

UNICEF's Involvement in Measuring Child Disability



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Measuring Child Disability

A society cannot be equitable unless all children are included, and Children with disabilities cannot be included unless sound data collection and analysis render them VISIBLE.

However, measuring child disability presents a unique set of challenges.

- The varying nature and severity of disabilities, together with the need to apply age-specific definitions and measures, usually complicate the data collection efforts.
- In addition, the poor quality of data on child disability stems, in some cases, from stigma or insufficient investment in improving measurement.



Challenges to ensure reliable data on Children with Disabilities

- Sex and age disaggregated estimates on children with disabilities are rarely available.
- The reasons are multiple:
- out- dated definitions and measures of disability are often used to gather data;
- inadequate resources and statistical capacity exist in many countries;
- children with disabilities are often rendered invisible in institutions or have their existence denied by their families due to stigma or poor detection systems that prevent the collection of reliable data (the hidden population);
- data collection methods are often too inconsistent to be reliable.



Some Statistics

Available figures may therefore be speculative Some estimates indicate the following:

- Over one billion people or 15% of the world's population live with some form of disability, and of these, between 110 and 190 million have significant difficulties in functioning, according to the World Report on Disability.
- The estimated number of children with disabilities between 0 and 18 years ranges between 93 million and 150 million, depending on the source.
- The World Report on Global Burden of Disease study of 2004 estimates that amongst those aged 0–14 years, roughly 5.1% of all children (93 million) live with a 'moderate or severe' disability and 0.7%, or 13 million children, live with severe difficulties.

Regional overview:

The situation of children with disabilities in EAP

- 650 million persons (15%) with disabilities live in Asia-Pacific.
- Government submitted data:
 - 200 million persons with disabilities (4.6%)
 - Large variations across countries
 - Predominance of medical and charity models
 - Lack of systematic cross-sectoral approaches at policy and implementation levels
 - Low enrolment and completion rates in education

The 2014-2015 East Asia and Pacific regional study on the situation of children with disabilities revealed that there is a serious under-estimation of the number of children with disabilities (often at around 1-2%).

Why do we need data ?

- Reliable data are central when advocating for legislation, policies, funding, programming and the inclusion of disability on national and international political agendas.
- Data allows policymakers, programme staff and researchers to monitor the level of disability within child population (especially children) and to understand trends in disability prevalence, serious diseases and trauma; and plan interventions/services designed to improve child health and development.
- Having statistics that are comparable can also highlight international and intra-national inequities between different populations of children with disabilities, for example by ethnicity, sex, age, region, or type of impairment.



Sources of data and Children with Disabilities

- Data on child disability are available from a large array of sources, including censuses, administrative records, national disability surveys and national household surveys.
- However, the varying methodologies used and overall quality of data collected makes comparisons across countries problematic.
- General data collection instruments are likely to underestimate the number of children with disabilities.
- Children with disabilities in particular are likely to be overlooked in surveys that do not specifically ask about them.



Tools used by UNICEF

- As a first step in addressing the need for comparable and reliable data, UNICEF has implemented, since 2000, the Ten Questions Screen (TQ) for childhood disability. This screening instrument was included as part of the Multiple Indicator Cluster Surveys (MICS).
- The objective was to create a low-cost and rapid method for identifying children who have congenital and developmental disabilities in populations where professional resources are extremely scarce.
- By including the Ten Questions Screen, MICS has become the largest source of internationally comparable data on children with disabilities in developing countries. Since 2000, more than 50 MICS have collected data on this topic.
- UNICEF's methodology for gathering data on children with disabilities is currently undergoing a careful process of revision through a series of ongoing and planned activities.



Tools used by UNICEF

- These revisions were motivated by a desire to develop tools that are in line with the WHO International Classification of Functioning, Disability and Health – Children and Youth version (ICF-CY) and the UN Convention on the Rights of Persons with Disabilities.
- The goal is to assess child functioning in light of barriers and supports to daily living and social participation and to ensure that the entire age spectrum and additional relevant domains are captured.
- UN group on Disability Statistics (called Washington Group) formed a subgroup in 2009 on child functioning and disability that is chaired by the National Statistical Office of Italy (ISTAT). UNICEF joined the subgroup in 2011.



Tools used by UNICEF

 The objective is development of a short set of questions to reflect current thinking on child functioning and disability for inclusion in censuses and surveys. The new module uses the ICF-CY as the conceptual framework and relies on a functional approach to measuring disability.

The new Washington Group/UNICEF module covers children between 2 and 17 years of age and assesses speech and language, hearing, vision, learning (cognition and intellectual development), mobility and motor skills, emotions and behaviours.

- Two separate questionnaires are available: one for children aged 2 to 4 and another covering children aged 5 to 17.
- To better reflect the degree of disability, each area is assessed against a rating scale.



Guidelines for the Production of Statistics on Children with Disabilities

The guidelines discuss conceptual and theoretical issues related to measuring disability in children and review methods and tools. Considerations for designing and implementing a child disability data collection effort are also presented. The guidelines are currently being drafted with inputs from 40 international experts and are expected to be finalized in late 2016.

Workshops on the Measurement of Disability

The purpose of the workshops is to strengthen local capacity for data collection, data analysis and data use. Training is offered to National Statistical Offices, other Government staff, representatives of Disabled Persons' Organizations and researchers on concepts, models and measures of disability, data interpretation and dissemination. The workshops began in 2015 and will continue to take place through 2016 and 2017.



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With thanks to our partners





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Realizing the Rights of Children with Disabilities through Inclusive Statistics





Other initiatives leading from invisibility to inclusion for Children with Disabilities

- The State of the World's Children 2013: Children with Disabilities
- Enhanced data through MICS and household surveys, Out of school Children Initiative and SEA-PLM, Factsheet on disability in East Asia and Pacific (Sept 2015)
- Guideline for Situation Analysis on children with disabilities already used in research in a few countries
- Disability analyses across sectors
- New Survey Module on Inclusive Education
 This new survey module is to measure the school environment and participation in education
 by children with and without disabilities.



Invest in promoting equity and inclusion of all children!

THANK YOU.

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