A data revolution for disability-inclusive development

7 years after the Convention on the Rights of Persons with Disabilities was adopted, disability is still largely absent from data collection and monitoring mechanisms in international development and global health. However, some isolated data collection efforts have documented the experiences of people with disabilities in a few low-income and middle-income countries (LMICs). The upcoming High-Level Meeting of the United Nations General Assembly on Disability on Sept 23, 2013, and the ongoing preparation of the post-2015 development agenda provide a unique opportunity to integrate disability in data collection mechanisms in development and global health.

The Millennium Development Goals (MDGs) did not make any mention of people with disabilities. By contrast, a report by the High-Level Panel on the Post-2015 Development Agenda refers to disability in several sections. Tackling disability is part of the call to end extreme poverty and leave no one behind: “we should ensure that no person—regardless of ethnicity, gender, geography, disability, race or other status—is denied universal human rights and basic economic opportunities”. The report also calls for a plan to measure progress and for an overhaul of data collection: “data must also enable us to reach the neediest, and find out whether they are receiving essential services. This means that data gathered will need to be disaggregated by gender, geography, disability, and other categories, to make sure that no group is left behind”. It adds that such disaggregation should be part of all targets.

At present, such measurement of progress and disaggregation by disability is impossible because of missing data. A disability data revolution is needed. Disability is complex: no gold standard measure exists, different measures exist for different purposes, and the use of different measures in different countries makes international comparison of prevalence or outcomes difficult. However, more is now known about disability prevalence, recently estimated at 15% or 1 billion people worldwide, 80% of whom live in LMICs. The ground for a data revolution has been prepared. We now know more about how to measure disability than when the MDGs were adopted. Since 2001, a worldwide effort has been made to collect internationally comparable disability data through the UN’s Washington City Group on Disability Statistics. This group includes more than 100 representatives of government, non-government, and disabled people’s organisations, organised under the UN’s Statistical Office. It has made recommendations for a shortlist and an extended list of questions to measure disability consistently worldwide. The shortlist includes six questions—five of functional limitation (limitations in seeing, hearing, walking or climbing steps, concentrating, and communicating) and one of self-care (limitation in showering or dressing). A list of questions for children is also undergoing cognitive and field testing. The Washington Group’s recommended questions capture many but not all aspects of functioning. They have been developed to assess equal opportunities and are not suitable for other purposes, such as identifying needs for rehabilitation or barriers in the environment, which might need a longer set of questions or a dedicated disability survey. However, the questions enable disability to be measured in a valid and internationally comparable manner that does not entail a long separate module or survey.

The UN encourages governments to include (at a minimum) the short set of questions in censuses and surveys. Several countries have already adopted the recommended questions, but these individual country efforts are still insufficient to ensure the global and systematic monitoring of progress called for by the High-Level Panel on the Post-2015 Development Agenda. International agencies and donors also have an important part to play. Two widely available data sources on global health and poverty in LMICs are the Demographic and Health Survey of the United States Agency for International Development and the Living Standard Measurement Study of the World Bank. Data from these studies do not generally have questions on disability and if they do, they sometimes do not apply the best evidence for disability measurement. For instance, in Haiti, the 2012 Living Standard Measurement Study includes questions about impairment, although they lead to under-reporting of disability.

The adoption of the questions of the Washington Group in the Demographic and Health Survey and the Living Standard Measurement Study would start the data revolution that is needed to measure progress towards inclusive development and global health and to monitor
the implementation of the post-2015 development agenda as well as the Convention on the Rights of Persons with Disabilities. Such data is needed to assess whether people with disabilities are left behind or if they have proper opportunities and human rights.

Sophie Mitra
Fordham University, Bronx, NY 10458, USA
mitra@fordham.edu

I declare that I have no conflicts of interest.