structures (e.g., organs, limbs and structures of the nervous, visual, auditory and musculoskeletal systems), body functions (physiological functions of body systems, such as listening or remembering), limitations on activity (e.g., walking, climbing, dressing) and restrictions on participation (e.g., playing with caregivers or other children, performing simple chores).117

**Putting disability in context**

Data should be interpreted 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.118 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. For instance, in one study, 50 per cent of children were ‘able to use a cup’ at about 35 months of age in urban India, while the corresponding milestone was reached around 10 months of age in Thailand.119 It is therefore important to assess children against reference values appropriate to local circumstances and understanding.

For these reasons, assessment tools developed in high-income countries, such as the Wechsler Intelligence Scale for Children and Griffith’s

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**Four case studies:**

*Percentage of population reporting some form of disability*

- **Uganda**
  - One question asked:
    - Is anyone who was in the household on census night disabled?
  - Census 1991: 1%
  - Census 2002: 4%
  - Uganda National Household Survey 2005/2006: 7%
  - Demographic and Health Survey (DHS) 2006: 20%

Source: UNICEF, from surveys and censuses identified above.
Mental Development Scale,\textsuperscript{120} cannot be indiscriminately applied in other countries or communities, as their capacity to detect and accurately measure disability in different sociocultural contexts is often untested. Frames of reference may vary, and survey tools may fail to sufficiently capture local customs, cultural understanding, languages or expressions. For example, questionnaires that evaluate child development on the basis of such ‘standard’ activities as preparing breakfast cereal or playing board games may be appropriate in some places but not in those where children do not routinely engage in these activities.\textsuperscript{121}

### Data collection

The specific objectives of the data collection are likely to influence the definition of what constitutes ‘disability’, the questions asked and the resulting figures. The measurement of disability type and prevalence is frequently tied to specific political initiatives, such as social protection schemes. Results may be used to determine benefit entitlement or to plan and determine support provision. For example, the criteria used to define eligibility for a disability benefit are likely to be more restrictive than criteria for a survey conducted to identify all persons with a functional limitation, yielding dramatically different numbers.\textsuperscript{122}

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.\textsuperscript{123}

Where schooling or other formal services for children with disabilities are lacking, other methods

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### Australia

<table>
<thead>
<tr>
<th>12 questions asked, including:</th>
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<tbody>
<tr>
<td>Is there anyone in the household who has any loss of sight?</td>
</tr>
<tr>
<td>Does everyone have full use of their arms and fingers?</td>
</tr>
<tr>
<td>Is anyone receiving treatment for nerves or any emotional condition?</td>
</tr>
<tr>
<td>Is anyone having long-term treatment or taking any medicine or tablets for a condition or ailment?</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>13 questions asked, including:</th>
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<tbody>
<tr>
<td>Does anyone have any loss of hearing?</td>
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<tr>
<td>Does anyone have any condition that makes them slow at learning or understanding things?</td>
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<tr>
<td>Does anyone have any condition that restricts them in physical activities, or in doing physical work?</td>
</tr>
<tr>
<td>Does anyone have any disfigurement or deformity?</td>
</tr>
<tr>
<td>Does anyone ever need to be helped or supervised in doing things because of any mental illness?</td>
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<tr>
<th>4 questions asked, including:</th>
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<tr>
<td>Does the person ever need someone to help with, or be with them for, self-care activities?</td>
</tr>
<tr>
<td>Does the person ever need someone to help with, or be with them for, communication activities?</td>
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</tbody>
</table>

**Australia:**

- **Survey of Handicapped Persons 1981:**
  - One question asked: Is this person handicapped by a serious long-term illness or physical or mental condition?
  - 5%

- **Survey of Disability, Ageing and Carers 1993:**
  - 4%

- **Census 2006:**
  - 4%

- **Survey of Disability, Ageing and Carers 2009:**
  - 19%

**CONTINUED**
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. They typically employ a generic or filter question, such as whether anyone in the household ‘is disabled’, or use the same questions for all household members regardless of their age. Children in particular are likely to be overlooked in surveys that do not specifically ask about them.

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.

Questionnaire design

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. Some domains, such as self-care (e.g., washing and dressing), will not be appropriate for very young children. Given the complexity of developmental processes that take place over the first two years of life, it can be difficult to distinguish disability from variations in normal development without specialized tools or assessment.

Questions designed to assess disability in the adult population are not always applicable to children, yet many survey instruments use a...
single set of questions for both groups. Examples of questions with limited relevance to children include those about falling down or memory loss, as well as questions about tasks children may be too young to accomplish independently. Questions that link disability with an elderly population are not only irrelevant to child assessment but may also introduce a bias in the respondent’s mind as to which should be considered disability and thus affect the nature and quality of the response. In order to accurately assess disability in children, care must be taken to use questionnaires specifically designed for the purpose.

Many data collection instruments, including household surveys and censuses, are based on parental responses only, with caregivers normally expected to assess and report the disability status of children under their care. While parents and other caregivers are often very well placed to identify difficulties that their children may experience in performing specific tasks, their responses alone are not sufficient to diagnose disabilities or establish a prevalence of disability. Accurate assessment of disability in a child requires a thorough understanding of age-appropriate behaviours. Survey respondents may have limited knowledge of specific benchmarks used for evaluating children at each stage of development and may not be in a position to adequately detect manifestations of particular types of disability. Certain temporary conditions, such as an ear infection, may cause acute difficulties in performing certain tasks and be reported as a form of disability. At the same time, parents may overlook certain signs, or hesitate to report them, because of a lack of acceptance or stigma surrounding disability in their culture. The choice of terminology used in questionnaires can either reinforce or correct such statistically distorting and socially discriminatory phenomena.

**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 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.

Data that capture the type and severity of children’s disabilities as well as the barriers to the functioning and community participation of children with disabilities, when combined with relevant socio-economic indicators, help to inform decisions about how to allocate resources, eliminate barriers, design and provide services and meaningfully evaluate such interventions. For instance, data can be used to map whether income, gender or minority status affects access...