Chapter 3: Mainstreaming disability data collection

A major issue in disability data collection is the extent to which data needs can be met by mainstreaming information on disability into existing surveys and censuses, and to what extent special modules or even special disability surveys are required. Mainstreaming disability data collection has several important advantages. First, it allows the disaggregation of existing indicators that are well understood. Second, it effectively reduces the cost of collecting disability data by only adding a disability module into existing tools. And third, it provides a signal that the considerations of persons with disabilities are a core policy issue, rather than being tangential and suitable only for special surveys.

Nevertheless, there are times when a special disability survey may be required. The government may wish to obtain information that goes beyond what is appropriate for existing instruments. Maybe the desired information is too detailed, and thus would require excessive space when using the data tool. Sometimes a different sample is needed to disaggregate results by type of disability or some other sub-population characteristic. Finally, some indicators may be expected to change slowly, and are thus not required to be collected as regularly as some core economic or social indicators. For example, the key barriers to employment may not change much on a yearly basis, so information on those barriers should only be collected every few years. For these reasons, there are times when a special disability survey is required — or a special module on disability that can be included with ongoing survey instruments — but only at certain periodic intervals.

Given space constraints on many surveys, censuses, and administrative forms, it is often necessary to minimize the number of questions. As the WG questions were specifically designed to represent the minimum set for a reliable identification — and have been tested widely in many developed and developing countries — it is recommended that they be considered the core disability questions to be used across data instruments.

When it comes to constructing Incheon Strategy Indicators, people should be considered to have a disability if they answer "a lot of difficulty", or "cannot do at all", to at least one of the WG questions (Box 1). This is the measure of disability used in the World Report on Disability.

However, more in-depth analysis can be done to look at persons with lower levels of difficulty (possibly in more than one functional domain) to understand the impact of more moderate disabilities. In some country contexts, persons with more mild functional difficulty may have significantly poorer outcomes than people without disabilities. For example, having a vision problem correctable by glasses is a minor medical condition that in most places would not be disabling. But if there were no access to glasses, then those people may, for instance, experience higher dropout rates from school and thus have poorer economic outcomes. It would be therefore useful to report a number of the Incheon Strategy Indicators not only for persons with more restrictive levels of disability ("a lot of difficulty", or "cannot do at all"), but also for the population of persons with any level of difficulty (Box 1).

It is very important that a common approach is taken to measuring disability across all of the associated instruments. If, for example, the method for identifying persons with a disability in a health survey is different from that used in an expenditure survey, then one cannot make inferences across surveys. As stated in the previous chapter, however, this does not mean that the eligibility rules for all programmes need to be the same, or that the same severity thresholds are used to define the disabled population of interest for every purpose. It only means that the questions being asked in different data instruments are the same, so that the relationship between different subgroups of interest can be better understood.

When more detailed information on disability is required — or where space permits — additional questions can be added to existing tools. Extended questions on disability have also been developed and tested by the WG, and WHO is currently designing an extended survey on disability. These can serve as examples of disability questions, though they may have to be adjusted somewhat to meet the local context. The core questions provided in Box 1, however, should always be included in order to create a crosswalk to better understand the relationship between indicators derived from different instruments.

Guidance on the appropriate data instrument and frequency of data collection is presented in this guidebook for all of the Incheon Strategy Indicators.

Moving forward on creating better disability data may require a few steps:

1   A review of existing data collection on disability to assess its quality, gaps and, where the data are appropriate, to generate baseline information;

2   Testing and adapting internationally recognized measures of disability for use in a country's censuses, surveys and administrative data for the purpose of identifying persons with disabilities, so their outcomes can be compared to the outcomes of persons without disabilities;

3   Development of questions for a national disability survey (or other survey) that focuses on environmental barriers to participation. This should be done in consultation with disabled people's organizations (DPOs) and other potential users of the data to capture the concerns of the particular country context and policy issues;

4   Review donor-driven data tools to suggest modifications to make them consistent with the country's needs for disability indicators;

5   Coordinate between line ministries to ensure that a consistent approach is taken that can meet both the needs of users within each ministry, but also with regards to cross-cutting issues.

ESCAP Guide on Disability Indicators for the Incheon Strategy