that focused on the work limitations of individuals and on actual work performance (3).

Disability can be conceptualized on a continuum from minor difficulties in functioning to major impacts on a person’s life. Countries are

increasingly switching to a continuum approach to measurement, where estimates of prevalence of disability – and functioning – are derived from assessing levels of disability in multiple domains (4–8). Estimates vary according to where the thresholds on the continuum of disability are set, and the way environmental influences are taken into account. Disaggregating these data further by sex, age, income, or occupation is important for uncovering patterns, trends, and other information about “subgroups” of people experiencing disability.

The data collection method also influences results. Censuses and surveys take varying approaches to measuring disability, and the use of these approaches to data collection in the same country often report different rates of disability (see [Box 2.1](#)). Censuses cover entire populations, occur at long intervals, and by their nature can incorporate only a few disability-relevant questions. While considerable socioeconomic data, such as employment rates and marital status, are available from censuses, they can provide only limited information about participation. On the other hand, censuses tend to be carried out regularly and so can also give information on trends over a certain period. Surveys have the possibility of providing richer information through more comprehensive questions including on institutionalized populations. In developed countries, for example, survey questions identify people with disabilities for impairments in body function and structure, but also increasingly for activities, participation, and environmental factors. Some surveys also provide information on the origins of impairments, the degree of assistance provided, service accessibility, and unmet needs.

Countries reporting a low disability prevalence rate – predominantly developing countries – tend to collect disability data through censuses or use measures focused exclusively on a narrow choice of impairments (10–12). Countries reporting higher disability prevalence tend to collect their data through surveys and apply a measurement approach that records activity limitations and participation restrictions in

**Box 2.1. The Irish census and the disability survey of 2006**

In April 2006 the Central Statistics Office in Ireland carried out a population census that included two questions on disability relating the presence of a long-term health condition and the impact of that condition on functioning. It found that 393 785 people in Ireland were disabled, a rate of 9.3%. Later in 2006 the Central Statistics Office's National Disability Survey (NDS) followed up with a sample of those who had reported a disability in the census, plus a group of people in private households who had not reported a disability. The NDS used a broader definition of disability than the census, with more domains, including pain and breathing, and a measure of severity. Completed questionnaires were received from 14 518 people who had reported a disability in the census and from 1551 who had not done so.

There was a high degree of consistency between the responses to the census and the NDS:

- of those in private households who reported a disability in the census, 88% also reported a disability in the NDS;
- of those in non-private households who reported a disability in the census, 97% also reported a disability in the NDS;
- of those in private households who did not report a disability in the census, 11.5% were found to have a disability in the NDS.

Extrapolating the NDS findings to the whole population produced an overall national disability rate of 18.5%. The differences in the disability rates obtained in the census and the NDS may result from the following:

- The NDS used face-to-face interviews, while the census forms were self-completed.
- The census was a large survey designed for a range of purposes. The NDS focused solely on disability defined as difficulties in functioning in any of the following domains: seeing, hearing, speech, mobility and dexterity, remembering and concentrating, intellectual and learning, emotional, psychological, and mental health, and pain and breathing.
- The inclusion of a pain domain in the NDS resulted in a significantly higher disability rate, with 46% of those not reporting disabilities in the census reporting pain in the NDS.
- Those who only reported a disability in the NDS had a lower level of difficulty and were more likely to have only a single disability, rather than disabilities in several domains.
- More children reported a disability in the NDS than in the census, perhaps because of the more detailed questions in the NDS.

This example shows that prevalence estimates can be affected by the number and type of questions, the level-of-difficulty scale, the range of explicit disabilities, and the survey methodology. The differences between the two measures are mainly due to the domains included and the threshold of the definition of disability. If the domain coverage is narrow (for example, pain is excluded) many people experiencing difficulties in functioning may be excluded. Where resources permit, specific surveys on disability, with comprehensive domain coverage, should be carried out in addition to a census. They provide more comprehensive data, across age groups, for policy and programmes.

**Note:** The actual questions used in the two surveys are available in the published reports.

Sources (5, 9).

addition to impairments. If institutionalized populations are included in a survey, prevalence rates will also be higher (13). These factors influence comparability at the national and international levels and the relevance of the data to a wider set of users. While progress is being made – as with activity limitation studies in Lesotho, Malawi, Mozambique, Zambia, and Zimbabwe – accurate data on disability are mostly lacking for developing countries.

The question design and reporting source can affect estimates. The underlying purpose of a survey – whether a health or general survey, for instance – will affect how people respond (14). Several studies have found differences in “prevalence” between self-reported and measured aspects of disability (15–18). Disability is interpreted in relation to what is considered normal functioning, which can vary based on the context, age group, or even income group

(2). For example, older persons may not self-identify as having a disability, despite having significant difficulties in functioning, because they consider their level of functioning appropriate for their age.

Where children are involved, there are further complexities. Parents or caregivers – the natural proxy responders in surveys – may not accurately represent the experience of the child (19). Questions in surveys developed for adults but used for children may also skew results. Imprecise or off-putting wording in the questions – such as using the word “disabled” when asking about difficulty with an activity (20, 21) – can also result in under-reporting (2).

Comparisons across populations must take these factors into account. Ideally, comparisons should adjust the data for differences in certain methodological effects – such as interviews and examination surveys – where such adjustments are soundly based.

A primary goal of collecting population data on people with disabilities is to identify strategies to improve their well-being. Comprehensive and systematic documentation of all aspects of functioning of the population can support the design and monitoring of interventions. For instance, such data would enable policy-makers to assess the potential benefit of assistance programmes to help people with mobility limitations get to work or to assess interventions to reduce depression (2). Data on prevalence and need should be population-based and relevant to policy, but at the same time not dependent on policy. If data are dependent on policy, estimated prevalence rates can suddenly change if, for example, the benefit system changed and people switched from an unemployment benefit to a disability benefit. With population data and administrative and service data based on the same basic concepts and frameworks, a strong integrated national information database can be developed.

International standards on data and standardized question sets can improve harmonization across the various approaches. There have been attempts in recent years to standardize

disability surveys (see Technical appendix B) (22, 23). But the definitions and methodologies used vary so greatly between countries that international comparisons still remain difficult. This also makes it hard for signatories of the CRPD to monitor their progress in implementing the Convention against a common set of indicators.

Data gathered need to be relevant at the national level and comparable at the global level – both of which can be achieved by basing design on international standards, like the *International Classification of Functioning, Disability and Health* (ICF).

International frameworks and resources are important in these efforts.

- Policy frameworks and agreed principles are set out in the CRPD.
- Information-related standards are provided by the ICF (24, 25).
- Attempts to harmonize and standardize question sets for assessment of health status and disability at population level are in progress (see Technical appendix B for information on European Statistical System, United Nations Washington Group on Disability Statistics, United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP), WHO Regional Office for the Americas/Pan American Health Organization/Budapest Initiative).
- A training manual on disability statistics, prepared by WHO and UNESCAP, provides useful guidance on how countries can enhance their national statistics (26).

## Prevalence of disability – difficulties in functioning

In examining the prevalence of disability in the world today, this Report presents country-reported estimates of disability prevalence, as well as prevalence estimates based on two large data sources: the WHO *World Health Survey* of 2002–2004, from 59 countries, and the WHO

*Global Burden of Disease* study, 2004 update. These sources can be used to examine the prevalence of disability, but they are not directly comparable because they use different approaches to estimating and measuring disability.

### Country-reported disability prevalence

More countries have been collecting prevalence data on disability through censuses and surveys, with many having moved from an “impairment” approach to a “difficulties in functioning” approach. Estimated prevalence rates vary widely across and within countries (2, 11, 27). **Box 2.1** shows variations between two sources of disability data in Ireland. Technical appendix A gives an idea of the variation across countries in conceptual framework, method, and prevalence – from under 1% of the population to over 30% – and illustrates the difficulties surrounding the comparison of existing national data sets. As discussed previously, most developing countries report disability prevalence rates below those reported in many developed countries, because they collect data on a narrow set of impairments, which yield lower disability prevalence estimates.

A growing number of countries are using the ICF framework and related question sets in their national surveys and censuses (5–8, 28–30). Experience in Zambia that makes use of the Washington Group’s six questions for census is outlined in **Box 2.2**. These efforts by countries – together with global and regional initiatives (see technical appendices A and B for details) – will eventually lead to more standardized and thus more comparable estimates of country disability prevalence.

### Global estimates of disability prevalence

The two sources of statistical information to estimate global disability prevalence in this Report, the *World Health Survey* and the *Global Burden of Disease*, both have limitations with regard to

disability. So the prevalence estimates presented here should be taken not as definitive but as reflecting current knowledge and available data.

### Estimates based on the WHO World Health Survey

The *World Health Survey*, a face-to-face household survey in 2002–2004, is the largest multinational health and disability survey ever using a single set of questions and consistent methods to collect comparable health data across countries. The conceptual framework and functioning domains for the *World Health Survey* came from the ICF (24, 32). The questionnaire covered the health of individuals in various domains, health system responsiveness, household expenditures, and living conditions (33). A total of 70 countries were surveyed, of which 59 countries, representing 64% of the world population, had weighted data sets that were used for estimating the prevalence of disability of the world’s adult population aged 18 years and older (33). The countries in the survey were chosen based on several considerations:

- the need to fill data gaps in geographical regions where data were most lacking, such as sub-Saharan Africa;
- a spread of countries that would include high-income, middle-income, and low-income countries with a focus on low-income and middle-income countries;
- inclusion of countries with large adult populations.

The samples were drawn from each country’s sampling frame at the time of the *World Health Survey*, using a stratified, multistage cluster. The survey used a consistent conceptual framework to identify measurement domains.

The choice of domains to include in the *World Health Survey* was informed by analysis of WHO’s MultiCountry Survey Study (MCSS). To arrive at the most parsimonious set of domains that would explain most of the variance in the valuation of health and functioning, the domains of affect, cognition, interpersonal relationships, mobility, pain, sleep and energy,

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self-care, and vision were included. Although hearing impairment is the most common of sensory impairments and markedly increases with age, reporting biases in general population surveys, low-endorsement rates in the general population, and the domain of hearing not contributing significantly to explaining the variance led to this domain being dropped from the *World Health Survey* (15, 34).

Possible self-reported responses to the questions on difficulties in functioning included: no

difficulty, mild difficulty, moderate difficulty, severe difficulty, and extreme difficulty. These were scored, and a composite disability score calculated, ranging from 0 to 100, where 0 represented “no disability” and 100 was “complete disability”. This process produced a continuous score range. To divide the population into “disabled” and “not disabled” groups it was necessary to create a threshold value (cut-off point). A threshold of 40 on the scale 0–100 was set to include within estimates of disability, those experiencing significant

### Box 2.2. Using the Washington Group questions to understand disability in Zambia

The Washington Group on Disability Statistics was set up by the United Nations Statistical Commission in 2001 as an international, consultative group of experts to facilitate the measurement of disability and the comparison of data on disability across countries. The Washington Group applies an ICF-based approach to disability and follows the principles and practices of national statistical agencies as defined by the United Nations Statistical Commission. Its questions cover six functional domains or basic actions: seeing, hearing, mobility, cognition, self-care, and communication. The questions asking about difficulties in performing certain activities because of a health problem are as follows.

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty with self-care, such as washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating (for example, understanding or being understood by others)?

Each question has four types of response, designed to capture the full spectrum of functioning, from mild to severe: no difficulty, some difficulty, a lot of difficulty and unable to do it at all.

This set of Washington Group questions was included in a 2006 survey of living conditions in Zambia. They had screened people with conditions, which had lasted or were expected to last for six months or more. The prevalence of difficulty in each of the six domains could be calculated from the responses (see table below).

#### Prevalence of disability by domain and degree of difficulty, Zambia 2006

Core domains	Degree of difficulty		
	At least some difficulty (%)	At least a lot of difficulty (%)	Unable to do it at all (%)
Seeing	4.7	2.6	0.5
Hearing	3.7	2.3	0.5
Mobility	5.1	3.8	0.8
Cognition	2.0	1.5	0.3
Self-care	2.0	1.3	0.4
Communication	2.1	1.4	0.5

**Note:**  $n = 28\ 010$ ; 179 missing.  
Source (31).

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Within each degree of difficulty, problems encountered with mobility were the most prevalent, followed by seeing and hearing difficulties. The results in the table were not mutually exclusive, and many individuals had a disability that covered more than one domain.

Measures that reflect the multidimensionality of disability, constructed from the results of the Washington Group questions, are in the table below.

#### Measures reflecting multidimensionality of disability, Zambia 2006

	Number	Percent
At least one domain is scored "some difficulty" (or higher)	4053	14.5
At least one domain is scored "a lot of difficulty" (or higher). This measure excludes those with the mildest degrees of difficulty.	2368	8.5
At least one domain is scored "cannot do it at all". This measure focuses on the most severe levels of difficulty.	673	2.4
More than one domain is scored "some difficulty" (or higher). This measure focuses on difficulties with multiple actions.	1718	6.1

**Note:**  $n = 28\ 010$ .

Source (37).

As in the first table, higher prevalence rates are associated with definitions of disability that include milder or lesser degrees of difficulty. The relatively low overall prevalence rates for disability reported in many low-income countries (such as the figure of 2.7% in Zambia in 2000) may correspond more closely to rates of severe disability in these countries.

difficulties in their everyday lives. A threshold of 50 was set to estimate the prevalence of persons experiencing very significant difficulties. A full account of the survey method and the process of setting the threshold is in Technical appendix C.

Across all 59 countries the average prevalence rate in the adult population aged 18 years and over derived from the *World Health Survey* was 15.6% (some 650 million people of the estimated 4.2 billion adults aged 18 and older in 2004 (35)) (see [Table 2.1](#)) ranging from 11.8% in higher income countries to 18.0% in lower income countries. This figure refers to adults who experienced significant functioning difficulties in their everyday lives (see Technical appendix C). The average prevalence rate for adults with very significant difficulties was estimated at 2.2% or about 92 million people in 2004.

If the prevalence figures are extrapolated to cover adults 15 years and older, around 720 million people have difficulties in functioning with around 100 million experiencing very significant difficulties.

These estimates do not directly indicate the need for specific services. Estimating the size of the target group for services requires more specific information about the aims of services and the domain and extent of disability.

Across all countries, vulnerable groups such as women, those in the poorest wealth quintile, and older people had higher prevalences of disability. For all these groups the rate was higher in developing countries. The prevalence of disability in lower income countries among people aged 60 years and above, for instance, was 43.4%, compared with 29.5% in higher income countries.

Several limitations or uncertainties surrounding the *World Health Survey* data, described further in Technical appendix C, need to be noted. These include the valid debate regarding how best to set the threshold for disability, and the still unexplained variations across countries in self-reported difficulties in functioning, and the influence of cultural differences in expectations about functional

**Table 2.1. Disability prevalence rates for thresholds 40 and 50 derived from multidomain functioning levels in 59 countries, by country income level, sex, age, place of residence, and wealth**

Population subgroup	Threshold of 40			Threshold of 50		
	Higher income countries (standard error)	Lower income countries (standard error)	All countries (standard error)	Higher income countries (standard error)	Lower income countries (standard error)	All countries (standard error)
<b>Sex</b>						
Male	9.1 (0.32)	13.8 (0.22)	12.0 (0.18)	1.0 (0.09)	1.7 (0.07)	1.4 (0.06)
Female	14.4 (0.32)	22.1 (0.24)	19.2 (0.19)	1.8 (0.10)	3.3 (0.10)	2.7 (0.07)
<b>Age group</b>						
18–49	6.4 (0.27)	10.4 (0.20)	8.9 (0.16)	0.5 (0.06)	0.8 (0.04)	0.7 (0.03)
50–59	15.9 (0.63)	23.4 (0.48)	20.6 (0.38)	1.7 (0.23)	2.7 (0.19)	2.4 (0.14)
60 and over	29.5 (0.66)	43.4 (0.47)	38.1 (0.38)	4.4 (0.25)	9.1 (0.27)	7.4 (0.19)
<b>Place of residence</b>						
Urban	11.3 (0.29)	16.5 (0.25)	14.6 (0.19)	1.2 (0.08)	2.2 (0.09)	2.0 (0.07)
Rural	12.3 (0.34)	18.6 (0.24)	16.4 (0.19)	1.7 (0.13)	2.6 (0.08)	2.3 (0.07)
<b>Wealth quintile</b>						
Q1(poorest)	17.6 (0.58)	22.4 (0.36)	20.7 (0.31)	2.4 (0.22)	3.6 (0.13)	3.2 (0.11)
Q2	13.2 (0.46)	19.7 (0.31)	17.4 (0.25)	1.8 (0.19)	2.5 (0.11)	2.3 (0.10)
Q3	11.6 (0.44)	18.3 (0.30)	15.9 (0.25)	1.1 (0.14)	2.1 (0.11)	1.8 (0.09)
Q4	8.8 (0.36)	16.2 (0.27)	13.6 (0.22)	0.8 (0.08)	2.3 (0.11)	1.7 (0.08)
Q5(richest)	6.5 (0.35)	13.3 (0.25)	11.0 (0.20)	0.5 (0.07)	1.6 (0.09)	1.2 (0.07)
<b>Total</b>	11.8 (0.24)	18.0 (0.19)	15.6 (0.15)	2.0 (0.13)	2.3 (0.09)	2.2 (0.07)

**Note:** Prevalence rates are standardized for age and sex. Countries are divided between low-income and high-income according to their 2004 gross national income (GNI) per capita (36). The dividing point is a GNI of US\$ 3255. Source (37).

requirements and other environmental factors, which the statistical methods could not adjust for.

### Estimates based on the WHO Global Burden of Disease study

The second set of estimates of the global disability prevalence is derived from the *Global Burden of Disease* study, 2004 update. The first *Global Burden of Disease* study was commissioned in 1990 by the World Bank to assess the relative burden of premature mortality and disability from different diseases, injuries, and risk factors (38, 39).

In response to criticisms of disability-adjusted life-years (DALYs) in the original *Global Burden of Disease* study (10, 40–42), the concept has been further developed – for example, the use of population-based health state valuations in preference to expert opinion and better methods for cross-national comparability of survey data on health states (43, 44). The disability weights – years lived with disability (YLD) – used in the DALYs attempt to quantify the functional status of individuals in terms of their capacities and ignore environmental factors. The YLD uses a set of core health domains including mobility, dexterity, affect, pain, cognition, vision, and hearing.

In recent years the WHO has reassessed the *Global Burden of Disease* for 2000–2004, drawing on available data sources to produce estimates of incidence, prevalence, severity, duration, and mortality for more than 130 health conditions for 17 subregions of the world (45, 46). The *Global Burden of Disease* study starts with the prevalence of diseases and injuries and distributions of limitations in functioning – where available – in different regions of the world, and then estimates the severity of related disability (46).

The analysis of the *Global Burden of Disease* 2004 data for this Report estimates that 15.3% of the world population (some 978 million people of the estimated 6.4 billion in 2004 (35)) had “moderate or severe disability”, while 2.9% or about 185 million experienced “severe disability” (see [Table 2.2](#)). Among those aged 0–14 years, the figures were 5.1% and 0.7%, or 93 million and 13 million children, respectively. Among those 15 years and older, the figures were 19.4% and 3.8%, or 892 million and 175 million, respectively.

The *Global Burden of Disease* study has given considerable attention to the internal consistency and comparability of estimates across populations for specific diseases and causes of injury, severity, and distributions of limitations in functioning. But it is not appropriate to infer the overall picture of disability from health conditions and impairments alone. There is substantial uncertainty about the *Global Burden of Disease* estimates – particularly for regions of the world and for conditions where the data are scarce or of poor quality – and about assessments of the average severity of related disability, whether based on published studies or expert opinion (see Technical appendix D).

### About the prevalence estimates

National survey and census data cannot be compared directly with the *World Health Survey* or *Global Burden of Disease* estimates, because there is no consistent approach across countries to disability definitions and survey questions.

In 2004, the latest year for which data are available from surveys and burden of disease

estimates, the *World Health Survey* and *Global Burden of Disease* results based on very different measurement approaches and assumptions, give global prevalence estimates among the adult population of 15.6% and 19.4% respectively. The *World Health Survey* gives the prevalence of adults with very significant difficulties in functioning at 2.2%, while the *Global Burden of Disease* data indicate that 3.8% of the adult population is estimated to have “severe disability” – the equivalent of disability inferred for conditions such as quadriplegia, severe depression, or blindness.

Based on 2010 population estimates – 6.9 billion with 5.04 billion 15 years and over and 1.86 billion under 15 years – and 2004 disability prevalence estimates (*World Health Survey* and *Global Burden of Disease*) there were around 785 (15.6%) to 975 (19.4%) million persons 15 years and older living with disability. Of these, around 110 (2.2%) to 190 (3.8%) million experienced significant difficulties in functioning. Including children, over a billion people (or about 15% of the world’s population) were estimated to be living with disability.

This is higher than WHO estimates from the 1970s, which suggested a global prevalence of around 10% (47). The *World Health Survey* estimate includes respondents who reported significant difficulties in everyday functioning. Against this, the *Global Burden of Disease* estimates result from setting a cut-off based on average disability weights that corresponds to the disability weights for typical health states associated with such conditions as low vision, arthritis, and angina. From these two sources, only the *Global Burden of Disease* provides data on prevalence of disability in children – see the section below on factors affecting disability prevalence for a broader discussion on childhood disability.

The overall prevalence rates from both the *World Health Survey* and *Global Burden of Disease* analyses are determined by the thresholds chosen for disability. Different choices of thresholds result in different overall prevalence rates, even if fairly similar approaches are used

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**Table 2.2. Estimated prevalence of moderate and severe disability, by region, sex, and age, Global Burden of Disease estimates for 2004**

Sex/age group	Percent							
	World	High-income countries	Low-income and middle-income countries, WHO region					
			African	Americas	South-East Asia	European	Eastern Mediterranean	Western Pacific
<b>Severe disability</b>								
Males								
0–14 years	0.7	0.4	1.2	0.7	0.7	0.9	0.9	0.5
15–59 years	2.6	2.2	3.3	2.6	2.7	2.8	2.9	2.4
≥ 60 years	9.8	7.9	15.7	9.2	11.9	7.3	11.8	9.8
Females								
0–14 years	0.7	0.4	1.2	0.6	0.7	0.8	0.8	0.5
15–59 years	2.8	2.5	3.3	2.6	3.1	2.7	3.0	2.4
≥ 60 years	10.5	9.0	17.9	9.2	13.2	7.2	13.0	10.3
All people								
0–14 years	0.7	0.4	1.2	0.6	0.7	0.8	0.9	0.5
15–59 years	2.7	2.3	3.3	2.6	2.9	2.7	3.0	2.4
≥ 60 years	10.2	8.5	16.9	9.2	12.6	7.2	12.4	10.0
≥ 15 years	3.8	3.8	4.5	3.4	4.0	3.6	3.9	3.4
All ages	2.9	3.2	3.1	2.6	2.9	3.0	2.8	2.7
<b>Moderate and severe disability</b>								
Males								
0–14 years	5.2	2.9	6.4	4.6	5.3	4.4	5.3	5.4
15–59 years	14.2	12.3	16.4	14.3	14.8	14.9	13.7	14.0
≥ 60 years	45.9	36.1	52.1	45.1	57.5	41.9	53.1	46.4
Females								
0–14 years	5.0	2.8	6.5	4.3	5.2	4.0	5.2	5.2
15–59 years	15.7	12.6	21.6	14.9	18.0	13.7	17.3	13.3
≥ 60 years	46.3	37.4	54.3	43.6	60.1	41.1	54.4	47.0
All people								
0–14 years	5.1	2.8	6.4	4.5	5.2	4.2	5.2	5.3
15–59 years	14.9	12.4	19.1	14.6	16.3	14.3	15.5	13.7
≥ 60 years	46.1	36.8	53.3	44.3	58.8	41.4	53.7	46.7
≥ 15 years	19.4	18.3	22.0	18.3	21.1	19.5	19.1	18.1
All ages	15.3	15.4	15.3	14.1	16.0	16.4	14.0	15.0

**Note:** High-income countries are those with a 2004 gross national income (GNI) per capita of US\$ 10 066 or more in 2004, as estimated by the World Bank. Low-income and middle-income countries are grouped according to WHO region and are those with a 2004 GNI per capita of less than US\$ 10 066 in 2004, as estimated by the World Bank. Severe disability comprises classes VI and VII, moderate and severe disability, classes III and above.

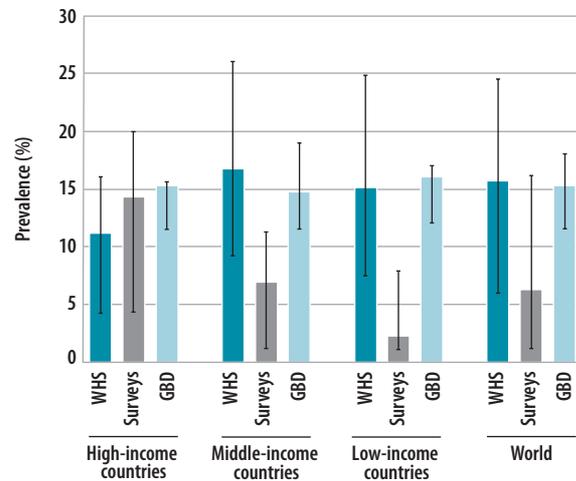
Source (36).

in setting the threshold. This methodological point needs to be borne in mind when considering these new estimates of global prevalence.

The *World Health Survey* and *Global Burden of Disease* results appear reasonably similar in Fig. 2.1, which shows average prevalence for countries by income band. But the sex ratio for disability differs greatly between the *World Health Survey* and the *Global Burden of Disease* (see Table 2.1 and Table 2.2). At the global level, the *Global Burden of Disease* estimates of moderate and severe disability prevalence are 11% higher for females than males, reflecting somewhat higher age-specific prevalences in females, but also the greater number of older women in the population than older men. But the *World Health Survey* estimates give a female prevalence of disability nearly 60% higher than that for males. It is likely that the differences between females and males in the *World Health Survey* study result to some extent from differences in the use of response categories.

The average prevalences from country surveys and censuses, calculated from population-weighted average prevalences in Technical appendix A, are much lower in low-income and middle-income countries than in high-income countries, and much lower than prevalences derived from the *World Health Survey* or *Global Burden of Disease* (see Fig. 2.1). This probably reflects the fact that most developing countries tend to focus on impairment questions in their surveys, while some developed country surveys are more concerned with broader areas of participation and the need for services. The *World Health Survey* results show variation across countries within each income band, possibly reflecting cross-country and within-country differences in the interpretation of categories by people with the same levels of difficulty in functioning. The variation across countries in the *Global Burden of Disease* results is smaller, but this is due to some extent to the extrapolation of country estimates from regional analyses.

**Fig. 2.1. Global disability prevalence estimates from different sources**



**Note:** This figure compares the population-weighted average prevalence of disability for high-income, middle-income, and low-income countries from multiple sources. The solid grey bars show the average prevalence based on available data, the range lines indicate the 10<sup>th</sup> and 90<sup>th</sup> percentiles for available country prevalence within each income group. The data used for this figure are not age standardized and cannot be directly compared with Table 2.1 and Table 2.3. WHS = *World Health Survey*; GBD = the *Global Burden of Disease*, 2004 update; Surveys = Technical appendix A. Sources (37, 46).

While the prevalence data in this Report draw on the best available global data sets, they are not definitive estimates. There is an urgent need for more robust, comparable, and complete data collection. Generally, a better knowledge base is required on the prevalence, nature, and extent of disability—both at a national level where policies are designed and implemented, but also in a globally comparable manner, with changes monitored over time. In the quest for more reliable and comprehensive national and international data on disability, the ICF provides a common platform for measurement and data collection. The ICF is neither a measurement tool nor a survey instrument, but a classification that can provide a standard for health and disability statistics and help in the difficult

## World report on disability

task of harmonizing approaches towards estimating disability prevalence.

Disability prevalence is the result of a complex and dynamic relationship between health conditions and contextual factors, both personal and environmental.

## Health conditions

The relationship between health conditions and disabilities is complicated. Whether a health condition, interacting with contextual factors, will result in disability is determined by inter-related factors.

Often the interaction of several conditions rather than a single one contributes to the relationship between health conditions and disability. Co-morbidity, associated with more severe disability than single conditions, has implications for disability. Also the presence of multiple health problems can make the management of health care and rehabilitation services more difficult (48–50). Chronic health problems often occur together. For example, one chronic physical health condition, such as arthritis, significantly increases the likelihood of another physical health condition and mental health conditions (51, 52). So the aspect of disability that may be reported as primarily associated with one health condition may often be related to several coexisting conditions.

It is not possible to produce definitive global statistics on the relationship between disability and health conditions. Studies that try to correlate health conditions and disability without taking into account environmental effects are likely to be deficient.

The evidence suggests that the two main approaches to dealing with disability and associated health conditions yield different results. These approaches:

- Estimate disability and then look at associated health conditions – as in population surveys such as those mentioned under the section on noncommunicable diseases,

which can contribute to developing an empirical base.

- Estimate the prevalence of health conditions and then apportion disability – as in the synthetic estimates derived from the *Global Burden of Disease* study (see Technical appendix D) (46).

## Trends in health conditions associated with disability

A growing body of statistical evidence presents a complex picture of shifting risk factors for different age and socioeconomic groups, with a pronounced increase in the prevalence of chronic conditions in the general population. Discussed here are trends in three broad categories of health conditions – infectious diseases, chronic conditions, and injuries.

### Infectious diseases

Infectious diseases, may create, or be defined in terms of impairments. They are estimated to account for 9% of the years lived with disability in low-income and middle-income countries (46). Prominent among them are lymphatic filariasis, tuberculosis, HIV/AIDS, and other sexually transmitted diseases. Less prominent are diseases with neurological consequences, such as encephalitis (53, 54), meningitis (55, 56), and childhood cluster diseases – such as measles, mumps, and poliomyelitis (57).

Some of the trends in significant infectious diseases associated with disability:

- At the end of 2008 an estimated 33.4 million people worldwide – about 0.5% of the world population – were living with HIV. Between 2000 and 2008 the number of people living with HIV rose by 20%, but the annual global incidence of HIV infection is estimated to have declined by 17%. Sub-Saharan Africa remains the region most affected (58).
- Malaria is endemic in 109 countries, compared with 140 in the 1950s. In 7 of 45 African countries or territories with smaller populations, malaria cases

and deaths fell by at least 50% between 2000 and 2006. In 22 countries in other regions, malaria cases also fell by at least 50% (59).

- Polio cases fell more than 99% in 18 years, from an estimated 350 000 cases in 1988, to 1604 in 2009 (60). In 2010 only four countries – Afghanistan, India, Nigeria, and Pakistan – remain polio-endemic, down from more than 125 in 1988 (60, 61).
- The elimination of leprosy, to less than 1 per 10 000 population, was attained at the global level by 2000. At the beginning of 2003 the number of leprosy patients in the world was around 530 000, as reported by 106 countries. The number of countries with prevalence rates above 1 per 10 000 population fell from 122 in 1985 to 12 in 2002. Brazil, India, Madagascar, Mozambique, and Nepal are the most endemic countries (62).
- Trachoma, once endemic in many countries, is now largely confined to the poorest population groups in 40 developing countries, affecting about 84 million people, 8 million of them visually impaired (63). The prevalence of trachoma-related visual impairment has fallen considerably over the past two decades due to disease control and socioeconomic development (64).

### Noncommunicable chronic diseases

The increase in diabetes, cardiovascular diseases (heart disease and stroke), mental disorders, cancer, and respiratory illnesses, observed in all parts of the world, will have a profound effect on disability (65–73). They are estimated to account for 66.5% of all years lived with disability in low-income and middle-income countries (46).

National surveys present a more detailed picture of the types of health conditions associated with disabilities:

- In a 1998 population survey in Australia of people (of all ages) with disabilities, the most common disability-related health conditions reported were: arthritis, back

problems, hearing disorders, hypertension, heart disease, asthma, and vision disorders, followed by noise-induced hearing loss, speech problems, diabetes, stroke, depression, and dementia (74). The pattern varied with age and the extent of disability (74).

- In Canada, for adults aged 15 years and over with disabilities, a 2006 study found that the most common health conditions related to disability were arthritis, back problems, and hearing disorders. Other conditions included heart disease, soft tissue disorders such as bursitis and fibromyalgia, affective disorders, asthma, vision disorders, and diabetes. Among children aged 0–14 years, many of the most common health conditions were related to difficulties in learning. They included learning disabilities, specifically autism and attention deficit (with and without hyperactivity), as well as high levels of asthma and hearing problems. Other health conditions found in young people included speech problems, dyslexia, cerebral palsy, vision disorders, and congenital abnormalities (75).
- A 2001 OECD study in the United States of the top 10 conditions associated with disability found rheumatism to be the leading cause among elderly people, accounting for 30% of adults aged 65 years or older who reported limitations in their “activities of daily living”. Heart problems were second, accounting for 23%. The other main disabling conditions were hypertension, back or neck problems, diabetes, vision disorders, lung and breathing problems, fractures, stroke, and hearing problems (76).

It is projected that there will continue to be large increases in non-communicable disease-related YLDs in rapidly developing regions (65, 77, 78). Several factors help explain the upward trend: population ageing, reduction in infectious conditions, lower fertility, and changing lifestyles related to tobacco, alcohol, diet, and physical activity (39, 65, 79, 80).

### Box 2.3. Assistance for people with disabilities in conflict situations

Armed conflict generates injuries and trauma that can result in disabilities. For those incurring such injuries, the situation is often exacerbated by delays in obtaining emergency health care and longer-term rehabilitation. In 2009 in Gaza an assessment found such problems as (81):

- complications and long-term disability from traumatic injuries, from lack of appropriate follow-up;
- complications and premature mortality in individuals with chronic diseases, as a result of suspended treatment and delayed access to health care;
- permanent hearing loss caused by explosions, stemming from the lack of early screening and appropriate treatment;
- long-term mental health problems from the continuing insecurity and the lack of protection.

As many as half of the 5000 men, women, and children injured over the first three weeks of the conflict could have permanent impairments, aggravated by the inability of rehabilitation workers to provide early intervention (82).

In situations of conflict, those with disabilities are entitled to assistance and protection. Humanitarian organizations do not always respond to the needs of people with disabilities promptly, and gaining access to persons with disabilities who are scattered among affected communities can be difficult. A variety of measures can reduce the vulnerability of persons with disabilities including:

- effective planning to meet disability needs by humanitarian organizations before crises;
- assessments of the specific needs of people with disabilities;
- provisions of appropriate services;
- referral and follow-up services where necessary.

These measures may be carried out directly or through mainstreaming. The needs of families and carers must also be taken into account, both among the displaced population and in the host communities. In emergencies linked to conflicts, the measures need to be flexible and capable of following the target population, adjusting quickly as the situation evolves.

## Injuries

Road traffic injury, occupational injury, violence, and humanitarian crises have long been recognized as contributors to disability (see Box 2.3). However, data on the magnitude of their contribution are very limited. Injury surveillance tends to focus exclusively on near-term outcomes such as mortality or the acute-care consequences of injury (83). For example, between 1.2 million and 1.4 million people die every year as a result of road traffic crashes. A further 20 to 50 million more are injured (84–86). The number of people disabled as a result of these crashes is not well documented.

A recent systematic review of the risk of disability among motor vehicle drivers surviving crashes showed substantial variability in derived estimates. Prevalence estimates of post-crash disability varied from 2% to 87%, largely a result of the methodological difficulties in measuring the non-fatal outcomes

following injuries (87). In Belgium a study using the country's Official Disability Rating Scale (a tool insurance companies use to assess disability rates among specific patients) found that 11% of workers injured in a road traffic crash on their way to or from work sustained a permanent disability (88). In Sweden 10% of all car occupants with an Abbreviated Injury Scale of 1 (the lowest injury score) sustained a permanent impairment (89).

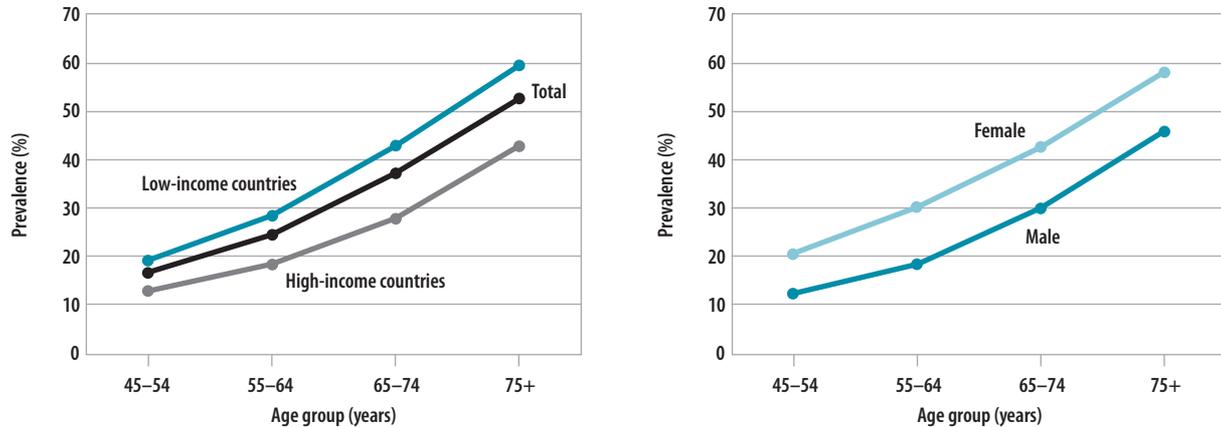
Road traffic injuries are estimated to account for 1.7% of all years lived with disability – violence and conflict, for an additional 1.4% (46).

## Demographics

### Older persons

Global ageing has a major influence on disability trends. The relationship here is straightforward: there is higher risk of disability at older

**Fig. 2.2. Age-specific disability prevalence, derived from multidomain functioning levels in 59 countries, by country income level and sex**



Source (37).

ages, and national populations are ageing at unprecedented rates.

Higher disability rates among older people reflect an accumulation of health risks across a lifespan of disease, injury, and chronic illness (74). The disability prevalence among people 45 years and older in low-income countries is higher than in high-income countries, and higher among women than among men.

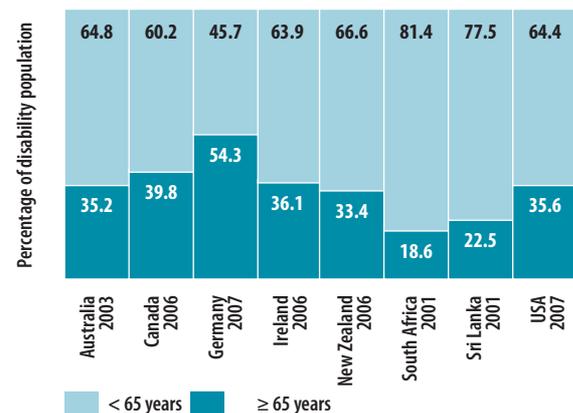
Older people are disproportionately represented in disability populations (see Fig. 2.2). They make up 10.7% of the general population of Australia and 35.2% of Australians with disabilities (29). In Sri Lanka, 6.6% of the general population are 65 years or older representing 22.5% of people with disabilities. Rates of disability are much higher among those aged 80 to 89 years, the fastest-growing age cohort worldwide, increasing at 3.9% a year (90) and projected to account for 20% of the global population 60 years or older by 2050 (91). See Fig. 2.3 for the contribution of ageing to the disability prevalence in selected countries.

The ageing population in many countries is associated with higher rates of survival to an older age and reduced fertility (99). Despite differences between developing and developed nations, median ages are projected to increase markedly in all countries (99). This is an historically important demographic transition, well

under way in high-income nations, and projected to become more marked across the globe throughout the 21st century (see Table 2.3) (90, 99, 100).

Studies report contradictory trends in the prevalence of disability among older age groups in some countries, but the growing proportions of older people in national populations and the increased numbers of the “oldest old” most at risk of disability are well documented (76, 101). The Organisation for Economic Co-operation and Development (OECD) has concluded that it would be unwise for policy-makers to expect

**Fig. 2.3. Distribution of ages within disability populations**



Sources (5, 92–98).

**Table 2.3. Global ageing trends: median age by country income**

Country income level	Median Age (years)			
	1950	1975	2005	2050
High-income countries	29.0	31.1	38.6	45.7
Middle-income countries	21.8	19.6	26.6	39.4
Low-income countries	19.5	17.6	19.0	27.9
World	23.9	22.4	28.0	38.1

**Note:** Middle estimate.  
Source (97).

that reductions in severe disability among older people will offset increased demands for long-term care (76).

## Children

Estimates of the prevalence of children with disabilities vary substantially depending on the definition and measure of disability. As presented above, the *Global Burden of Disease* estimates the number of children aged 0–14 years experiencing “moderate or severe disability” at 93 million (5.1%), with 13 million (0.7%) children experiencing severe difficulties (46). In 2005 the United Nations Children’s Fund (UNICEF) estimated the number of children with disabilities under age 18 at 150 million (102). A recent review of the literature in low- and middle-income countries reports child disability prevalence from 0.4% to 12.7% depending on the study and assessment tool (103). A review in low-income countries pointed to the problems in identifying and characterizing disability as a result of the lack of cultural and language-specific tools for assessment (104). This may account in part for the variation in prevalence figures and suggests that children with disabilities are not being identified or receiving needed services.

The functioning of a child should be seen not in isolation but in the context of the family and the social environment. Children under age 5 in developing countries are exposed to multiple risks, including poverty, malnutrition, poor health, and unstimulating home environments, which can impair cognitive, motor, and

social-emotional development (105). Children screening positive for increased risk of disability are less likely to have been breastfed or to have received a vitamin A supplement. As the severity of stunting and being underweight increases, so does the proportion of children screening positive for risk of disability (106). An estimated 200 million children under age 5 fail to reach their potential in cognitive and social-emotional development (105).

In its Multiple Indicator Cluster Surveys (MICS), for ages 2–9, UNICEF used 10 questions to screen children for risk of disability (106). These studies were found to lead to a large number of false positives – an overestimate of the prevalence of disability (107). Clinical and diagnostic evaluation of children who screen positive is required to obtain more definitive data on the prevalence of child disability. The MICS were administered in 19 languages to more than 200 000 children in 20 participating countries. Between 14% and 35% of children screened positive for risk of disability in most countries. Some authors argue that the screening was less able to identify children at risk of disabilities related to mental health conditions (108, 109). Also data from selected countries indicated that children in ethnic minority groups were more likely than other children to screen positive for disability. There was also evidence of regional variation within countries. Children who screened positive for increased risk of disability were also more likely than others:

- to come from poorer households;

- to face discrimination and restricted access to social services, including early-childhood education;
- to be underweight and have stunted growth;
- to be subject to severe physical punishment from their parents (106).

## The environment

The effects of environmental factors on disability are complex.

### Health conditions are affected by environmental factors

For some environmental factors such as low birth weight and a lack of essential dietary nutrients, such as iodine or folic acid, the impact on the incidence and prevalence of health conditions associated with disability is well established in the epidemiological literature (106, 110, 111). But the picture differs greatly because exposure to poor sanitation, malnutrition, and a lack of access to health care (say, for immunization) are all highly variable around the world,

often associated with other social phenomena such as poverty, which also represents a risk for disability (see Table 2.4) (80).

People's environments have a huge effect on the prevalence and extent of disability. Major environmental changes, such as those caused by natural disasters or conflict situations, will also affect the prevalence of disability not only by changing impairments but also by creating barriers in the physical environment. By contrast, campaigns to change negative attitudes towards persons with disabilities and large-scale changes to improve accessibility in the transport system or to public infrastructure will reduce barriers to activities and participation for many persons with disabilities. Other environmental changes include assistance provided by another person or an adapted or specially designed tool, device, or vehicle, or any form of environmental modification to a room, home, or workplace.

Measuring these interactions can provide useful information on whether to target the individual (providing an assistive device), the society (implementing anti-discrimination laws), or both (see Box 2.4) (118).

**Table 2.4. Selected risk trends in selected countries**

Country	Access to adequate sanitation (%)		Households consuming iodine (%) <sup>a</sup>		Infants with low birth weight (%) <sup>a</sup>		One-year-olds with DTP immunization (%) <sup>b</sup>	
	1990	2006	1992–1996	1998–2005	1990–1994	1998–2005	1997–1999	2005
Argentina	81	91	90	90 <sup>c</sup>	7	8	86	90
Bangladesh	26	36	44	70	50	36	69	96
China	48	65	51	93	9	4	85	95
Egypt	50	66	0	78	10	12	94	98
Ghana	6	10	10	28	7	16	72	88
Iran	83	–	82	94	9	7 <sup>c</sup>	100	97
Mexico	56	81	87	91	8	8	87	99
Thailand	78	96	50	63	13	9	97	99

a. Data refer to the most recent year available during the period specified in the column heading.

b. DTP = Diphtheria, tetanus, and pertussis.

c. Data refer to years or periods other than those specified in the column heading, differ from the standard definition, or refer to only part of a country.

Sources (112–115).

**Box 2.4. Measuring the effect of environment on disability**

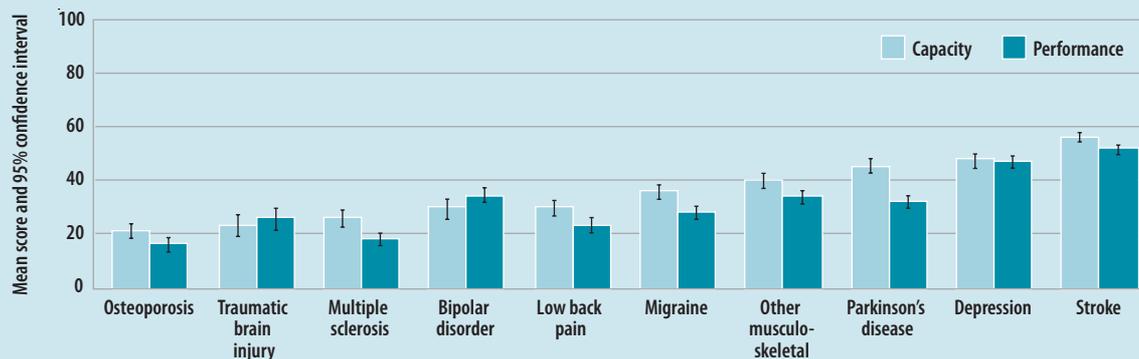
The ICF model of disability provides a tool for measuring the effect of changes in the environment on the prevalence and severity of disability. It uses capacity and performance to assess the influence of the environment on disability. These constructs are as follows:

- **Capacity** indicates what a person can do in a standardized environment, often a clinical setting, without the barriers or facilitators of the person’s usual environment;
- **Performance** indicates what a person does in the current or usual environment, with all barriers and facilitators in place.

Using these notions provides one way of identifying the effect of the environment and judging how a person’s performance might be improved by modifying the environment.

Data were collected from a range of settings (research, primary care, rehabilitation) in the Czech Republic, Germany, Italy, Slovenia, and Spain on 1200 individuals with bipolar disorder, depression, low back pain, migraine, multiple sclerosis, other musculoskeletal conditions (including chronic widespread pain, rheumatoid arthritis and osteoarthritis), osteoporosis, Parkinson disease, stroke, or traumatic brain injury (116). Participants were rated on a five-point scale by interviewers using the ICF checklist recording levels of problems across all dimensions (117). Activity and participation items were scored using both the capacity and the performance constructs. Data were reported using a 0–100 score, with higher scores representing greater difficulties, and a composite score was created (see accompanying figure).

**Mean and 95% confidence interval of the overall scores of capacity and performance in selected health conditions.**



**Note:** Score 0 = no problems; score 100 = maximum problems. The data in Box Fig. 1 should be taken not as necessarily representative of these conditions at large, but as an indication that a consistent conceptual framework can be applied in clinical settings to a wide range of health conditions.

Source (116).

Capacity scores were worst in people with stroke, depression, and Parkinson disease, while individuals with osteoporosis had the fewest limitations. Performance scores tended to be better than capacity scores, except for individuals with bipolar disorder or traumatic brain injury. This suggests that most individuals had supportive environments that promoted their functioning at or above the level of their intrinsic ability – something that applied particularly for multiple sclerosis and Parkinson disease. For people with conditions such as bipolar disorder and traumatic brain injury, the environmental factors hindered optimal performance. The data suggest that it is possible in clinical settings to disentangle aspects of disability that are particular to the individual (the capacity score) from the effects of a person’s physical environment (the difference between capacity and performance).

## Disability and poverty

Empirical evidence on the relation between disability and poverty in its various dimensions (income and non-income) differs greatly between developed and developing countries with most of the evidence from developed countries. But longitudinal data sets to establish the causal relation between disability and poverty are seldom available, even in developed countries.

### Developed countries

Persons with disabilities experience worse educational and labour market outcomes and are more likely to be poor than persons without disabilities (119–129). A 2009 OECD study covering 21 upper-middle and high-income countries shows higher poverty rates among working-age people with disabilities than among working-age people without disability in all but three countries (Norway, Slovakia, and Sweden) (130). The relative poverty risk (poverty rate of working-age disabled relative to that of working-age non-disabled people) was shown to be the highest – more than two times higher – in Australia, Ireland, and the Republic of Korea, and the lowest – only slightly higher than for nondisabled people – in Iceland, Mexico, and the Netherlands. Working-age people with disabilities were found to be twice as likely to be unemployed. When employed, they are more likely to work part-time. And unless they were highly educated and have a job, they had low incomes.

Most studies provide a snapshot of the labour market outcomes and poverty situation of working-age persons with disabilities. Few studies provide information about people's socioeconomic status before the onset of disability and what has happened after it. A study using the British Household Panel Survey between 1991 and 1998 found that having less education, or not being in paid work, was a “selection” factor for disability (131). The study also found that employment rates fell with the

onset of disability, and continue to fall with the duration of disability – indicating that people left the workforce early if they became disabled. Average income fell sharply with onset, but recovered subsequently, though not to pre-disability levels (131).

Some studies have attempted to estimate poverty rates among households with disability taking into account the extra cost of living with disabilities. A United Kingdom study found that in the late 1990s, the poverty rate among households with disabled people, depending on the assumptions used, was 20% to 44% higher after equalizing for disability (using 60% median income threshold) (124).

### Developing countries

Quantitative research on the socioeconomic status of persons with disabilities in developing countries, while small, has recently grown. As with developed countries, descriptive data suggest that persons with disabilities are at a disadvantage in educational attainment and labour market outcomes. The evidence is less conclusive for poverty status measured by asset ownership, living conditions, and income and consumption expenditures.

The majority of studies find that persons with disability have lower employment rates and lower educational attainment than persons without disability (31, 132–143). In Chile and Uruguay the situation is better for younger persons with disabilities than older cohorts, as younger cohorts may have better access to education, through the allocation of additional resources (133). Most of the cross-section data for education suggests that children with disabilities tend to have lower school attendance rates (30, 31, 133–136, 139, 142–146).

An analysis of the *World Health Survey* data for 15 developing countries suggests that households with disabled members spend relatively more on health care than households without disabled members (for 51 *World Health Survey* countries, see Chapter 3 of this Report) (132).

A study on Sierra Leone found that households with persons with severe or very severe disabilities spent on average 1.3 times more on health care than did non-disabled respondents (147). While many studies find that households with disabled members generally have fewer assets (31, 132, 134, 139, 143, 146, 147) and worse living conditions compared with households without a disabled member (134, 139, 146) some studies found no significant difference in assets (30, 140) or living conditions (30, 31).

Data for income and household consumption expenditures are less conclusive. For example households with disabilities in Malawi and Namibia have lower incomes (139, 146) while households in Sierra Leone, Zambia, and Zimbabwe do not (30, 31, 147). In South Africa research suggests that, as a result of the provision of disability grants, households with a disabled member in the Eastern Cape Province had higher income than households without a disabled member (136).

Evidence on poverty as measured by per capita consumption expenditures is also mixed. An analysis of 14 household surveys in 13 developing countries found that adults with disabilities as a group were poorer than average households (144). However, a study of 15 developing countries, using *World Health Survey* data, found that households with disabilities experienced higher poverty as measured by nonhealth per capita consumption expenditures in only 5 of the countries (132).

Data in developing countries on whether having a disability increases the probability of being poor are mixed. In Uruguay disability has no significant effect on the probability of being poor except in households headed by severely disabled persons. By contrast, in Chile disability is found to increase the probability of being poor by 3–4 percent (133). In a cross-country study of 13 developing countries disability is associated with a higher probability of being poor in most countries – when poverty is measured by belonging to the two lowest quintiles in household expenditures or asset ownership. But this association disappears in most of

the countries when controls for schooling are introduced (144).

One study attempted to account for the extra cost of disability in poverty estimates in two developing countries: Viet Nam and Bosnia and Herzegovina. Before the adjustments, the overall poverty rate in Viet Nam was 13.5% and the poverty rate among households with disability was 16.4%. The extra cost of disability was estimated at 9.0% resulting in an increase in the poverty rate among households with disability to 20.1% and in the overall poverty rate to 15.7%. In Bosnia and Herzegovina the overall poverty rate was estimated at 19.5% and among households with disability at 21.2%. The extra cost of disability was estimated at 14%, resulting in an increase in the poverty rate among households with disability to 30.8% and in the overall poverty rate to 22.4% (148).

Very few studies have looked at the prevalence of disability among the poor, or across the distribution of a particular welfare indicator (income, consumption, assets), or across education status. A study of 20 countries found that children in the poorest three quintiles of households in most countries are at greater risk of disability than the others (106). Disability across expenditure and asset quintiles in 15 developing countries, using several disability measures suggests higher prevalence in lower quintiles, but the difference is statistically significant in only a few countries (132).

## Needs for services and assistance

People with disabilities may require a range of services – from relatively minor and inexpensive interventions to complex and costly ones. Data on the needs – both met and unmet – are important for policy and programmes. Unmet needs for support may relate to everyday activities – such as personal care, access to aids and equipment, participation in education, employment, and social activities, and modifications to the home or workplace.

In developed countries, national estimates of need are largely related to specific daily activities, rather than to types of service (92, 149–152). In Germany, for instance, it is estimated that 2.9% of the total population aged 8 years and older has a need for support services. In Sweden this figure has been estimated at 8.1%, solely in the 15–75 years age group (153). See also [Box 2.5](#) for data on Australia.

Several developing countries have conducted national studies or representative surveys on unmet needs for broad categories of services for people with disabilities (159–161). Estimates of unmet needs have been included as a subcomponent in some national studies on people with disabilities in low-income and middle-income countries. The estimate of unmet needs is often based on data from a single survey and related to broad service programmes such as health, welfare, aids and equipment, education, and employment. The ICF conceptual framework has been used in the definitions of disability in most of the studies.

- In Africa national studies on living conditions of people with disabilities were conducted between 2001 and 2006 in Malawi, Namibia, Zambia, and Zimbabwe (159). Across the four countries the only sector that met more than 50% of reported needs for people with disabilities was health care.

The studies revealed large gaps in service provision for people with disabilities, with unmet needs particularly high for welfare, assistive devices, education, vocational training, and counselling services (see [Table 2.5](#)).

- In 2006 a national study on disability in Morocco estimated the expressed need for improved access to a range of services (160). People with disabilities in the study expressed a strong need for better access to health care services (55.3%), medications (21.3%), and technical devices (17.5%), and financial help for basic needs (52.5%).
- A 2006 study on unmet needs in Tonga found that 41% of people with disabilities reported a need for medical advice for their disability – more than twice the proportion of people who received such advice (161). Some 20% of people with disabilities needed physiotherapy, but only 6% received it.
- A 2007 national study on rehabilitation needs in China found that about 40% of people with disabilities who needed services and assistance received no help. The unmet need for rehabilitation services was particularly high for aids and equipment, rehabilitation therapy and financial support for poor people (162).

### **Box 2.5. Combining sources to better understand need and unmet need – an example from Australia**

Four special national studies on unmet needs for specific disability support services were conducted in Australia over a recent decade (154–157). These studies relied on a combination of different data sources, especially the national population disability surveys and administrative data collections on disability services (158).

The use of the *International Classification of Functioning, Disability and Health* (ICF) was critical to the success of these studies; first to underpin national data standards, so as to give the maximum comparability of different sets of disability data; and second to create a framework that related data on support needs (the “demand” data from population surveys) to data on the needs for specific types of service (the “supply” data, also known as “registration data”, from disability services).

An analysis of these demand and supply data combined provided an estimate of unmet needs for services. Furthermore, because the concepts were stable over time it was possible to update the estimates of unmet needs. For example, the estimate of unmet needs for accommodation and respite services was 26 700 people in 2003 and 23 800 people in 2005, after adjusting for population growth and increases in service supply during the period 2003–2005 (157). The users of accommodation and respite services increased from 53 722 people in 2003–2004 to 57 738 in 2004–2005, an increase of 7.5%.

**Table 2.5. Met and unmet need for services reported by people with a disability, selected developing countries**

Service	Namibia		Zimbabwe		Malawi		Zambia	
	Needed <sup>a</sup> (%)	Received <sup>b</sup> (%)						
Health services	90.5	72.9	93.7	92.0	83.4	61.0	76.7	79.3
Welfare services	79.5	23.3	76.0	23.6	69.0	5.0	62.6	8.4
Counselling for parent or family	67.4	41.7	49.2	45.4	50.5	19.5	47.3	21.9
Assistive device services	67.0	17.3	56.6	36.6	65.1	17.9	57.3	18.4
Medical rehabilitation	64.6	26.3	68.2	54.8	59.6	23.8	63.2	37.5
Counselling for disabled person	64.6	15.2	52.1	40.8	52.7	10.7	51.2	14.3
Educational services	58.1	27.4	43.4	51.2	43.9	20.3	47.0	17.8
Vocational training	47.3	5.2	41.1	22.7	45.0	5.6	35.1	8.4
Traditional healer	33.1	46.8	48.9	90.1	57.7	59.7	32.3	62.9

a. Percentage of total number of people with disabilities who expressed a need for the service.

b. Percentage of total number of people with disabilities who expressed a need for service who received the service.

Sources (30, 31, 139, 146).

## Costs of disability

The economic and social costs of disability are significant, but difficult to quantify. They include direct and indirect costs, some borne by people with disabilities and their families and friends and employers, and some by society. Many of these costs arise because of inaccessible environments and could be reduced in a more inclusive setting. Knowing the cost of disability is important not only for making a case for investment, but also for the design of public programmes.

Comprehensive estimates of the cost of disability are scarce and fragmented, even in developed countries. Many reasons account for this situation, including:

- Definitions of disability often vary, across disciplines, different data collection instruments, and different public programmes for disability, making it difficult to compare

data from various sources, let alone compile national estimates.

- There are limited data on the cost components of disability. For instance, reliable estimates of lost productivity require data on labour market participation and productivity of persons with disabilities across gender, age, and education levels.
- There are no commonly agreed methods for cost estimation.

Progress in the technical aspects of disability cost estimates and better data are required to achieve reliable national estimates of the cost of disability – for example, the cost of productivity losses because of disability, the cost of lost taxes because of non-employment or reduced employment of disabled people, the cost of health care, social protection, and labour market programmes, and the cost of reasonable accommodation. The situation is better for data

on public spending on disability benefits in cash, both contributory (social insurance benefits) and non-contributory (social assistance benefits), particularly in developed countries (130). But even for these programmes, consolidated data at the national level are scarce.

### Direct costs of disability

Direct costs fall into two categories: additional costs that people with disabilities and their families incur to achieve a reasonable standard of living, and disability benefits, in cash and in kind, paid for by governments and delivered through various public programmes.

#### Extra costs of living with disability

People with disabilities and their families often incur additional costs to achieve a standard of living equivalent to that of non-disabled people (120, 124, 148, 163). This additional spending may go towards health care services, assistive devices, costlier transportation options, heating, laundry services, special diets, or personal assistance. Researchers have attempted to calculate these costs by asking disabled people to estimate them by pricing the goods and services that disabled people report they need, by comparing actual spending patterns of people with and without disabilities, and by using econometric techniques (120, 124, 164).

Several recent studies have attempted to estimate the extra cost of disability. In the United Kingdom estimates range from 11% to 69% of income (124). In Australia the estimated costs – depending on the degree of severity of the disability – are between 29% and 37% of income (120). In Ireland the estimated cost varied from 20% to 37% of average weekly income, depending on the duration and severity of disability (164). In Viet Nam, the estimated extra costs were 9%, and in Bosnia and Herzegovina 14% (148). While all studies conclude that there are extra costs related to disability, there is no technical agreement on how to measure and estimate them (163).

### Public spending on disability programmes

Nearly all countries have some type of public programmes targeted at persons with disabilities, but in poorer countries these are often restricted to those with the most significant difficulties in functioning (165). They include health and rehabilitation services, labour market programmes, vocational education and training, disability social insurance (contributory) benefits, social assistance (non-contributory) disability benefits in cash, provision of assistive devices, subsidized access to transport, subsidized utilities, various support services including personal assistants and sign language interpreters, together with administrative overheads.

The cost of all programmes is significant, but no estimates of the total cost are available. For OECD countries an average of 1.2% of GDP is spent on contributory and non-contributory disability benefits, covering 6% of the working age population in 2007 (130). The benefits include full and partial disability benefits, as well as early retirement schemes specific to disability or reduced work capacity. The figure reaches 2% of GDP when sickness benefits are included, or almost 2.5 times the spending on unemployment benefits. The expenditure is particularly high in the Netherlands and Norway (about 5% of GDP). The cost of disability is around 10% of public social expenditure across OECD (up to 25% in some countries). At 6% of the working age population in 2007, the disability benefit reciprocity rate was similar to the unemployment rate. In some countries it was close to 10%. Both the number of recipients and public spending have risen during the last two decades, creating significant fiscal concerns about affordability and sustainability of the programmes and motivating some countries, including the Netherlands and Sweden, to take steps to reduce the disability benefit dependency and to foster labour market inclusion of disabled people (166).

## Indirect costs

Indirect economic and non-economic costs as a result of disability can be wide-ranging and substantial. The major components of economic cost are the loss of productivity from insufficient investment in educating disabled children, and exits from work or reduced work related to the onset of disability, and the loss of taxes related to the loss of productivity. Non-economic costs include social isolation and stress and are difficult to quantify.

An important indirect cost of disability is related to lost labour productivity of persons with disability and associated loss of taxes. Losses increase when family members leave employment or reduce the number of hours worked to care for family members with disabilities. The lost productivity can result from insufficient accumulation of human capital (underinvestment in human capital), from a lack of employment, or from underemployment.

Estimating disability-related loss in productivity and associated taxes is complex and requires statistical information, which is seldom available. For example, it is hard to predict the productivity that a person who has dropped out of the labour market because of disability would have if they were working. Hence, estimates of the loss of productivity are rare. One such estimate, for Canada using data from the 1998 National Population Health Survey, reports disability by type of impairment, age, and sex as well as the number of days in bed or with reduced activity. It suggests that the loss of work through short-term and long-term disability was 6.7% of GDP (167).

## Conclusion and recommendations

Using multiple surveys from more than 100 countries, this chapter has shown that disability is a universal experience with economic and social costs to individuals, families, communities and nations.

There are around 785 (15.6% according to the *World Health Survey*) to 975 (19.4% according to the *Global Burden of Disease*) million persons 15 years and older living with disability, based on 2010 population estimates (6.9 billion with 1.86 billion under 15 years). 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 190 million (3.8%) have “severe disability” – the equivalent of disability inferred for conditions such as quadriplegia, severe depression, or blindness. Including children, over a billion people (or about 15% of the world’s population) were estimated to be living with disability.

Disability varies according to a complex mix of factors, including age, sex, stage of life, exposure to environmental risks, socioeconomic status, culture and available resources – all of which vary markedly across locations. Increasing rates of disability in many places are associated with increases in chronic health condition – diabetes, cardiovascular diseases, mental disorders, cancer, and respiratory illnesses – and injuries. Global ageing also has a major influence on disability trends because there is higher risk of disability at older ages. The environment has a huge effect on the prevalence and extent of disability, and on the disadvantage faced by persons with disabilities. Persons with disabilities and households with disabilities experience worse social and economic outcomes compared with persons without disabilities. In all settings, disabled people and their families often incur additional costs to achieve a standard of living equivalent to that of nondisabled people.

Because disability is measured on a spectrum and varies with the environment, prevalence rates are related to thresholds and context. Countries requiring estimates of the number of people needing income support, daily assistance with activities, or other services will construct their own estimates relevant to local policy.

Although the prevalence data in this Report draw on the best available global data

sets, they are not definitive. Considerable and commendable efforts are being made in many countries and by major international agencies to improve disability data. Nevertheless, data quality requires further collaborative effort and there is an urgent need for more robust, comparable, and complete data collection especially in developing countries. Improving disability data may be a long-term enterprise, but it will provide essential underpinning for enhanced functioning of individuals, communities and nations. In the quest for more reliable and comprehensive national and international data on disability, the ICF provides a common platform for measurement and data collection. Improving the quality of information in this way, both nationally and internationally, is essential for monitoring progress in the implementation of the CRPD and in the achievement of internationally agreed development goals.

The following recommendations can contribute to enhancing the availability and quality of data on disability.

### Adopt the ICF

Using the ICF, as a universal framework for disability data collection related to policy goals of participation, inclusion, and health will help create better data design and also ensure that different sources of data relate well to each other. The ICF is neither a measurement tool nor a survey instrument – it is a classification that can provide a standard for health and disability statistics and help in the difficult task of harmonizing approaches across sources of disability data. To achieve this, countries can:

- Base definitions and national data standards on the ICF.
- Ensure that data collection cover the broad array of ICF domains – impairments, activity limitations and participation restrictions, related health condition, environmental factors – even if a minimal set of data items is to be selected.

### Improve national disability statistics

At the national level, information about people with disabilities is derived from censuses, population surveys and administrative data registries. Decisions on how and when to collect data depend on the resources available. Steps that can be taken to improve disability data, prevalence, need and unmet need, and socioeconomic status are outlined below. Disaggregating data by sex, age, and income or occupation will provide information about subgroups of persons with disabilities, such as children and older persons.

- Employ a “difficulties in functioning approach” instead of an “impairment approach” to determine prevalence of disability to better capture the extent of disability.
- 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. Census data can provide an estimate of prevalence, information on socioeconomic situation, and geographical data and be used to identify populations at risk. It can also be used to screen respondents to implement more detailed follow up surveys.
- A cost-effective and efficient approach to gain comprehensive data on persons with disabilities is to add disability questions – or a disability module – to existing sample surveys such as a national household survey, national health survey, a general social survey or labour force survey.
- Dedicated disability surveys can be carried out to gain extensive information on disability and functioning – such as prevalence, health conditions associated with disability, use of and need for services, and other environmental factors, including on persons living in institutions and children.
- Data on persons with disabilities or those at particular risk of disability, including displaced persons, can also be collected through specific surveys in humanitarian crises.

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- Administrative data collections can provide information on users, types and quantity of services and cost of services. In mainstream administrative data collections, standard disability identifiers can be included to monitor access to services by people with disabilities.
  - Statistical linkage of various data sets can allow countries to bring together an array of information on a person from different time points, while at the same time protecting that individual's confidentiality. These linkage studies can often be conducted quickly and at relatively low cost.
  - Where resources exist, collect longitudinal data that include questions on disability. Longitudinal data – the study of cohorts of people and their environments over time – allow researchers and policy-makers to understand better the dynamics of disability. Such analyses would provide better indications of what happens to individuals and their households after disability onset, how their situation is impacted by public policies aimed at improving the social and economic status of disabled people, of the causal relationship between poverty and disability, and how and when to instigate prevention programmes, modify interventions, and make environmental changes.
- Comparable definitions of disability, based on the ICF, and uniform methods for collecting data on people with disabilities need to be developed, tested across cultures, and applied consistently in surveys, censuses and administrative data.
  - Extended measures of disability should be developed and tested that can be incorporated into population surveys, or used as supplements to surveys, or as the core of a disability survey as initiated by the United Nations Washington Group on Disability Statistics and the Budapest Initiative.
  - Develop appropriate instruments for measuring childhood disability.
  - Improve collaboration and coordination between various initiatives to measure disability prevalence at global, regional and national levels (including the Budapest Initiative, European Statistical Commission, UNESCAP, United Nations Statistical Commission, Washington Group, WHO, United States and Canada).

### Improve the comparability of data

Data gathered at the national level need to be comparable at the international level.

- Standardize metadata on national disability prevalence, for example, by defining the measures of disability, purpose a measurement, indicate which aspects of disability are included, and define the cut-off on the continuum. This will facilitate the compilation of country-reported disability prevalence in international data repositories such as WHO's Global Health Observatory.
- Refine methods of generating prevalence rates using a continuous metric that measures multidomain functioning levels. This

### Develop appropriate tools and fill the research gaps

- To improve validity of estimates – further research is needed on different types of investigation, such as self-report and professional assessment.
- To gain a clearer understanding of people in their environments and their interactions – better measures of the environment and its impacts on the different aspects of disability need to be developed. These will facilitate the identification of cost-effective environmental interventions.
- To understand the lived experiences of people with disabilities, more qualitative research is required. Measures of the lived experience of disability need to be coupled

with measurements of the well-being and quality of life of people with disabilities.

- To better understand the interrelationships and develop a true epidemiology of disability – studies are needed that bring health condition (including co-morbidity) aspects of disability into a single data set describing disability, and that explore the interactions between health conditions and disability and environmental factors.
- To better understand the costs of disability – technical agreement is required on definitions and methods of calculating the extra costs of living with a disability. Data are needed on labour market participation and lost productivity due to disability as well as estimates of the cost of public spending

on disability programmes, including cost-benefit and cost-effectiveness analyses.

Data and information to inform national policies on disability should be sought in a wide range of places – including data collected by statistical agencies, administrative data collected by government agencies, reports by government bodies, international organizations, nongovernmental organizations, and disabled people's organizations – in addition to the usual academic journals. It is vital that such information – including on good practices – be shared among a wider network of countries. This will help disseminate experiences from developing countries, which are often innovative and cost-effective.

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