Learning Objectives: Chapter 1

Disability Statistics: Why Are They Important and What Does the ICF Add?

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

1. **Understand the nature and importance of disability statistics**
2. **Understand the aims and purposes of disability statistics**
3. **Recognise the role of ICF in international disability statistics**

"Good vision" Natalie Behring-Chisholm
WHO Photo Contest "Images of Health and Disability 2003/2004"

1. DISABILITY STATISTICS: WHY ARE THEY IMPORTANT AND WHAT DOES ICF ADD?

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1.1 Introduction

Compared to other areas of statistics such as labour force, education, women, and older people, disability statistics has not been well developed or utilized. It is only very recently that governments have begun to recognize the urgency and importance of such statistics for better policies and program developments.

Both global and regional instruments on disability stress the importance of appropriate data collection. World Programme of Action Concerning Disabled Persons (1982), Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993) and the landmark disability-specific human rights treaty, the Convention on the Rights of Persons with Disabilities and its Optional Protocol adopted in 2006 state a need of appropriate information collection, which would protect and promote and fulfil all human rights of persons with disabilities. Biwako Millennium Framework for Action Towards an Inclusive, Barrier-free and Rights-based Society for Persons with Disabilities in Asia and the Pacific (BMF), the regional policy guideline for the Second Asian and Pacific Decade of Disabled Persons, and the Biwako Plus Five, the supplement to the BMF, both stress the need to develop valid, reliable, and internationally comparable disability statistics in order to put into place effective disability policies and projects.

1.1.1 What is disability statistics?

Traditionally, disability statistics has been conceived as a matter of counting people who fall into specific groups – 'the blind', 'the deaf', 'wheelchair users' – in order to determine who qualifies for benefits. With very limited purpose in mind, this categorical approach gives a fragmented and distorted picture of disability since it suggests that person with disability fall neatly into a few categories with clear boundaries.

However, disability statistics can provide a wealth of information on the full lived experience of persons with disabilities ranging from impairments, difficulties in undertaking and participating in activities, and barriers they face in their lives. Information can be extended from an individual to the whole population – to determine prevalence of domains of disability, for example – and further developed by adding demographic or other population features, such as age, sex, race, and socio-economic status.

1.1.2 The importance of disability statistics

With a broader understanding of disability, disability statistics can play a pivotal role in all areas of policy-making, and in each every stage from development and implementation, to monitoring and assessment of effectiveness, to the analysis of cost-effectiveness. Policy without valid and reliable data is potentially costly and wasteful guesswork; it is policy without a basis of evidence and good science. Invalid or incomplete disability data, of the kind often found in the developing world, can be worse than no data at all.

Below are some specific reasons why national disability statistics and valid disability databases are essential for national policy:

- The aspirations of the UN Disability Convention, Standard Rules and the BMF, Biwako Plus Five for the protection and promotion of the rights and the dignity of persons with disabilities are mere hopeful words without sound data to monitor and assess progress towards these goals.

- Information about functional status is integral to identify needs since two individuals with the same impairment may face different types of difficulties in undertaking certain activities, and so have different needs that require different kinds of interventions.

- Functional status data is essential for determining the broader social needs of persons with disabilities, such as provision of assistive technology for use in employment or education or broader policy and laws.

- Population disability data is essential for monitoring the quality and outcomes of policies for persons with disabilities. In particular, these data help to identify policy outcomes that maximize the participation of persons with disabilities in all areas of social life from transportation and communication, to participation in religious and community life.

Finally, with valid and complete disability statistics, state agencies will have the tools for assessing the cost-effectiveness of policies for persons with disabilities, which in turn can provide the evidence to persuade governments of their ultimate benefit for all citizens.

1.1.3 Purposes of disability statistics

A number of countries in the Asia Pacific Region have conducted disability surveys or included disability questions in their censuses, but users were not satisfied with the results. The most common complaint was that the statistics were based on a handful of severe impairments and did not capture broader measures of disability.

This is an example of a failure by data collection agencies to understand the needs of those who will be using the data. The lesson is obvious: design your tools to collect data that are 'fit for purpose'. Failure to match disability questions with purposes results in unusable statistics that becomes a waste of public expenditure.

Of course, clearly identifying the purposes for disability statistics is not an easy task. In **Chapter 5**, we will look at a process for determining data user needs, one that has been successfully used in the Australian context. It is first important to note, though, that considerable work, international and regional, has been done in identifying **needs** that quality disability data can serve.

1.1.4 Purposes: International and regional perspectives

In the abstract, the question 'What is the purpose of disability statistics?' seems daunting. Fortunately, at the international and regional levels there are clear statements of purpose that we can turn to.

Internationally, explicit recommendations for the use of disability statistics are contained in three important UN documents:

- **The World Programme of Action Concerning Disabled Persons (1982)**
- **Standard Rules for the Equalization of Opportunities of Persons with Disabilities (1993)**
- **The Convention on the Rights of Persons with Disabilities and its Optional Protocol (2006)**

In 2001, the **Washington Group on Disability Statistics** was formed as a response to a suggestion made during a UN International Seminar on Measurement of Disability. Since then the Group has brought together international representatives to work on important methodological issues for improving disability data and, in particular, to facilitate the comparability of data around the globe. The Group's primary task is to come up with general disability questions that can be used in censuses and national surveys. Along the way, the Group has offered guidance on what it took to be the overriding purposes of disability statistics:

1. To assist in the development and evaluation of programmes and policies for service provision;
2. To monitor the level of functioning in the population; and
3. To assess equalization of opportunities.

Regionally, a major statement of the important purposes of disability statistics is provided by the BMF (2002). It outlines the following seven priority areas for governments in Asia and the Pacific:

1. Self-help organizations of persons with disabilities and related family and parent associations,
2. Women with disabilities,
3. Early detection, early intervention and education,
4. Training and employment, including self-employment,
5. Access to built environment and public transportation,
6. Access to information and communication, including information, communication and assistive technologies, and
7. Poverty alleviation through capacity-building, social security and sustainable livelihood programmes

Each of these areas has been neglected in part because of a lack of adequate data on persons with disabilities.

BMF and Biwako Plus Five, the supplement to the BMF, both have a strategy on disability data collection, emphasizing a urgent need to build capacities of governments, NGOs and other stakeholders to effectively collect data on disability.

At its September 2003 meeting, ESCAP held a Workshop on Improving Disability Statistics for Policy Needs. The group reaffirmed the priority areas in BMF and identified specific areas where quality disability data is needed: service programming and development, capacity building, budgeting, and seeking international assistance, among many others.

These international and regional documents report a consensus among nations of the world and within Asia and the Pacific, about what is required of a better way of gathering information on disability data. Both groups agreed that there is a need for a scientific basis and valid conceptual framework in establishing disability statistics. The World Health Organization's (WHO) **International Classification of Functioning, Disability, and Health** (**ICF**) is response to this need. The ICF has truly created a new paradigm for disability statistics.

1.2 ICF and its purposes in disability and health statistics

The ICF is both a classification system and a model of the complete experience of disability. The ICF is a member of WHO's family of health classifications, the other prominent member of which is the **International Statistical Classification of Diseases and Related Health Conditions** (ICD-10). As a classification system, ICF provides a common language, which guarantees the comparability of disability data between sectors within a country, and between countries. As a model of disability, the ICF offers a conceptual framework for structuring disability data.

1.2.1 ICF and the ESCAP Region

In Asia and the Pacific, the ICF has been implemented in Australia and New Zealand. Indonesia and Thailand have also begun to use its concepts in some of their disability data collections. The experience of integrating the ICF concepts into disability data collections has been that disability phenomenon has been described with greater clarity and precision.

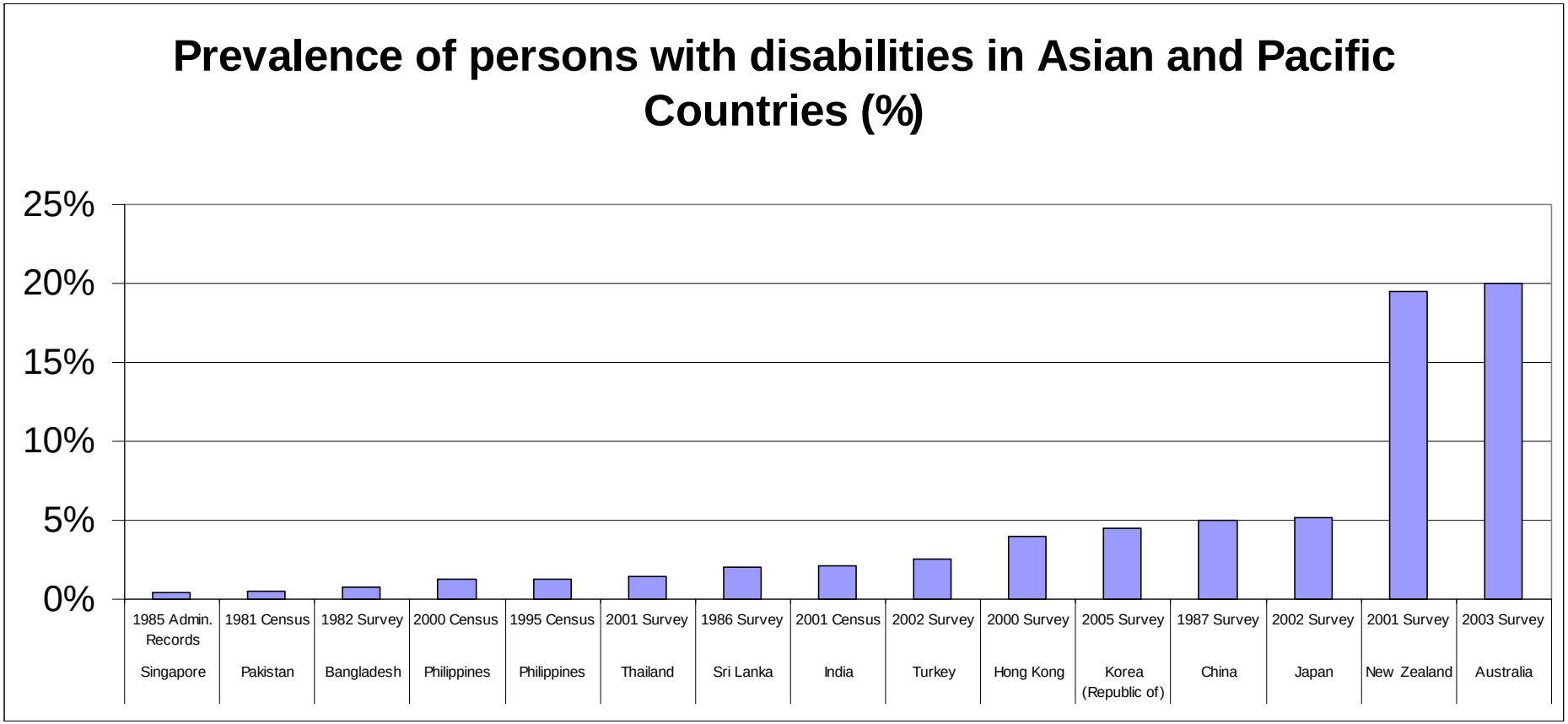
Yet for the majority of the countries in the ESCAP region, disability statistics are unreliable. Many of these countries report a prevalence of disability at less than 3 percent, which is implausibly low. More worrisome, the UN Disability Statistics database (DISTAT2) shows huge differences in the prevalence of disability across the countries of the region (*see Chart 1.1*). Disability prevalence ranges from less than 1 percent for Singapore and Lao PDR, to a high of about 19 percent for Australia and New Zealand.[1]

It is very hard to believe that these differences in prevalence are based in reality. It is more likely that they result from using different definitions of disability. The data for the different countries cannot be compared because they do not follow the same concept.

Without reliable demographic profiles of persons with disabilities, where they live and what problems they experience, the prospects for developing and improving national plans and disability policies remain poor. Furthermore, without basic estimates of prevalence in terms that are comparable across the ESCAP region, it is difficult to see how the goals in the BMF and the Biwako Plus Five can be monitored, let alone achieved. This issue of non-comparable standards applied in the measurement and collection of disability information is precisely why implementation of the ICF is so important.

[1] Responses to the ESCAP survey on the mid-point review of the BMF implementation revealed data are on the proportion of persons with disabilities from 31 Governments in the region. The proportion ranges from a low of 0.7 per cent in the Cook Islands to a high of 20 per cent in Australia, but in the majority of cases, it is below 5 per cent. Please see E/ESCAP/APDDP(2)/1 for more details.

Chart 1.1: Prevalence of Persons with Disabilities in Asian and Pacific Countries



Sources: United Nations Demographic Yearbook System (Nov.2006) and United Nations Disability Statistics Database (DISTAT)

1.2.2 ICF and the purposes of disability statistics

How can the ICF help with the task of identifying the purposes of disability statistics and determining the needs of data users?

The details of the ICF will be the subject of the next chapter, but the role of the ICF in identifying purposes and determining data needs can be quickly summarised. The ICF helps because it is both a model of the concept of disability and an international language of disability:

1.2.3 ICF: Concept of disability

At the core of ICF's concept of disability are the facts that disability is multidimensional and the product of an interaction between an individual's certain conditions and his or her physical, social, and attitudinal barriers. The bio-psychosocial model embedded in the ICF broadens the perspective of disability and allows medical, individual, social, and environmental influences on functioning and disability to be examined. Structurally, the ICF is based on three levels of functioning (body functions and structures, activities, and participation) with parallel levels of disability (impairments, activity limitations, and participation restrictions). Human functioning is understood as a continuum of health states and every human being exhibits one or another degree of functioning in each domain, at the body, person and society levels. In the ICF language, contextual factors (environmental factors and personal factors) also constitute disability. Environmental factors include availability of assistive devices, family and community support, supportive services and policies and attitudes of different people. Personal factors include health conditions (diseases, disorders and injuries). ICF conceptualizes disability, not solely as a problem that resides in the individual, but as a health experience that occurs in a context.

The ICF tells us that any discussion of the purpose of disability statistics must begin with the question:

Which dimension of disability do you want to collect data on?

Data about impairments (problems at the level of organs and anatomical structures) is different from data about activity limitations (limitations on the capacity of a person to act or behave in a desired manner, because of a health condition), which again is different from data about participation restrictions (limitations in what a person does that result from an interaction between impairments or activity limitations and barriers created by the person's environment).

There are legitimate and vitally important needs served by all three kinds of data. However:

Different purposes require different kinds of disability data

- If your purpose is to collect information about the prevalence of physiological or psychological functions such as mental functions,

perceptual functions, voice and speech function, functions of the organ systems, and so on, then you will need **impairment data**.

- If your purpose is to collect information about the capacity of a population to perform daily activities such as mobility, communication, self-care, and interpersonal relations, then you will need **data about activity limitations**.

- If your purpose is to collect information about what members of a population actually are able to do in their lives, and, in particular, what features of their physical, built, interpersonal, or social environment help or hinder them, then you need **data about participation restrictions.**

Although it is theoretically possible to separate activity limitation information from participation restriction information, for all practical purposes, it is essential that both sets of data are collected. Otherwise, a much distorted picture of disability is presented, one that ignores the role of environmental factors in the actual lived experienced of a person with health decrements that affect capacity.

For this reason, although it adds another level of information that needs to be collected, a realistic measurement of disability across a population requires the collection of information about environment. This information takes the form either of facilitators (assistive technology, accommodations to the built environment, such as curb ramps or accessible housing or transportation, or accommodations in law or social policy) or barriers (unaccommodating physical or built environments, or stereotypical and stigmatizing attitudes). For data about environmental factors, ICF is the essential instrument.

Because the ICF clearly and systematically separates these dimensions of disability, it is the ideal tool for structuring and organizing any discussion of the purposes of disability statistics or the needs that a disability statistics can serve.

The details of how the conception of disability that underlies the ICF makes it possible to coherently develop any questions that are ‘fit for purpose’ for any data collection activity (survey, census, or administrative collection) will be discussed in **Chapter 4**.

1.2.4 ICF: International language of disability

The ICF is a set of classifications of the dimensions of disability phenomena and environmental factors. With their hierarchical arrangement, operational definitions of each category, and coding structure, these classifications together form an international common language of disability. Whatever purpose data users seek to achieve with a survey or other tool, that purpose is greatly enhanced by its international comparability of data.

The absence of a common language of disability, including a common understanding of the multidimensional concept of disability, is the principal cause of the lack of agreement on disability data around the globe. The primary aim of the ICF and WHO's motivation to engage in a decade-long, international collaborative venture to revise the 1980 version of the **International Classification of Impairments, Disabilities and Handicaps** (ICIDH) was to realize the dream of valid, reliable, and internationally comparable disability statistics. By using the common language of the ICF, every country in Asia and the Pacific will be able to benefit from the integration of disability statistics into a common worldwide data collection.

1.3 Purpose and outline of the manual

This new manual on disability statistics for the ESCAP region is needed to integrate the ICF into the process of collecting and analyzing disability statistics at the national, and eventually, international levels. ICF was endorsed by all 191 member states of the World Health Assembly in May, 2001 and WHO strongly recommends its use for all health and disability statistics worldwide.

The purpose of this manual, therefore, is to provide countries and areas in the ESCAP region with a new appreciation of disability statistics in light of the framework and classification of the ICF, as well as the factors affecting the development and collection of disability data, so that national disability statistical offices can produce disability data that genuinely meets their policy needs.

Another important reference material is the *2001* **UN Guidelines and Principles for the Development of Disability Statistics**. This provides guidelines for collecting, compiling and disseminating statistics on persons with disabilities. It includes examples from both developing and developed countries. While primarily aimed at statisticians in the collection of disability data, it is also useful to disability policy makers and program managers who develop the objectives of any data collection activity and will be the ultimate users of the resulting disability data. (Note: The **UN Guidelines** were published before completion of the ICF and so it does not provide much detail on applying the ICF to statistical collections.)

Outline of the manual

Chapter 1 introduces the basic purposes of disability statistics, and their importance for regular national statistics collections. The chapter also emphasizes the need to use the ICF as the framework for collecting disability statistics.

Chapter 2 describes the basic features of the ICF in the context of disability statistics.

Chapter 3 outlines data collection methods and instruments, including censuses, surveys and administrative collections of disability data and indicates how the ICF model can increase the usefulness of the data sets.

Chapter 4 provides details of the application of ICF to data collections, an important step in operationalizing the ICF concepts of functioning and disability into statistical measurements.

Chapter 5 discusses planning processes for and some measurement issues concerning quality of data from surveys, censuses and administrative-based data collection.

Chapter 6 looks at instrument development techniques and testing strategies.

Chapter 7 talks about the different activities that should be undertaken in preparing for data collection such as publicity campaign, coordination and others. It also guides the interviewers and supervisors on how to conduct the fieldwork and provides some guidelines on how to conduct interviews properly.

Chapter 8 shows and discusses the data processing flow. This chapter is for subject matter specialists/statisticians, processors/editors, computer system analysts and programmers.

Chapter 9 reviews issues on data collected, including analysing and disseminating disability data, an area sometimes overlooked in planning for statistical collections.

Chapter 10 lists some examples of types of statistics particularly relevant for national policies, and describes some policies that could emanate from improved disability data.

Appendix material includes a history of international mandates for disability statistics, selected case studies, a sample of the questionnaire used in pilot tests conducted in selected countries, and a guide that can be used for developing a new disability data collection.