

Model Disability Survey: Providing evidence for accountability and decision-making

Consensus in the global human rights, development and health communities demands action to improve the health and well-being of people with disability, and to reduce the barriers that hinder their participation in society on an equal basis with others. Effective policy-making in this area requires reliable, detailed data on all aspects of disability – impairments, activity limitations, participation restrictions, related health conditions, environmental factors—information that is lacking in most countries. The Model Disability Survey (MDS) is designed to address these data gaps.

WHAT IS THE MODEL DISABILITY SURVEY (MDS)?

The MDS is a general population survey that provides detailed and nuanced information on the lives of people with disability. It allows direct comparison between groups with differing levels and profiles of disability, including comparison to people without disability. The evidence resulting from the MDS will help policy-makers identify which interventions are required to maximize the inclusion and functioning of people with disability.

The MDS is grounded in the International Classification of Functioning, Disability and Health (ICF) and represents an evolution in the concept of disability measurement. It explores disability as an outcome of interactions between a person with a health condition and various environmental and personal factors, rather than focusing only on a person's health or impairments. This gives a more complete understanding of the lived experience of people with disability and provides a better approximation of the true size of the population with disability.

WHY IS THE MDS NEEDED?

- There is no standardized instrument for data collection on disability that provides comprehensive and systematic documentation of all aspects of functioning in a population.
- Existing data focus mainly on impairment or activity limitation and do not provide the evidence base needed for effective public policy that improves the well-being of people with disability.
- To implement the *Convention on the Rights of Persons with Disabilities (CRPD, 2008)*, countries need reliable data and evidence. The CRPD therefore requires Governments to collect statistical and research data to identify and address barriers faced by people with disability, to formulate and implement policies, and to help assess progress implementing States Parties obligations under the Convention (*CRPD, Article 31*).
- Both the *UN High-Level Meeting of the United Nations General Assembly on Disability and Development (2013)* and the *UN High-Level Panel of Eminent Persons on the Post-2015 Development Agenda (2013)* call for radical improvements in disability data collection, analysis and monitoring.
- The *World report on disability*, the most recent World Health Assembly resolution on disability (*A66/12, 2013*) and the *WHO global disability action plan 2014-2020 (A67, 2014)* urge WHO Member States to establish and strengthen monitoring and evaluation systems for disability that include information on needs and unmet needs, costs, barriers and quality of life.

GUIDING PRINCIPLES

- People with disability have a right to participation in society on an equal basis with others.

- Disability is an outcome of the interaction between a person with a health condition and contextual factors. It is not merely an attribute of the person.
- Disability is a continuum, a matter of degree. The experience of disability is diverse.
- Disability measurement should consider societal or environmental barriers that can have a strong disabling effect, as well as an individual's impairments and health condition.
- Questions that focus on the respondents' lived experience and real-life environment will yield a better understanding of how disability affects people's daily lives, and what can be done to improve their lives.
- Cross-national relevance and standardization of the questionnaire are essential. A modular format allows it to be used as a stand-alone survey or incorporated into other national surveys.

USES OF MDS DATA

- The understanding of how people live their lives and the identification of key barriers to full participation are crucial to helping Governments actualize their *CRPD* obligations, and to determine what actions are required to promote and protect the human rights of people with disability.
- The MDS provides for more robust prevalence estimates for tracking national trends and making international comparisons.
- Analysis of the interaction between health conditions and environmental factors will facilitate more effective policy in many areas, e.g. assistive devices and accessible environments.
- Sufficiently detailed analysis facilitates monitoring the situation of people with disability, to make sure they are not left behind in the wake of development progress, and to identify ways to include disability in national development agendas. These are priorities of the Post-2015 Development Agenda.
- MDS data can be used in intersectoral policy-making, e.g. national poverty reduction strategies, and in sector-specific policies, e.g. to monitor the reach of universal health coverage and to plan improvements in health service policy and delivery, to maximize the likelihood that people with disability may obtain the health services they need without suffering financial hardship.

MDS DEVELOPMENT PROCESS

The World Health Organization and the World Bank have developed the MDS questionnaire in collaboration with the Washington Group on Disability Statistics, Statistics Norway, and a diverse range of other stakeholders, including the International Disability Alliance. Throughout the process, steps have been taken to insure comparability with existing instruments. This work is funded by the Governments of Australia, Germany and Norway.

The MDS draws on questions from 179 disability surveys, which have been analyzed and mapped to the ICF. Drafts of the questionnaire have been reviewed in expert consultations. The revised questionnaire is undergoing cognitive testing to evaluate whether the questions perform as intended. Results from the first round of cognitive testing are highly favourable. The concept of the MDS is fully supported by organizations representing people with disabilities.

Pilot studies and the first national survey are planned for 2014. The final questionnaire and supporting materials are expected to be made freely available on the WHO website. Planning has begun for a Multi-Country Study on Disability, and for providing support for data collection, analysis and utilization.

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