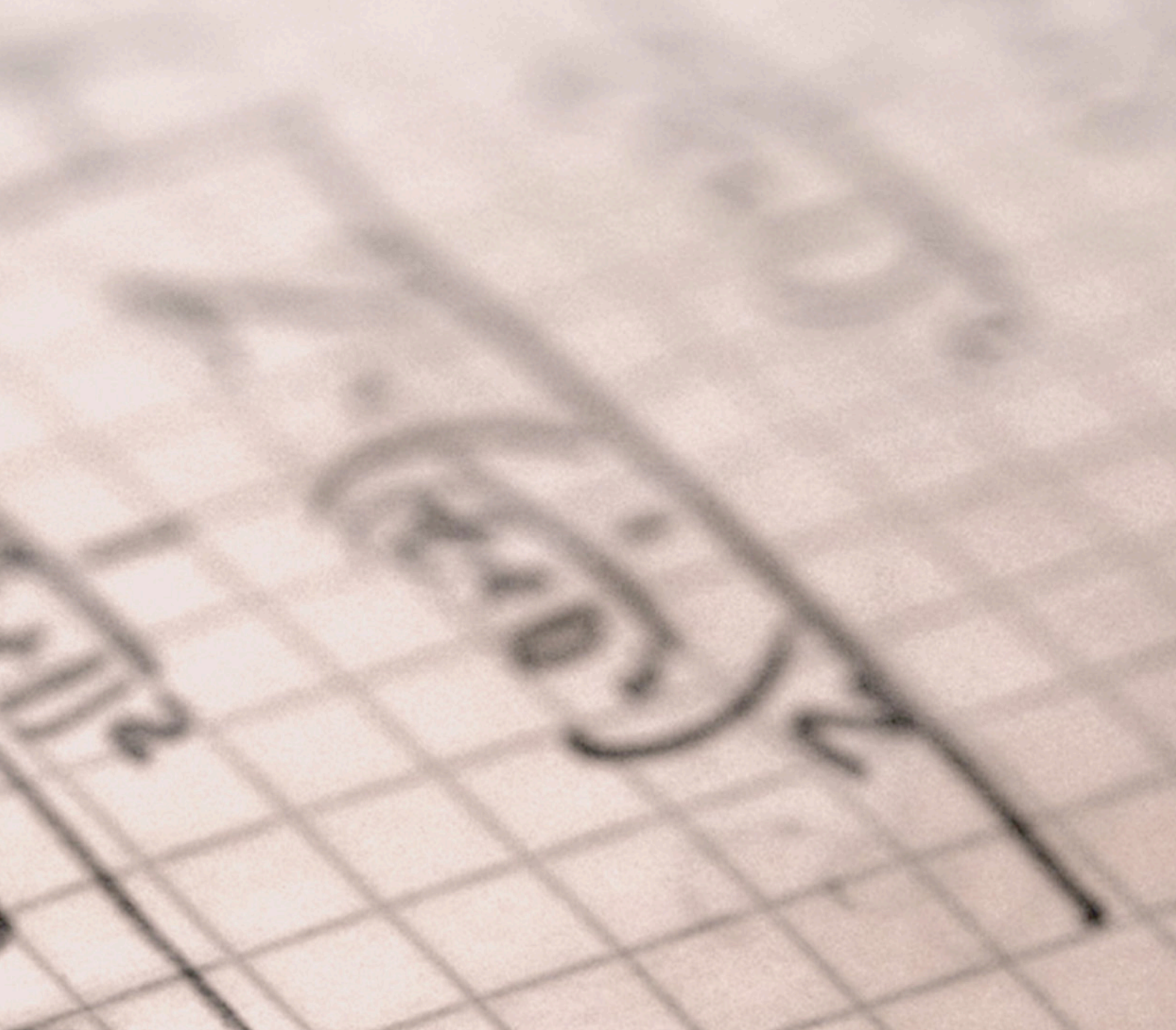


Part One: **Issues on Disability** **Measurement**



Chapter 1:

Defining, classifying and measuring disability

Disability is a complicated concept. In common usage, it means different things to different people. Disability is also very heterogeneous, varying by type, severity, cause, age of onset, and in the way people's impairments interact with a wide range of environments. In fact, the identification of persons with disabilities and the tools one uses can change depending on the purpose for doing so. Therefore, before discussing specific indicators, it is important to explicitly set out the approach to disability taken by the Incheon Strategy and how it relates to the issue of disability identification.

The CRPD's definition of disability

The Incheon Strategy follows the definition of disability adopted by the CRPD. According to the CRPD, "persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".

An impairment is a personal characteristic that can limit an individual's functional capacity separate from their environment. That is, it describes difficulties people have in basic body functions. One example of an impairment would be having paralyzed legs. An impairment such as this might prohibit basic activities such as standing, walking or climbing stairs. However, environmental barriers are what make this person disabled.

In other words, environmental barriers disable people by preventing (or limiting) those with such impairments from exercising their rights to participate fully in society. These barriers go beyond simply physical ones to include social and policy barriers. Inaccessible buildings, roads and transport systems, and the lack of assistive devices, can pose barriers to participating in education and training, employment, and family and community life, but so can negative attitudes, low expectations, and laws and institutions that do not support inclusion.

Thus, disability should not be thought of as a medical condition but rather as something that emerges from the interaction between personal functioning and the environment. The old medical model or charity model approaches tend to focus policy solely on the individual — “fixing” their condition or supplying them with a safety net. The approach in the CRPD broadens the role of policy to creating inclusive environments where people, regardless of their impairments, can fully participate in society, which is seen as their right.

The International Classification of Functioning, Disability and Health

The CRPD’s approach to disability is similar to that taken by WHO’s International Classification of Functioning, Disability and Health (ICF). The ICF defines disability as “...an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors)”.⁴

The ICF model is captured in Figure 1. A health condition can create an impairment at the Body functions and structures level, but it also can impact functioning in regard to Activities and Participation. In the earlier example, not being able to move one’s legs is a limitation in Body functions and structures. Walking would be an associated activity, and participation refers to higher order undertakings like attending school, being employed and participating in civic and family life. The difference between Activities and Participation is sometimes unclear, but for practical purposes not that important. Typically, Participation involves the coordination of many activities. Going to school requires getting to school, communicating, learning, etc.

Using this model, the ICF delineates the full range of body functions, structures, activities, and participation of which a human is potentially capable. It also contains a detailed classification of environmental factors that can be used to classify what a person is capable of in their current environment and in an ideal one that has eliminated structural and attitudinal barriers to participation. The ICF is not a measurement tool, but it is rather a

4 WHO (2001). *International Classification of Functioning, Disability and Health*. Geneva.

Figure 1: The ICF Model



guide to develop statistics and indicators in a way consistent with the CRPD's approach to disability. How this is done, depends on the purposes for measuring disability.

The purposes for measuring disability

At the first meeting of the United Nations Statistical Commission's Washington Group on Disability Statistics (WG) in 2002, the over 40 countries participating were asked why they wanted to collect information on disability. Their reasons were collected and analysed. They fell into three main categories:

- Providing services
- Monitoring the functioning of the population
- Assessing the equality of opportunities for persons with disabilities and persons without disabilities

This section elaborates on these purposes and explains the data needs associated with them.

Providing Services. One reason for collecting data on disability is to design and implement services for persons with disabilities — either via special programmes for them, or by making general programmes more inclusive. Estimating the need for services requires collecting information that serves for eligibility determination. But, beyond that, the need exists for gathering information on the specific types of services required and the specific barriers limiting the delivery of those services, such as: what types and what quantities of assistive devices, trained personnel and distribution systems are needed.

Monitoring the Functioning of the Population. Monitoring can also take place at various levels of functioning — body function, activity or participation — depending on the goal of the monitoring. A government might want to assess the scope of potential concerns relating to disability. Monitoring body functioning pertains more to programmes designed for the prevention of impairments associated with disability. This requires less detailed information than providing for services.

Equalization of Opportunities. The third main reason for collecting data on disability is to track whether society is becoming more inclusive; that is to determine whether the opportunity gap between persons with disabilities and those without disabilities is closing.

One may want to see if and to what extent participation of persons with disabilities is limited because of an inaccessible and disabling environment.

An approach for assessing this is to focus on people's basic activities — such as walking, seeing, hearing, communicating, concentrating and remembering — and to formulate questions around these activities. This is the approach to disability used in the World

Disability Report,⁵ that generates the widely cited 15.3 per cent global disability prevalence, and the same approach is taken by the WG for writing census questions. This does not mean that 15.3 per cent represents the share of people who need disability benefits. Instead, this represents the share of people experiencing functional difficulties that could potentially limit their participation if they are faced with an unaccommodating environment (built, social or policy). The prevalence for severe disability listed in the World Disability Report is about 3 per cent.

Questions for identifying persons with disabilities

This guidebook will continually come back to this issue as it discusses the various indicators in the Incheon Strategy. Some important principles cut across all attempts to measure disability — that is, to identify persons with disabilities with quantitative data instruments.

The first principle is to avoid using the question “Do you have a disability?”, a very poor way to identify persons with disabilities. Censuses and surveys which have used this question continually come up with very low rates of disability.⁶ Many people think that the word “disability” refers only to the most serious limitations, so persons with mild or moderate disabilities will often respond in the negative. The word is often associated with stigma, which also leads to underreporting. Sometimes older persons view their functional limitations as just a part of ageing and not a disability, even if it limits their participation in several dimensions. For policy purposes, it might be important to separate out people whose disability is caused by age or other reasons, but for identification purposes or for determining prevalence it is important that all persons with disabilities be included.

The second principle is to avoid using a list of diagnoses — for example, epilepsy, leprosy, paralysis, cerebral palsy, etc. — to detect respondents’ disabilities. This also leads to underreporting. Any list of diagnoses is not going to be complete. It also introduces bias, because people who are better educated or who have better access to health care are going to be more likely to have a diagnosis. Moreover, a diagnosis does not tell much about the person’s ability to function, even at a body function and structure or basic activity level.

Instead, the third principle, and the standard approach to identify persons with disabilities in quantitative data instruments, is to focus on people’s level of difficulty undertaking various activities (Box 1). It is best practice for the response categories to avoid the use of Yes/No questions. Depending on the purpose for identifying people, different thresholds of difficulty can be used as cut-offs for considering a person to have a disability; but collecting a full range of difficulties leads to richer and more accurate data.

5 WHO, World Bank (2011). *World Report on Disability*. The World Bank, Washington, DC.

6 Mont, Daniel (2007). *Measuring Disability Prevalence*, SP Discussion Paper No. 0706. The World Bank.

Box 1:
Short set of questions on disability endorsed by the Washington Group

- 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 scales to the questions above:

- a No — no difficulty
- b Yes — some difficulty
- c Yes — a lot of difficulty
- d Cannot do at all

The heterogeneity of the population of persons with disabilities

A single estimate of disability — like the 15.3 per cent prevalence from the World Report on Disability — masks a great deal of heterogeneity. The World Report points this out and notes that the rate of severe disability is closer to 3 per cent. In fact, when examining people's functional capacity, it is clear that functioning (and disability) is far from a discrete

variable. People's functional difficulties lie along a relatively smooth distribution.⁷ Again, the cut-off between a person being disabled or not disabled depends on the reason for identification. For the purpose of providing permanent cash benefits, the cut-off might be quite high. A government might only want to provide such benefits to people for whom there is no possibility of work. However, for designing an inclusive school system it might be important to be aware of the full range of difficulties that children confront in school — from mild to severe. This is why estimates of child disability prevalence in developed countries are so much lower than the percentage of children receiving special services in school.⁸ It is important to keep the concepts of programme eligibility for particular programmes and the disability prevalence for other purposes distinct, even if they are related.

Another axis of heterogeneity is the wide range of impairments. They can be physical, mental, sensory (seeing and hearing), or psychosocial. The latter category is generally the most difficult to measure, especially in quantitative instruments, and therefore often gets overlooked.

Date of onset is another important factor in collecting information on disability. For example, in the context of the impact of disability on education, if a person gets a disability during his or her prime working years, then disability will have no impact on their primary or secondary schooling. Simply looking at school completion rates of adults who have some form of disability versus those without disability will thus underestimate the impact of disability on children. Or, considering people who become blinded in industrial accidents, at first they might barely be able to care for themselves and may also be suffering from debilitating psychological issues. Over time, though, with rehabilitation and support, their ability to participate will improve.

This leads into the last type of heterogeneity, which is the nature of the environment. Even people in the same country — but in different regions or economic groups — might face very different environments which have a big impact on the extent of their disability. Capturing this is the topic of the next chapter.

Childhood disability

It is very important to note that identifying disability in children under the age of 10 is more difficult than identifying disability in adults. A short set of questions, like those proposed by the WG for censuses, may therefore be inappropriate. Childhood functioning is more varied than functioning in adults and identifying functional difficulties is confounded by

7 Loeb, Mitchell, and Mont, Daniel (2010). A Functional Approach to Assessing Health Impacts on People with Disabilities, *ALTER: European Journal of Disability Research*, Vol. 4, issue 3, pp. 159-173, July-September 2010.

8 OECD (2004). *Students with Disabilities, Learning Difficulties, and Disadvantages: Statistics and Indicators*. Paris.

underlying variation in typical childhood development. For that reason, special procedures are needed for identifying childhood disability.⁹

A first stage screening device is used to identify children who are expected to have a high probability of being disabled. Then, a second stage more detailed assessment by health-care professionals is administered to those screening positive and a small percentage of those screening negative in order to account for false negatives in the initial screen. Until now, the most commonly used first stage screening instrument has been the Ten Question Screening Instrument (TQSI). However, UNICEF and the WG have recently developed an updated set of questions, which have been tested in several countries. UNICEF is also currently working on a set of recommendations for the second stage assessment.

Because of the difficulty of assessing disability in young children, several of the indicators in this guidebook focus on people aged 10 and older. Special studies are needed to monitor the well-being of children with disabilities. UNICEF will recommend the adoption of its new procedure into the sixth round of the Multiple Indicator Cluster Survey (MICS), their tool for monitoring children's well-being.

9 UNICEF (2008). *Monitoring Child Disability in Developing Countries: Results from the Multiple Indicator Cluster Surveys*. UNICEF, New York.