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.

Challenges in data collection

Measuring child disability presents a unique set of challenges. Because children develop and learn to perform basic tasks at different speeds, it can be difficult to assess function and distinguish significant limitations from variations in normal development. The varying nature and severity of disabilities, together with the need to apply age-specific definitions and measures, further complicate data collection efforts. In addition, the poor quality of data on child disability stems, in some cases, from a limited understanding of what disability is in children and, in other cases, from stigma or insufficient investment in improving measurement. The lack of evidence that results from such difficulties hinders the development of good policies and the delivery of vital services. Efforts to improve data collection, however, are under way and the very act of gathering information is leading to positive change.

Evolving definitions

While there is general agreement that definitions of disability should incorporate both medical and social determinants, the measurement of disability is still predominantly medical, with a focus on specific physical or mental impairments. Estimates of disability prevalence vary depending on what definition of disability is used. Narrow, medical definitions are likely to yield lower estimates than broader ones that take into account social barriers to functioning and participation.

Putting disability in context

Estimates of disability prevalence are a function of both incidence and survival, and the results should be interpreted with caution, particularly in countries where infant and child mortality rates are high. A low reported prevalence of disability may be the consequence of low survival rates for young children with disabilities, or it may reflect the failure to count children with disabilities who are confined to institutions, who are hidden away by families fearful of discrimination, or who live and work on the streets.

Culture also plays an important role. The interpretation of what may be considered ‘normal’ functioning varies across contexts and influences measurement outcomes. The attainment of certain milestones may not only vary among children, but differ also by culture. Children may be encouraged to experiment with new activities at different stages of development. It is therefore important to assess children against reference values appropriate to local circumstances and understanding.

Data collection

Many children are identified as having a disability when they come into contact with education or health-care systems. However, in low-income countries or communities, school and clinic staff may not be able to routinely recognize or register the presence of children with disabilities. The resulting paucity of information about children with disabilities in low-income countries has contributed to a misconception that disability does not merit global priority.

1 For a complete list of references, please see the full SOWC 2013 report at: www.unicef.org/SOWC2013
Where schooling or other formal services for children with disabilities are lacking, other methods of enumeration, such as censuses, general and targeted household surveys, and interviews with key informants have been used to estimate disability prevalence.

General data collection instruments are likely to underestimate the number of children with disabilities. Targeted household surveys that specifically address the issue of child disability or include measures specifically designed to evaluate disability in children have produced more accurate results than household surveys or censuses that ask about disability in general. Such surveys tend to report higher prevalence rates because they usually include more numerous and detailed questions.

Even well-designed surveys can misreport disability if a single set of questions is applied to children across the age spectrum. The choice of questions must be tailored to a child’s age in order to reflect the developmental stages and evolving capacities of children.

**Purpose and consequences**

Efforts to measure child disability represent an opportunity to link assessment with intervention strategies. Often, an assessment provides the first chance for a child with a disability to be identified and referred to, or to receive some form of immediate care. Unfortunately, capacity and resources for follow-up assessment and support for those children who screen positive for disability are often scarce. Recognizing the critical role of early intervention, the possibility of linking screening and assessment with simple interventions should be explored, especially in low- and middle-income settings.

**A question of human rights**

Under the UN Convention on the Rights of the Child (CRC) and the UN Convention on the Rights of Persons with Disabilities (CRPD), children with disabilities have the right to the full enjoyment of their rights and freedoms on an equal basis with other children. The CRPD specifically calls on State Parties to undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to enable the rights laid out in the Convention and to identify and address barriers faced by persons with disabilities in exercising their rights.

**A call to action**

Progress has been made to improve the measurement of child disability, but more work needs to be done. There is a clear need to harmonize child disability measurement in order to produce estimates that are reliable, valid and internationally comparable. This would facilitate appropriate policy and programmatic responses by governments and their international partners, and thus fulfill a requirement of the CRPD. Collecting reliable data is a critical part of a range of actions to ensure children with disabilities realize their rights, actions which include:

- Ratify and implement the Conventions (CRPD and CRC).
- Fight discrimination against children with disabilities.
- Dismantle socio-economic and other barriers to inclusion.
- End residential institutionalization.
- Provide families with social welfare, health and other services to meet their needs.
- Ensure that national standards are aligned with international standards and support their implementation.
- Coordinate services among sectors to support the child.
- Involve children with disabilities in making decisions.
- Collect reliable and objective data on disabilities to inform planning and assess impact.


This thematic note presents excerpts from the report related to Measuring Child Disability. All references and original sources can be found in the full report.

**For the full report or more information:**

Visit our Website: [www.unicef.org/SOWC2013](http://www.unicef.org/SOWC2013)

Or contact: disabilities@unicef.org or cmills@unicef.org