Original Article

The development and testing of a module on child functioning for identifying children with disabilities on surveys. I: Background

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ABSTRACT

This is the first of three papers that will document the development of a survey module on child functioning developed by UNICEF in collaboration with the Washington Group on Disability Statistics (WG), and demonstrate — both conceptually and through test results — the strengths of that module compared with alternative tools for identifying children with disabilities in household surveys.

This first paper in the series sets the background and reviews the literature leading to the development of the UNICEF/WG Child Functioning Module (CFM) and presents the WG Short Set of questions (WG-SS) and the Ten Question Screening Instrument (TQSI) as precursors, outlining some of their shortcomings and how the UNICEF/WG CFM was designed to meet those challenges.

Subsequent articles will summarize results from the cognitive and field testing of the CFM including comparisons with results derived from the TQSI and the WG-SS.

Published by Elsevier Inc.

Adoption and enforcement of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD),[1] currently ratified by more than 160 countries, has renewed efforts to mainstream disability on the international agenda. The UNCRPD is a milestone in the promotion and protection of disabled persons' rights: it reaffirms that all persons with disabilities should enjoy every human right and fundamental freedom to effectively participate and be fully included in society on an equal basis with others. Furthermore, the Convention dedicates a specific article to children (art. 7) that outlines the obligation of States to ensure the realization of all rights for children with disabilities, to promote their best interests, and to ensure their right to be heard. Furthermore, the Convention incorporates, within its general principles (art. 3), the respect for the evolving capacities of children with disabilities and their right to preserve their identities.

The Convention also recognizes (art. 31) the importance of data collection on disability, stating that "Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention" and that "States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others". The World Report on Disability also states that "internationally, methodologies for collecting data on people with disabilities need to be developed, tested cross-culturally, and applied consistently" [2 page 26 7] and that data need to be standardized and internationally comparable for monitoring progress on disability policies, and on the implementation of the UNCRPD across the world. Disability has been explicitly included in the recent post-2015 Sustainable Development Goals, including, in addition to various disability-specific indicators, as a characteristic for disaggregating all personal level indicators.

Disability is a complex and dynamic process that presents considerable challenges for data collection. The first step towards producing good indicators of disability is to have a clear definition that can be operationalized in a quantitative data collection instrument, such as a survey or census. 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 activities) and an unaccommodating environment resulting in the inability to fully participate in society. In

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the past, in part due to the complex nature of disability, measures of disability have either been excluded from data collections or have varied widely both across countries and within countries across different instruments. Therefore, it is not surprising that past estimates of disability prevalence have also varied widely, depending upon the approach.[3]

When it comes to estimates of childhood disability, across countries prevalence rates range from below one percent to nearly 50 percent depending on the methodology used.[4] Without a high quality, internationally agreed upon measure of childhood disability it is impossible to know if these differences are the result of true differences in the underlying rates of disability or simply an artifact of different methodologies.[1] Moreover, it is not just prevalence rates that are affected by the lack of standardization in measurement. Comparisons of outcomes for children with and without disabilities are also affected by how disability is measured.

The lack of data on disability in children is widely acknowledged.[2,5] This lack stems in large part from conceptual difficulties in defining disability in children, and methodological challenges in the operationalization of the selected definition.[6] Providing reliable data on children with disabilities through population surveys poses complex theoretical, philosophical and technical issues.[7]

Even if data collection on childhood disability has generally increased over recent years, these data are still limited and inadequate in terms of description of children with disabilities and how the disabilities affect their lives. This is especially true in low- and middle-income countries[5,8,9] where the lack of cultural and language-specific tools for assessment[10] and high cost of administering population-based surveys of childhood disability[11,12] are common obstacles.

Indeed, several factors undermine the cross-national comparability of the data available on child disability.[5,6,13–15] Disability is defined and conceptualized differently across countries affecting how different cultures count their citizens with disability. Differences in values, or attitudes towards individuals with disabilities, influence not only the type of data being collected (what questions are asked and how questions are framed) and the data collection process but also how individuals will respond to these questions.[16]

Cappa et al.[4] provide a comprehensive review of data collection instruments that have been operationalized over the past 190 years from among 716 data sources in 198 countries. A variety of methodologies have been actualized to measure child disability. While some countries use questions specifically developed to assess childhood disability (e.g. MICS[9]), others pose the same questions to children as those used for adults (e.g. American Community Survey[4]). Considering the age of the reference population, some surveys or censuses pose the questions from birth (Tanzania 2008 Household survey[4]) while others from a certain age (Egypt 1999, 2 years and above,[4] or MICS,[9] 2–9 years). Furthermore, some surveys (e.g. Timor-Leste 2004 Census[4]) adopt a dichotomous answer category, while others use multiple response categories with severity qualifiers (e.g. Serbia 2011 Census[4]). When a severity scale is applied, different types and numbers of items are used and the threshold selected may be different. Therefore, there is a clear need to harmonize child disability measurement in order to produce estimates that are reliable, valid and internationally comparable.[5]

The dichotomous approach of asking if a household member "is disabled" or "has a disability" leads to significant underestimates of disability prevalence. Stigma, and the notion that disability refers only to a severe – often only a medically diagnosed – impairment, results in further under-identification of people with disabilities, especially of people with more moderate or less visible difficulties.[3] When the conception of disability is based on the medical model, questions are formulated around impairments or medical diagnoses. Such an approach also tends to under-estimate disability. Lists of diagnoses are never fully comprehensive and people with less access to health care are less likely to know their diagnosis, which leads not only to underestimates, but biased ones, as well. In addition, research shows that in responding to questions about disability in the household, children and people of lower socioeconomic status are often overlooked, making them even more under-identified.[17,18]

In wealthier countries where services are available, children are often identified as having a disability in educational or medical settings, and then, often by diagnosis. Identification of children with disabilities in poorer countries, where such settings are lacking or not universally available, varies or simply does not occur. Even in the wealthier countries, children with disabilities who lack access to services, or who do not fit into certain diagnostic categories, can also be missed.[17,19]

The bio-psychosocial model of disability approaches the issue differently, looking at the interaction between a person's capabilities and environmental barriers that may limit their participation in society.[1,3,20] This is also consistent with the conception of disability recognized by the International Classification of Functioning, Disability, and Health (ICF).[21]

The focus is thus not on what condition a person may have, but rather on what they have difficulty doing – for example, not asking if a person has cerebral palsy or an amputated leg, but rather asking if the person has difficulty walking. While numerous countries have collected data on children with disabilities over a long period of time, this approach – which is known to produce higher estimates of disability prevalence – is rather recent.[20]

Prior to the adoption of the ICF, the Ten Question Screening Instrument (TQSI) was accepted as a standard tool to measure disability among children in low- and middle-income countries.[19] These questions, designed to be answered by mothers in a relatively short amount of time, do not ask about diagnoses or the presence of a "disability", but rather ask whether the child is capable of doing basic activities appropriate to his or her age. In recent years, this tool has been used in many data collection efforts, including as part of UNICEF-supported Multiple Cluster Indicator Survey (MICS) program, the largest source of comparable data on several indicators of child well-being for low- and middle-income countries.[9] While the TQSI was an improvement over previous methodologies, various problems emerged with its continued use as a method for generating population estimates of childhood disability. One problem was that the TQSI was not used as intended. As explained below, the TQSI was designed as a two-stage procedure.[9,22] The ten questions were designed to cast a relatively large net, and then be followed up by a more extensive clinical assessment in a second stage. The second stage, however, is rarely conducted because it is expensive and logistically complicated. Most surveys using the TQSI only administer the first stage, which tends to generate significant levels of false positives.

In order to address these challenges, the Washington Group on Disability Statistics (WG)[2] and UNICEF have developed a module specifically on child functioning that can be used as a component of national population surveys or as a supplement to surveys on

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[1] For a comprehensive review of past efforts to collect childhood disability data see.[4]