Learning Objectives: Chapter 4

Using ICF in Survey and Census Design

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

1. Describe issues in operationalizing disability for data collection needs.
2. Distinguish and describe approaches to disability measurement.
3. Describe issues in question development for disability data collection.

“Buddha and boatman” Serge Corrieras
WHO Photo Contest “Images of Health and Disability 2002/2003”
4. USING ICF IN SURVEY AND CENSUS DESIGN

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4.1 Operationalization of ICF in disability data collections

ICF makes it clear that disability is a multi-dimensional concept and cautions us to be clear about which dimension of disability we want information about. At the same time, the term comes with many different connotations and associated meanings with wide variations across time, culture, and age groups.

Some people firmly believe that to be disabled is to be completely unproductive and useless in society, so will insist that they do not have a disability, even though they do have a functional restriction obvious to any observer. Some believe that disabilities are only physical, and refuse to believe that depression, or another mental disorder constitutes disability. Others insist that you cannot be disabled if your functional limitation is something many or even most people have, such as poor eyesight.

In everyday language, disability means many different things to different people. Data collection developers face an enormous challenge: devise questions that avoid as many irrelevant beliefs or outright misconceptions about disability as possible. Even among experts, different ways of operationalizing disability, when incorporated in a data collection instrument, can yield very different prevalence results.

A dated but useful example involves the three distinct operational measures of disability collected in the 1992/93 New Zealand Household Health Survey. The survey included data on self-reported disability, diagnosed disability and a measure of functional disability. The proportions of persons with disabilities varied widely across these three measures, ranging from 15 percent with a self-identified disability to 29 percent with a diagnosed disability. Given the disparity, these disability measures are no longer used in New Zealand. Recent surveys are designed to collect only measures of functional disability consistent with the ICF.

Users' needs must be clearly defined in order to determine how the population of persons with disabilities is to be measured. For example, if the users require small area data in order to have information for service planning at a local level, then the question is whether the population can be captured using one simple but broad question or whether several more specific questions would be better. Box 4.1 describes such a situation.
Box 4.1: Australian Experience with Disability Census Questions

During the development phases of its 1996 and 2001 population censuses, the Australian Bureau of Statistics (ABS) tried using a single question to identify a broad disability population. Testing showed that the disability population identified using this single census question was significantly different from that identified by a more detailed set of questions used in a national disability survey. In particular, the ABS noticed that a large number of people who reported disabilities in the survey questions did not report in the census, and people reporting disabilities in the census question did not always do so in the survey. Even though the proportions of persons with disabilities linked to the two question sets were very similar, the actual populations identified were different. In light of this, the ABS decided not to include a disability question in either the 1996 or 2001 census.

In preparations for the 2006 census, the ABS looked at questions that focus on a different population. The new census questions attempt to identify people who need assistance with mobility, self-care or communication because of a disability or long-term health condition. Results were very promising and the disability-related module was included in the 2006 census.

ICF tells us that the first thing the data collection developer must do is to be absolutely clear which dimension of disability they are interested in. Is it impairment, activity limitation, participation restriction or environmental and social barriers? 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.

In this chapter, we focus on some basic issues of operationalization – the transition from ICF concepts and categories to the wording of questions usable for a variety of data collection vehicles. In the next chapter we look in more detail at these data collection instruments for collecting disability data, and later in Chapter 6 consider problems in developing and testing these instruments.

4.2 Key Issues

As it is true of statistics in any subject-matter area, there are a number of methodological issues involved in the production of disability statistics. Here we look at those issues related directly to the operationalization of ICF’s concept of disability.
4.2.1 Reduction of ICF items

Anyone opening the ICF ‘Red Book’ will be struck with one obvious problem: as a comprehensive classification of all dimensions of disability and environmental factors – with over 1400 separate categories – there are far too many domains to possibly be covered in a set of questions measuring aspects of disability. Even at the highest level of categories, the ICF gives nine domains of the activity and participation component. This number of domains is too many for data collection in most surveys, let alone in censuses.

Even if a single domain is selected, for example, “self-care”, the ICF divides it into “caring for oneself”, “washing and drying oneself”, “caring for one’s body and body parts”, “dressing”, “eating and drinking”, and “looking after one’s health”. It is difficult to imagine how a single survey question could capture the complete range of activities covered by all of the activity and participation domains.

There is no easy way to reduce the hundreds of body functions and structure codes to a small number of impairment questions; nor can the nine domains of activity and participation be easily reduced to a single ‘disability question’. Of course, users’ need is the key. But even so, considerable thought, and often testing, needs to go into the selection process.

Examples of how Australia and Canada have made the selection of ICF Activity and Participation domains are given in Box 4.2.

Box 4.2: ICF Items in Australian and Canadian Measures of Disability

In Australia, key disability data users wanted to define the disability population as broadly as possible. They were also interested in a specific population: people with a disability who need help or assistance in the areas of mobility, self-care and communication. These needs drove the decision to develop survey questions to identify these populations. In the early testing for the 1981 disability survey, a comprehensive set of screening questions was developed to cover all nine of the chapters of the ICF Activities and Participation classification. Analysis of test results showed that some of the screening questions were simply redundant, as people who had a disability in one area almost always had a disability in another area. Some screens were therefore dropped.

Statistics Canada had a similar experience when developing the census screening items for their 2001 Participation and Activity Limitation Survey. They found out that there was very little additional benefit in including the term “toileting” in their list of activities, as almost everyone identified through this screening item also had difficulties with mobility. Therefore, toileting was dropped from the screening question.
Although a country may want to identify disability as broadly as possible, such as activity limitations in any of the Activity and Participation domains of the ICF, it may be impossible to develop a small question set that would adequately identify everyone in the relevant 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 necessarily persons with disabilities themselves and persons with disabilities “Self-help Organizations”, 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 use of the data.

4.2.2 Scope and Coverage

An important step in the development of a statistical collection is to define the scope of the inquiry. Who is to be included in this data collection: children, adults, or older people? All of these people or only some of them? Should the data collection identify people living in private households, collective dwellings or institutions? Should the data collection cover all geographical areas, urban and rural, or some restricted part of a large urban centre?

Care must also be given to the coverage of the survey, census, or administrative-based data collection. Serious consideration should be given to the following questions: Which dimensions of the concept of disability should be included – impairments, activity limitations, participation restrictions, social and environmental barriers or some combination? Should the data collection focus on selected disabilities (those associated with a specific disease or public health problem) or with all types of disabilities? Finally, should the data collection cover specific levels of severity of disability (severe, or moderate to severe) or all levels, including mild disability?

The ICF is flexible and places no limitation on scope or coverage. Instead, the ICF provides a complete descriptive framework for all aspects of human functioning, a framework that systematically organizes these data. Nonetheless, decisions about scope and coverage are essential, unavoidable, and have a profound effect on the usefulness of resulting data. These decisions should be driven by the purposes of data collection, and therefore the needs of the ultimate data user.

For example, if the objective is to produce national estimates of disability for different age groups in the population, people living in both private households and institutions should be included. If people living in institutions, particularly health institutions and institutions for the elderly, are excluded from the scope of the collection, the results are likely to be biased in favour of the younger population. Specifically, the data collected would tend to underestimate the true level of disability amongst older people and people with certain types of disability associated with higher levels of institutionalization, such as intellectual disabilities (see Box 4.3 for the New Zealand experience).
Box 4.3: Inclusion of People Living in Institutions in Disability Surveys in New Zealand

The total disability rate for the New Zealand population aged 75 years and over, is 66 percent. The rate is only 62 percent for people living in private dwellings. If the purpose of a survey in New Zealand was to get information about the frequency of severe disabilities, then people living in institutions should be included since they are generally more likely to have severe disabilities. Excluding the institutionalised population from the scope of the collection would result in an underestimation of the occurrence of severe disability.

People living in prisons or other custodial institutions are notably absent from most disability surveys. In many national disability surveys, this has led to underestimates of the prevalence of developmental disabilities, and intellectual and psychological disabilities. However, if the coverage of the survey is restricted to physical disabilities then, in part because these individuals make up a relatively small proportion of the total population, excluding them may not have a significant effect on the survey results.

The level of severity of disabilities covered will affect assessments of progress made on the social goals of inclusiveness and full participation in economic activities. Very broad disability coverage is likely to show greater levels of employment of persons with disabilities as compared with disability populations made up of people with severe impairments. Any comparisons within countries over time, or across regions or countries, need to first identify the disability severity of the populations taken into account.

The consistency of disability populations over time is also important when evaluating progress towards the achievement of social goals of inclusiveness and full participation. If the population coverage changes every data collection, then comparison is difficult or impossible. In Australia, for example, the measurement of changes in the disability population and their characteristics was identified as the highest priority need by the user community when developing the 2003 Australian disability survey. To meet this need, the Australian Bureau of Statistics made as few changes to the previous survey instrument and procedures as possible, to ensure as close a replication of the previous survey as possible.

4.2.3 Duration of disability

As far as the ICF is concerned, the duration or chronicity of a disability is merely a matter of severity. When developing surveys or censuses, however, duration may pose a significant problem.

Should a person who is completely unable to perform some activity, or go to school or work, because of a temporary condition or health problem (such as a broken leg) be counted as having a disability? Should a person who has the
flu or some other debilitating, but short term, illness, be counted as disabled? Or, is a ‘person with a disability’ someone who has a chronic health condition and lives, and will always live, with the functional consequences of it?

There is no standard solution to the duration issue used internationally. In most of the collections in the Asia-Pacific region, the issue is ignored and no time period is cited for an activity limitation to count as a disability. Some national collections use the phrase “long-term” health condition, or “a condition which has lasted or is likely to last for 6 months or more”. For example, the 2001 UK Census asked:

**Do you have any long-term illness, health problem or disability which limits your daily activities or the work you can do?**
- Include problems which are due to old age
  - Yes
  - No

No guidance is given to respondents on what ‘long-term’ means, and presumably different respondents interpret the phrase differently – 6 months, a year, 2 years or longer. This ambiguity obviously affects the reliability of the data.

Other national data collections are very clear about duration – 6 months in many cases (see the Canadian Health and Activity Limitation Survey, the New Zealand Household Disability Survey, and the Australian Survey of Disability, Ageing and Carers). Others have asked questions in the context of difficulties experienced on an average day e.g., the Canadian General Social Survey disability module.

Two further complications make the issue of duration a concern:

First, duration may apply either to the underlying health condition, or to the length of time that the person has been restricted in their activities. It is possible for a person to have a long-term illness that does not restrict their activities. This is particularly true of many progressive illnesses, such as Parkinson's Disease, which often do not limit people in the early stages of the illness.

The second complication involves episodic and degenerative conditions. For example, some forms of schizophrenia are episodic, and the person’s life is unaffected when he or she is in the ‘up’ cycle of the disease. Is that person disabled all the time, or only when they actually experience the effects of the illness?

In the case of progressively degenerative diseases, the concern is somewhat different. For example, in the case of HIV/AIDS the underlying health condition is long-term, but at any particular point in time, the disease may have more or less effect on functioning. As the disease progresses, the activity limitations
and participation restrictions are likely to become more frequent and more extensive. Another example is arthritis. While the condition itself is long-term, many people have symptoms that cause limitations in their activities for short or long periods of time.

These and other duration-related issues obviously need to be carefully thought through when designing questions. For some purposes, the duration question may not matter at all. For other purposes, duration may be an essential factor in determining the utility of the resulting data.

4.2.4 Use of assistive devices

Should people who use assistive devices or aids – such as reading glasses, contact lens, or hearing aids – which completely eliminate any restriction to their activities be counted as having a disability? And when assistive devices do not eliminate, but merely reduce activity restrictions, such as in the case of a crutch, cane or wheelchair, how will the severity of the disability be assessed?

Generally, including people who use assistive devices or technical aids within the scope of a statistical collection means that the prevalence of disability will increase, particularly among the older population with a higher proportion of people wearing glasses, hearing aids and other devices.

The answer to the question: “Should assistive device use be part of the operationalization of disability or not?” depends on the purpose of the data gathering tool and the needs of the data user:

If the purpose of collecting the data is to obtain prevalence data on impairments, then obviously it is important to include people who use assistive devices since these devices have absolutely no effect on the presence of an impairment. If wearing glasses puts a person’s visual acuity in the normal range, this does not mean that the underlying impairment or impairments have been corrected.

If a data user wants to get a sense of the potential market for assistive devices – needs assessment for a sub-population, for example – then people who already have and use assistive devices ought not to be part of the scope of the data collection activity.

If the purpose of collecting the data is to determine how many people have difficulties performing activities of everyday living (e.g. bathing, dressing, preparing meals, shopping) then, it is essential that the scope include people who rely on assistive devices and technical aids, since only then will the data reflect the actual level of participation restriction in this area.

Again, there is no international standard practice in statistical collections. In some cases, the questions designed to detect the presence of an impairment or activity limitation do not mention the use of assistive devices or technical
aids. This is particularly true of census questions where there is little scope for detailed qualifications or explanations of definitions and terms.

In some detailed inquiries, people who wear glasses and contact lenses are excluded from the count of persons with disabilities. This is done by asking questions about levels of difficulty where, it is presumed, the person who wears glasses will indicate ‘no difficulty’ and so will not be counted. For example, the Australian and New Zealand surveys ask:

**Do you have any difficulty seeing ordinary newsprint, with glasses or contact lenses if usually worn?**

**Do you have difficulty clearly seeing the face of someone across a room (that is from 4 metres/12 feet), with glasses or contact lenses if usually worn?**

The Canadian Participation and Activity Limitation Survey (2001) adopts a different technique. For each activity domain (such as hearing), the survey first asks whether the respondent uses a common assistive device for that domain (hearing aids), then, depending on what answer is given, the survey asks about level of difficulty with or without the device:

**Do you use a hearing aid or hearing aids?**

(1) Yes
(3) No
(x) Don't know
(r) Refusal

With your hearing aid, how much difficulty do you have hearing what is said in a conversation with ONE other person

(1) No difficulty
(2) Some difficulty
(3) A lot of difficulty
(4) You cannot hear

If hearing aid is not used:
Which of the following best describes your ability to hear?

(1) You cannot hear
(2) You have difficulty hearing
(3) You have no problem

In this manner, data about activity limitations with and without the use of hearing aids is collected.

Whichever technique is used, and whether the intention is to count people whose assistive device eliminates or lessens the severity of the impairment or
not, the decision should be clearly documented in any output from the survey. Users can then understand how the numbers have been arrived at, and can take this survey decision into account when comparing the survey results with those from other collections.

4.3 Approaches to measurement

As mentioned in Chapter 1, analysis of UN DISTAT data shows disability prevalence rates ranging from less than 2 percent in Syria, Bangladesh and Tunisia, to about 20 percent in Australia and New Zealand. This enormous range of prevalence rates is obviously 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. Since this decision occurs after data collection and during analysis, it is transparent and open to debate. This is appropriate since prevalence rates directly affect policy decisions with respect to eligibility for pensions, access to resources, or other benefits.

In this section, we outline three partial measurement approaches in terms of the ICF model of disability. Each approach has its virtues and drawbacks which we shall review. We conclude with what we call the ‘comprehensive approach’ in which the disability question set covers all dimensions of disability; and in terms of a set of activity and participation questions, produces a summary result that can be used to determine disability prevalence. The advantages of this approach will then be reviewed.

4.3.1 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 in, to quote the ICF, “physiological functions of body systems, including psychological functions [and] structural or anatomical parts of the body”.

The impairment approach would be appropriate if the aim of the data collection was to gather health data about the direct consequences of diseases, disorders and injuries. Such data can be used for tracking health service usages and need 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 naive 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. An example of an impairment-oriented question is this from a Philippines census:

**Do you have any long-term impairments?**

**Check all that apply:**

- Missing limbs
- Unequal length of limbs
- Deformity of limbs
- Deformity of spine
- Joint/muscle pain
- Weakness/paralysis of limbs
- Impairment of sensation
- Abnormality in limb tone
- Abnormal movement of limb
- Weakness/paralysis of face
- Impairment of bowel/urinary control
- Impotence
- Hearing disorders
- Speech disorders
- Visual disorders
- Disfigurement
- Chronic respiratory disorders
- Mental impairments
- Others. Please specify

Other forms of impairment questions focus on a small set of severe impairments, such as blindness or deafness, total paralysis, or severe mental illness. This type of question has been used extensively in population censuses across the developing world. Only a very small number of people (usually less than 2% of the population) can be identified using this approach.

Although the data collected from the impairment approach has 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 fulfil simple and complex social roles.

As questions about impairment strike respondents as being about their medical condition, rather than their day-to-day lives, there is a tendency for impairments to be under-reported. 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 will not tell us how the impairment affects people’s lives. We cannot directly infer from the presence of an impairment, even if severe, the extent to which the person’s life is actually affected by the impairment. The same degree of impairment in two individuals living with different demands and different environmental contexts may produce entirely different levels of disability. Not only do decrements in body functioning affect the person’s capacity to perform actions differently, in different environments people’s performance may be radically different.

We can only understand disability itself if we have information about what a person can do, and what they actually do in their day-to-day environment. This, of course, is information about activities and participation.

4.3.2 Activity and Participation Approach

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

The Activity and Participation classification includes Activities of Daily Living (ADLs) such as the personal care activities of bathing, dressing, getting in and out of bed or a chair, using the toilet and eating, as well as Instrumental Activities of Daily Living (IADLs) or activities related to independent living such as preparing meals, managing money, shopping, performing housework, and using the telephone. In addition, the Activity and Participation classification adds the complex activities in interpersonal interactions and relationships, and major life areas such as school, work, family, community, social and civic life.

Integral to the ICF is the view that disability is essentially and centrally a matter of how the interaction between a person’s health and their personal and environmental context affects the person’s life and living. In order to gather information about disability, therefore, it is essential to ask questions about these domains of living. That is the strength of the Activity and Participation Approach to measuring disability.

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 is 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.

Here are two examples of Activity and Participation questions. The first uses an ADL checklist to capture a portrait of a person’s day-to-day disability experience:

**Is this person limited in his/her daily activities (at home, at work, at school) because of a long-term physical or mental condition (lasting six months or more)?**

No

Yes -- Check all that apply:

- Seeing (even with glasses, if worn)
- Hearing (even with hearing aid, if used)
- Communicating (talking, conveying information, listening)
- Moving/mobility (walking, climbing stairs, standing)
- Body movements (reaching, crouching, kneeling)
- Gripping (using fingers to grip or handle objects)
- Learning (intellectual difficulties, retardation)
- Behaviour (psychological, emotional problems)
- Other. Please specify

The second question probes the particular domain of employment:

**Because of the condition that you have told me about, do you have any difficulties with employment such as these?**

No

Yes -- Check all that apply:

- Restricted in type of work can do
- Restricted in the number of hours can work
- Difficult to change jobs or get a better job
- Other. Please specify

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 their day-to-day life.

There is, however, an additional dimension of information that can be only caught by means of the Activity and Participation classification. This data is derived from the ICF constructs of capacity and performance (represented within the Activity and Participation classification by the qualifiers).

For any domain of ADL, IADL or major life area, it is possible to ask whether a person's health condition includes a limitation in the person's inherent capacity to perform the required actions, or whether in the person's actual environment, there is a restriction in the performance of the actions. Information about capacity is information about the person's functioning, and so a matter of his or her state of health, whereas information about the person's actual performance goes beyond the person's intrinsic health state to consider the positive or negative impact of the physical, social and attitudinal environment on what they actually do.

Strictly speaking, an objective measure of a person’s capacity to listen, read, speak, walk, carry objects, and so on, can only be determined in a standardised environment in which the person’s actual, inherent capacity is measured, not the effect of environmental facilitators (such as personal assistance or an assistive device) or barriers (such as stigmatising attitudes).

In addition, because it is a difficult matter to determine one’s capacity to perform the complex activities required in working, going to school, being a parent, or being a citizen, activity limitation questions usually deal with ADL or IADL actions -- simple actions or simple clusters of action involved in sensing, learning, communication, mobility, self-care and domestic life.

Still, with careful phrasing the distinction between capacity and performance can be captured in self-report questions. The aim is to direct the respondent's attention to both areas. The respondent is firstly asked to consider features of their own capacity to perform actions (capacity). They are then asked to consider in their actual environment, whether, in light of their inherent capacity, they have more or less difficulty performing the actions than would be expected.

For the ADL of washing oneself, for example, a capacity question might be:

\[
\text{In your present state of health, how much difficulty do you have washing yourself, without assistance?}
\]
Whereas a question about the same domain, but from the perspective of performance, might be:

**In your own home, how much of a problem do you actually have washing yourself?**

**Box 4.4** shows the different methodologies used by nine countries in Asia and the Pacific. Only Fiji reported that the disability data were collected using the Activity and Participation Approach while Thailand used the Activity Limitation Approach. The rest of the countries used the Impairment Approach.

The strengths of the Activity and Participation Approach for disability statistics are obvious. But 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.

<table>
<thead>
<tr>
<th>Country</th>
<th>Method of Data Collection</th>
<th>Approach Used</th>
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<tbody>
<tr>
<td>Cambodia</td>
<td>Social Economic Surveys and Population Census</td>
<td>Impairment-based questions focusing on “type” and “cause” of disability</td>
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<tr>
<td>Fiji Islands</td>
<td>Census of Population and Household Income and Expenditure Survey</td>
<td>Three-question short set includes one activity and participation question referring to difficulties with communication and “other usual activities”</td>
</tr>
<tr>
<td>Hong Kong, China</td>
<td>Survey on Persons with Disabilities and Chronic Diseases</td>
<td>Impairment-based questions and medical diagnosis; mental disability is not included in reported prevalence rate</td>
</tr>
<tr>
<td>India</td>
<td>Census, National Sample Survey Organization Survey, Voluntary Registry</td>
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</tr>
<tr>
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<tr>
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<tr>
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</tr>
</tbody>
</table>
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 countries in the region.

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 far preferable than the purely Impairment Approach, it too has its limitations. Specifically, the approach does not provide us 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.

### 4.3.3 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).

Here is an example of an Environmental Factors question that collects data about the use of aids and equipment:

**Do you use any of these aids to help you move around?**

- Canes
- Crutches
- Walking frames
- Walking sticks
- Wheelchair (manual or electric)
- Scooter
- Specially modified car or car aids
- Other. Please specify

Here is an example of an Environmental Factors question that asks about personal assistance:

**Do you receive assistance from any of these sources?**

- Nurse
- Home care worker
- Voluntary worker
- Other. Please specify

This is another example asking information on external barriers of a person with disability:

**How much of a problem did you have because of barriers or hindrances in the world around you?**

Environmental Factors questions are less common than other kinds, but more and more national surveys are using them. Although they cannot be used to estimate disability prevalence, we know from the ICF that a person’s environment is an essential factor in the existence and severity of the participation restrictions they confront.

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. 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 of the ICF.

### 4.3.4 Comprehensive Approach

As outlined earlier, it is clear that, on their own, each of the approaches will be 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, including Environmental Factors, are brought together – will provide valid measurement data.

As we have discussed in Chapter 2, the model of disability given in the ICF makes it clear that valid disability prevalence data must arise from information on actual restrictions in an individual's performance of actions, tasks, and social roles in the actual physical, social, and attitudinal environment in which that person lives. This is the core data that determines disability prevalence.

In addition, and in order to understand disability prevalence, 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 – is 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 would have Activity and Participation questions at its core, combined with Impairment and Environmental Factor questions. Optimally, and for practical reasons, it is essential that each component be composed of questions about a well-tested minimal or parsimonious set of domains: 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.

An example of the Comprehensive Approach would be a combination of the Activity and Participation questions found in the WHO Disability Assessment Schedule II (WHO DAS II), coupled with the set of impairment questions used in the WHO World Health Survey. The relevant domains are as follows:

**WHO DAS II  (Activities and Participation)**

**DOMAIN 1** Understanding and Communicating (concentrating, remembering, analysing and finding solution to problems...)

**DOMAIN 2** Getting Around (standing, standing up, moving around inside your home...)

**DOMAIN 3** Self-Care (washing, getting dressed, eating...)

**DOMAIN 4** Getting along with people (dealing with people you do not know, maintaining a friendship...)

**DOMAIN 5** Life Activities (household responsibilities, getting household work done, doing work/school tasks well...)

**DOMAIN 6** Participation in Society (joining in community activities, doing things by yourself for relaxation or pleasure...)
World Health Survey (Impairment elements)

- Aches and pains
- Discomfort
- Skin defect
- Using hands and fingers
- Seeing and recognizing a person
- Seeing and recognizing at arm's length
- Hearing someone talking
- Hearing what is said in conversation
- Urinating
- Defecating
- Shortness of breath at rest
- Shortness of breath with mild exercise
- Coughing or wheezing
- Sleeping
- Feeling sad
- Worry or anxiety

4.3.5 Advantages of the Comprehensive Approach

The advantage of using questions from the WHO DAS II and the World Health Survey is that both were developed in multiple-year, international collaborative ventures. They have been exhaustively field tested and have been used in thousands of interviews. WHO DAS II questions have proven psychometric qualities (sensitivity\(^3\), specificity\(^4\), reliability and validity) demonstrated in general population surveys, in clinical sensitivity-to-change studies and cost-effectiveness studies.

Impairment or Activity and Participation Approaches in practice tend to assume what is sometimes called the 'minority model of disability', namely that disability status is dichotomous – everyone is either a person with a disability or not. The ICF rejects this approach in favour of a universal model, in which disability is a continuous state, which everyone shares. That is, everyone has some degree of functional limitation at the body, person or societal levels, people differ in the extent and range of functional limitation.

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 analysed 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 disabled from non-disabled. Once such a threshold is established, prevalence can be determined on the basis of the data derived from the data collection activity.

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3 Sensitivity: the probability that someone with a disability (according to a predetermined standard) will also identify themselves as having a disability according to the survey/census question.
4 Specificity: the probability that someone who does not have a disability (according to a predetermined standard) will also identify themselves as not having a disability according to the survey/census question. Detailed discussions about sensitivity and specificity are in Chapter 6.
Diagram 4.1 graphically shows how threshold decisions can be used to produce a range of, in this case, age-distributed prevalence data sets. The results are from a 2003 Mexican survey, held in conjunction with WHO's World Health Survey. Four lines are displayed, representing age-distributed prevalence rates based on four severity threshold decisions: 65 percent, 80 percent, 90 percent, and 95 percent. As would be expected, age-related prevalence differs depending on level of severity: the lower the threshold, the higher the prevalence. In addition, the shapes of the lines differ, representing differences in how age-groups experience different levels of functional limitation.

What is significant about this way of portraying disability prevalence is that the threshold decision represents a separate decision during analysis, and the data itself does not force or mandate that a particular threshold be used. This is important because decisions about thresholds are highly political. They have direct financial consequences when programming eligibility is determined by level of severity. A policy planner will need to know how severe the problem is (i.e., the level of prevalence), and can employ prevalence decisions to gauge the level of access to pensions, insurance, or other disability programme.

The comprehensive, multidimensional approach to disability questions makes it clear that threshold decisions must be independently justified and are not simple consequences of prevalence rates. These decisions are politically important and should be transparently made, in light of social conditions, the state of the economy, or other issues that ought to be a matter of public knowledge and debate.

Obviously, threshold decisions will always be controversial. Where the line is drawn between who qualifies as having a disability for the purpose of a social programme and who does not, will directly affect the lives of people. These decisions should not be disguised as statistical or technical matters. A comprehensive approach to disability statistics ensures that political and social issues remain in the political and social sphere, where they belong, while at the same time providing valid and reliable data that is directly relevant to decision-making.

- 65% threshold
- 80% threshold
- 90% threshold
- 95% threshold
4.4 Question formats and response scales

In addition to the content of the questions, there is, of course, the question 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.

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

Disability questions can take the form of a simple response, a list, or a multiple choices (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-itemised response. The disability screen question of the New Zealand Census is an example:

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

Yes, sometimes
Yes, often
No

For most uses of disability data, itemised responses are preferred to composite questions, as the value of much of the data is lost in non-itemised 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 respondent 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.

4.4.2 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.

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.
This issue was the subject of a test for the 2001 Australian Census. The two questions tested were:

A.  Does the person have difficulty in:

   doing everyday activities such as eating, showering or dressing?  Yes/ No

   hearing  Yes/ No

   ... 

B.  How much difficulty does the person have in:

   doing everyday activities such as eating, showering or dressing?  None/ A little/ A lot

   hearing  None/ A little/ A lot

   ... 

The disability prevalence rate from question A was 15%, while that for question B was 22.4%. The tests were conducted in the same fashion in similar areas, the only difference being the format of the question. 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.

The severity or 'extent of' qualifiers used in the ICF offer a 5-point scale that is available for use as scaled responses in survey/census questions (and is used in the WHO DAS II):

<table>
<thead>
<tr>
<th>Value</th>
<th>Description</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>NO problem</td>
<td>0-4 %</td>
</tr>
<tr>
<td>1</td>
<td>MILD problem</td>
<td>5-24 %</td>
</tr>
<tr>
<td>2</td>
<td>MODERATE problem</td>
<td>25-49 %</td>
</tr>
<tr>
<td>3</td>
<td>SEVERE problem</td>
<td>50-95 %</td>
</tr>
<tr>
<td>4</td>
<td>COMPLETE problem</td>
<td>96-100 %</td>
</tr>
</tbody>
</table>

This five-point scale may be the most intuitive one for any data collection activity since it identifies and distinguishes the primary empirical values of an observable **phenomenon: its presence and absence, and its presence in low, medium and high...
degrees. The ICF scale is also highly flexible as it can be easily mapped onto other intuitive scales that might be used to identify classes of responses. Diagram 4.2 shows how this mapping could be done for the examples of 2 (or dichotomous), 3, 4, 6, and 7-point response scales.

The five-point scale used in the ICF provides a convenient and consistent technique for determining the extent or magnitude of the functional problem being codified. The qualitative description of the five points, and the associated percent scale, are heuristic suggestions for how to calibrate these levels. Different users may find it possible to calibrate these levels more precisely, depending on the requirements of the users.

Whether ICF’s scaling response options are used or not, the data from these responses is only useful if the response options can be calibrated against a common metric or standard. In order words, it is not helpful that two respondents both answer that their disabilities are ‘mild’, if one respondent’s mental representation of ‘mild’ is more or less equivalent to what the other respondent would call ‘moderate’. Whenever scaled response questions are relied on in a disability survey/census, some technique must be used to transform the qualitative scale into a quantitative scale. This is called response calibration.

There are several successful strategies that can be employed to calibrate response options to insure consistency of data. The primary focus of these strategies is to devise ways of linking levels of ‘difficulty’ with the response options available. The details of these strategies, and the levels of confidence that can be achieved in different circumstances, are beyond the scope of this manual.

4.5 Additional issues in question development

4.5.1 Language

If you look at censuses in the Asia-Pacific region, the disability question most commonly asked is 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”. We know that when these general words are used, the results underestimate prevalence. The reason is that people object to being labelled 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 your data will be useless. A person may flatly refuse or ignore a question that asked about being ‘cripple’ or ‘dumb’, even if they would readily answer a question about difficulties in walking or carrying on a conversation. Table 4.2 gives some examples of offensive or negative terms in English, with reasons why it is best to avoid them.
Diagram 4.2: Response Scales

- Complete 95-100%
- Severe 50-95%
- Moderate 25-49%
- Mild 5-24%
- None 0-4%

ICF 2-point 3-point 4-point 5-point 6-point 7-point
### Table 4.2: Negative Terms Relating to Disability

<table>
<thead>
<tr>
<th>Term</th>
<th>Reason to avoid term</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Able-bodied,” “normal” or “ordinary” people vs “abnormal” people</td>
<td>Creates an unwarranted dichotomy: everyone has (or will have) some level of disability and everyone is, to some degree, able-bodied, normal or ordinary in some respect.</td>
</tr>
<tr>
<td>Disabled persons</td>
<td>This phrase emphasizes the disability rather than the person. A more acceptable alternative is “person with a disability”. (Although, in England and throughout English-speaking Europe, disabled person is preferred. In the academic discipline of disability studies, “disabled persons” is preferred as it connotes that persons are disabled by society.)</td>
</tr>
<tr>
<td>Handicapped</td>
<td>This term has a submissively “cap in hand” connotation which is offensive. ‘Handicap’ has long been used (e.g., in the ICIDH) to refer to the effects of an unaccommodating environment on persons with impairments. More recently, however, the term has regained its previous, more stigmatising connotation.</td>
</tr>
<tr>
<td>The disabled</td>
<td>Though historically, persons with disabilities used this term to raise their collective political voice, others object to being put into a broad and negative category. It is both more acceptable and more informative to describe people specifically, as, for example, a person with mobility difficulty, or intellectual disability.</td>
</tr>
<tr>
<td>Your ‘problem’</td>
<td>Assumes that the disability is an individual problem, rather than one also created by the social environment. This also connotes that one is expected to fix the problem.</td>
</tr>
<tr>
<td>Afflicted/suffering</td>
<td>These words reinforce the stereotype of a person with a disability as a victim or unfortunate sufferer.</td>
</tr>
<tr>
<td>Cripple, mongol, dwarf, spastic, epileptic, deaf/ mute, insane, crazy, mental retardation</td>
<td>These words are examples of negative labelling, in which the whole person is regarded as those who are something wrong. It is better to refer to &quot;a person with a physical disability&quot;, &quot;a person with Down Syndrome&quot;, and so on. In addition, these terms are often used inappropriately as negative and often derogatory generalizations rather than as descriptions of specific impairments.</td>
</tr>
<tr>
<td>Deaf and dumb</td>
<td>Inability to hear and speak doesn't mean a person is stupid, as “dumb” suggests.</td>
</tr>
<tr>
<td>Confined to a Wheelchair</td>
<td>Say &quot;uses a wheelchair&quot;. ‘Confined’ implies suffering and victim status.</td>
</tr>
</tbody>
</table>

Language is often at the forefront of battles by advocacy groups to change social perceptions of marginalised people. Question designers must be aware that people will resist being labelled and slotted into boxes. The appropriateness of the language of interview questions should be checked in pre-testing, in consultation with persons with disabilities and amended where necessary. In the 2001 Australian Census, testing indicated that the term ‘mental condition’ in the disability screening question
significantly reduced the number of positive responses, especially among older people. Focus group testing indicated that grouping together mental conditions with health or physical conditions offended people who refused to include themselves in that combined category.

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:

1. problems with the body (impairments),
2. problems with a person’s capacity to do actions (activity limitations), and
3. 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.

4.5.2 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 need not be intentional; it can arise indirectly. An example of this is the 2001 Sri Lankan Census which defined persons with disabilities as those who are “unable or have limitations to carry on their own work, without the help of others, due to congenital or long term physical/mental disability...”. Were women who worked at home without pay included in this description? The sex ratio of disabled persons reported from the 2001 census in Sri Lanka was 136.2, suggesting higher disability prevalence in men than in women. Unfortunately, since testing by focus group and cognitive interviewing was not done, we cannot be sure that the census questions were gender biased or not.
4.5.3 Cultural issues

Cultural differences in the perception of disability affect how it is reported. For international statistics, this is an issue of great importance. As has been mentioned, 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.

4.5.4 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.
4.6 Census format questions

Censuses are common tools for collecting a wide variety of data about the population of a country. Since they are used for many purposes, there is pressure to keep the number of questions low and their length short. Each of the approaches described in Section 4.3 above can be, and have been, used in the development of censuses. Instead, or in addition, a census may include a simple, one-line question asking whether the respondent has disabilities or whether disability is a reason for lack of employment or educational participation.

Here are a few examples of questions that have been used in censuses to collect information about persons with disabilities:

4.6.1 Single general question

Census disability questions that ask only a single question about disability are common in the Asia-Pacific region:

A. Do you have any long-term disabilities or handicaps?
   - No
   - Yes

B. Is (name of person) limited in his/her daily activities (at home, at work or at school) because of a long-term physical or mental condition (lasting six months or more)?
   - No
   - Yes

C. Do you have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities?
   - Yes, sometimes
   - Yes, often
   - No

Although A, B, and C are similar, ‘Yes/No’ questions, there are important differences between them which result in very different populations being identified.

As noted above, Question A is likely to pick up only a very small number of people since many people object to the labels of ‘disabled or handicapped’. Even if followed by a detailed question about types of impairments, activity limitations or participation restriction, unless people respond positively to the first question, they will not answer what follows. As a result, most useful disability questions do not use the term ‘disability’ in the question.

Question B avoids the problems with A by being explicit about problems in daily activities. By adding that the limitations can occur anywhere in daily life – home, work or school – the question directs the respondent’s attention to severe or at least moderate disabilities. Also, the reference to ‘physical or mental condition’ makes it
clear that the question is directed to disability, rather than other reasons why daily activities might be limited, such as gender discrimination, poverty, or lack of opportunity.

Finally, Question C is a composite question, since a string of activities are listed, with a (slightly modified) ‘Yes/No’ response. This question has been used as a screening question to identify a sample population for a follow-up survey. The follow-up survey included much more detail about disability. In most cases, it is more useful to try to collect the detail rather than rely on a single, ‘Yes/No’ response.

Roughly, the disability prevalence rates that one might expect from each of these questions are likely to be less than 2 percent for Question A, 8 -12 percent for B, and 20 percent for C.

Results from New Zealand and Canada indicate that there are both false positive and negative responses to single general questions. In the case of Canada, 20 percent of people who responded ‘yes’ to the census questions were found not to have a disability after being asked a more rigorous set of questions, and 5 percent of those who answered ‘no’ to the census questions were found to in fact have a disability. This suggests that census questions provide at best a very crude indicator of disability prevalence. Mild disabilities, and disabilities among children and older people are especially under-reported in census questions.

4.6.2 Checklist questions

Some countries have used the technique of setting out a short checklist of problems with regard to impairments, activity limitations, or participation restrictions.

Here are two examples:

A. Does the person have any long-term impairments, disabilities or handicaps?

   No

   Yes - Check all that apply

   - Incomplete use of legs, feet
   - Incomplete use of arms, fingers
   - Partial or total loss of sight even with glasses
   - Partial or total loss of hearing
   - Partial or total loss of speech
   - Slow development/learning difficulties
   - Behavioural problems/mental impairment
   - Other. Please specify
B. How much difficulty does the person have in:

- Doing everyday activities such as eating, showering or dressing?
- Hearing?
- Learning, understanding or remembering things?
- Reading or seeing even with glasses?
- Walking, kneeling or climbing stairs?
- Living independently?
- Doing any other things people of the same age usually do (for example, working, studying, etc.)

(Three scale response to each item: None, a little, a lot)

What causes this difficulty for the person?

- Short term health condition (lasting less than 6 months)
- Long term health condition
- Disability
- Age
- Difficulty with English language
- Other cause – Please specify

A uses a checklist of impairments and B of activity limitations. The second part of B serves to identify positive responses that are associated with health conditions, and hence, true disabilities.

These questions tend to obtain higher prevalence rates than simple screener questions, as respondents are forced to respond to each of the question items.

4.6.3 Including a response category on disability

In a few national censuses – Myanmar, the Central African Republic, and Venezuela – the category of disability is added to an existing question on economic inactivity. In this way the respondent can cite disability as a reason for the inactivity (at par with being a homemaker, student or retired person). In a similar way, Mexico, Belize, and Cuba add disability as a possible reason for a child not attending school.

This technique is unlikely to produce valid prevalence rates of disability in the population since the question is only asked of people who are experiencing economic inactivity or not going to school. It is perfectly possible to have a disability and not being restricted in these two domains. This kind of question also picks up on severe impairments associated with a complete participation restriction, rather than merely limited participation.
4.7 International disability question sets

Below are outlined a range of suggestions for disability question short sets made by the Washington Group on Disability Statistics (WG), WHO and ESCAP. The reader will notice that establishment of a consensus on recommendations for operationalizing ICF is a minimal or core list of domains and questions. It should be noted that there are currently projects underway at both international (Washington Group) and regional (ESCAP) levels which aim to revise and improve these recommendations.

4.7.1 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

If the respondent indicates one or more of the activity limitations in this list, then they are identified as having a disability for the purposes of the census.

Compared to the cost of fielding a separate disability survey, including one or two questions on disability in a census questionnaire is a relatively inexpensive way of getting prevalence data on disability and type of disability.

A major benefit from including disability in the census is that the data set can be analysed more extensively with other census variables (age, sex, marital status, income, labour force status, family status, and so on). In this way, the results for the disability population are easily comparable to those of the total population. These data can then be used for poverty analysis or detailed family analysis, in order to get a better picture of the situations of person with disability and their families. The UN global recommendations were updated in 2007 in the revised version of the Principles and Recommendations for Population and Housing Censuses (Rev. 2). Development of the UN recommendations on disability in censuses is based on the Washington Group’s suggestions.
4.7.2 **UN Global Census Recommendation**

After several discussions, the Washington Group on Disability Statistics (WG) which is an expert group to address the issues related to disability measurement and to report to UN Statistical Commission was able to devise the list of questions recommended for censuses below:

**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

WG performed pilot tests and analysis of the cognitive qualities of the questions, completed in 2006. The detailed recommendations and tabulation instructions are presented in Principles and Recommendations for Population and Housing Censuses (Rev. 2).\(^5\)

4.7.3 **WHO/ESCAP’s pilot tested disability questions**

The WHO/ESCAP Project on Improvement for Disability Statistics and Measurement conducted pilot test of WHO, the Washington Group, and ABS question sets (see Appendix 2) 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

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- 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

Examples from the Washington Group, WHO, and ABS question sets are given in Table 4.3 below.

Table 4.3: Example of WG and WHO/ESCAP question sets

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Example of Washington Group question set</th>
<th>Example of WHO and ABS question sets</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you have difficulty seeing, even if wearing glasses?</td>
<td></td>
<td>How much difficulty did you have in seeing and recognizing a person you know across the road? (take into account eye glasses, if you wear them)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Activity and Participation</th>
<th>Example of Washington Group question set</th>
<th>Example of WHO and ABS question sets</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you have difficulty walking or climbing steps?</td>
<td></td>
<td>How much difficulty did you have in walking a long distance such as a kilometre (or equivalent)?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Environmental Factors</th>
<th>Example of Washington Group question set</th>
<th>Example of WHO and ABS question sets</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you ever need someone to help with, or be with you for, body movement activities? For example: getting out of bed, moving around at home or at places away from home.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The questions sets were comprehensively tested in five pilot countries of the ESCAP region using the following study protocols. The first study examined the sensitivity (ability to pick up true positive cases) and the specificity (ability to pick up true negative cases) of specified disability questions. The second study assessed the reliability of individual questions by a standard test-retest procedure. The aim was to flag unreliable questions for later attention in the production of a recommended question set. The third study aimed to record the respondents’ understanding of the question’s intent.

The findings of the pilot test are summarized as follow:

- **Validity**

Generally, the construct validity of the Washington Group questions for the seeing, hearing, mobility and self care domains is good when WHO questions for the corresponding domains are used as a benchmark. This does not, however, apply to the questions for the cognition and communication domains. The Washington Group (WG) questions perform similar to corresponding WHO questions in terms of predictive validity.

The number of subjects reporting any difficulty in response to the combined WHO questions is larger than in response to the Washington Group questions for every domain. This is especially the case for the hearing, mobility and communication domains, where the combined WHO questions pick up more than twice the number of people with at least some difficulty than the Washington Group questions. Moreover, each individual WHO question for these domains, as well as the cognition domain, generates higher disability prevalence than the corresponding Washington Group question. WHO questions have five scale responses while WG questions have four choices. It could be that more scaled response questions increase the number of positive responses, since the respondent has more choices that may fit their situation.

In terms of item properties, generally, the body functions and six domains (World Health Survey and WHO DAS II) questions that included thresholds (e.g., walking >1 km or seeing “across the road”) were more sensitive and therefore appear to result in less serious under-reporting.

The WG Short Set of questions showed good specificity but low sensitivity. WHO DAS II domains like life activities, interpersonal relations, cognition, and mobility together with environmental and mental health related questions showed the highest power in explaining difficulties in participation.

In terms of frequencies, within the WG set of questions, the domains of mobility, cognition, and vision had high endorsement rates. Body functions and the six domains had very high endorsement rates across the whole severity spectrum but in particular for Activity and Participation and Environmental Factor questions.

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6 For details of empirical results and predictive validity, see Smit and Liu, 2007.
Regarding utility, from the WG questions, one fixed prevalence rate (<5% for severe and complete difficulties, and >20% for any and mild difficulties) was generated. Body functions and the six domains allowed the production of multiple and scalable prevalence rates which in turn allowed the same data set to be used for various purposes.

- **Reliability**

All questions showed moderate to good reliability. Within a given domain differently phrased questions have similar levels of reliability. For example, Kappa statistics of W1 Seeing is 0.57; Kappa statistics of B1.6 Seeing short sighted is 0.65; and Kappa statistics of B1.7 Seeing long sighted is 0.53.

- **Cognitive debriefing**

Most questions were understood well. Approximately 95 percent of the respondents responded to the questions without any difficulties. The few cases where difficulties in question understanding were observed or reported involved questions that referred to mental health related domains (cognition, anxiety, and self esteem) and certain environmental factors. Respondents also had difficulties in understanding compound questions. Regarding the question wording, the inclusion of meaningful thresholds was found to be useful. Further studies were deemed necessary to determine the extent that translation difficulties influenced these outcomes.

Some of the results of these pilot studies were presented at the 4th Workshop on Improving Disability Statistics held in Bangkok, Thailand (20-22 June, 2006). The workshop was attended by representatives from 16 countries in the ESCAP region. After discussing the results of the pilot studies, the participants at the workshop tentatively suggested that the following domains could be included in census.

- Walking
- Seeing
- Hearing
- Life Activities
- Self Care
- Communication

A working group was also formed at the workshop in order to follow up on remaining issues related to these tentative results through conducting more in-depth analysis of pilot study outputs.

More detailed analysis of the results from the pilot studies is still ongoing by ESCAP, WG and WHO researchers and more work need to be done on development of the extended question sets for surveys, therefore complete recommendations on selecting among ICF domains is not yet concluded.
4.7.4 Development of disability statistics from census/survey: An example

In most countries, the development of disability statistics is a slow and step-by-step process. Once the need for disability data is identified and basic questions about coverage and scope are settled, the next task is to find the best data collection tool to use. This will be both an issue of statistical adequacy and of cost and feasibility. Most likely, for reasons already mentioned, the use of existing censuses, modified by the addition of a few disability questions, will be the first step. In time, these data can form the basis for a separate survey, dedicated to disability issues. Box 4.5 describes a hypothetical example of this process in action.

Box 4.5: Case Study of Middle Earth: Developing Disability Measures

The situation
Middle Earth is a land of groups of people at war, a war that has lasted for so many generations it seems to be entrenched. As a consequence of battle, many have severe impairments, such as lost limbs, severe hearing problems and burns to the skin.

Middle Earth is a very poor land. Most inhabitants cannot afford to buy the aids and equipment that would overcome at least some of their disability, and the state lacks programmes for the provision of these. For example, some people have poor eyesight but simply cannot afford to buy glasses.

The built environment of Middle Earth does not suit all of the people. Most buildings are suitable only for small ethnic groups and persons with disabilities often find that features of the built environment hinder their participation in a range of activities.

Need for statistical information on disability
In 1986, the state decided to collect information about the prevalence of disability in the population. They felt that information was needed for each of the country’s ethnic groups in order to understand both the prevalence and the experience of disability for each group.

Planning for data collection
Planning commenced immediately, with the intention of collecting disability data as soon as possible. Issues considered were:

- What collection vehicle to use
- How to define disability
- How to word the questions
- How aids and equipment should be taken into account
- How the environment should be addressed

Collection of data
It took several years to plan, but in 1990, the National Statistical Office (NSO) of Middle Earth included a single question on disability in the census: “Are you disabled?” with simple response categories of Yes/No. Middle Earth interviewers reported a widespread misunderstanding of the question and a reluctance to answer yes. The resulting estimates of disability for Middle Earth were less than 1%.

Persons with disabilities and government disability policy staff did not believe the estimates from the census, and lobbied the NSO to improve the information.

In the next Middle Earth Census in 1995, the NSO developed a disability question that was longer and collected more detail. The 1995 question covered a range of 6 impairments, mostly severe impairments such as blindness, deafness and loss of limbs. The key disability data users were happy to see disability prevalence increase to 2% of the population; but they were still concerned that the true picture of persons with disabilities was not being presented.

In 2000, the NSO decided to conduct a dedicated survey of disability as well as the census. The
census and survey questions used similar concepts of disability, based on the ICF. A combination of impairments, activity limitations and participation restrictions was used to identify the disability population in the broadest possible sense. Details of disabilities, including type, severity, cause and age of onset were collected in the dedicated survey. The census question focussed on activity limitations with the highest expected prevalence rates. The census question used 6 items, while the survey had a series of 15 screening questions. Disability estimates from the Census increased to 10% of the population, while the survey reported even higher rates of about 20%. Disability data users were very satisfied with the results of the 2000 census and survey program. Even though the estimates from the two sources were not identical, estimates of a similar concept (selected activity limitations) were similar, as were characteristics of the populations.

4.8 Administrative data collections, with an Australian example

Using ICF concepts in administrative data collections promotes data consistency and comparability. In developing data collections, and data items within collections, the ICF may be used in different ways, and at different levels of detail:

- The overall framework of the ICF can be used to guide the development of data items: what dimensions of functioning and disability should the data items cover – impairments, activity limitations or participation restrictions, or some combination?
- The classifications within each of the components of the ICF can be used as a ‘pick list’ from which relevant domains can be selected, either at broad chapter level, or at more detailed levels.
- ICF codes can be used as the basis for capturing and recording data.

A good example of the use of ICF concepts in the collection of administrative data is that of the Australian experience developing a “support needs” data item.

The new support needs question was developed as part of a major development of Australia’s data collection system. In consultation with stakeholders, it was agreed that a standard indicator was required to compare support needs of different clients at the national level. The data item is not a new assessment tool, but rather a framework into which assessment information already collected by agencies could be mapped. The data had to be comparable with disability population survey data, and it needed to relate to existing data standards (in particular, the ICF) and current practice in assessing support needs.

Box 4.6 presents the data collection form that was used in Australia, with the new “needs support” Question 11. It can be seen that the question is set out: “How often does the consumer need personal help or supervision with activities or participation in the following life areas?” This is followed by nine life areas (based on chapter headings from the Activity and Participation component of the ICF) and a five-point scale for recording levels of supervision needed.

As operationalised by this question, the concept of ‘need for help or supervision’ was perfectly compatible with measures used in the Australian Disability Population
Survey, so that data from the two sources were consistent and could be used together.

For analysis purposes, the nine activity areas where support is needed were then divided into three groups:

- **Activities of Daily Living** – self-care, mobility, and communication.
- **Activities of Independent Living** – interpersonal interactions and relationships; learning, applying knowledge, and general tasks and demands; and domestic life.
- **Activities of Work, Education, and Community Living** – education; community and economic life; and work.

Data collected in 2002 could then be used to show some interesting facts about the support needs of persons identified as having a disability, based on category of activity area:

- 42 percent always needed help or were unable to do Activities of Daily Living; 48 percent always needed help or were unable to do Activities of Independent Living;
- 58 percent always needed help or were unable to do Activities of Work, Education, and Community Living;
- Those who used housing and accommodation support services had the highest support needs, while those using employment services had the lowest support needs;
- Persons with disabilities living with their family or spouse had higher support needs than those who lived alone;
- Among those living with family or spouse, 38 percent were unable to do or always needed help with Activities of Daily Living, 43 percent with Activities of Independent Living, and 48 percent with Activities of Work, Education, and Community Living;
- For persons with disabilities living alone, 17 percent were unable to do or always needed help with Activities of Daily Living, 23 percent with Activities of Independent Living, and 34 percent with Activities of Work, Education, and Community Living.

These conclusions are of considerable use in service planning and administration. These results were possible because data from the two administrative data sources were comparable since both rely on the ICF.
Box 4.6: Australian National Minimum Dataset: Data Collection Form

11. How often does the service user need personal help or supervision with activities or participation in the following life areas?

Please indicate the level of help or supervision required for each life area (rows a–i) by ticking only one level of help or supervision (columns 1–5).

The person can undertake activities or participate in this life area with this level of personal help or supervision (or would require this level of help or supervision if the person currently helping were not available)

<table>
<thead>
<tr>
<th>LIFE AREA</th>
<th>1) Unable to do or always needs help/supervision in this life area</th>
<th>2) Sometimes needs help/supervision in this life area</th>
<th>3) Does not need help/supervision in this life area but uses aids or equipment</th>
<th>4) Does not need help/supervision in this life area and does not use aids or equipment</th>
<th>5) Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Self-care e.g. washing oneself, dressing, eating, toileting</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
</tr>
<tr>
<td>b) Mobility e.g. moving around the home and/or moving around away from home (including using public transport or driving a motor vehicle), getting in or out of bed or a chair</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
</tr>
<tr>
<td>c) Communication e.g. making self understood, in own native language or preferred method of communication if applicable, and understanding others</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
</tr>
<tr>
<td>d) Interpersonal interactions and relationships e.g. actions and behaviours that an individual does to make and keep friends and relationships, behaving within accepted limits, coping with feelings and emotions</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
</tr>
<tr>
<td>e) Learning, applying knowledge and general tasks and demands e.g. understanding new ideas, remembering, problem solving, decision making, paying attention, undertaking single or multiple tasks, carrying out daily routine</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
</tr>
<tr>
<td>f) Education e.g. the actions, behaviours and tasks an individual performs at school, college, or any educational setting</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
</tr>
<tr>
<td>g) Community (civic) and economic life e.g. recreation and leisure, religion and spirituality, human rights, political life and citizenship, economic life such as handling money</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
</tr>
<tr>
<td>h) Domestic life e.g. organising meals, cleaning, disposing of garbage, housekeeping, shopping, cooking, home maintenance</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
</tr>
<tr>
<td>i) Working e.g. actions, behaviours and tasks to obtain and retain paid employment</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
</tr>
</tbody>
</table>

**NOTE:** In the following questions ‘not applicable’ is a valid response only if the person is 0–4 years old.

**NOTE:** In the following questions ‘not applicable’ is a valid response only if the person is 0–14 years old.