

Learning Objectives: Chapter 2

The ICF Framework

After reading this chapter, the reader should be able to:

1. Understand ICF's model and structure
2. Appreciate importance of standards to disability statistics
3. Describe ICF's structure and coding for population data collection



**“Counting the disabled” Jerome Chatin
WHO Photo Contest “Images of Health and Disability 2004/2005”**

2. THE ICF FRAMEWORK

2.1 The ICF model and conceptual framework: Defining features

- 2.1.1 Biopsychosocial
- 2.1.2 Multidimensional
- 2.1.3 Universal
- 2.1.4 Continuous
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2.1 The ICF model and conceptual framework: Defining features

The WHO's ICF reflects the modern day thinking about disability and embodies a paradigm shift in the way health and disability are understood and measured. ICF is based on a bio-psychosocial model of functioning and disability, in which functioning and disability are multi-dimensional phenomena experienced at the level of the body, the person, and society. In addition, a classification of environmental factors is included that allows users of the ICF to record the positive or negative impact of the environment on a person's functioning.

ICF 'mainstreams' the experience of disability by viewing it, not as the mark of a social minority, but as a universal human experience. By placing the capacity aspects of disability on a continuum with health, ICF makes it possible to measure health and disability with the same domains of functioning. Hence, ICF provides a common conceptual platform that links health and disability statistics.

The ICF model and its underlying principles represent a significant development from its predecessor the ICIDH. In the ICIDH, disability was understood as a limitation in the person's activity that resulted from impairment. Neither disabilities nor handicaps could be assessed in terms of degree of severity. Environmental factors were acknowledged but not classified and no linkages between disability and health status measurement were made. Due to these limitations, ICIDH was generally viewed as flawed and so was ignored by disability data users in general and advocates of the

social model of disability (especially organizations representing people with disabilities) in particular.

In response to these and other criticisms, the ICF was developed over a seven-year period in an international collaborative process and validated by means of field trials in over 70 countries before officially being endorsed by all WHO Member States in 2001. The key, interlocking features of the ICF model are described in what follows, with particular emphasis on the value they add to disability statistics.

2.1.1 Bio-psychosocial

The literature on the 'models of disability' is extensive. It has been dominated by an ongoing debate between a 'medical model of disability', in which disability is entirely a medical matter that resides within the individual and requires medical interventions, and the 'social model of disability' in which the physical and social world is entirely responsible for the disadvantages suffered by so-called PWDs. Social action aimed at increasing equality and full participation is the only relevant intervention under this latter model.

Expressed as an 'either-or' debate, the controversy is irresolvable and futile. The ICF model rejects both extreme positions and adopts the common sense view that both extremes are partly true since they capture different elements of the overall, multi-dimensional phenomena that, unfortunately, goes by one single name, 'disability'.

As a result, the ICF adopts a bio-psychosocial model of disability that incorporates what is true and useful in both models, and rejects what is counterproductive and distorted. Disability is a complex phenomenon that includes both a dimension at the level of a person's body, and a dimension that is a complex and primarily social phenomenon. Medical and rehabilitative interventions are perfectly relevant to the body-level aspects of disability (impairments and limitations in a person's capacity to perform actions). By the same token, environmental and social interventions are relevant to deal with restrictions in a person's social participation in education, work, and community.

For producers and users of disability statistics, the use of the bio-psychosocial model embedded in the ICF broadens the perspective of disability and allows medical, individual, social, and environmental influences on functioning and disability to be examined. Furthermore, advocates of both models can use the ICF as a platform for communication and choosing and comparing interventions.

2.1.2 Multi-dimensional

Structurally, the ICF is based on three levels of functioning (body functions and structures, activities, and participation) with parallel levels of disability (impairments, activity limitations and participation restrictions). These are

classified in terms of domains appropriate to each level, and can be seen in Table 2.1 below:

Table 2.1: ICF Levels of Functioning and Disability

Dimensions of Functioning	Dimensions of Disability
Body Functions and Body Structures	Impairments
Activities	Activity limitations
Participation	Participation restrictions

Notice that the term 'disability' in the ICF refers to **all three** dimensions taken together.

In the case of Body Functions, the domains include mental functions, voice and speech functions, and functions of the various organ systems. In the case of Activities and Participation, the domains include learning and applying knowledge, communication, movement, self care, major life areas, and so on.

The ICF is a **health** classification, in the sense that all aspects of human functioning and disability it classified are presumed to occur in the context of health, and so (typically) in the presence of one or more health conditions – diseases, disorders, injuries, and traumas. As such, the ICF provides the language for health statistics, the data that characterize the health of individuals and populations.

Information can be collected about each dimension of disability for an individual; and it is only when all three kinds of information are collected that we have a complete portrait of the lived experience of disability for a particular person. Information about impairments alone, i.e., problems in body functions or structures, although certainly relevant to the disability experience, provides a very limited perspective on disability.

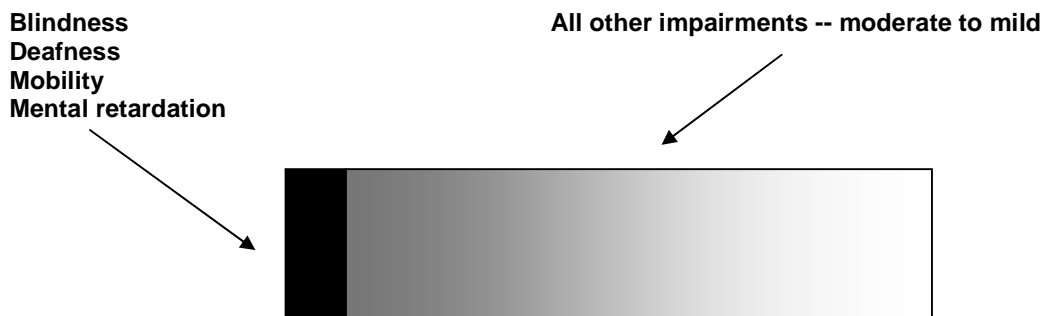
From a statistical point of view, collecting data on impairments alone, although traditional in population surveys and censuses, tends to under-describe disability, and under-estimates the prevalence rate of disabilities as a whole. Holistic ICF-based disability information gives us the data required for a wide variety of data applications, including needs assessment, and intervention planning, monitoring and evaluation.

Using a traditional list of impairments such as blindness, deafness, mobility problems (as characterised by paralysis or loss of use of a limb) and mental retardation can identify a sub-population with severe disabilities. The population of individuals with mental retardation is very small, and for self-report surveys, people who have seeing or hearing problems, but who are neither blind nor deaf, will not respond in the affirmative. Similarly, a person

who has trouble walking, but is relatively mobile, will answer the question negatively. People with communication difficulties, or chronic health conditions, or other impairments will also answer in the negative.

Relying on the impairment approach, in other words, identifies the people with disabilities as a core minority of severely disabled individuals, ignoring a substantial group of individuals with moderate and mild disabilities. **Diagram 2.1** indicates how disability prevalence can be seriously distorted if one adopts the traditional 'core impairment' approach.

Diagram 2.1: Core Impairment vs. Impairment Continuum



But it still might be asked:

Why isn't impairment information enough? Aren't impairment data good proxies for disability?

There are three interconnected reasons why impairment information, though obviously relevant to disability statistics, is inadequate:

1. Impairment information is a partial picture of disability

Public health professionals and epidemiologists have known for decades that the effects of health conditions on people's lives can differ radically depending on the kinds of impairments, the effect of these impairments on a person's capacity to act, and most importantly, personal factors particular to the individual and the overall environmental context including social expectations about 'normality'. These contextual factors can either facilitate a person's capacity levels to enhance his/her performance, or further hinder the kinds of activities the person can perform.

Impairment information alone, in short, does not give us a complete picture of the situation of disability, either in an individual or in a population. For an individual, being told that they are blind, deaf, have

mental retardation, or mobility problems does not tell us anything about how these impairments affect the range of capacities the person has to carry out day-to-day activities. And without information about the environment in which the person lives, nothing can be said about what the person actually does in their life -- whether they have a family, go to school successfully or hold a job. These paint the full picture of disability without which we would have no idea what resources or services the individual may require.

2. Impairment data are inadequate proxies for disability

At the population level, though a few severe impairments can serve as proxies for a fairly large proportion of the overall prevalence of disability, without information about how these impairments play out in people's lives, policy makers would have no idea about the relative seriousness, or cost, of the disability associated with these impairments.

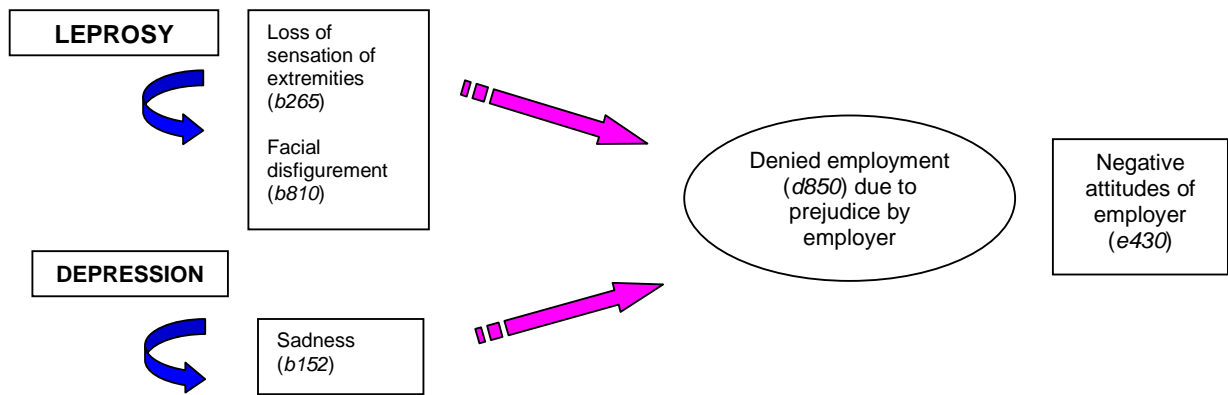
Moreover, we have solid evidence from the Global Burden of Disease Study that, in terms of the top ten most 'burdensome' health conditions in terms of years of life lived with disability (YLD) amongst the 15-44 year old group, five are mental health problems such as depression and schizophrenia. The burden associated with these conditions arises from the effects they have on people's capacity to perform day-to-day activities and to live, learn, and work independently. The traditional impairments due to blindness, deafness, mobility, and mental retardation fail to identify persons who are significantly disabled from these health problems, which could prove costly to society.

3. Impairments are not predictors of the lived experience of disability

People with the same impairments experience different kinds and degrees of incapacity and vastly different restrictions on what actually happens in their lives. Impairments are not proxies for disability; they give only one particular perspective on disability. Disability is the complete lived experience of non-fatal health outcomes, not merely body level decrements in functioning.

The converse is also true: people can experience the same restrictions in what they can do in their day-to-day lives even though they have different impairments. At the level of actual performance, the contrast is even greater. Impairments as diverse as missing limbs and anxiety can both attract stigma and discrimination that may limit a person's participation in work, as illustrated in **Diagram 2.2**.

Diagram 2.2: Different Health Conditions with the Same Participation Restriction



2.1.3 Universal

Another essential aspect of the ICF model is that human functioning is understood as a **continuum of health states** and every human being exhibits one or another degree of functioning in each domain, at the body, person and society levels.

This means that every human being has some degree of disability in at least one domain –and, more accurately, most people have many domains of functioning that are considerably less than perfect. Disability across the domains of health, in other words, is a matter of less than perfect health, from the very trivial to the very serious. (Disability is therefore a universal human situation, not some special trait of a minority group.)

ICF applies to all people irrespective of their health condition, gender, or age. Instead of making disability a distinguishing mark of a discrete minority group, ICF sets out all of the domains of functioning and disability that apply to everyone. This universal approach ensures that ICF presents a comprehensive, inclusive and non-discriminatory framework applicable to all individuals around the globe.

During the development stage of the ICF, enormous care was given to the applicability, both of ICF categories and the conceptual model, across cultures and languages. Specially designed culturally applicable protocols were devised for field testing of several iterations of ICF. These trials took place in 61 countries involving several thousands of participants. Translation of the ICF is regulated by protocols that guarantee the applicability of ICF terms and concepts.

Because ICF follows a universal approach it is not restricted to the traditional diagnostic or impairment categories of PWDs that are commonly used in

surveys and censuses. Not only the deaf, blind, paraplegic wheelchair user, or intellectually impaired individual counts as 'disabled', anyone by virtue of any impairment whose activities are restricted above a threshold set by policy makers is a person with disabilities.

In disability statistics, the importance of adopting a universal perspective of disability has been recognized. Faced with the objections about the underreporting of disability and confronted with the emergence of disabling conditions like HIV/AIDS, obesity, depression, and an increasingly aging population, many countries have come to realize that the time has come to abandon the traditional categories of disability in favour of a more flexible conceptualization. Censuses, surveys, registers, and other data collection tools based on ICF's universal model will make it possible to gather more accurate and more relevant data about the full extent of disability.

2.1.4 Continuous

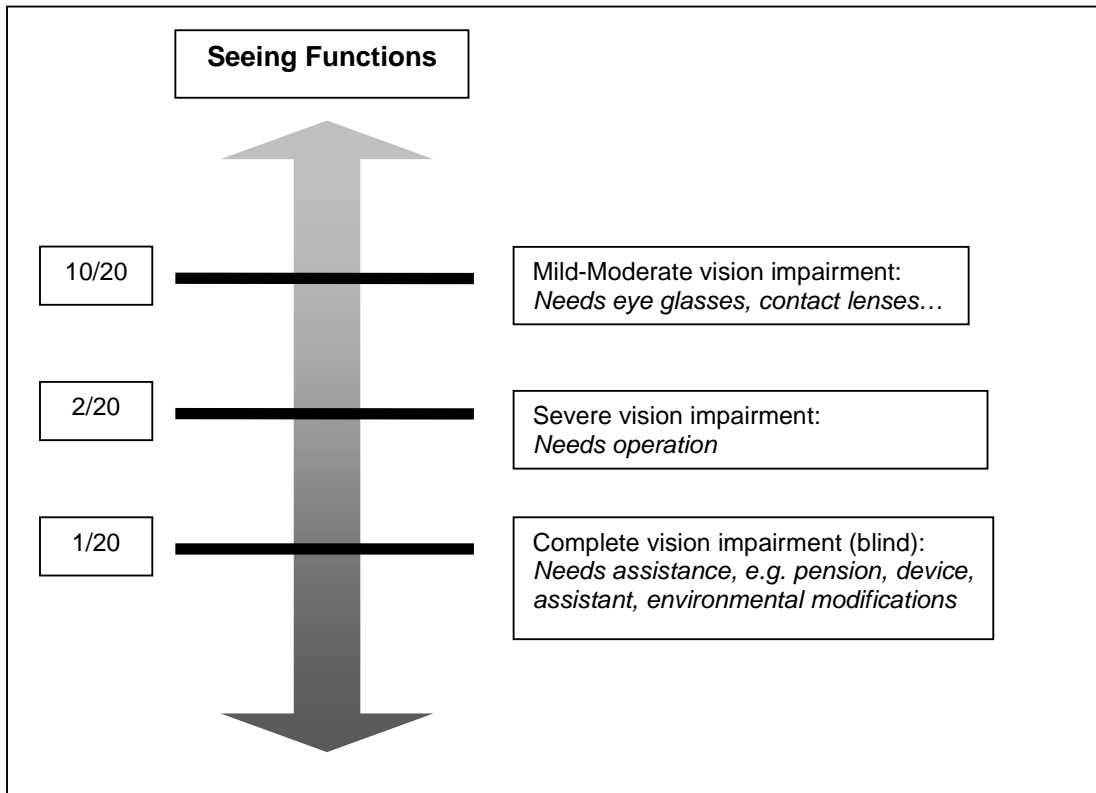
The universal approach may seem unconventional or difficult to operationalize, because traditionally we think of disability, not as a matter of more or less, but as a matter of 'yes or no': you are either disabled or not. This is because, for administrative and policy purposes, it is common to use the concept of disability for eligibility requirements for benefits programmes and services, and so to think in terms of who qualifies and who does not.

Disability becomes a 'yes or no' matter as soon as we identify a qualitative **threshold** of disability ('substantial', 'moderate', 'severe') or a more precise, quantitative threshold ('IQ less than 70', 'eyesight of 20/200', 'BMI over 30'). The threshold in each case divides everyone into two classes, those who are disabled (in this domain) and those who are not.

For scientifically-based disability statistics, however, we must remember that the threshold is arbitrary, and the truth of the matter is that disability, like human functioning, is a continuous not a dichotomous phenomenon. This insight is preserved in ICF's model of functioning and disability.

In the ICF model, disability is a decrement in body, personal, or social functioning. As such, the continuum of functioning partially coincides with the continuum of health. That is, impairments and person-level incapacities are health decrements. ICF domains can therefore be used in both health and disability surveys, which could contribute for a more comparable and meaningful population data. The concept of disability as a continuum is illustrated in **Diagram 2.3** below, which shows varying levels of vision impairment.

Diagram 2.3: Seeing Functions as a Continuum



Since disability, like health, lies on a continuum, there is no *a priori* answer to the question: 'What is the level of functioning, for a specified domain, below which a person can be said to have a disability (or be unhealthy)?'. Of course, at the extremes (total lack of functioning, or complete functioning) the thresholds are logically determined. But, in principle, any line on the continuum could be the threshold one might use to make the cut between 'disability' and 'no disability' (or health and ill-health).

This makes complete sense, since every person (not merely a member of a diagnostically-specific group) either currently has, or will eventually experience some measures of functional decrement. Although, given how the term is generally used, we probably should not say that everyone is or will be a 'person with a disability'. It remains true that functional decrement is a salient fact of life for everyone and the difference between 'people with disabilities' and people not so-called is entirely a matter of degree, not membership in a minority group.

For some standard impairments (visual acuity, hearing, intelligence), the thresholds are well-established and supported by prevalence. In rehabilitation science, the same is true for many simple actions (limb movements) and even for some activities of standard living such as eating and moving around. But, for the most part, for many domains of body functions and structures and most domains of activities and participation, we have no standardized thresholds.

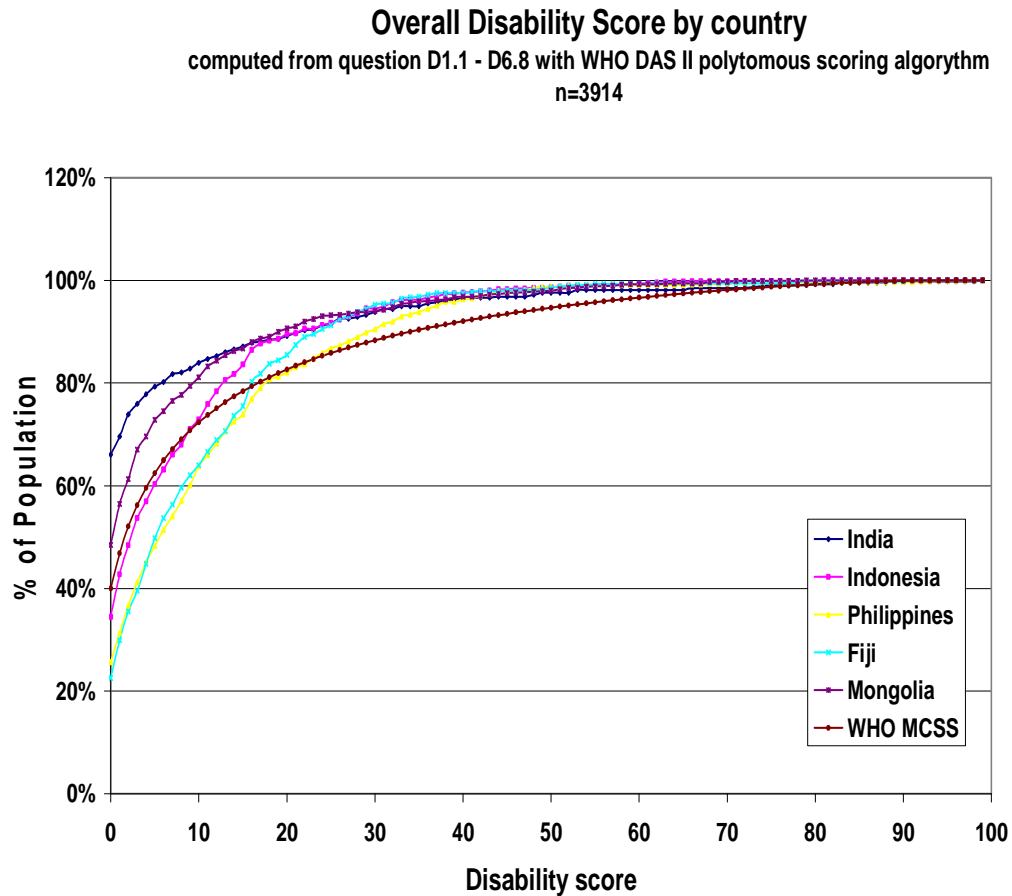
The ICF does not establish, nor presume, *a priori* thresholds. The user can determine, for specific purposes and on whatever grounds are relevant to those purposes, where the threshold should be placed for each domain of functioning. In particular, this feature of the ICF means that collecting data about functioning and disability at the population level is independent of determining threshold levels, and so prevalence results. Thresholds can be left to the analysis stage, where the purposes of collecting the data can determine where the thresholds should be drawn. The data remains comparable though, and in fact is effectively more comparable across sources, by simply applying the same threshold to multiple population samples.

There are several important advantages for disability statistics to determine where on the continuum of functioning the disability threshold should be drawn:

- Data collection developers are not locked into pre-existing definitions of who counts as disabled, or traditional thresholds for the domains of functioning they are interested in collecting.
- The threshold decision of who should be considered as disabled and who should not be can be explicitly stated by the data collector and that the method of measurement can be tailored to suit the purpose of the data collection activity, thus making the data more flexible.

Diagram 2.4 below provides an example of comparisons of “disability score” continuums across five ESCAP region countries. These scores were computed from the six domains of the World Health Organization Disability Assessment Schedule II (WHO DAS II). Note that the data was collected from questionnaire pilot studies using samples with prototypical representations of the general population and thus is not data that actually represents disability in each country. However, the graph provides an example of how prevalence information can be displayed and compared on a continuum, instead of as a single percentage derived from arbitrary thresholds. If, in providing programme services, a single prevalence rate or identified PWD population is necessary, a particular composite disability score can be determined that is fit for the specific purpose.

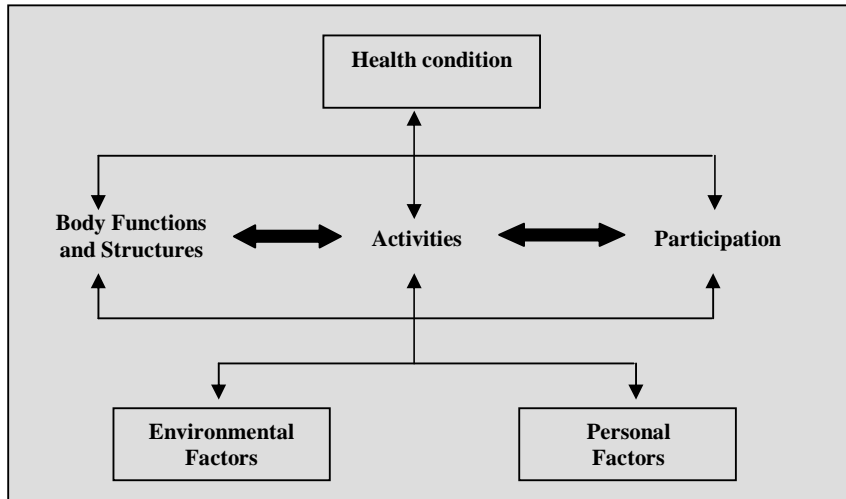
Diagram 2.4: Overall Disability Score by country



2.1.5 Interactive

The ICF model reflects the dynamic non-linear interaction between different constructs including health conditions, the components of disability as well as the personal and environmental factors. As shown in **Diagram 2.5**, there is also interaction among components of disability (Body Functions and Structures, Activities, and Participation). At the same time, the dimensions of disability are independent. A person may have impairments of body functions or structures without having activity limitation or participation restriction (e.g., a disfigurement in leprosy may have no effect on a person's capacity or to walk). A person may have an activity limitation without participation restriction (e.g., an individual with mobility limitations may be provided by society with a wheelchair that makes it possible for them to get around).

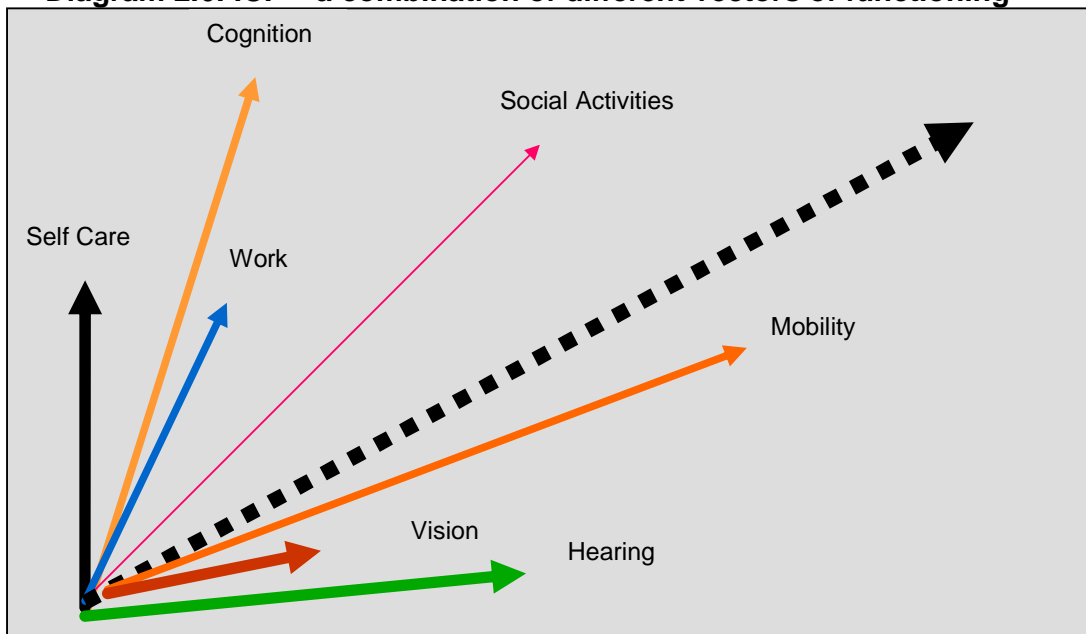
Diagram 2.5: Interactions between the Components of ICF



One of the main objections to the ICIDH-1980 was that it appeared to offer a unidirectional causal model that directly linked health condition and impairments, and from there, disabilities and handicaps. ICIDH appeared to suggest that a health condition causes impairments, impairments cause disabilities, and disabilities produce a handicap.

As illustrated in **Diagram 2.6**, ICF rejects this approach in favour of the multidimensional interactive approach in which whatever links there are between dimensions of disability, causal or otherwise, are based on evidence, not theory. In addition, for statistical purposes, the interactive non-linear ICF model facilitates the collection of data on these constructs independently and, subsequently, the analysis of the many linkages between them.

Diagram 2.6: ICF – a combination of different vectors of functioning



2.1.6 Context dependent

ICF conceptualises disability, not solely as a problem that resides in the individual, but as a health experience that occurs in a context. As **Diagram 3.3** indicates, in the ICF, disability and functioning are, conceptually speaking, outcomes of interactions between *health conditions* (diseases, disorders and injuries) and *contextual factors*.

Contextual factors consist of both *environmental factors* and *personal factors*. Environmental factors are all of the physical, social and attitudinal features that together characterize the environment in which a person lives, from climate and terrain to architectural characteristics and legal and social structures. Personal factors include gender, age, coping styles, social background, education, profession, past and current experience, overall behaviour pattern, character, and other factors that influence how disability is experienced by the individual. Personal factors are not currently classified in ICF but users may incorporate them in their applications of the classification.

Distinguishing between environmental factors and components of functioning and disability characterizes issues is of great help to producers and users of disability statistics. This is because the extent to which disability is a function of the person can be clearly distinguished from the extent of environmental impact. Disability policy depends crucially on whether improving outcomes is a matter of investing in changes to the person's capacity levels, by means of medical or rehabilitative interventions, or investing in accessibility, accommodation and other environmental changes.

2.1.7 Inclusive

ICF does not make a distinction between health conditions that are 'physical' and those that are 'mental'. Both mental and physical diseases and disorders can be linked to the same kinds of activity and participation issues. So, from a disability point of view, saying that a person has a mental illness tells us very little about the associated disabilities he or she may experience. ICF subscribes to the parity of mental and physical health.

Similarly, the model of the ICF ignores etiology of health conditions since there is no *a priori* link between a health condition and disability as it is experienced. Research into the precise determinants of disability is of course of great importance, but unwarranted assumptions about what a person with a certain disease can or cannot do in life are detrimental to good science.

Thus, in the ICF we would record the loss of limb as such, regardless of whether the loss was the result of a landmine, diabetes or a traffic accident. The impairment remains the same. Similarly, we would document the fact that a person was not working regardless of whether the underlying health condition was 'flu, depression, or back pain.

ICF-based disability statistics therefore provides the measures for assessing the disability burden of all health conditions, and that is a great asset when clarifying and focusing disability data on the true phenomenon of disability.

2.1.8 *Neutral (language)*

The ICF classification system uses, to the extent possible, neutral language to name its components and categories. For example, you will find in the ICF:

- *Vision functions* instead of *blindness*
- *Intellectual functions, complete impairment* instead of *totally dull*
- *Participation restriction* instead of *handicap*
- *Persons with disabilities* instead of *disabled person*

The use of neutral language is a helpful challenge in the practice of using discriminatory and offensive language sometimes found in questionnaires or other data collection instruments, and which directly affects refusal rates.

2.2 **Importance of classifications and standards**

As a classification system, ICF offers a number of key benefits for users and producers of disability data which are listed below.

The ICF taxonomy allows the aggregation and disaggregation of data: Three or four level ICF codes, mainly relevant to clinical settings, can be aggregated to two or one level codes that are generally more useful for capturing disability information at population level. Similarly, one or two level ICF items often included in census and general population surveys can be expanded to the third and fourth level for detailed follow-up studies.

The ICF allows integration of disparate data sets: As a coding system, ICF makes it possible to consider multiple sources of health and disability information at various levels, and to integrate these into a common and coherent information system. This facilitates tracking the change of an individual's or a population's disability profile and service needs over time across different settings. Through analysis we can assess and compare the impact of different kind of interventions along the service and policy spectrum.

The ICF provides a cross-cultural language which allows communication across countries and sectors: As a result of the extensive pilot test performed during the development stage, we know that the ICF functioning and disability framework, as well as the classification hierarchy and categories, are cross-culturally applicable. ICF provides a truly common language for describing and measuring health and disability. The need for such common language is strong in

the area of disability statistics, which for decades has been hampered by lack of data uniformity and absence of comparability. Currently, disability survey data shows as much as 40 fold difference compared to a three-fold difference in mortality statistics and a six to eight fold difference in health survey data.

The ICF is accepted as the international standard for describing and measuring health and disability: The ICF forms part of the WHO Family of International Classifications (WHO-FIC) and together with the ICD-10 it constitutes the two building blocks of health and disability statistics. The ICD-10 classifies health conditions (diseases, disorders, or injuries) and is used primarily for reporting mortality and morbidity. The ICF has been endorsed by 191 countries as the framework for disability and health data collection around the world. As such, ICF is an international standard of supreme importance for users and producers of disability data.

2.3 ICF terminology and definitions of disability

Beyond a common understanding of the ICF concepts, it is also essential that the terminology and definitions that express these concepts be understood, used and translated into other languages. ICF, as a written classification, builds on a pre-existing language (international English), and then introduces new terms and sometimes changes the meaning of commonly used terms. ICF requires, to a certain extent, users to learn a new language. The key term 'disability' is a clear example of a notion that means a variety of different things in ordinary language. That variety is the cause of confusion that is reflected in disability statistics world wide. ICF clarifies and explicitly defines the term, not by taking sides on disputed issues, but leaving behind the controversies caused by people using the same word differently and opening the door to a consensus.

Definitions of some of the key terms used in ICF are given below. The terminology used in data collection vehicles such as survey questionnaires should be aligned to reflect these definitions in order to achieve consistency with ICF.

Health condition is an umbrella term for disease (acute or chronic), disorder, injury, or trauma. A health condition may also include other circumstances such as pregnancy, ageing, stress, congenital anomaly, or genetic predisposition. Health conditions are coded using ICD-10.

Functioning is an umbrella term for body functions, body structures, activities, and participation. It denotes the positive aspects of the interaction between an individual (with a health condition) and that of individual's contextual factors (environmental and personal factors).

Disability is an umbrella term for impairments, activity limitations, and participation restrictions. It denotes the negative aspects of the

interaction between an individual (with a health condition) and that of individual's contextual factors (environmental and personal factors).

Body functions are the physiological functions of body systems, including psychological functions. "Body" refers to the human organism as a whole, and thus, includes the brain. Hence, mental (or psychological) functions are subsumed under body functions. The standard for these functions is considered to be the statistical norm for humans.

Body structures are the structural or anatomical parts of the body such as organs, limbs and their components classified according to body systems. The standard for these structures is considered to be the statistical norm for humans.

Impairment is a loss or abnormality in body structure or physiological function (including mental functions). Abnormality here is used strictly to refer to a significant variation from established statistical norms (i.e., as a deviation from a population mean within measured standard norms) and should be used only in this sense.

Activity is the execution of a task or action by an individual. It represents the individual's perspective of functioning.

Activity limitations are difficulties an individual may have in executing activities. An activity limitation may range from a slight to a severe deviation in terms of quality or quantity in executing the activity in a manner or to the extent that is expected of people without the health condition.

Participation is a person's involvement in a life situation. It represents the societal perspective of functioning.

Participation restrictions are problems an individual may experience in involvement in life situations. The presence of a participation restriction is determined by comparing an individual's participation to that which is expected of an individual without disability in that culture or society.

Contextual factors are the factors that together constitute the complete context of an individual's life, and in particular, the background against which health states are classified in ICF. There are two components of contextual factors: Environmental Factors and Personal Factors.

Environmental factors constitute a component of ICF, and refer to all aspects of the external or extrinsic world that form the context of an individual's life and, as such, have an impact on that person's functioning. Environmental factors include the physical world and its features, the human-made physical world, other people in different

relationships and roles, attitudes and values, social systems and services, and policies, rules and laws.

Personal factors are contextual factors that relate to the individual such as age, gender, social status, life experiences, and so on, which are not currently classified in ICF but which users may incorporate in their applications of the classification.

Facilitators are factors in a person's environment that, through their absence or presence, improve functioning and reduce disability. These include aspects such as a physical environment that is accessible, the availability of relevant assistive technology, and positive attitudes of people towards disability, as well as services, systems and policies that aim to increase the involvement of all people with a health condition in any area of life. Absence of a factor can also be facilitating, for example, the absence of stigma or negative attitudes. Facilitators can prevent an impairment or activity limitation from becoming a participation restriction.

Barriers are factors in a person's environment that, through their absence or presence, limit functioning and create disability. These include aspects such as a physical environment that is inaccessible, lack of relevant assistive technology, and negative attitudes of people towards disability, as well as services, systems and policies that are either non-existent or that hinder the involvement of all people with a health condition in any area of life.

Capacity is a construct that indicates, as a qualifier, the highest probable level of functioning that a person may reach in a domain in the Activities and Participation list at a given moment. Capacity is measured in a uniform or standard environment, and thus reflects the environmentally adjusted ability of the individual. The Environmental Factors component can be used to describe the features of this uniform or standard environment.

Performance is a construct that describes, as a qualifier, what individuals do in their current environment, and so brings in the aspect of a person's involvement in life situations. The current environment is also described using the Environmental Factors component.

2.4 ICF structure and coding – for population data collections

ICF is organized into two parts. Part 1 classifies functioning and disability formulated in two components:

- (1) Body functions and structures and
- (2) Activities and participation

Part 2 comprises the contextual factors which include the following two components:

- (1) Environmental factors and
- (2) Personal factors (currently not classified).

These components are denoted by prefixes in each code.

- b** for Body Functions and
- s** for Body Structures
- d** for Activities and Participation
- e** for Environmental Factors

The letters **b**, **s**, **d** and **e** are followed by a numeric code that starts with the chapter number (one digit), followed by the second level (two digits), and the third and fourth level (one digit each).

Table 2.2 shows the hierarchy of ICF domains and its reflection in the coding.

Table 2.2: The ICF Domain Hierarchy

Level	Example	Coding
Chapter	Chapter 2: Sensory Functions and Pain	b2
Second level	Seeing Functions	b210
Third level	Quality of Vision	b2102
Fourth level	Colour Vision	b21021

In the ICF, a person's health state and disability state may be characterized by means of an array of codes across the domains of the components of the classification, health and non-health.

The maximum number of codes available for each application is 34 at the chapter level (as indicated in **Table 2.3**, eight Body Functions, eight Body Structures, nine Activity/Participation), and 362 at the second level. At the third and fourth level, there are up to 1424 codes available, which together constitute the full version of the classification. In real-life applications of ICF, a set of 3 to 18 codes may be adequate to describe a case with two-level (three-digit) precision.

Generally, the more detailed four-level version is intended for specialist services (e.g., rehabilitation outcomes, geriatrics, or mental health), whereas

the two-level classification can be used for surveys/census/administrative data collection and health outcome evaluation.

Table 2.3: ICF Chapters

Body	
<p>Function:</p> <p>b1 Mental Functions</p> <p>b2 Sensory Functions and Pain</p> <p>b3 Voice and Speech Functions</p> <p>b4 Functions of the Cardiovascular, Haematological, Immunological and Respiratory Systems</p> <p>b5 Functions of the Digestive, Metabolic, Endocrine Systems</p> <p>b6 Genitourinary and Reproductive Functions</p> <p>b7 Neuromusculoskeletal and Movement-Related Functions</p> <p>b8 Functions of the Skin and Related Structures</p>	<p>Structure:</p> <p>s1 Structure of the Nervous System</p> <p>s2 The Eye, Ear and Related Structures</p> <p>s3 Structures Involved in Voice and Speech</p> <p>s4 Structure of the Cardiovascular, Immunological and Respiratory Systems</p> <p>s5 Structures Related to the Digestive, Metabolic and Endocrine Systems</p> <p>s6 Structure Related to Genitourinary and s8 Reproductive Systems</p> <p>s7 Structure Related to Movement</p> <p>s8 Skin and Related Structures</p>
Activities and Participation	
<p>d1 Learning and Applying Knowledge</p> <p>d2 General Tasks and Demands</p> <p>d3 Communication</p> <p>d4 Mobility</p> <p>d5 Self Care</p> <p>d6 Domestic Life</p> <p>d7 Interpersonal Interactions and Relationships</p> <p>d8 Major Life Areas</p> <p>d9 Community, Social and Civic Life</p>	
Environmental Factors	
<p>e1 Products and Technology</p> <p>e2 Natural Environment and Human-Made Changes to Environment</p> <p>e3 Support and Relationships</p> <p>e4 Attitudes</p> <p>e5 Services, Systems and Policies</p>	

For reporting of health and disability for statistical purposes, however, only a few of the total 1495 codes will be needed. **Table 2.4** below lists the WHO recommended ICF item pool for use in health and disability statistics. The items have been identified and used in large scale population based studies (WHO Multi-Country Survey Study, World Health Survey) and are recommended as minimum data sets for surveys and health information systems (See ICF, Annex 9).

Table 2.4: WHO Recommended ICF Item Pool

Dimension	Chapter	Code	Classification block or category
Body Functions and Structures			
Vision	2	b210–b220	Seeing and related functions
Hearing	2	b230–b240	Hearing and vestibular functions
Speech	3	b310–b340	Voice and speech functions
Digestion	5	b510–b535	Functions of the digestive system
Bodily excretion	6	b610–b630	Urinary functions
Fertility	6	b640–b670	Genital and reproductive functions
Sexual activity	6	b640	Genital and reproductive health
Skin and disfigurement	8	b810–b830	Skin and related structures
Breathing	4	b440–b460	Functions of the respiratory system
Pain *	2	b280	Pain
Affect *	1	b152–b180	Specific mental functions
Sleep	1	b134	Global mental functions
Energy/vitality	1	b130	Global mental functions
Cognition *	1	b140,b144, b164	Attention, memory and higher–level cognitive functions
Activities and Participation			
Communication	3	d310–d345	Communication receiving – producing
Mobility *	4	d450–d465	Walking and moving
Dexterity	4	d430–d445	Carrying, moving and handling objects
Self-care *	5	d510–d570	Self-care
Usual activities *	6 and 8		Domestic life; Major life areas
Interpersonal relations	7	d730–d770	Particular interpersonal relationships
Social functioning	9	d910–d930	Community social and civic life

* Indicates “Candidate items for a minimal list” according to ICF, Annex 9, and by a High Level WHO Expert Committee in preparation for the WHO surveys mentioned above

The ICF codes require the use of qualifiers, which record the presence and severity of the functioning problem on a five-point scale (e.g., no difficulty, mild, moderate, severe, and complete). For health and disability statistics, the use of qualifiers is an important issue when deciding on the type of response scale to be used for questions in census and surveys. To ensure compatibility with ICF, a four, or preferably, five-point scale is suggested (*refer to **Chapter 4** for a detailed discussion on this topic*).

2.5 ICF training and assistance available

ICF training and technical assistance is provided by the WHO in collaboration with its network of WHO Collaborating Centres. Further information can be found on the ICF website: www.who.int/classifications/icf.

Learning Objectives: Chapter 3

Data Collection Methods and Instruments

After reading this chapter, the reader should be able to:

1. Understand process of disability data collection.
2. Describe and evaluate population censuses, surveys, and administrative data collection.
3. Match data collection tools to disability statistics users' needs.



**“Welded to work” Serge Corrieras
WHO Photo Contest “Images of Health and Disability 2002/2003”**

3. DATA COLLECTION METHODS AND INSTRUMENTS

3.1 Measurement of disability

3.1.1 Collection instruments

3.1.2 Choice of selection and measurement unit

3.2 Population censuses

3.3 Sample surveys

3.3.1 As dedicated disability surveys

3.3.2 As a module to other sample surveys

3.4 Administrative collections

3.4.1 What is an administrative data collection?

3.4.2 What are the benefits?

3.4.3 How can administrative data be used?

3.5 Joint use of census and sample survey – census screen

3.6 Strengths and weaknesses of the data collection methods

3.7 Relatable data

3.1 Measurement of disability

Collecting data about people with disabilities and their lives is difficult. It poses unique problems that data collection developers need to address in the design phase of the collection process. Two issues need to be addressed at the outset: what kind of data collection instrument should be used, and what unit of measurement should be employed.

3.1.1 Collection instruments

The main types of instruments for collecting data about people with disabilities are:

- Population censuses
- Sample surveys (either general social surveys or specific health and disability surveys)
- Administrative collections and registries

Each of these tools can be used to measure aspects of disability in a population and each has its strengths and weaknesses.

The **Population Census** certainly has the advantage of providing complete population coverage. Unfortunately, it is difficult to collect accurate information about disability in a census since time constraints make it unlikely that more than one to 4 or 6 general disability question can be asked. Censuses, in some instances, also undercount children with disabilities and people with mild or moderate disabilities (in cases where the response categories are limited to 'Yes or No' options only). Still, for a crude measure of disability, and in the absence of other collection instruments, the census is useful.

Sample surveys are shorter surveys designed to be administered to a sub-population selected by some other instrument (often a census) that focus on specific issues. They are often put into the field to answer specific questions about a population. As such, they provide the opportunity to ask more detailed questions about disability. More detailed information is useful in itself, of course, but it also helps to reduce the number of false positive and negative responses, thereby offering a more accurate prevalence measure. A sample survey may be an independent survey focusing entirely on disability, or a disability module added to an existing survey.

Administrative collections and registers are composed of data that is collected as part of the normal operation of some service or programme. An example is the information found on a client intake form. These collections provide useful information on the characteristics of people accessing disability services as well as details about the services provided. They cannot give an accurate measure of disability prevalence since there is no guarantee of coverage and they tend to incorporate double counting. The quality of administrative register data is closely related to the quality of the administrative system, in particular, how well it has been maintained and how closely the concepts align with the disability concepts of interest.

These three instruments for gathering disability information are discussed in detail in the rest of this chapter.

3.1.2 Choice of selection and measurement unit

The second preliminary issue that needs to be addressed, whatever data collection instrument is chosen, is how to select the unit for which disability is to be measured. If the selection unit is the individual, then the individual will also be the measurement unit; if the selection unit is a collection of people – invariably a household – then, a decision has to be made as to whether the measurement unit is the household itself (that is, all individuals in the household) or some individual in the household that meets specified criteria (age, gender, unemployed, and/or others).

These decisions depend in part on what kinds of data are needed. Is data required for the number of people with disabilities and their characteristics, or for an estimate on the number of households that include individuals with disabilities? Data about individuals is important, but estimates at the household level are also useful for detailed analysis of living arrangements and access to help and assistance.

There are also issues of practicality and efficiency. Having the household as the selection unit means that the survey or interview can be conducted in a setting in which information about other people can be efficiently collected, even if only one member of the household is given the full interview. Questions asked of a single household member may reveal another individual with a disability, thereby increasing the sample of people with disability, without adding to the number of households screened.

A note of caution applies, however, if the private household is chosen as the measuring unit. In such a case, thought needs to be given to the fact that this choice excludes residential care units, retirement homes, and other institutions such as prisons. Excluding people living in institutions underestimates the levels of disability for older people and for those with particular types of disability such as psychiatric disabilities. For a complete picture, if feasible, household surveys should be supplemented with institutional surveys of disability.

3.2 Population censuses

Many countries have collected information about disability in their national population censuses (*refer to **Box 3.6** for the examples of countries using population censuses to collect disability statistics*). The United Nations' 2001 **Guidelines and Principles for the Development of Disability Statistics** suggests the inclusion of a 'general' disability question in censuses in order to get a rough idea of prevalence. In countries without a good household survey program, the census may be the only possible source for estimating disability prevalence and gaining an approximate estimate of types of disability in the country.

The amount of information on disability that can be collected in the population census is very limited, and is often confined to a single question. With only one question, false positive and false negative responses are more common and no complete measure of the number of people with disabilities is possible, especially among children and the elderly. Still, census data should be readily used, where available, to develop more detailed follow-up surveys (*see **Box 3.5** for a discussion of the Canadian experience with a post-census survey on disability*).

Many countries use both short and long forms of census questionnaires (*see **Box 3.1***). The short form is for complete coverage of core topics, such as age, sex and location, and may also have a question on disability. A probability sample is then selected for the long form to be administered. The long form includes all questions in the short form plus supplementary questions for more detailed coverage of selected topics. Questions more detailed than a single general question on disability may be included in the long form.

Box 3.1: 2001 Short Form/Long Form Census in Macau

In response to an increasing concern for more information on the population of people with disabilities, the Statistics and Census Service of Macau included questions on disability in its 2001 Census. The short form, which was administered to 80 percent of households, included one generic question: "Is anyone in your household physically or mentally disabled?". In the long form questionnaire, completed by 20 percent of households, the same disability identification question was asked followed by a question about the respondent's primary disability, and a second question asking whether they had ever used any disability services.

The resulting estimate of the number of people with disability from the census was 1.3 percent of the resident population.

3.3 Sample surveys

Sample surveys are good methods of collecting data about people with disabilities. They use sample selection procedures to identify a sub-population that is representative of the total population, unlike censuses that are designed to enumerate every household or individual in the country.

While sample surveys are considerably cheaper than censuses, the size of the sample affects the quality of the data, which is particularly subject to sampling error (*refer to **Chapter 5** for the detailed discussion of sampling error*). This can frustrate analyses that rely on cross-tabulation.

A small sample size also means that sample surveys cannot provide detailed information for very small geographical areas. Where such data is needed, census or administrative data collections or sophisticated data modeling techniques are more useful options.

Determining sample sizes required to produce statistics with an acceptable level of sampling error is the job of experienced survey methodologists. Unfortunately, the technical details of sample designs are beyond the scope of this manual. The **UN Guidelines and Principles for the Development of Disability Statistics** has some helpful comments on sample size for disability surveys. (As a rough guide, surveys that have sufficient size to yield valid unemployment estimates for a given geographic area are usually large enough to produce disability estimates for the same area for as long as the prevalence rates are similar.)

As mentioned, a sample survey for disability can either be an independent or dedicated survey, or a module to other surveys, such as a national health survey, a general social survey or labour force survey. Where these general

social surveys are cyclical, it is very useful to have a disability module or a small set of disability questions added on.

3.3.1 As dedicated disability surveys

Surveys specifically dedicated to collect disability data are good sources of information about prevalence rates, the causes and types of disability, underlying health conditions, severity and duration of disability, and the use of and need for assistive devices and other accommodations.

Dedicated disability surveys maximise the amount of information that can be collected to meet users' needs. Many countries have not attempted to conduct such disability surveys because they are more costly than simply adding a few questions into a census or already existing sample surveys. An example of a country that conducts a dedicated disability survey is provided in **Box 3.2**

Box 3.2 Dedicated Sample Survey for Disability: Australian 2003 Survey of Disability

The Survey of Disability, Ageing and Carers provides data on disability prevalence, need for support, and characteristics of people with disabilities, older people and those who provide care. Information is collected from private households and cared accommodations (hospitals, nursing homes, aged care and disability hostels and other homes such as children's homes). The survey uses computer-assisted personal interviews. Since 1981, it has been conducted every five years.

Sample size:

The sample size is approximately 14,000 private dwellings and 300 non-private dwelling units. The carer sample is approximately 550 dwellings. The final sample depends on the number of people in each household or non-private dwelling, and comprises approximately 36 000 people for the household component and 5 000 people for the cared accommodation component.

Data collected:

- Household composition
- Demographic information about all household members
- People selected for personal follow-up interview (people with long-term health conditions or with a disability, who are aged 60 years or over, or someone who regularly provides informal care to someone with a disability)
 - Socio-economic characteristics (education, labour force participation, income, and housing)
 - Impairments, long term health conditions associated with main disability condition
 - Difficulties experienced and help required for activities such as self care and mobility
 - Types of assistance received for a range of activities, met and unmet needs for assistance
 - Use of aids and equipment

Results are available in *Disability, Ageing and Carers, Australia: Summary of Findings, 2003* (Cat. No. 4430.0).

3.3.2 As a module to other sample surveys

In many countries, national household surveys – covering topics such as health, education, living conditions, family income and expenditure, labour force participation, nutrition, time use, crime, and so on – are conducted on a regular basis. Whether every five years, annually, quarterly or monthly, these surveys try to identify short and long-term social trends.

A cost-efficient and effective way of collecting disability data is to add disability questions – or a '**disability module**' – to one or several of these cyclical surveys. This approach has been used in many countries. Most commonly, disability modules have been added to labour force or health surveys, and sometimes to living conditions surveys. **Box 3.3** gives an example of a disability module in a socio-economic survey.

Box 3.3: Disability Module in the Indonesian Socio Economy Survey

A disability module was added to Indonesia's 2003 Socio Economy Survey. The disability population was identified using the question, "Does he/she have a disability?" with a Yes/No response. Where positive responses were received to the disability question, codes for 'type of disability' (7 codes for mostly severe impairments) and 'main cause of disability' (5 codes) were entered into the person's matrix.

This form of questions is expected to yield low disability prevalence rates because the survey relies on self-identification of disability and the only types of disability asked about are severe impairments.

The general approach to including a disability module on a non-disability survey will be useful for the Indonesian government, because disability data can be combined with the other social and economic data collected to analyse the experiences of people with disabilities (or, at least, those with selected severe impairments).

There are advantages to on-going sample surveys rather than ad hoc or one-off sample surveys for disability. On-going surveys can make maximum use of the resources initially expended, including the time and other resources used in preparing for the data collection, as well as the trained personnel and other resources dedicated to collecting, processing, and analyzing the data on a regular basis.

On-going survey programs also offer opportunities to learn from previous experiences so that the quality and usefulness of the information produced can be improved. They allow for measurement of change over time in key indicators such as frequency of types of disability, severity of disability, quality of life, opportunities and participation of people with disabilities, and rehabilitation needs. These data can be exceedingly valuable for policy development and evaluation.

3.4 Administrative collections

3.4.1 *What is an administrative data collection?*

Besides surveys and censuses, administrative data collection (general purpose **administrative systems** or **administrative registries**) intended to serve PWDs can be an important method of gathering information about these people and their characteristics. In this method, any information collected is organized and becomes part of normal service administration procedure such as the information gathered using standard client intake forms for health, rehabilitation, or social work services. Administrative data collections can take several forms, depending on the nature of the service, the format used, the type of information collected, and the method and frequency of collection. Some examples are population registers, vital registration systems, social security systems, registries of occupational injuries, rehabilitation programmes, assistive device services, and other services specifically designed to serve the needs of PWDs.

Administrative registries are databases of records of people with particular characteristics and set up as part of the administration of services to these individuals. Registers are either established during a registration survey or other point in time or they can be on-going and regularly updated.

Administrative records and registers, moreover, often provide **unique information** about PWDs. The information is usually collected for reasons concerning the administration of the programme or service, but with care, can prove to be useful. For example, data about children and adolescents in special education programmes is an indication of participation rates in education; general invalid pension registries are often organized by disease or impairment; and domestic care allowances help to track rates of children and adults with severe disabilities.

Often these data are **collected annually**, which provides a source for trend data on the prevalence of impairments or disabilities.

Ministries, government departments, advocacy groups, and service providers often maintain administrative records which they use to monitor and evaluate programs and services. Given confidentiality concerns, only aggregated data may be available, but this can still be useful.

It must be kept in mind, however, that data from registration systems cannot provide information about people with disabilities who **need a service** or programme but **do not receive it**. Data about unmet need has to come from other sources.

Since the information collected in administrative data collections is limited to people receiving services, or otherwise known to the service agency (as in the case of people on a waiting list), these collections have limited coverage. Therefore administrative collections, despite all their benefits, are not good sources for estimating overall disability prevalence.

3.4.2 *What are the benefits?*

As compared with censuses and sample surveys, administrative data collections have some advantages for disability data users:

Data from administrative collections are generally available on a regular or on-going basis, as they are part of regularly updated information systems linked to a service.

As administrative data are collected as part of the day-to-day running of a service, they use fewer resources than special purpose surveys.

If the government or other fund provider requires data collection as a condition of on-going funding to a service, the data collected by that service will tend to be more reliable, complete and of higher quality.

Information from administrative data collections is likely to be useful to a wide range of stakeholders such as service providers, higher-level bureaucrats, disability consumer groups, and researchers.

3.4.3 *How can administrative data be used?*

Administrative data collections provide information on numbers and characteristics of service users, and the type, quantity and cost of services provided. Depending on the detail of the dataset and the complexity of the data collection format, a substantial amount of information about services, service users and service providers can be collected in this manner. Administrative data of this sort can then be adopted by service agencies, planners, consumer advocacy groups, and funding department for a variety of purposes:

- to provide an evidence base to support planning for future service delivery (e.g., by monitoring trends in client age or disability type);
- to indicate whether identified groups of people (e.g., particular ethnic groups) are accessing services as much as expected;
- to monitor the cost-effectiveness of service provision;
- to support a budget submission for increased funding.

Moreover, with only minimal analysis, these data can answer basic administrative questions such as:

- How many people were supported by the service in a given time period, and what were their characteristics and support needs?
- What type of support was provided and received?

- What quantity of support – e.g., in terms of staff hours – was provided and received?
- From whom was the support received (in terms of details of the service agency, such as size, staff profile, and hours)?
- What was the cost (total, per service type, per client) of providing these services?
- What were the outcomes for clients? (Examples of outcome questions include: Were clients satisfied with the services received? Were there increased levels of client participation in key life areas such as employment?)

Box 3.4 gives an overview of the Australian National Disability Service data collection as a concrete example of an administrative data collection. It outlines the information collected, the method of collection, and how the data is used.

Box 3.4: An Overview of the Australian Disability Services Data Collection

In Australia, the Commonwealth/State/Territory Disability Agreement (CSTDA) funds a national program of disability support services for people with on-going support needs. Under the agreement, the Commonwealth Government is responsible for the overall planning and management of employment services, while the States and Territories are responsible for all other disability support services (including accommodation support, community access, community support, and respite services). All three jurisdictions share responsibility for advocacy, information, and print disability services. Services are provided by government and non-government service provision agencies.

‘People with disabilities’ are defined as people with a disability attributable to an intellectual, psychiatric, sensory, physical or neurological impairment or acquired brain injury (or some combination of these), which is likely to be permanent and to result in substantially reduced capacity in self-care, mobility or communication, requiring on-going or episodic support.

National data on disability services

From 1995-2002, the National Minimum Data Set (NMDS) collected data about services received on a single ‘snapshot’ day each year. Since then, data have been collected on a full-year, on-going basis, so that the collection now includes data on all people with disabilities who receive a CSTDA-funded service during the year. The NMDS collects the minimal, essential set of data about disability services and clients. It is a set of nationally-agreed upon data items, and an agreed method of collection and transmission.

The data collected includes:

- Demographic information, e.g., age, sex, indigenous status
- Support needs and whether the person has a carer

- Primary disability and other disabilities
- Living arrangements and communication method
- Work, income, and funding, e.g., main source income
- Services the person receives

It also contains data items on service provider agencies, including the type of service provided, staff hours, operating hours per day, and number of service users.

How the data is used

The CSTDA-NMDS data provides valuable information about those who are receiving services, their characteristics (age, disability type, and support needs) as well as trends in types of services used. Data for nine years is now available.

The data is used in funding negotiations between Commonwealth and State governments, and between departments and service providers. It is also used for developing national performance indicators, by which service outcomes can be monitored. The Australian Institute of Health and Welfare publishes a national data report on the collection each year.

For more information on the Australian NMDS data collection see <http://www.aihw.gov.au/disability/pubs.html>

3.5 Joint use of census and sample survey – census screen

Most countries in the Asia Pacific Region do not have registers of the population to use as sample frames for social surveys and instead use area-based samples in their household data collections to select respondents for their surveys. People with disabilities are a relatively small population and so obtaining a sufficient sample can be very costly.

Some countries use a small number of disability screening questions to provide the sampling frame for a follow-up survey. When this is done, it is important that the screening questions are effective in identifying as many people with disabilities as possible. In particular, screening questions should attempt to minimize the number of “false negative” responses.

Another method to find a targeted sample inexpensively is to use the census as a screening device to identify a population of people with disabilities who are then the sample for a follow-up (or “post-census”) survey (see **Box 3.5**). As mentioned, relying on one or two screening questions will increase the number of false negatives. To compensate for this, it is wise to include in the follow-up survey a sufficient sample of negative responders to avoid biasing the survey population. Studies have shown that children with disabilities and people with mild disabilities are the most likely to be under-reported by the census screening questions.

Whenever the census is used as part of a data collection strategy, timing becomes a factor. In order to add questions into a census, steps must be taken several years in advance of the actual data collection. Furthermore, it

will take one or two additional years to have the census data processed and available for post-census surveys or other uses.

Box 3.6 shows the different methods used by some countries in collecting disability data. Four of the nine countries (Cambodia, Fiji Islands, India, and Thailand) employed at least two methods of gathering disability data. (See also *Appendix 1*).

Box 3.5: Use of the Post-Census Survey Approach to Collect Disability Data in Canada

The post-census survey approach was used by Statistics Canada in its comprehensive surveys on disability following the 1986, 1991 and 2001 censuses. The censuses included two screening questions on disability and impairment. In 2001, the questions were:

1. Does this person have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities?

Yes, sometimes

Yes, often

No

2. Does a physical condition or mental condition or health problem reduce the amount or the kind of activity this person can do

At home?

At work or at school?

In other activities, for example, transportation?

The purpose of these questions was not to estimate the prevalence of impairment or activity limitations. They merely defined a sample of individuals likely to have a disability. Following the census, a national sample survey based on census results was prepared. Those who screened positive in the census by answering **yes** to at least one of the questions were then asked detailed questions to confirm whether they had disability. A small sample of people who screened negative in the census was also included.

The post-census survey results provided far more accurate information on the prevalence of disability than possible with a census. The survey also provided detailed data about the nature of the disability and other characteristics of persons identified.

It has become the practice not to publish the disability data from the census at all, but only to use it to determine the sample frame for the follow-up survey.

Box 3.6: Disability Data Collection Methods Practiced in Selected Countries	
Country	Method of Data Collection
Cambodia	Social Economic Surveys and Population Census
Fiji Islands	Census of Population and Household Income and Expenditure Survey
Hong Kong, China	Survey on Persons with Disabilities and Chronic Diseases
India	Census, National Sample Survey Organisation, Survey and Voluntary Registry
Indonesia	National Socio-Economic Surveys
Islamic Republic of Iran	Census
Mongolia	Limited registry in capital city (voluntary, impairment-based registry)
Philippines	Population and Housing Censuses
Thailand	Disability Surveys, Bureau of Empowerment for Persons with Disabilities National Registry and Censuses

3.6 Strengths and weaknesses of the different data collection methods

Tables 3.1 to 3.4 below summarise the salient advantages and disadvantages of census, sample surveys, and administrative data collections (both one-time and continuous) as approaches to the collection of disability data.

Table 3.1: Population Censuses: Advantages and Disadvantages ¹

Advantages	Disadvantages
Data can be tabulated for small, local areas.	Questions limited to basic socio-economic and demographic characteristics, restricting the scope of disability questions.
Prevalence rates can be calculated for small geographical areas because data are also gathered for the population at risk.	Data collection is infrequent – usually every 10 years. The time between data collection and data dissemination can be considerable.
Detailed descriptive cross-tabulations are not subject to sampling errors.	In some censuses, populations in institutions with disabilities may not be included.

¹ This information was taken from the **United Nations' 2001 Guidelines and Principles for the Development of Disability Statistics**. See this document for further details.

If disability questions remain comparable, they can be useful analysis of disability rates across time.	Subject to high non-response rates and under-enumeration because of the complexity and sensitivity of the question.
Identified set of people with disabilities is usually large, allowing more detailed cross-tabulations and analyses.	It is costly and time-consuming to identify a relative small population of people with disabilities by asking questions of the entire population.
Can provide a useful sampling frame for research on people with disabilities who are otherwise difficult to find.	May be too costly to train enumerators in the specific guidelines required for disability questions.

Table 3.2: Sample Surveys: Advantages and Disadvantages

Advantages	Disadvantages
Flexibility in the depth and range of topics covered.	Limited sample size for small geographic area resulting to higher sampling errors, thus, limited ability to analyse prevalence rate for local areas.
Special probes can be used to ensure that people with disabilities are identified.	People with disabilities account for less than 20 percent of any population, so unless the survey is very large, the sample size of people with disabilities will be small
If sampling frame and survey infrastructure in place, relatively easy to initiate.	Coverage poor for institutionalised persons, the homeless, refugees or nomadic populations.
If comparable with census and other surveys, can be used for detecting change over time.	Time-series analysis of ad hoc surveys is uncertain.
Because of limited coverage and smaller sample, there is greater control over the conditions of observation and interviewing.	Detailed surveys require close supervision of fieldwork and special disability training for field supervisors and interviewers.
Capacity to locate people with disabilities can be increased with design modifications (e.g. co-coordinating probability sample selection with the census, using registered population lists, stratifying the sampling stage, or increasing the sampling fraction).	
Greater opportunity for field work supervision, specialised field training, question pre-testing.	

Table 3.3: One-time Registration Data Collection: Advantages and Disadvantages

Advantages	Disadvantages
Easy to initiate.	Extent of coverage and the degree of representation are unknown and sampling error cannot be estimated.
Does not require a large, on-going staff.	Population at risk is unknown, so prevalence and incidence rates of disability cannot be calculated.
Can provide a large number of cases for complex data analysis where extensive cross-tabulations and dis-aggregation are required.	Double counting is a problem, given many classes of informants and multiple registration lists of registered people with disabilities.
May be used to assist governmental and private agencies (e.g. social security and social welfare offices and medical and educational organizations) locating people with disabilities in need of services.	Findings can be easily or validly extrapolated to a larger population of people with disabilities.
May be used to prepare sampling frame for research on populations with specific disabilities.	

Table 3.4: Continuous Registration Data Collection: Advantages and Disadvantages

Advantages	Disadvantages
Tabulations can be prepared for small geographical areas.	Reporting based on when disability was diagnosed rather than onset.
Detailed dis-aggregation is not subject to sampling error.	Population at risk must be determined independently from census data or from population estimates or projections.
Can provide numerator data for incidence and prevalence rates.	Registration systems are inflexible to changes to content and procedure.
Both short and long-term series are easier to compile and more reliable because of institutional continuity in the collection process.	Organization and administration require well-trained statistical personnel.
Data collection can be closely linked to the provision of special services.	Data collection and compilation over time is complex.
Provides a sampling frame for in-depth research on populations with specific disabilities.	Multiple registration, and double counting, is difficult to detect.

A comparative summary of the strengths and weaknesses of these four principal data collection methods for estimating and describing disability is given in **Table 3.5**.

Like mortality and fertility, disability is a phenomenon that is neither uniformly nor normally distributed across the total population. Disability reporting has many of the same problems as in the reporting of mortality, such as the reliance on non-expert description of medical events, difficulty recalling the time of an illness or disability, and problems determining the most eligible and knowledgeable respondents. The 12 criteria for evaluating the data sources shown in the table below are particularly relevant to the collection of data about disability.

Table 3.5: Data Collection Methods for Disability Statistics: Comparative Summary

Criterion	Population Census	Sample Surveys	One-time Registration	Continuous Registration
Ability to capture detailed disability characteristics	Weak	Weak to moderate	Moderate to strong	Moderate to strong
Ability to capture topical detail (richness and diversity of non-disability characteristics)	Moderate	Strong	Moderate	Weak
Accuracy and coverage	Moderate	Strong	Weak to moderate	Weak to moderate
Absence of sampling error	Strong	Weak	Weak	Weak
Timeliness of data	Weak	Moderate to strong	Strong	Moderate
Geographical detail	Strong	Weak	Strong	Strong
Ability to obtain information on the population at risk	Strong	Strong	Weak	Weak
Ease of organization in a developing country	Moderate	Strong	Strong	Weak
Number of cases available for the analysis of selected disabilities	Moderate to strong	Weak to moderate	Moderate	Strong
Ability to estimate prevalence rates	Strong	Strong	Weak	Weak to moderate
Can identify persons requiring special services	Weak	Weak	Strong	Strong
Usefulness for community-based project planning for people with disabilities	Weak to moderate	Weak	Moderate to strong	Moderate to strong

3.7 Relatable data

Table 3.5 illustrates that each data collection method has its strengths and weaknesses concerning disability statistics. If more than one method is used, in a coordinated fashion, then the strengths of each method will be preserved and the weaknesses of each avoided. Deficiencies with census data, for example, can be addressed through disability surveys or disability modules in other surveys. The inadequacies with survey data can be partly overcome by using censuses, registered populations, and other administrative data.

Undoubtedly, a major challenge when assessing the life situation of people with disabilities is locating and integrating data from various sources. First of all, there must be a variety of data sources to draw upon, and in many developing countries this is not true. Secondly, even if there are various data sources, the data must be **relatable**, that is based on a common conceptual framework and using comparable concepts and language. The ICF provides just what is required for relatability: a universal framework and a common language of disability.

Box 3.7 gives an Australian example of the use of data from a variety of sources to examine the unmet needs for disability services, showing in particular how survey and administrative data can be analysed together to provide information regarding the lives of people with disabilities.

Box 3.7: Using Data from a Variety of Sources: The Australian Disability Services Project

In 2001, the Australian Institute of Health and Welfare was commissioned to estimate levels of unmet need for disability services among people with disabilities in Australia. Specifically, the project aimed to:

- assess the effectiveness of previously allocated funding in reducing unmet need for disability services, by quantifying and describing additional services provided as a result of the funding; and
- identify any remaining unmet need for disability accommodation, in-home support, day programs, respite services, and disability employment.

The two sources of data used were the NMDS data on services and consumers (the source of information on the supply of services); and disability population survey data (a source of information on unmet need for services). In conducting the analysis, the ICF was used as a common framework to which concepts and data items from these two data sources were mapped. Overlapping ICF concepts could then be identified in both data sources:

<i>Disability services data collection</i>	<i>Disability survey</i>
Impairments	
<i>(Need for assistance with...)</i>	<i>(Need for assistance with...)</i>
Activities: Self-care, Mobility Communication, other activities	Activities: Self-care, Mobility Communication, other activities
Participation	

Thus, a single 'indicator' of disability – "need for assistance" – was linked to the core purpose

of a range of disability services. Estimation of the number of people in the Australian population with unmet needs for disability services was then based on an analysis of the survey data. The analysis involved:

- Using survey data to identify people who reported a need for help with self-care, mobility, or communication. This group corresponds to the 'target population' for funded disability services; and
- Applying 'filters' to refine the estimate, focusing on people who were living in households (not in institutional accommodation) and who reported unmet need for formal help in addition to a need for frequent assistance.

The analysis produced the following estimates of unmet need across Australia

- 12,500 people needing accommodation and respite services
- 8,200 places needed for community access
- 5,400 people needing employment support

Though thought to be too low, the findings informed negotiations between State, Territory and Commonwealth governments regarding funding for disability supports.

This powerful analysis was only possible because common concepts were used defining the target population for disability services and the disability population survey. This was accomplished because both sets of concepts could be mapped to the ICF framework.

The report on this study is available at <http://www.aihw.gov.au/publications/index.cfm/title/7741>