Ethiopian National Disability Action Network (ENDAN)
Comitato Collaborazione Medica (CCM)

Guidelines for Disability Data Collection Tools and Measurement

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Addis Ababa
Ethiopia
Acknowledgements

These Guidelines have been prepared based on a research on existing disability data collection and measurement systems by governmental and non-governmental actors in Addis Ababa. Commissioned by CCM and ENDAN, the guidelines have been prepared by Siseraw Consultancy (SiCon) with the support of, and input from, a significant number of organizations and people working in disability related areas. It would be inappropriate to try and name all individuals who have contributed, however thanks to all those who have provided their time and ideas during the research. Special thanks are due to staff members of CCM and ENDAN.

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Introduction

The preparation of these Guidelines was preceded by a research on the tools, measurements and methods development actors employ in collecting disability data in Addis Ababa, Ethiopia (refer to the research report). The research revealed that standard disability measurements are lacking and information and data on disability are unreliable, scattered and often misleading.

Purpose of the Guidelines:
Reliable information on people with disabilities is necessary for planning meaningful interventions to solve their problems and restore their hope for a meaningful future. It brings out the prevalence of disability and articulates the magnitude of the problem as well as its ramifications in the society. It provides clarity on what the real issues are and a basis for appropriate responses.

The purpose of these Guidelines is thus to support ENDAN member organizations to help achieve this by adopting a uniform disability data collection and measurement approach, that is aligned with international standards, and thereby contribute for the creation of a centralized database on the areas of disability in the future.

Users and use:
While the Guidelines are primarily targeted at ENDAN members, they can also assist other stakeholders such as NGOs, government agencies and other non-state bodies who are engaged in producing disability information. The Guidelines can be used in a variety of ways, depending on the work responsibilities of the reader and the purposes of data collection.

Newcomers to the issue of disability should familiarize themselves with the basic concepts in Section 2 of the Guidelines before referring to the Tools and practical guides of tools design and implementation in the remaining Sections (3-5). Those more experienced with disability data collection, and who are conversant with the international standards (such as the ICF), should focus on reading the operational guidelines in the final sections. For all users, it is advised to read the guidelines in conjunction with the background research report to have a comprehensive understanding of the situation of disability data collection and measurement in Ethiopia and at the international level.

Overview of contents:
The next section (Section 2) provides the internationally accepted model and framework for conceptualizing disability. It defines the components and terminologies relevant for understanding disability and for designing disability data collection and measurement methodologies.

Section 3 explains the main sources of disability information: census, survey and administrative databases, as well as disability measurement approaches. In addition to defining these sources, the section enumerates the strengths and limitations of each of the sources and the various disability measurement approaches.

Section 4 presents practical step-by-step guides for the planning and execution of data collection. The final section explains the processes of data analysis, forms of presentation and dissemination.
2 The ICF Framework

2.1 The ICF model and conceptual framework

One major challenge in terms of producing internationally comparable disability information relates to the relative and dynamic nature of the concept “disability”. Disability is a relative concept because it is differently understood according to cultures, attitudes and prevailing social norms. However, at global level the need to have a framework for understanding and analyzing disability was felt decades ago and efforts made towards this have produced the bio-psychosocial model as widely acceptable model for understanding disability.

The bio-psychosocial model follows multidimensional approach in understanding disability. According to the bio-psychosocial model, disability is the result of interactions between the person’s health condition (disease, disorders and injuries), environmental factors (social attitudes, architectural characteristics, social structures, etc) and personal factors (gender, age, coping styles, social background, education, etc).

Development of the concept “disability” by the bio-psychosocial model reflects the incorporation of “an ever increasing set of complex concepts and relationships to explain the disabling process”. Considering, for example, a person losing a limb due to car accident, the accident and the resulting impairment are simply what initiate the disability process. The victim’s disability is described by interaction of several interrelated factors including “the effect the trauma has on the individual, the characteristics of the individual who experiences the health trauma, the characteristics of those around them, the social and structural context they inhabit, the cultural orientation of the community and the policies of the governing bodies”.

The model which established the framework for contemporary understanding of disability is the bio-psychosocial model. This approach views disability as multi-dimensional phenomena and acknowledges the significance of addressing both the medical and social dimensions of disability. According to this model, disability is understood as a product of interaction between a person’s certain conditions or functional limitations and his or her physical, social, and attitudinal barriers. According to this model, medical and rehabilitative interventions are important in addressing body-level aspects of disability, i.e. impairments and limitations in a person’s capacity to perform actions; while at the same time environmental and social interventions are essential to deal with restrictions in a person’s participation in educational, economic, social, cultural and political activities.

The bio-psychosocial model is the World Health Organization’s (WHO) framework for understanding disability and has formed the basis for the International Classification of Functioning, Disability and Health (ICF).

The WHO’s ICF is a scientific tool for consistent, internationally comparable information about the experience of health and disability. ICF reflects the modern day thinking about disability and embodies a paradigm shift in the way health and disability are understood and measured. ICF was endorsed by all 191 member states of the World Health Assembly in May, 2001 and WHO strongly recommends its use for all health and disability statistics worldwide.

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1 ICF Guide, p. 10
4 Ditto
5 Disability Statistics Manual, p. 14
6 ICF towards …2002 p.5
7 WHO/ESCAP Training Manual on Disability Statistics, p.9
Box 1: The ICF framework

ICF is WHO’s framework for health and disability. The International Classification of Functioning, Disability and Health (ICF) provide a standardized framework for conceptualising disability, recommended to improve consistency of surveys. It is the conceptual basis for the definition, measurement and policy formulations for health and disability. It is a universal classification of disability and health for use in health and health related sectors. ICF therefore looks like a simple health classification, but it can be used for a number of purposes. The most important is as a planning and policy tool for decision-makers.


Underlying principles of ICF

There are general principles that underlay the conception of ICF as a health classification of functioning and disability, and are closely linked to the bio-psycho-social model of disability. These principles are:

**Universality:** A classification of functioning and disability should be applicable to all people irrespective of health condition. Therefore, ICF is about all people. It concerns everyone’s functioning. Thus, it should not become a tool for labeling persons with disabilities as a separate group.

**Parity:** There should not be, explicitly or implicitly, a distinction between different health conditions as ‘mental’ and ‘physical’ that affect the structure of content of a classification of functioning and disability. In other words, disability must not differentiated by etiology.

**Neutrality:** Wherever possible, domain names should be worded in neutral language so that the classification can express both positive and negative aspects of each aspect of functioning and disability.

**Environmental factors:** In order to complete the social model of disability, ICF includes Contextual Factors, in which environmental factors are listed. These factors range from physical factors such as climate and terrain, to social attitudes, institutions, and laws. Interaction with environmental factors is an essential aspect of the scientific understanding of the phenomena included under the umbrella terms ‘functioning and disability’

Disability therefore involves impairments, activity limitations and participation restrictions. The formal definitions of these components of ICF are provided in the box below.

Box 2: Definitions of components

Disability is the umbrella term for any or all of: an impairment of body structure or function, a limitation in activities, or a restriction in participation. The key components of disability are defined as follows:

**Body Functions** are physiological functions of body systems (including psychological functions).
**Body Structures** are anatomical parts of the body such as organs, limbs and their components.
**Impairments** are problems in body function or structure such as a significant deviation or loss.
**Activity** is the execution of a task or action by an individual.
**Participation** is involvement in a life situation.
**Activity Limitations** are difficulties an individual may have in executing activities.
**Participation Restrictions** are problems an individual may experience in involvement in life situations.
**Environmental Factors** make up the physical, social and attitudinal environment in which people live and conduct their lives. These are recorded as either facilitators or barriers (both on a 5-point scale) to indicate the effect they have on the person’s functioning.

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8 Washington Group on Disability Statistics, Understanding and Interpreting Disability as Measured using the WG Short Set of Questions (WG, 04/20/09), p.13-14
The ICF conceptual framework thus provides standardized concepts and terminology that can be used in disability measurement instead of the un-standardised and often pejorative terms used in many national studies on disability. The use of a common framework also contributes to greater comparability of data at the national and international levels, thereby increasing the relevance of the data to a wide set of users.

2.2 ICF classification, terminologies and definitions

As noted before, development in conceptualization of disability from the medical model to the bio-psychosocial model has brought about a complex set of dimensions that need to be considered in explaining disability.

Based on the bio-psychosocial model, three domains of human functioning are classified by ICF: functioning at the level of body or body part, the whole person, and the whole person in a social context. Disability therefore involves dysfunctioning at one or more of these same levels: impairments, activity limitations and participation restrictions.\(^9\) Notwithstanding its complexity, classification of disability into three domains by ICF underlies much of the efforts to obtain national and international data sets in the disability field.\(^10\)

Diagram 1:: Interaction between ICF components

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.

**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).

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10 Colin Robson, EDUCATING CHILDREN WITH DISABILITIES IN DEVELOPING COUNTRIES:THE ROLE OF DATA SETS. The University of Huddersfield with Peter Evans, The OECD Secretariat. P.3
Disability is an umbrella term for impairments, activity limitations, and participation restrictions. It denotes the negative aspects of the 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 backgrounds 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.

What these components of ICF refer to is illustrated in the box below:

<table>
<thead>
<tr>
<th>Box 3: Description of components</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Body</strong></td>
</tr>
<tr>
<td>Function:</td>
</tr>
<tr>
<td>• Mental Functions</td>
</tr>
<tr>
<td>• Sensory Functions and Pain</td>
</tr>
<tr>
<td>• Voice and Speech Functions</td>
</tr>
<tr>
<td>• Functions of the Cardiovascular, Hematological, Immunological and Respiratory Systems</td>
</tr>
<tr>
<td>• Functions of the Digestive, Metabolic, Endocrine Systems</td>
</tr>
<tr>
<td>• Genitourinary and Reproductive Functions</td>
</tr>
<tr>
<td>• Neuromusculoskeletal and Movement-Related Functions</td>
</tr>
<tr>
<td>• Functions of the Skin and Related Structures</td>
</tr>
<tr>
<td>Structure:</td>
</tr>
<tr>
<td>• Structure of the Nervous System</td>
</tr>
<tr>
<td>• The Eye, Ear and Related Structures</td>
</tr>
<tr>
<td>• Structures Involved in Voice and Speech</td>
</tr>
<tr>
<td>• Structure of the Cardiovascular, Immunological and Respiratory Systems</td>
</tr>
<tr>
<td>• Structures Related to the Digestive, Metabolic and Endocrine Systems</td>
</tr>
<tr>
<td>• Structure Related to Genitourinary and Reproductive Systems</td>
</tr>
<tr>
<td>• Structure Related to Movement</td>
</tr>
<tr>
<td>• Skin and Related Structures</td>
</tr>
<tr>
<td><strong>Activities and Participation</strong></td>
</tr>
<tr>
<td>• Learning and Applying Knowledge</td>
</tr>
<tr>
<td>• General Tasks and Demands</td>
</tr>
<tr>
<td>• Communication</td>
</tr>
<tr>
<td>• Mobility</td>
</tr>
<tr>
<td>• Self Care</td>
</tr>
<tr>
<td>• Domestic Life</td>
</tr>
<tr>
<td>• Interpersonal Interactions and Relationships</td>
</tr>
<tr>
<td>• Major Life Areas</td>
</tr>
<tr>
<td>• Community, Social and Civic Life</td>
</tr>
<tr>
<td><strong>Environmental Factors</strong></td>
</tr>
<tr>
<td>• Products and Technology</td>
</tr>
<tr>
<td>• Natural Environment and Human-Made Changes to Environment</td>
</tr>
<tr>
<td>• Support and Relationships</td>
</tr>
<tr>
<td>• Attitudes</td>
</tr>
<tr>
<td>• Services, Systems and Policies</td>
</tr>
</tbody>
</table>
As can be understood from the Box provided above, data about impairments is different from data about activity limitations, which again is different from data about participation restriction.

It should be remembered here that disability according to the ICF refers all three dimensions taken together. Therefore, it is only when all three kinds of information are collected that one can have a complete picture of the lived experience of disability for a particular person.\textsuperscript{12} For this reason, information on impairment alone, though certainly relevant to disability experience, provides a very limited perspective on disability.\textsuperscript{13}

Accordingly, population surveys and censuses directed at collecting data on impairments alone are considered to “under-describe disability and under-estimates the prevalence rate of disabilities as a whole”.\textsuperscript{14} Relying on the impairment approach, in other words, identifies the persons with disabilities as a core minority of severely disabled individuals, ignoring a substantial group of individuals with moderate and mild disabilities.\textsuperscript{15}

2.3 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).

The following table shows the hierarchy of ICF domains and its reflection in the coding.

<table>
<thead>
<tr>
<th>Level</th>
<th>Example</th>
<th>Coding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chapter</td>
<td>Chapter 2: Sensory Functions and Pain</td>
<td>$b2$</td>
</tr>
<tr>
<td>Second level</td>
<td>Seeing Functions</td>
<td>$b210$</td>
</tr>
<tr>
<td>Third level</td>
<td>Quality of Vision</td>
<td>$b2102$</td>
</tr>
<tr>
<td>Fourth level</td>
<td>Colour Vision</td>
<td>$b21021$</td>
</tr>
</tbody>
</table>

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.

\textsuperscript{12} Daniel Mont and Mitchell Loeb, Beyond DALYs: Developing Indicators to Assess the Impact of Public Health Interventions on the Lives of People with Disabilities. (The World Bank, May 2008).p.4

\textsuperscript{13} Ditto.

\textsuperscript{14} Ditto.

\textsuperscript{15} Ditto.
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 (threedigit) 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.

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.

Table 2: Classification and coding of disabilities

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Chapter</th>
<th>Code</th>
<th>Classification block or category</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Body Functions and Structures</strong></td>
<td></td>
<td><strong>2</strong></td>
<td><strong>b210–b220</strong> Seeing and related functions</td>
</tr>
<tr>
<td><strong>Vision</strong></td>
<td><strong>2</strong></td>
<td><strong>b210–b220</strong></td>
<td>Seeing and related functions</td>
</tr>
<tr>
<td><strong>Hearing</strong></td>
<td><strong>2</strong></td>
<td><strong>b230–b240</strong></td>
<td>Hearing and vestibular functions</td>
</tr>
<tr>
<td><strong>Speech</strong></td>
<td><strong>3</strong></td>
<td><strong>b310–b340</strong></td>
<td>Voice and speech functions</td>
</tr>
<tr>
<td><strong>Digestion</strong></td>
<td><strong>5</strong></td>
<td><strong>b510–b535</strong></td>
<td>Functions of the digestive system</td>
</tr>
<tr>
<td><strong>Bodily excretion</strong></td>
<td><strong>6</strong></td>
<td><strong>b610–b630</strong></td>
<td>Urinary functions</td>
</tr>
<tr>
<td><strong>Fertility</strong></td>
<td><strong>6</strong></td>
<td><strong>b640–b670</strong></td>
<td>Genital functions</td>
</tr>
<tr>
<td><strong>Sexual activity</strong></td>
<td><strong>6</strong></td>
<td><strong>b640</strong></td>
<td>Genital and reproductive health</td>
</tr>
<tr>
<td><strong>Skin and disfigurement</strong></td>
<td><strong>8</strong></td>
<td><strong>b810–b830</strong></td>
<td>Skin and related structures</td>
</tr>
<tr>
<td><strong>Breathing</strong></td>
<td><strong>4</strong></td>
<td><strong>b440–b460</strong></td>
<td>Functions of the respiratory system</td>
</tr>
<tr>
<td><strong>Pain</strong></td>
<td><strong>2</strong></td>
<td><strong>b280</strong></td>
<td>Pain</td>
</tr>
<tr>
<td><strong>Affect</strong></td>
<td><strong>1</strong></td>
<td><strong>b152–b180</strong></td>
<td>Specific mental functions</td>
</tr>
<tr>
<td><strong>Sleep</strong></td>
<td><strong>1</strong></td>
<td><strong>b134</strong></td>
<td>Global mental functions</td>
</tr>
<tr>
<td><strong>Energy/vitality</strong></td>
<td><strong>1</strong></td>
<td><strong>b130</strong></td>
<td>Global mental functions</td>
</tr>
<tr>
<td><strong>Cognition</strong></td>
<td><strong>1</strong></td>
<td><strong>b140,b144,</strong> b164</td>
<td>Attention, memory and higher-level cognitive functions</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Activities and Participation</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Communication</strong></td>
<td><strong>3</strong></td>
<td><strong>d310–d345</strong></td>
<td>Communication receiving – producing</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td><strong>4</strong></td>
<td><strong>d450–d465</strong></td>
<td>Walking and moving</td>
</tr>
<tr>
<td><strong>Dexterity</strong></td>
<td><strong>4</strong></td>
<td><strong>d430–d445</strong></td>
<td>Carrying, moving and handling objects</td>
</tr>
<tr>
<td><strong>Self-care</strong></td>
<td><strong>5</strong></td>
<td><strong>d510–d570</strong></td>
<td>Self-care</td>
</tr>
<tr>
<td><strong>Usual activities</strong></td>
<td><strong>6 and 8</strong></td>
<td><strong>d730–d770</strong></td>
<td>Domestic life; Major life areas</td>
</tr>
<tr>
<td><strong>Interpersonal relations</strong></td>
<td><strong>7</strong></td>
<td><strong>d730–d770</strong></td>
<td>Particular interpersonal relationships</td>
</tr>
<tr>
<td><strong>Social functioning</strong></td>
<td><strong>9</strong></td>
<td><strong>d910–d930</strong></td>
<td>Community social and civic life</td>
</tr>
</tbody>
</table>
Data Sources in Disability

2.4 Measurement of disability

As pointed out earlier, collecting data about persons with disabilities and their lives is difficult. It presents unique challenges to disability data producers in the designing stage of the data collection process. Two issues data producers need to grapple with at the beginning of this stage are: 1) what kind of data collection instrument should be used, and 2) what unit of measurement should be employed. Both issues are examined in detail below.

2.4.1 Collection instruments

The main types of instruments or tools for collecting data about persons with disabilities are:
- Population censuses
- Sample surveys (either general social surveys or specific health and disability surveys)
- Administrative collections and registries.

As explained in the up-coming sections below, disability data producers employ any of these data collection instruments separately or jointly, depending on the type of information they seek to generate.

Before delving into the details, however, it is important to have clear understanding on important terminologies concerning data collection instruments or tools in general. Doing so will also help establish common understanding on key terminologies to be discussed in this section. At this point, it is worth citing definitions and meanings given by the Cambridge Dictionary of Statistics (2006)\(^\text{16}\) below:

**Census:** A study that aims to observe every member of a population. The fundamental purpose of the population census is to provide the facts essential to government policy-making, planning and administration.\(^\text{17}\)

**Sample survey:** A study that collects planned information from a sample of individuals about their history, habits, knowledge, attitudes or behavior in order to estimate particular population characteristics.\(^\text{18}\)

**Administrative databases:** Databases storing information routinely collected for purposes of managing a health-care system. Used by hospitals and insurers to examine admissions, procedures and lengths of stay.\(^\text{19}\) [N.B. This definition is narrow in terms of the users and purposes of information as in the context of disability other administrative databases can be established by others as well and used for variety of purposes.]

**Post-enumeration survey:** A survey composed of a sample of census enumerations and a sample of the population. The two samples are based on a common area sample of census blocks and of housing units within blocks. Used in making dual system estimates.\(^\text{20}\)

**Dual system estimates:** Estimates which are based on a census and a post-enumeration survey, which try to overcome the problems that arise from the former in trying, but typically failing, to count everyone.\(^\text{21}\)

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17 Id. P.68
18 Id. P.350
19 Id. P.7
20 Id. P.309
21 Id. P.134
These main types of data collection tools are further elaborated in the context of disability data collection as follows:

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 4 to 6 general disability questions 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, census is useful.

**Sample surveys** are shorter surveys designed to be administered to a subpopulation 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 program. 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.

Advantages and disadvantages of the three instruments for gathering disability information are enumerated in more detail in the following table.

**Table 3: Advantages and disadvantages of data collection methods**

<table>
<thead>
<tr>
<th>Population Census</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Data can be tabulated for small, local areas.</td>
<td>• Questions limited to basic socioeconomic and demographic characteristics, restricting the scope of disability questions.</td>
</tr>
<tr>
<td>• Prevalence rates can be calculated for small geographical areas because data are also gathered for the population at risk.</td>
<td>• Data collection is infrequent – usually every 10 years. The time between data collection and data dissemination can be considerable.</td>
</tr>
<tr>
<td>• Detailed descriptive cross-tabulations are not subject to sampling errors.</td>
<td>• In some censuses, populations in institutions with disabilities may not be included.</td>
</tr>
<tr>
<td>• If disability questions remain comparable, they can be useful analysis of disability rates across time.</td>
<td>• Subject to high non-response rates and under-enumeration because of the complexity and sensitivity of the question.</td>
</tr>
<tr>
<td>• Identified set of persons with disabilities is usually large, allowing more detailed cross-tabulations and analyses.</td>
<td>• It is costly and time-consuming to identify a relative small population of persons with disabilities by asking questions of the entire population.</td>
</tr>
<tr>
<td>• Can provide a useful sampling frame for research on persons with disabilities who are otherwise difficult to find.</td>
<td>• May be too costly to train enumerators in the specific guidelines required for disability questions.</td>
</tr>
</tbody>
</table>
### Sample Surveys

<table>
<thead>
<tr>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Flexibility in the depth and range of topics covered.</td>
<td>• Limited sample size for small geographic area resulting to higher sampling</td>
</tr>
<tr>
<td>• Special probes can be used to ensure that persons with disabilities are</td>
<td>errors, thus, limited ability to analyze prevalence rate for local areas.</td>
</tr>
<tr>
<td>identified.</td>
<td>• Persons with disabilities account for less than 20 percent of any population,</td>
</tr>
<tr>
<td>• If sampling frame and survey infrastructure in place, relatively easy</td>
<td>so unless the survey is very large, the sample size of persons with disabilities</td>
</tr>
<tr>
<td>to initiate.</td>
<td>will be small.</td>
</tr>
<tr>
<td>• If comparable with census and other surveys, can be used for detecting</td>
<td>• Coverage poor for institutionalized persons, the homeless, refugees or</td>
</tr>
<tr>
<td>change over time.</td>
<td>nomadic populations.</td>
</tr>
<tr>
<td>• Because of limited coverage and smaller sample, there is greater control</td>
<td>• Time-series analysis of ad hoc surveys is uncertain.</td>
</tr>
<tr>
<td>over the conditions of observation and interviewing.</td>
<td>• Detailed surveys require close supervision of fieldwork and special disability</td>
</tr>
<tr>
<td>• Capacity to locate persons with disabilities can be increased with</td>
<td>training for field supervisors and interviewers.</td>
</tr>
<tr>
<td>design modifications (e.g. co-coordinating probability sample selection</td>
<td></td>
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<tr>
<td>with the census, using registered population lists, stratifying the</td>
<td></td>
</tr>
<tr>
<td>sampling stage, or increasing the sampling fraction).</td>
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<tr>
<td>• Greater opportunity for field work supervision, specialized field</td>
<td></td>
</tr>
<tr>
<td>training, question pre-testing</td>
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<table>
<thead>
<tr>
<th>Advantage</th>
<th>Disadvantage</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Limited sample size for small geographic area resulting to higher</td>
<td>• Population at risk is unknown, so prevalence and incidence rates of</td>
</tr>
<tr>
<td>sampling errors, thus, limited ability to analyze prevalence rate for</td>
<td>disability cannot be calculated.</td>
</tr>
<tr>
<td>local areas.</td>
<td>• Double counting is a problem, given many classes of informants and multiple</td>
</tr>
<tr>
<td></td>
<td>registration lists of registered persons with disabilities.</td>
</tr>
<tr>
<td>• Persons with disabilities account for less than 20 percent of any</td>
<td>• Findings cannot be easily or validly extrapolated to a larger population of</td>
</tr>
<tr>
<td>population, so unless the survey is very large, the sample size of</td>
<td>persons with disabilities.</td>
</tr>
<tr>
<td>persons with disabilities will be small.</td>
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<tr>
<td>• Coverage poor for institutionalized persons, the homeless, refugees or</td>
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<td>nomadic populations.</td>
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<tr>
<td>• Time-series analysis of ad hoc surveys is uncertain.</td>
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<tr>
<td>• Detailed surveys require close supervision of fieldwork and special</td>
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<tr>
<td>disability training for field supervisors and interviewers.</td>
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Disability data producers’ decision on selection of data collection instrument or tool depends in part on what kinds of data are needed. Are data required for the number of persons with disabilities and their characteristics, or for an estimate on the number of households that includes individuals with disabilities? An important consideration here is, for instance, data about individuals are important, but estimates at the household level are also useful for detailed analysis of living arrangements and access to help and assistance.

#### 2.4.2 Approaches to disability measurement

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).
There is a huge discrepancy in disability prevalence figures among different countries. This discrepancy is pointed out to be caused by different conceptions and measures of functional limitation, all described by the same, ambiguous term, ‘disability’. Different approaches to measurement produce different rates. The virtue of the ICF is that it clearly distinguishes the different dimensions of the overall disability experience so that ‘disability’ survey questions can refer to the same phenomenon. It also enables a comprehensive, multi-dimensional measurement strategy in which prevalence is determined by an active decision about the threshold value.

In this regard, it is important to consider three partial measurement approaches based on the ICF model of disability. As will be examined later, each approach has its own strengths and drawbacks. Finally, what is called as the ‘comprehensive approach’ will be discussed.

**Impairment Approach**

This approach relies entirely on the Body Functions and Structures component of the ICF, the dimension of disability concerned with health related problems referred to as “physiological functions of body systems, including psychological functions [and] structural or anatomical parts of the body” by ICF.

The impairment approach could be appropriate if the aim of the data collection is to gather health data about the direct consequences of diseases, disorders and injuries. Such data can be used for tracking health service usages and needs for medical and rehabilitative services. For determining disability prevalence, what is commonly done is to add together positive response rates for each of the sets of impairments given to produce an overall ‘prevalence’ rate.

Impairment measurement of disability is very common. It is straightforward and, on naïve and purely medical conceptions of disability, appears to capture all the data that one would need to estimate prevalence. Other than the challenge of determining which impairments to include and which to ignore, it is a simple approach to use for developing questions.

Although the data collected from the impairment approach have important uses, as far as disability is concerned, the approach is severely limited, and indeed, leads to a highly distorted picture of disability at the population level. Disability is ultimately a matter of the lived experience of a person with a decrement in health, how they get on with their life, perform actions and tasks, and fulfill simple and complex social roles.

As questions about impairment strike respondents about their medical condition, rather than their day-to-day lives, there is a tendency for impairments to be under-reported. For instance, an individual with a slight hearing disorder may think the impairment is not worth mentioning, or may even forget that they have the problem.

However, even accurate information about incidence and prevalence of impairments does not tell us how the impairment affects people’s lives.

**Activity and Participation Approach**

The domains in the ICF Activity and Participation classification cover the full range of behaviors, actions, tasks, simple and complex activities, and roles that make up all of a person’s active life, alone and in society.

Activity and Participation questions provide data about health-related functional limitations in a person’s ability to perform actions in one or another domain. Such data are essential to estimate the level of need for assistive devices, modifications of environments, training, or rehabilitative services to increase capacity. These questions give information about the day-to-day lives of persons with disabilities, information
directly relevant to the disability experience, from an overall social, rather than merely medical or rehabilitative, point of view. In turn, these data are relevant to all aspects of disability social policy, from employment and education policy, to communication, transportation and social security.

As a rule, Activity and Participation questions yield higher rates of disability prevalence compared to impairment questions. In part, this is because most impairments, if they affect any activity, tend to affect more than one. More importantly, prevalence is higher because activity and participation domains circumscribe an individual’s direct experience with disability. While people may not be completely aware of their impairments (such as those of the metabolic or endocrine systems, for example), people will usually be all too aware of difficulties they experience in these domains.

The strength of the Activity and Participation Approach to disability measurement is the range of questions about real-life domains of activity that it allows to be included in surveys and censuses.

Impairment questions, no matter how long the list provided, will never be able to identify, or measure, functional difficulties that are experienced by persons with disabilities across the complete spectrum of health conditions. People with vastly different impairments may well experience the same kind of difficulty in their day-to-day life: a person who has depression may well share with the person who has a mobility problem, or a communication difficulty, difficulties in getting and keeping a job. This feature of disability can only be captured by asking questions about what is at the core of the concept, namely difficulties a person has in his/her day-to-day life.

The strengths of the Activity and Participation Approach for disability statistics are obvious. However, there are challenges as well. The choice of impairments to use in a question can be motivated by available national and international health datasets about incidence and prevalence of diseases and other health conditions which involve those impairments. It is not so easy to determine which domains of the Activity and Participation classification should be used in the questions.

Ideally, extensive field-testing across a sufficiently rich pool of items would be required to guide a data collection developer in the construction of a parsimonious list of essential Activity and Participation domains for data collection purposes. Finding such a list, however, is both an expensive and highly technical endeavour far beyond the resources of many developing countries.

The second challenge would be to devise a weighted summation of the scores on the Activity and Participation questions so that a determination of disability status can be interpreted from the responses to the questions. The impairment approach merely adds together the positive responses, treating the occurrence of any impairment equally. The same may not be true of Activity and Participation questions, since some difficulties (e.g., being employed) might be viewed as far more important for disability status than others (e.g., having difficulties grasping).

Although the Activity and Participation Approach, its challenges notwithstanding, is by far preferable than the purely Impairment Approach, it too has its limitations. Specifically, the approach does not provide with enough information to account for the kind and degree of difficulty that responses to the questions would indicate. Even if capacity and performance questions are asked, the answers will still not reveal what has brought about the difficulty. The Activity and Participation Approach misses information, not only about impairments, but also about the environment in which the actions and tasks are, or are not, satisfactorily performed. The Environmental Factors Approach, discussed below, aims to provide that data.
Environmental Factors Approach

Environmental Factor questions ask, not about the disability itself, but about factors that make up the physical, social, and attitudinal environment in which people live and conduct their lives, and which in turn affect the presence, or the severity of the disability. On the ICF model of the disablement process, environmental factors can either facilitate functioning (hence alleviating or eliminating the functional difficulty) or can hinder functioning (hence exacerbating a functional problem or creating one).

There are many uses for these kinds of questions. They provide information on needs for assistive devices or accommodations; on kinds of physical and attitudinal barriers that people with various kinds of impairments face in everyday life; and on the effect on participation in a domain of the introduction of barrier-removal policies (for example, anti-discrimination law) or facilitating policies (for example, policies to support accommodation at the workplace or school environment).

Environmental Factors questions are less common than other kinds, but more and more national surveys are using them.

Although these questions are generally not used for estimates of prevalence of disability, they can provide very useful information about the experiences of person with disability as a person’s environment is an essential factor in the existence and severity of the participation restrictions he/she confronts. The most common forms of environment questions relate to need for and receipt of assistance, including elements from the Products and Technology, Support and Relationships and Services, Systems and Policies chapters of Environmental Factors.

Comprehensive Approach

As outlined earlier, it is clear that, on their own, each of the approaches is unable to create a disability question set for any data collection method that will adequately provide the data needed for a valid measurement of disability prevalence. Each approach provides relevant data, yet only a comprehensive approach – in which all dimensions of disability provides valid measurement data.

As highlighted above, the model of disability given by the ICF makes it clear that valid disability prevalence data must arise from information on actual restrictions on an individual’s performance of actions, tasks, and social roles in the actual physical, social, and attitudinal environment in which that person lives. These are the core data that determine disability prevalence.

In order to understand disability prevalence, furthermore, data on impairments and limitations in a person’s capacity to perform activities and tasks attributable to a health condition, on the one hand, and the facilitating or hindering features of the person’s context on the other – both in terms of personal and environmental factors – are needed. To explain disability in an individual case, and to explain disability prevalence across a population, these data are essential.

Therefore, a comprehensive approach to the development of a disability question set will have Activity and Participation questions at its core, combined with Impairment and Environmental Factor questions.

Optimally, each component should be composed of a set of questions about a parsimonious set of domains as there are far too many domains in the three classifications of the ICF for all of them to be used in a feasible survey/ census/ administrative-based data collection.

The comprehensive approach is multidimensional and covers the full range of the disability experience. It does not directly yield a fixed prevalence value, nor does it directly identify the set of persons with disabilities. Rather, it provides data that can be analyzed along a continuum. That is, prevalence depends
on threshold decisions concerning where – on a continuum of difficulty or severity – to draw the line that separates those with disability from without. Once such a threshold is established, prevalence can be determined on the basis of the data derived from the data collection activity.
Planning and Designing Methodologies

3.1 Planning for data collection

Some of the issues that must be addressed during the planning stage of data collection are:

- What are the objectives of the data collection?
- What are the questions to ask?
- What should be the scope and coverage?
- How should disability be operationalised?
- What should the screening questions look like?
- Should proxy interviews be used?
- Should we use telephone or face-to-face interviews, or both?
- Should there be different questions or questionnaires for different sub-populations?
- How do we solve issues with the language and terminology we use?
- How do we solve basic methodology issues of sample design, sample frame, sample unit, stratification, weighting and so on?
- How do we preserve privacy and confidentiality or respondents’ response?

3.1.1 Identifying the objectives of data collection

Objectives should be stated as clearly as possible because they determine the scope, methodology and content of the survey/census, and ultimately, its statistical outputs. The first two of the above planning questions can be ascertained through consultation with data users and those persons with disabilities.

ICF tells us that the first thing the data collection developers must do is to be absolutely clear on which dimension of disability they are interested in. Is it:

1) impairment,
2) activity limitation and participation restriction
3) environmental and social barriers?

The question: Which dimension of disability does disability data producer want to collect data on? - is thus critical.

In reality, there are legitimate and vitally important needs served by all three kinds of data. However, different purposes require different kinds of disability data:

- If the purpose is to collect information about the prevalence of physiological or psychological functions such as mental functions and systems, then impairment data will be needed.
- If the purpose is to collect information about the capacity of a population to perform daily activities such as mobility, communication, self-care, and interpersonal relations, then data about activity limitations will be needed.
- If the purpose is to collect information about what members of a population actually are able to work in their lives, and, in particular, what features of their physical, built, interpersonal, or social environment help or hinder them, then data about participation restrictions will be needed.

Unfortunately, although many national surveys, censuses or administrative data collection use these broad concepts of the ICF in their disability data collections, there is not yet a final international standard method or instrument for measuring disability linked to ICF categories. Such a method or instrument is still under deliberation by international experts on disability statistics - by the Washington City Group on Disability Statistics, in particular.
3.1.2 Consulting users and persons with disabilities, and examining relevant existing data

Although a country may want to identify disability as broadly as possible, such as activity limitations in any of the Activity and Participation domains, it may be impossible to develop a small question set that would adequately identify everyone in the target population. The most sensible and practical solution is to go back to the data users and ask them which are the most important domains to measure, and use this information to include questions that would measure limitations in each of the high priority domains.

Included in these data users, groups are persons with disabilities themselves and “Self-help Organizations” of persons with disabilities, i.e. NGOs run by persons with disabilities. The obvious reason for including persons with disabilities in disability collection design is the fact that they are not only important data users, but also represent those that will be most affected by the use of the data.

3.1.3 Question formats and response scales

In addition to the content of the questions, there is the issue of form and format. In this section, we look at some basic formats for questions before turning to the more challenging issue of the uses of response scaling in disability statistics.

**Simple, list, multiple choices, open-ended, closed**

- Disability questions can take the form of a simple response, a list, or a multiple choice (or composite) question.
- Single response questions ask a single question involving a single concept, and offer simple response categories (‘yes’, ‘no’, ‘sometimes’) with only one output item.
- List questions (like the ones in the impairment approach above) pose a single question followed by a list of items, with responses recorded for each item. List questions can allow for multiple output items.
- Multiple choice or composite questions, on the other hand, ask about a string of characteristics, but allow a single, non-itemized response.
- For most uses of disability data, itemized responses are preferred to composite questions, as the value of much of the data is lost in non-itemized responses. Sometimes questions are used to lay out options for more detailed questions that follow, and in that case, a list question makes sense and should be used.
- Open-ended questions are those that invite the respondent to reply without providing a set of options for selection or affirmation. Open-ended questions are most commonly used in qualitative research where it is deemed important to let the respondents use their own words to respond to a question and probe.

In survey or census context, this luxury is not often possible and instead closed questions are asked, where one or more response option is specified and the respondent must select one or more of these.

**Scaled response questions**

It is sometimes important to get information, not just about the existence of a disability (a dichotomous or ‘yes/no’ response), but also its severity. To do that, the question needs to use scaled response categories so that the respondent can select the appropriate level of difficulty experienced. For example, a five-points scaled response question can provide the following options:

- No difficulty
- Mild difficulty
- Moderate difficulty
- Severe difficulty
- Complete difficulty
As a rule, scaled response questions increase the number of positive responses, since the respondent has more choices that may fit their situation. For this reason, scaled responses are preferable to dichotomous ‘Yes/No’ responses in the identification of person with disability.

Given a scaled option, people seem much more likely to recognise difficulty with activities than with a dichotomous, ‘Yes/No’ response since respondents tend not to report mild, or even moderate disabilities, mentally reserving ‘yes’ for severe disabilities. There is a strong motivation, therefore, for data collection designers to include scaling options as responses.

There are several successful strategies that can be employed to calibrate response options to ensure consistency of data. The primary focus of these strategies is to devise ways of linking levels of ‘difficulty’ with the response options available.

### 3.1.4 Additional issues in question development

#### Language

Disability question such as whether anyone in the household has “a disability”, although sometimes the question asks about “physical or mental disabilities”, and sometimes “handicap”, “impairment”, “impairments, disabilities or handicaps”. It is known that when these general words are used, the results underestimate prevalence. The reason is that people object to being labeled or categorized – being ‘disabled’ or being ‘handicapped’ – and tend not to answer positively.

Obviously, it is a bad practice to use words that offend people. But it is also bad science. If people do not – or will not – identify themselves and the problems in their lives by the language you use in questions, then the data will be useless. A person may flatly refuse or ignore a question that asks about being ‘cripple’ or ‘dumb’, even if they would readily answer a question about difficulties in walking or carrying on a conversation.

The ICF uses language that is as non-offensive and neutral as possible, and completely avoids insulting terms such as ‘handicap’ or ‘idiot’. More importantly, the ICF makes it clear why survey/census questions should stay away from the term ‘disability’, even when people are not offended by it.

The problem is ambiguity. ‘Disability’ has many meanings and uses in everyday language. Most of these meanings fit into the three dimensions of the ICF:

a) problems with the body (impairments),

b) problems with a person’s capacity to do actions (activity limitations), and

c) Problems a person has, in the environment, in performing actions and major life roles.

When ‘disability’ is used, it is unclear to the respondent which dimension they are being asked about. That is a problem. It is far better to design the survey/census question explicitly to capture data about the dimension, or dimensions of disability of interest, and then ask questions that unambiguously elicit that information.

#### Gender issues

Another unexpected consequence of survey/census screeners is that differences in the percentage of males and females with disabilities may be affected by whether impairment or activity or participation questions are used to identify persons with disabilities.

As a rule, when a disability question is asked, the male to female ratios of the percentage with disabilities are close to 1, indicating that the same proportion of men and women self-identify as part of the disability population. By contrast, when impairment questions are used, the result is often a male-female
percentage of disabilities ratios greater than 1.0, suggesting that more men self-identify as ‘disabled’. This may happen because the impairment approach often focuses on the more severe impairments, which tend to have higher rates for men.

Disability questions should therefore be checked for gender bias. Bias needs not be intentional; it can arise indirectly.

**Cultural issues**

Cultural differences in the perception of disability affect how it is reported. For international statistics, this is an issue of great importance. During its development, the ICF has undergone extensive cross-cultural applicability research to ensure that the concept of disability is culturally accessible, and that the meaning and significance of specific categories of impairments, activity, and participation are preserved through translation.

There remain, however, cultural issues that are more difficult to solve. For example, whether someone reports having a difficulty with an activity will depend on their cultural expectations about whether they should be performing that activity or not. For example, women in some cultures would not be expected to work, but their failure to do so is not a disability. Other cultures are unwilling to report information about family members – because, for example, disability is viewed as a punishment for past sins or otherwise shameful. Sometimes there is a culturally based sensitivity on the part of men to answer questions about women in their household, or the other way around. The mere act of providing information to the government may be a problem for some cultures.

Experience suggests that these cultural differences can be minimised in survey administration. It is recommended that:

- Respondents are informed about the potential benefits to themselves or others of high quality data about persons with disabilities.
- Associations for persons with disabilities are approached to support and promote the data collection and to explain to their members the need for the data and how it can benefit their lives.
- As discussed earlier, the language used in any data collection activity is acceptable and not offensive.
- Interviewers are trained to be aware of cultural differences and to conduct interviews in ways that encourage response.

**Context of disability questions**

Disability prevalence rates may be affected by the context in which disability questions are embedded. For example, in the Australian Survey of Disability, Ageing and Carers, disability prevalence rates may have been affected by the fact that health status questions (from the Medical Outcomes Study 12 Item Short Form Health Survey) were asked before questions aimed at identifying the disability population. Perhaps focusing the respondent’s attention on their physical and mental health status immediately before asking about activity limitations may have led to more positive responses.
3.1.5 Privacy implications of collecting data

Prior to data collection, a plan has to be established as to how privacy and confidentiality will be guaranteed. These factors must be considered whenever data about individuals or service provider organizations are collected or disseminated. Privacy and confidentiality may be compromised by what information is collected, how it is collected (e.g., the manner in which the question is asked, and by whom), how the data are stored (e.g., who has access to the data and what protections are in place to stop unauthorized access), and how the data are analysed and reported.

Legislation or ministerial or departmental regulations may set out privacy requirements for data collections — it is important to be familiar with these rules as the development phase of the data collection begins. Even if no legislation or regulation exists, it is a good practice to follow the following principles:

a) Agencies and other data-collecting organizations should inform respondents of the information they are collecting and the purposes and intended uses of that data.

b) The respondent's consent – or in the case of someone unable to consent, the consent of a proxy – should always be obtained prior to collecting data, and the individual should be given the opportunity to refuse consent to the use or disclosure of information about them.

c) Agencies and other data-collecting organizations should give people reason to be confident that their privacy will be respected.

3.1.6 Data collection guide

Besides the format of the questions and the content of the questions themselves, additional material should be provided to support the collection of data and to ensure that the data will be of high quality.

The people who will collect the data must fully understand the purposes of the collection and their role as data collectors. The best way to accomplish this is to provide them with a data collection guide and to discuss this during training (refer to the next chapter for detailed discussion on this).

Instructions to interviewers and supervisors about how to conduct data collection can help ensure that the data collected are of good quality. A data collection guide should contain the following:

- background information, which includes an explanation of the overall purpose, content and structure of the collection, objectives of the survey/census/administrative data collection, and information about the users of the data;
- information on the scope and coverage of data collection;
- definitions of concepts;
- detailed explanation of each disability question, instructions on how to ask these questions with some examples and illustrations, and coding classifications; and,
- possible problems that may be encountered in data collection and suggestions to solve these problems.

The data collection guide should be simple and easy to understand. It is the only reference instrument that the interviewers and supervisors will be referring to while they are in the field conducting the interviews.

It is also important that the data collection guide clearly explores general and social perceptions of disability and persons with disabilities in order to expose underlying stereotypes and myths.
As pointed out earlier, it is very common, in any culture, for stereotypes and generalizations about persons with disabilities to dominate public perception. Persons with disabilities are often viewed as totally incapable of participating in normal social life, as lacking skills or talents, needing charity or putting a strain on social resources. These views are rarely overtly expressed, but form part of the accepted social view, found in advertising and the media, in language, religion, or social policy.

It is important in the interviewer instructions to review these myths and encourage interviewers to see if they unconsciously share them. To preserve the validity of the questionnaire, bias and presumptions about disability should be identified and corrected, wherever possible. Training sessions in which these issues can be discussed are the best way of getting myths and stereotypes out in the open where they can be most successfully dealt with.

It is imperative that a data collection guide be pre-tested and pilot tested together with the questionnaire. This is to determine if the instructions are also adequately simple, clear, and complete.

3.2 Preparatory activities prior to conducting the fieldwork

Once the questionnaire has been finalized, the data collection developer should begin preparing for data collection. There are a number of preparatory activities that are advised prior to the commencement of fieldwork. Below are the activities that should be followed.

3.2.1 Publicity campaign

The purpose of the publicity campaign is to raise awareness among the population of the forthcoming data collection activity, to help them understand the significance of the activity, and to encourage them to answer all the questions honestly.

Another important task of a publicity campaign is to introduce the agency responsible for the data collection. Such an introduction will help to reassure respondents about the legality of data collection, and consequently reduce the number of respondent refusals. Publicity can be done in a number of ways:

- Conduct an awareness campaign
- Have a regular column in a newspaper.
- Have regular segments in the broadcast media.
- Produce calendars and posters for distribution.
- Prepare brochures for distribution.
- Prepare streamers and banners for display.

3.2.2 Coordination with the organizations of persons with disabilities

As discussed earlier, it is important that persons with disabilities are consulted early in the development stage of the data collection project, as they can provide valuable information about which data should be collected. During publicity campaigns, persons with disabilities should likewise be involved. Their involvement may encourage other persons with disabilities, and the organizations they represent, to participate either as respondents or as endorsers of the census or disability survey. They are the best source of information on how to conduct a campaign in accessible format and means.
3.2.3 Coordination with local officials

It is essential that coordination takes place with the local officials. They need to be informed that the survey or census will be undertaken well in advance of the actual data collection. The local officials can assist in a number of ways, one of which is in the publicity campaign. They can also provide some assistance during enumeration such as security, transportation, accommodation, meals, guides, and translators. Gaining support from the local officials is also an effective way of gaining support from the respondents. In some instances, some respondents do not cooperate if they are not given notice from the local officials.

Coordination or courtesy calls with the local officials on the first day of data collection is also important to make them aware that the data collection in their area is starting. This will also help to reduce suspicion on the part of the residents regarding the arrival of non-resident data collectors/supervisors in the area.

3.2.4 Recruitment of interviewers and supervisors

The quality of output from the field relies heavily on the effectiveness of the interviewers. Having permanent field staff may guarantee a higher quality than recruiting a new batch of field workers each time data is collected. Obviously, staff with more training and experience will be advantaged in terms of their understanding of important concepts, their ability to deal with unusual circumstances, and so on.

Although interviewers do need to be sensitised to disability issues, they do not need medical training or backgrounds. Generally, high level of medical sophistication is not required since disability questions should be written in language that is clear and accessible to respondents.

One common problem in recruitment is the reluctance of interviewers to be assigned to a remote area. This becomes a serious problem if no qualified personnel are found in the area. One solution is to offer incentives such as a higher travelling allowance and/or higher wages.

In determining the number of interviewers needed for data collection activity, the following information is needed:

- the number of households/respondents to be covered or interviewed;
- the duration of data collection; and
- the average output of interviewer per day

The number of supervisors will depend on the extent of supervision that they will perform. Some supervisory duties include editing questionnaires, attending to problems during enumeration (refusals, resignation of interviewers etc.) and monitoring the availability of funds. In some countries, the average ratio of interviewers to supervisors is five interviewers for every supervisor.

3.2.5 Training of interviewers and supervisors

Thorough training is essential to ensure that both the interviewers and supervisors have the necessary knowledge and skills to collect valid and reliable data. The purpose of training is to:

- Ensure a standardized application of the survey materials
- Clarify the rationale of the study and study protocol
- Motivate interviewers
- Provide practical suggestions
- Improve the overall quality of the data
In particular, for the disability statistics the following points are important:

- Ensure understanding of comprehensive concepts of disability
- Ensure sensitivity for persons with diverse disabilities and their families

**Interviewing persons with disabilities – tips and traps**

Even well trained interviewers benefit from training specific to the problems and issues involved in interviewing persons with disabilities. Some tips and potential traps are listed below, grouped under common sense rules directed to the interviewer.

**a) Treat persons with disabilities as you would treat anyone else**

Persons with disabilities have the same needs, desires, aspirations and goals as anyone else. They differ in how they can satisfy their needs and desires, or reach their aspiration and goals.

It is a profound mistake to assume that disability changes everything about a person, or that their physical or mental differences would mean they will never understand you, or you understand them. As we know from the ICF, disability is a universal human phenomenon; limitations in functioning have been proven to be part of being human.

Persons with disabilities usually refer to daily activities in the same way others do. Do not hesitate to use the words ‘look’ and ‘see’ with people who are blind or have visually impairment, ‘listen’ and ‘hear’ with people who are deaf or have hearing impairment, or ‘walk’ and ‘run’ with people with mobility impairments.

It is also important to ask persons with disabilities on what communication needs and preference they have and accommodate the needs to the best possible extent.

**b) Be respectful of persons with disabilities**

We have already mentioned the need to be sensitive to language, since in most cultures, the common perceptions of persons with disabilities are distorted by stereotypes and misunderstanding.

At the same time, do not patronise persons with disabilities, or tell them that you admire their courage and strength. Establish trust and treat persons with disabilities as equal.

Never speak to a person with a disability in a tone of voice that suggests you think they are child-like or of limited intelligence. Use a normal tone of voice. If the respondent is accompanied by an attendant or a sign language interpreter, speak directly to the person with the disability. If a sign language interpreter is present, speak at a slower pace so that the interpreter does not miss what you say.

Fatigue may be a problem for people with head injuries or other neurological conditions. When fatigued, they may become angry or frustrated. Suggest a break or at the beginning of the interview, tell the individual to let you know when s/he would like to take a break.

**c) Be aware of, and accommodate communication differences**

Some impairments affect how people speak or communicate. A good interviewer will recognise these difficulties and, without being patronising, seek ways to increase communication.

Some people with communication disabilities have learned to compensate for them: persons who are deaf may be able to lip-read and converse orally.

A person with a speech impairment may have distinct speech patterns and what may appear at first to be uncontrolled can be understood after a few moments of listening. Be patient, but ask the person to repeat what s/he is saying if you do not understand. People who have unclear speech are used to people asking them to repeat things, so be honest about clarifying a response.
d) **Accommodate respondents with hearing impairment**

When interviewing a deaf person it is important to have his or her attention first before speaking. A deaf person may need a tap on the shoulder, a wave of the hand, or some other visual sign to get their attention.

Speak clearly, not loudly, to a person who is hearing impaired; face them and make sure your face is well lit and not obscured by your hand or facial hair.

The person will ask you to speak louder or slower if required. Do not exaggerate or overemphasize words. This distorts lip movements making lipreading difficult.

Since some lip movements are difficult to lip-read, try to rephrase the question if the person who is lip-reading does not understand it after a couple of repetitions. It is also helpful to rephrase the question if the individual with a hearing impairment has difficulty in understanding you. Body language and facial expression are important factors in successful communication.

It is a mistake to think that people who are deaf are also non-verbal. People who are deaf have normal vocal organs but may choose not to speak. Also, not all persons who have hearing impairments can lip-read.

e) **Accommodate respondents with visual impairment**

Announce your arrival and exit to a person who is blind or has a visual impairment. Identify yourself and let the person know that you are addressing them by using their name or touching their arm.

Never distract a guide dog. The dog is working and is responsible for the safety of the person who is blind.

Do not assume that all people who are blind can read Braille. If Braille materials are used, it is best to ask beforehand if the person can read them.

f) **Accommodate the individual with intellectual disabilities**

Persons with intellectual disabilities may need more time to understand the question. Do not rush. Make sure the person clearly understands what is being asked.

Persons with intellectual disabilities should not be treated like children; they should be treated like any other person of the same age.

Sometimes persons with intellectual disabilities may be anxious to please and say what they think you want to hear. Bear this in mind when conducting the interview.

3.2.6 **Checking for completed questionnaires**

After completing the interview, the interviewer should always check if all the questions are asked and if the answers are consistent. It is important to check the questionnaires before leaving the household so errors can be immediately rectified. It is clearly more difficult to correct an error after the interviewer has left the household as that involves another explanation to the respondent, as well as disruption to the interviewer’s schedule and additional cost.

3.2.7 **Responsibilities of the field supervisor**

In any data gathering activity, supervisors play a major role in attaining high quality statistics. It is the duty and responsibility of the supervisor to:
1. Accompany interviewers, especially those new in the area of interview, in the first few days of data collection to assist them in following the proper procedures. The supervisor should observe how they conduct the interview and provide suggestions for improvement. It is important, however, for the supervisor not to intervene and correct the interviewer while the interview is being conducted, unless the error would have a major effect on the response of the respondents. In this case, the supervisor should ensure that the process of correcting the interviewer does not irritate the respondent nor reduce the credibility or morale of the interviewer.

2. Conduct spot-checking. This is the process of checking if the interviewers are actually in the area visiting the households and conducting the interview. Despite the fact that interviewers have gone through rigid screening and training procedures, it is always possible that some may be tempted not to visit all the households they are assigned to.

3. Re-interview a sub-sample of households. Supervisors should always re-interview some households to determine if the interviewers asked the correct questions to the respondents. The supervisors do not have to ask all the questions in the questionnaire, and the data collection developer may design a specific form intended for this activity. The contents normally consist of important data items in the questionnaire, such as age, sex, and a few questions on disability.

   It is important, however, that supervisors provide clear explanation to the respondent why a re-interview is needed. It is crucial to emphasize to the respondent that they are being re-interviewed, not because the supervisor doubts the veracity of their answers, but merely to confirm some of the answers they provided. The supervisor should not tell the respondent that they are conducting a re-interview in order to check that the original interviewer was doing their job correctly, as this may call into question the interviewer’s credibility.

4. Review the completed questionnaires. Supervisors should review the work of the interviewers in order to correct errors at the earliest stage possible. Early detection of errors saves incorrect information being processed, and enables the supervisor to correct the interviewer’s mistake so it is not repeated in future interviews.

5. Attend to other problems during data collection such as refusals, lack of forms, supplies, and materials, lost questionnaires, and replacement of staff.

6. Hold regular meetings with interviewers. Such meetings are vital as they provide a venue where problems and solutions can be discussed. They also provide an opportunity for the supervisor to discuss their observations made whilst conducting the spot-checks, re-interviews, and reviews of completed questionnaires.

3.2.8 Interviewing Institutions

Interviewing people residing in institutions presents additional challenges that need to be planned for in advance. Institution staff members (administrators or other contacts, such as head nurses and ward clerks) are busy professionals. Scheduling appointments for proxy interviews at a mutually convenient time will require flexibility. Interviewers must be prepared for the possibility that appointments may change at short notice. When interviewing in institutions, the interviewer must be prepared to adapt the interviewing techniques to meet the requirements of a different situation. If the interviewer senses that the respondent is becoming upset, or is incapable of completing the interview, it is best to terminate the interview and discuss with the administrator or other contact person how best to continue.
4 Presentation, Analysis, Dissemination and Utilization of Results

4.1 Planning the outputs

Many developing countries do not put enough money into data compilation, analysis and dissemination. If the data collected is not analysed and disseminated, the resources used in planning, development and data collection are wasted. This is a problem of overall data collection planning, the key to which is effectively allocating resources to the design, collection, processing, analysis and dissemination phases.

Tabulation and analysis of data must be carefully planned during the early stages, not decided upon after the data has already been collected. The scope of analysis depends on the statistical variables (or data items) that the analyst can correlate. The output data items must be chosen at the planning stage of a collection. A well-planned data collection activity securely links the input of questions asked and data items derived with the output of statistical tables and usable information.

As always, decisions about which outputs are appropriate, how the individual data outputs are to be correlated, and how this material should be presented, all centre on the needs of the ultimate user of the data.

**Output items to meet user needs**

What information is usable depends on the questions the data users want answered. In general, for disability policy, the questions range from basic prevalence to particular questions about the impact of disability in specific areas of life. Here are some examples, depending on the variables included in the data collection instrument:

- How many people are there with disabilities in the population?
- How does the prevalence of disability vary by age, sex and rural or urban residency?
- What is the prevalence of severe disability in the population? How does it vary by age, sex and area of residence?
- What proportion of households has a member with a disability?
- How do persons with disabilities compare with others in terms of major socio-economic indicators?
- To what extent are persons with disabilities receiving effective assistance services?
- To what extent do persons with disabilities experience participation restrictions, e.g. unemployment, exclusion from school, unable to use public transport?

The kinds of data items that these and other policy questions require range from the most basic identification of populations of persons with disabilities, and their prevalence, distribution and characteristics, to highly detailed data sets which are possible mostly in a survey and not in a census. Some of the data items include:

- Prevalence of specific activity limitations in seeing, hearing, walking about, moving from one room to another, speaking, communicating, learning, and so on;
- Underlying cause of the impairments – congenital, disease or infection, injury or trauma;
- Severity of the disability;
- Age of onset of disability;
- Need for and use of medical and rehabilitative services, and personal assistance;
- Need for and use of assistive devices;
- Quality of life (or socio-economic profile) of persons with disabilities, compared with persons without disabilities; and
- Barriers to full and equal participation in society in areas such as education, work, housing, transportation and the political sphere.
4.2 Presentation

Output tabulations
Once the questions and kinds of information are settled on, it is possible to begin the task of identifying relevant cross-tabulations. Cross-tabulations can be specified in terms of a population, one or several output data items and, where appropriate, the counting unit to be used. For example, for the total population, one can identify the basic or minimum cross-tabulations based on age, sex and disability status.

A set of disability statistical tables for census was suggested in the United Nations’ Principles and Recommendations for Population and Housing Censuses (Revision I). These are the following with age, sex, and urban/rural residence as the main variables:

1. Total population, by type of disability, geographical division, urban/rural residence, whether living in household or institution, age and sex.
2. Households with one or more persons with disability, by type, size of household and urban/rural area.
3. Total population 15 years of age and over, by type of disability, marital status, urban/rural area, age and sex.
4. Population with disability, by cause and type of disability, urban/rural area, age and sex.
5. Population 5 to 29 years of age, by school attendance, type of disability, urban/rural area, age and sex.
6. Population 5 years of age and over, by educational attainment, type of disability, urban/rural area, age and sex.
7. Population 15 years of age and over, by activity status, type of disability, urban/rural area, age and sex.

For data on persons with disabilities, cross-tabulations can be based on:
- Age, sex, cause and type of disability,
- Age, sex, and severity of disability,
- Unmet need for health services in the last 12 months, severity of disability, and so on.

In 2010 the UN has re-revised the United Nations’ Principles and Recommendations for Population and Housing Censuses (Revision I); an example of revised recommended tabulation or disability statistical tables on disability characteristics specifically on information relating to Population with and without disabilities by age and sex is attached to this document as an annex.

Similar data items can be applied to more narrowly defined populations, for example populations of people with specific impairments. However, too detailed cross tabulations should be limited for surveys, especially if the sample size is small that the sampling design is not appropriate for generating statistics at a lower geographical division. It is always advisable to examine each cell in the table. There may be a need to collapse some of the categories so that those cells with zeroes or small frequencies can be avoided.

For surveys, it is always advisable to include a table on sampling error which is usually measured in terms of standard error and the confidence intervals. By providing this information, the users will be informed on the range in which the true value for the population could fall.

The counting unit is the unit used to quantify the cross tabulation data – most commonly in terms of appropriate population numbers (ones, hundreds, thousands, millions), or percentages and rates. For surveys, since the generated statistics are just estimates based on samples, percentages or rates are preferred. If the numbers are to be included they should be rounded off to hundreds or thousands.
The important thing to remember when designing cross-tabulations of data is that it is not an exercise in arithmetic. If a statistical collection uses six variables, then the challenge is not to present a series of tables in which all possible combinations of these six variables is displayed as two-by-three tables. Rather, the challenge is to produce tabulations that have a purpose and enable the end user to address issues of interest.

Each tabulation should be there for a reason: to provide data relevant to a purpose or issue. To ensure this, it is recommended to state, under each tabulation, the purpose and underlying issue that it has been designed to address.

**Graphical representation of disability data**

The final step is the presentation of the outputs for the ultimate data user. Graphical methods of presentation can provide the user with a clear picture of the significance of the data, highlighting aspects of the data that might otherwise be invisible.

There is often more than one way to present disability data. It is useful to think carefully about the aspect of the data that is important.

**Map representation of disability data**

When comparing statistics by geographical subdivisions, e.g., regional, provincial, towns, and others, one very effective way of presenting the results is through the use of statistical maps. The map shows different colors that reflect different values. The colours are used for easy identification of areas with the highest and lowest values.

4.3 Analysis – turning data into information

Statistical agencies are now taking a greater role in analyzing the data their instruments collect. Rather than solely producing tabulations and handing over raw data to other agencies for analysis, statistical agencies are now more in the business of “adding value” to their data by engaging in preliminary analyses. This can be as simple as converting the number of persons with disabilities into a percentage of the overall population, or as complex as employing sophisticated mathematical modeling techniques to interpret the data.

**High quality data**

The value and usefulness of output information depends on the quality of the input data. Previous chapters in this manual have outlined the phases in the data collection process – from consultation with clients, to sampling design, testing, and derivation of tabulations – that are designed to yield good data.

Disability statistics, perhaps more than any other area of social statistics, is vulnerable to distortions of data. Worldwide prevalence rates vary remarkably. Although in part this reflects real differences in chronic and infectious disease patterns, differential life expectancy, age structures, nutritional status, exposure rates to environmental hazards, war and other public health problems, most of the differences can be traced to the quality of the data.

Differences in the operationalization of disability, screening procedures, collection methods, and different methods of calculating disability rates, produce different prevalence estimates. Even within countries, different studies have produced widely different estimates of disability prevalence because they have used different definitions, instruments and procedures to collect the data. For instance, as earlier discussed, estimates of the percentage of persons with disabilities are lower when impairment questions rather than disability questions are used to identify persons with disabilities. This explains in part why the reported disability prevalence rates of Africa and Asia are lower than those of Europe and North America. In addition, when impairment questions are used for screening purposes,
the resulting disability rates for men are higher than those of women. In contrast, when activity and participation screening questions are used, rates are similar for women and men, and in some cases disability rates for women are higher.

It is widely believed, both among statisticians and persons with disabilities organizations, that the prevalence rates derived from impairment-based data collections largely under report actual disability incidence, thus compromising the quality and usefulness of the statistics.

**Pitfalls in analysing disability data**

Even with the highest quality disability data, the analyst must be aware of potential pitfalls in the analysis of this data. Many of the traps described below are standard and apply to the analysis of statistical data about any subject matter. Some of the traps, however, are particular to disability data analysis.

**Wrong population** - A common analytical mistake is to define the wrong population for the issue under analysis. More generally, a common source of error in analysis comes from ignoring the effect of sampling variability.

**Drawing unsupportable conclusions** - The task of a data analyst is to take valid, reliable, and high quality data then, draw conclusions about what the data mean and what they tell us about the disability. The process of drawing conclusions can go awry in many different ways, but these errors all share the same underlying problem: the data does not truly support the conclusion. The most common example is drawing conclusions that are plausible (because they appeal to unquestioned beliefs we hold) but which, when scrutinised, really do not have much data to support them.

There are other cases which are less obvious and so potentially more dangerous.

**Ignoring the impact of other variables** - A standard problem in an analysis is assuming that one or more variables are responsible for an observed phenomenon, when in fact it is yet another, independent variable that accounts for all the data.

Due to the nature of disability, age is almost always a relevant variable in analysis. In some social contexts, gender also matters. For example, men tend to work in jobs that have a high accident rate. Relevant cross tabulations are perhaps the best way to discover whether there are independent variables affecting disability prevalence rates.

**Endogenous factors** - A similar error can occur if the independent variable is a general social phenomenon that could easily go unnoticed, and would not normally be included in the analysis. These are sometimes called endogenous factors.

For example, between 1986 and 1991 the number of Canadians reporting some degree of disability increased from 13.2 per cent to 15.5 percent. While the increase could be partially attributed to an ageing population and a change in the survey methodology, analysts suspected that these factors alone did not account for the increase. It was suggested that the increase in awareness of disability in Canadian society between the two survey dates made people more willing to respond affirmatively to questions about limitations in their activities and barriers they encounter in their everyday lives.

Other potential endogenous factors might include promises of increases in welfare assistance and other programmes to those who identify themselves as having a disability, or outright payments to people who participate in the collection activity if they report their disability.

**Masking** - If an analysis is conducted on highly aggregated data, trends of magnitude or direction may be masked unless the data is disaggregated by region, population group, or some other parameter.
For example, the total disability rate in a country may not show any significant change over time, even though the rate may well have increased dramatically in a particular region because of a rapidly ageing population, natural disaster, or other factors. It is therefore a potential source of error not to consider conducting analyses on disaggregated data to confirm the validity of trends at the aggregated level.

**Causal confusions** - Analytical conclusions that claim that the data supports a causal link between variables are subject to many pitfalls. The most obvious error is to claim that there is a causal relationship between variables on the basis of data that merely shows a correlation (that may well be coincidental).

Causal errors are common in the analysis of disability data. For example, looking at the data for unemployment among people with intellectual disabilities, one might be strongly tempted to say that intellectual impairment might causally responsible for the low employment rates. Yet, although these variables are undoubtedly correlated, this may not be a cause at all. Recalling the mistake of ignoring independent variables described above, it may well be that the causes of unemployment are employers’ attitudes and behaviours, based on stereotypes and misunderstanding of the true work capacity of people with intellectual disabilities.

**Inconsistent definitions** - on several occasions it is noticed that disability statistics present special problems because the notion of ‘disability’ has been variously defined in surveys and censuses. The primary virtue of the ICF approach to disability statistics is that it makes absolutely clear that ‘disability’ is a complex term with three distinct dimensions, each of which can be precisely classified and measured. ICF makes it clear that the variability of definitions in statistical data collection has primarily been the result of data collection designers not clearly identifying which dimension, or which dimensions of disability, their collection is all about.

The problem for the analyst, of course, is that for data that is not grounded in the ICF model, it is very difficult to determine what the answers to disability questions actually mean. Data with different definitions will not be comparable, and conclusions drawn will be unsupported.

### 4.4 Forms of output and dissemination strategies

Data must be disseminated in a form that is both relevant and accessible to users. This requires an understanding of who the users are, and their needs, as well as a strategy for promoting the availability of data to maximise the use of the information.

There are various audiences for disability data: the general public; the media; persons with disabilities and their advocacy and support organizations; policy makers, in both public and private sectors; universities and research institutions; and other statistical organizations, local and international. Each audience has different information needs, and the form of dissemination should take these into account.

**Presentation of data collection details with the results**

Generally, statistical tabulations and analyses should be accompanied by sufficient technical detail to satisfy the needs of the data users. The general public will likely require less technical detail than researchers or other statistical agencies. But, in any case, survey results should always be accompanied by a description of the survey limitations — such as sampling errors, response rates, and others. This is especially important for disability data given the history of wide differences in definitions of disability, screening procedures, and collection methods.

**Accessibility of data to persons with disabilities**

An important consideration in the dissemination of statistical reports is their accessibility to persons with disabilities.
disabilities. The relevant modes of presentation include large-type, Braille, audio formats, electronic tables on disk with computer programmes and interfaces for people with intellectual disabilities. It is best to consult with disabled people’s organizations to enhance further strategies for ensuring its accessibility.

**Dissemination strategies**

In addition to hard copy publications, increasingly, there is a demand for electronic publication of statistical information, in CD-ROM format or via the Internet. Many statistical agencies have websites where they post reports and statistical information and this is becoming an important medium for disseminating statistical tabulations and analyses.

A dissemination strategy should be worked out during the initial planning phase (and certainly before data is available). The strategy should respond to the information needs of the users.

**Confidentiality**

Confidentiality of respondent data is an issue of great importance. Care must be taken to ensure that published data cannot be linked to particular individuals, either directly or by inference. The risk of releasing identifiable data is greatest when the data is very detailed or disaggregated, but even in these cases, procedures exist for guaranteeing anonymity. Furthermore, survey, census and registry respondents should always be made aware of confidentiality assurance policies as part of questionnaire introductions so that fear of disclosure of personal information does not affect results.

**Standard forms of output**

**Publications:** Paper or electronic publication is the conventional media of data dissemination. These may take the form of statistical compendia containing large numbers of statistical tabulations or reports containing descriptive commentary and graphics.

Reports are effective means of communicating statistical information in an accessible form to people who do not have the skills to extract the key trends and patterns from statistical tables. They can either give a general descriptive overview of the results or present focused results on specific areas of interest and concern.

Reports, however, require more resources to produce than statistical compendia, which can interfere with the timeliness of data dissemination. It is therefore advisable to choose cheaper and faster media – such as the Internet – to first release the data, with more detailed, and accessible, reports following later.

**Customised data service:** Many statistical agencies provide a service for clients that enables them to request their own datasets or tables derived from the survey data. This service can be extremely useful to technically-adept data users since all combinations of useful data could not possibly be provided in a single publication. Highly specialised combinations of data may be of interest to only a few users, but of great importance to them. A customised service makes it possible for all users to request tables of data that meet their specific needs. Usually, statistical agencies charge for this service.

**Microdata files:** More and more data users are demanding access to unit record or raw data so they can carry out their own manipulations and analyses of data. Published tabulations of data may not allow some users to undertake sophisticated analyses using multivariate and other statistical modelling techniques. Where raw data is released care should be taken to ensure that the files do not have personal identifiers that might undermine confidentiality.

**Ensuring secure data or accomplished questionnaires storage**

Once collected the data or completed questionnaires need to be managed and stored, at this stage, security and privacy issues become crucial since data either from survey, census or administrative-based
data collections contain personal information such as age, sex or address which could be used to identify an individual.

For paper-based data holdings, identifiable information should be kept securely locked away when not in use, and access should be limited to a small number of people directly involved in the data collection. Whenever possible, the questionnaires should be disposed of immediately after being encoded into the computer. Some countries, however, are required to wait a certain number of years before they dispose the accomplished questionnaires.

For data collected electronically, or where the data capture process includes the name, address and some detailed identification of individuals, a measure of security should be guaranteed by providing individual user accounts with password protection, and automatic screen shutdown or automatic log-off.

**Documentation**

Documentation is the process of recording all the events that transpired during the data collection process. It enumerates and describes the different procedures employed and reports all problems encountered and solutions adopted.

This documentation informs the public of how the operation was conducted, allowing them to analyse and interpret the results fully. Additionally, the information contained in the documentation report can serve as guide in planning for the next survey/census/administrative-based operation of the same type. Furthermore, it allows for international comparison for it provides the basis for an exchange of information on content and procedures.

The following should be included when preparing a documentation report:

a. Description of the methods used  
b. Production schedules and size of staff  
c. Budget estimates  
d. Calendar of activities  
e. Forms and manuals used  
f. Organization of statistical agency  
g. Definition of geographic areas  
h. List and description of equipment and facilities used  
i. Quality control instituted  
j. Memoranda and other additional instructions not included in the manuals  
k. Other relevant information

Documentation is one of the important aspects in any data collection but much of the time it is neglected. In many cases, statistical agencies find that the persons who are supposed to document the data collection process become tied up with new data collection operations. Documentation should not be passed on to whoever is available, but should be completed by those who were actually involved in the data collection.
Appendices: Sample Instruments

**UN Guidelines for the Development of Disability Statistics**

The United Nations’ 2001 Guidelines and Principles for the Development of Disability Statistics, suggested the following ‘generic’ disability question for censuses:

Because of a long-term physical or mental condition that has lasted or is expected to last six months or more, how much difficulty do you have? (Check all that apply)

- Seeing (even with glasses, if worn)
- Hearing (even with hearing aid, if used)
- Speaking (talking)
- Moving/mobility (walking, climbing stairs, standing)
- Body movements (reaching, crouching, kneeling)
- Body movements (reaching, crouching, kneeling)
- Gripping (using fingers to grip or handle objects)
- Learning (intellectual difficulties, retardation)
- Behaviour (psychological, emotional problems)
- Personal care (bathing, dressing, feeding)
- Others. Please specify

**The Washington Group on Disability Statistics (WG)**

List of questions the Washington Group on Disability Statistics (WG)/United Nations Statistical Commission recommended for censuses are put as follows:

*Introductory phrase:*

The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

*Question set:*

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?

*Response categories:*

a. No – no difficulty
b. Yes – some difficulty
c. Yes – a lot of difficulty
d. Cannot do at all
WHO/ESCAP’s pilot tested disability questions

<table>
<thead>
<tr>
<th>Geographical division, sex and age (in years)</th>
<th>Total</th>
<th>With disabilities</th>
<th>Without disabilities</th>
<th>Not stated</th>
</tr>
</thead>
</table>

The WHO/ESCAP Project on Improvement for Disability Statistics and Measurement conducted pilot test of question sets including WHO’s in five countries, namely Fiji, India, Indonesia, Mongolia and the Philippines.

The question sets from WHO for pilot test consisted of following modules:

- An impairment module derived from 17 ICF domains used in the WHO World Health Survey, for example
  - Seeing
  - Hearing
  - Pain
  - Worry or anxiety
  - Feeling sad or depressed

- An activity and participation module based on the following six domains of the World Health Organization Disability Assessment Schedule II (WHO DAS II):
  - Understanding and communication
  - Getting around
  - Self care
  - Getting along with people
  - Life Activities
  - Participation in Society

- An environmental factors module which comprises the three “need for assistance” questions used by the Australian Bureau of Statistics in the 2006 census:
  - Need for assistance in self care activities
  - Need for assistance in body movement activities
  - Need for assistance in communication activities
**UN Recommended Tabulation Tabulations on Disability Characteristics:**
*Population with and without disabilities by age and sex, is shown in the following page.*

<table>
<thead>
<tr>
<th>Total country Both sexes</th>
<th>Population included: total population</th>
</tr>
</thead>
<tbody>
<tr>
<td>All ages</td>
<td>Classification:</td>
</tr>
<tr>
<td>Under 1 year</td>
<td>a) Geographical divisions: (i) total country; (ii) each major civil division; (iii) each principal locality. Distinguish between urban and rural for (i), (ii) and (iii)</td>
</tr>
<tr>
<td>1-4</td>
<td>b) Disability status: total; without disabilities; with disabilities; not stated</td>
</tr>
<tr>
<td>5-9</td>
<td>c) Age: all ages; under 1 year; 1-4 years; 5-9 years; 10-14 years; 15-19 years; 20-24 years; 25-29 years; 30-34 years; 35-39 years; 40-44 years; 45-49 years; 50-54 years; 55-59 years; 60-64 years; 65-69 years; 70-74 years; 75-79 years; 80-84 years; 90-94 years; 95-99 years; 100 years and over; not stated</td>
</tr>
<tr>
<td>10-14</td>
<td>d) Sex: both sexes; male; female</td>
</tr>
<tr>
<td>15-19</td>
<td>Metadata for this tabulation:</td>
</tr>
<tr>
<td>20-24</td>
<td>(a) Source of statistics:</td>
</tr>
<tr>
<td>25-29</td>
<td>✓ Traditional population census</td>
</tr>
<tr>
<td>30-34</td>
<td>✓ Register-based population census</td>
</tr>
<tr>
<td>35-39</td>
<td>✓ Registers/Surveys systems</td>
</tr>
<tr>
<td>40-44</td>
<td>✓ Rolling surveys</td>
</tr>
<tr>
<td>45-49</td>
<td>✓ Civil registration</td>
</tr>
<tr>
<td>50-54</td>
<td>(b) De jure or de facto population or a combination with detailed description</td>
</tr>
<tr>
<td>55-59</td>
<td>(c) Definition of urban and rural areas</td>
</tr>
<tr>
<td>60-64</td>
<td>(d) Exact question wording</td>
</tr>
<tr>
<td>65-69</td>
<td>Core topics:</td>
</tr>
<tr>
<td>70-74</td>
<td>✓ Place of usual residence or Place where present at time of census</td>
</tr>
<tr>
<td>75-79</td>
<td>✓ Sex</td>
</tr>
<tr>
<td>80-84</td>
<td>✓ Age</td>
</tr>
<tr>
<td>85-89</td>
<td>✓ Disability status</td>
</tr>
<tr>
<td>90-94</td>
<td>Note: There is widespread interest in the prevalence of disability by age and sex in the population. This tabulation provides information for the calculation of prevalence rates distributed by geographical division, urban/rural residence and the living arrangements of persons with disabilities.</td>
</tr>
<tr>
<td>95-99</td>
<td></td>
</tr>
<tr>
<td>100 years and over</td>
<td></td>
</tr>
<tr>
<td>Not stated</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td></td>
</tr>
<tr>
<td>(age groups as above)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td></td>
</tr>
<tr>
<td>(age groups as above)</td>
<td></td>
</tr>
</tbody>
</table>