Washington Group Methodology

Disability is a complex and dynamic process that presents considerable challenges for data collection. The definition of disability has changed over time and is currently conceptualized as the outcome of the interaction between a person with a functional limitation (difficulties doing basic functional activities) and an unaccommodating environment resulting in the inability to fully participate in society. Thus, to provide complete information on all aspects of disability would require extensive and detailed data collection on almost all aspects of life including body structure and function, individual functional abilities across the full range of activities, a full description of all aspects (physical, cultural, legal) of the environment in which a person lives, and levels of participation across the full range of social roles (e.g. work, school, social interaction, community engagement, civil participation). This is not practical and for many purposes is not necessary.

Multiple tools can be used to address the different components of the disability framework. The data collection tools developed by the WG are easily incorporated into ongoing national data collection systems, as well as topic-specific surveys, programmatic, and research data collections. The tools are designed to complement each other, making it possible to use information from different sources together. When selecting a tool, it is critical to match the tool with the intended use of the data and the data collection method.

Data collection tools developed by the WG reflect advances in the conceptualization of disability and use the World Health Organization’s International Classification of Functioning, Disability, and Health (ICF) as a conceptual framework. In a break from the past and the medicalization of disability that placed disability within the person and characterized it by impairments or deficits in bodily functions, the ICF presents a bio-psychosocial model that locates disability as at the interaction between a person’s capabilities (limitation in functioning) and environmental barriers (physical, social, cultural or legislative) that may limit their participation in society.

ICF Model of Disability (WHO, 2001)

WG tools use the ICF as a framework, focusing on the component of activity, or functioning, limitations. Highlighted in green above.

As mentioned above, rather than a dichotomous (Yes/No) static state, disability is a dynamic, complex process that must be understood and ‘unraveled’ in order to create a measurement tool that would have international relevance and could produce cross-nationally comparable data. The complexity of the concept has resulted in the proliferation of statistics on disability that are neither comparable nor easy to interpret. Furthermore, disability data are collected for different purposes such as to estimate population prevalence or the need for providing certain services. Each purpose will elicit a different statistic and even when the intention is to measure the same concept, the actual questions used will differ in ways that severely limit comparability. The conclusion is not that some estimates are right and others are wrong, but that they are measuring different things. The WG chose to develop questions that would address the issue of whether persons with disability participate to the same extent as persons without disabilities in activities such as education, employment or family/civic life. A major reason for this choice is the pivotal importance of the issue of social participation and equal rights from a policy perspective as illustrated by the UN Convention on the Rights of Persons with Disabilities and the requirements established in the 2030 Agenda on Sustainable Development. To that end, the WG focused first on measuring difficulty functioning in six basic, universal actions that, in an unaccommodating environment would place an individual at risk of restricted social participation. (This is the WG Short Set on Functioning.) The measurement of environmental barriers and participation (e.g. access to education or employment) are extramural; the task then is in data analysis to determine whether persons identified with difficulties or limitations in these basic actions have participation rates equal to those without limitations.

The WG questions were designed to provide comparable data cross-nationally for populations living in a variety of cultures with varying economic resources. While the ideal would be to collect information on all aspects of the disablement process as depicted in the ICF (impairments, activity limitations, participation restrictions and environmental barriers and facilitators) and to identify every person with a disability within every community, this would not be possible given the limited number of questions that can be asked on a national census and in most surveys. The basic actions represented in this set of six questions are those that are most often found to limit an individual and result in participation restrictions. Domains were selected using the criteria of simplicity, brevity, universality and comparability. The information that results from the use of these questions will, a) represent the majority of, but not all, persons with limitation in basic actions, b) represent the most commonly occurring limitations in basic actions, and c) be able to capture persons with similar problems across countries.

For more detailed information on the methodology used by the WG please see the following pages: Implementation Guidelines, Translation Guidelines