

Disability among children: a statistical perspective

How are children defined?

In carrying out national surveys of children, three characteristics need to be clearly defined in terms of who to include in and who to exclude from the study – age range, kinship, and usual place of residence.

Making meaningful comparisons among surveys or censuses that produce disability data about children are made more difficult by the different age ranges covered and how single ages are aggregated into aged bands. The key question is what should be the minimum and maximum age of the target population. In some cases data are collected from birth; in other instances data are only available from children aged five and above. The maximum age is normally fifteen or sixteen.

The relationship between the child and the adults in the household is another important factor for data comparability. Biological children, step children and foster children are often treated in different ways in different surveys.

For survey purposes, it is also important that children are not double counted. Some children will live with one parent for a part of the week and the other parent for the remainder of the time. Therefore, it is necessary to establish the child's main residence. In some countries, children may board at schools during term time and only return home during vacations.

How is disability defined in relation to children.

It is generally assumed that the same question on disability is applicable to adults of all ages (though there is some evidence that they work less well with the elderly population). This is certainly not the case with children. Bone and Meltzer (1989) in their discussion of the national survey of disability among children in Great Britain, stated that for children, the notion of what is normal for a particular age is an inescapable basis for assessment of disability; very young children in particular can not do what adults can, and consequently questions designed to identify the presence and severity of disability among adults are inappropriate for them. Questions on disability addressed to adults may be inappropriate in a different way to older children. Some older children may be able to perform some of the tasks asked of adults such as washing or cooking but in some cultures they are not expected to do so, and their ability in those respects may be unknown. There are also activities like running which children but not adults need to perform to lead a normal daily life among their peer group. Finally, behavioural problems among children are predominantly of a different kind from those of adults as a whole.

However, there are different ways of measuring developmental delay and these affect prevalence estimates. In order to measure the prevalence of developmental delay among US infants and children Simps, Colpe and Greenspan (2003) asked two types of questions of parents in the 1994-95 National Health Interview Survey on Disability. To measure functional delay, questions from the Functional Developmental Growth Chart, which measures specific age-appropriate tasks, were used. General delay was defined using the general type of questions about

developmental delay that had been used in previous surveys. Using a nationally representative sample of 15 291 infants and children aged 4-59 months from the NHIS-D, they found that approximately 3.3% had functional delay and 3.4% of the children had general delay. However, only one-third of the children were identified by both sets of questions. Thus, two-thirds of the children identified as having a functional delay were not recognised by their parents as having a delay. Conversely, many parents responded to the general delay questions indicating that their child had a delay, but failed to indicate that their child had a functional problem. They concluded that the general types of developmental delay questions used in national surveys may not identify children with functional delays.

Westbrook, Silver and Stein (1998) also compared different ways of measuring disability among children. They looked at the extent to which prevalence estimates and characteristics of children varied by the way that disability is defined. Specifically, they calculated the proportions of children identified as disabled by one particular operationalization of disability based on parental reports of three types of consequences: functional limitations, dependence on compensatory mechanisms, and service use or need beyond routine. They also determined whether children identified as disabled by these three types of consequences differ by type of disorder or condition, age, socioeconomic status, or race. They analysed a national dataset representing a random sample of 712 households with 1388 children. The Questionnaire for Identifying Children with Chronic Conditions (QuICCC) was used to identify children with disabling conditions. The QuICCC items were divided into three discrete sets, reflecting the three definitional components of disability, and compared the proportions and characteristics of children fitting these components separately and in combination.

Using the QuICCC definition of disability, the use of specialised services identified the largest proportion of children (72%), followed by dependence on compensatory mechanisms (55%) and functional limitation (49%). Forty-four percent of children were identified by only one component, 36% by two components in any combination, and 20% by all three components. The type of disorder or condition generally did not vary by the three definitional components, although the functional limitation component appeared to be more effective at identifying children with sensory impairments. Children identified by two or more components were more likely to have multiple conditions and had more pervasive disorders than those identified by only one component. The youngest children (0 to 3 years old) may be less likely to be identified as disabled than children of other ages, especially by functional limitations.

They concluded that although the specific findings pertain to a single definitional approach (the QuICCC), the data highlight that who will be classified as disabled (and who will not) may be dependent on how disability is defined. The implications of using different definitions and definitional components on both the prevalence and the characteristics of children with disabilities need to be considered before data can be applied responsibly and appropriately.

Another key difference between surveys of the prevalence of disability among adults and children is that in some countries there is a more of a focus on impairments than

functional difficulties in the children' surveys (Cans, Baillie and Jouk, 1994; Li, 1991) probably as a result of the complexity in operationalising developmental delay.

McDougall and Miller (2003) reviewed the coverage of chronic health conditions and the domains of disability and related environmental factors as they are laid out in the ICD-10 and ICF, respectively, in national surveys of school-aged children conducted in Canada since 1980. Coverage of chronic health conditions, the domains of disability, and environmental factors in survey questions was identified by mapping question content onto ICD-10 and ICF codes. They found that surveys under review varied in the range and depth of coverage of the ICD-10 and ICF chapters. Disability surveys and health surveys for persons aged 12 and over contained the most comprehensive lists of chronic conditions. Coverage of impairments was limited. Coverage of activity limitations and participation restrictions was most limited in the domains of personal care and domestic life.

Wells and Hogan (2003) have commented that although several national health surveys have implemented data collection efforts to identify and characterise disability among children, the large number of items these surveys have required to measure childhood disability prohibit their use in general population surveys.

What is the purpose of collecting disability data for children? Is it the same as for adults?

In the discussion of the rationale behind collecting disability data on adults, three main purposes have been considered: equalisation of opportunity, monitoring service utilisation and measuring the health of the population.

Equalisation of opportunity is just as important for disabled children as for disabled adults. However, education takes the place of employment as the main focus for policies on equalisation of opportunity. There has been an on-going debate on whether disabled children should receive their education via mainstream schooling or within separate, specialised settings.

In many counties services for children are not so well developed as those for adults therefore, surveys which examine unmet need are of particular relevance for children.

It is also important to monitor the health of young people aged 15 or 16. It is at this time of transition from secondary to tertiary education or into employment that particular problems may arise for disabled children. There is often a lack of co-ordination of service provision for children during the transition to adulthood.

How are children dealt with in censuses and health interview surveys?

There seem to be different procedures in how children are dealt with in censuses and surveys. Various practices include:

- Censuses which include all children (from birth)
- Censuses which include children from a certain age.
- Surveys which ask questions about all household members including children

- Surveys which ask questions about all household members including children from a certain age.
- Separate surveys of children.

Undoubtedly, the decision on which procedure is used depends on the country's statistical infrastructure, the resources available for data collection and the political will to make data collection on children a priority.

How are children sampled for general population surveys?

One of the main challenges in carrying out surveys of children, regardless of topic, is obtaining a representative sample of the child population. Various methods have been tried, each have their advantages and disadvantages.

Sampling through school records is certainly one of the cheaper options but the hurdles that need to be overcome are: getting a representative sample of schools to co-operate, getting schools to allow access to data which may be covered by data protection acts or confidentiality agreements, getting to the parent to give consent via the child. Children with severe physical health problems may not be at school and those with behavioural problems may be excluded from school.

Another way of obtaining a sample of children is to carry out a postal sift of the population trying to identify households with children. This method is very expensive as one may need to send out ten times the number of letters in relation to the number of children who eventually become subjects of the survey.

Another method commonly used is to try and sample from centralised, computerised, administrative records. These may relate to health or universal benefits. Similar to the situation of sampling children via schools, confidentiality and data protection issues need to be addressed.

A fourth method is to "piggy-back" on another survey. This can entail obtaining disability data on children in households which have been selected for the adult health interview survey or using households which contain children sampled for various other purposes. In this case, the biggest problem is respondent burden.

What are the ethical issues in surveying children?

Participation of children

Wherever possible, children should be invited to participate in the survey process. Especially when dealing with mental health or sensitive issues, parents or carers may not be aware of all the child's problems. Some studies have involved children as young as eight while others wait until the child is eleven. However, it should be recognised that not all 11 year olds have the same intellectual capacity and simple language is essential if the child is answering questions posed by an interviewer, or filling in a self-completion questionnaire on paper or via a lap-top computer.

Parent/carer interview

Whether or not the child is old enough or capable of answering questions, questions about the child's health or disability will be put to the child's parent or carer first. Wherever possible the parent should answer the questions out of earshot of the child in the study. Most survey organisations have rules of confidentiality ensuring that what is said by the parent (or the child) is not passed on to anyone else including teachers.

Child is severely disabled

There is a possibility that some of children sampled in the survey may be so physically or mental disabled (e.g., no movement, no speech, no sight and hearing) that the questions may seem inappropriate or indelicate. Therefore, introductions to sections of questions need to be carefully crafted to avoid parental distress or discomfort.

Cases of abuse

In a child health survey, there is a possibility, however unlikely that a child may report on-going abuse. There is a greater likelihood that the child might talk about abuse in the past. Another scenario may be a child reporting suicidal thoughts. Procedures need to be put in place to deal with these issues.

Any empirical evidence, lessons learnt

Despite all the methodological, ethical and logistical problems in conducting surveys among children quite a body of material has been published reflecting the importance all over the world of the need to obtain data on disabled children.

Bendel J, Palti H, Winter S, Ornoy A. Prevalence of disabilities in a national sample of 3-year-old Israeli children, *Isr J Med Sci*. 1989 May;25(5):264-70.

Benedict RE, Farel AM, Identifying children in need of ancillary and enabling services: a population approach, *Soc Sci Med*. 2003 Dec;57(11):2035-47

Bone M and Meltzer H (1988) *OPCS Surveys of Disability in Great Britain, Report 3, The prevalence of disability among children*, London HMSO

Biritwum RB, Devres JP, Ofosu-Amaah S, Marfo C, Essah ER, Prevalence of children with disabilities in central region, Ghana, *West Afr J Med*. 2001 Jul-Sep;20(3):249-55

Cadman D, Boyle M, Szatmari P, Offord DR.,(YYYY) Chronic illness, disability, and mental and social well-being: findings of the Ontario Child Health Study, *Pediatrics*. 1987 May;79(5):805-13

Cans C, Baille F, Jouk PS, How to measure disability in children? Different methodologies, values and applications, *Arch Pediatr*. 1994 Dec;1(12):1144-52

Chen J, Simeonsson RJ, Child disability and family needs in the People's Republic of China. *Int J Rehabil Res.* 1994 Mar;17(1):25-37.

Couper J, Prevalence of childhood disability in rural KwaZulu-Natal S Afr Med J. 2002 Jul;92(7):549-52.

Gorter KA (1993) Survey methods for the assessment of physical disability among children, *Disability and Rehabilitation* Jan-Mar;15(1):47-51.

Hogan DP, Msall ME, Rogers ML, Avery RC. (1997) Improved disability population estimates of functional limitation among American children aged 5-17, *Matern Child Health J.* Dec;1(4):203-16

Kohler L. Children with and without disabilities in the Nordic countries. A Nordic project, *Scand J Soc Med.* 1993 Sep;21(3):146-9

McDougall J, King G, de Wit DJ, Miller LT, Hong S, Offord DR, LaPorta J, Meyer K (2004) Chronic physical health conditions and disability among Canadian school-aged children: a national profile, *Disabil Rehabil.* Jan 7;26(1):35-45

Newacheck PW and Halfon N (1998) Prevalence and impact of disabling chronic conditions in childhood, *Am J Public Health.* Apr;88(4):610-7

McDougall J, Miller LT, Measuring chronic health condition and disability as distinct concepts in national surveys of school-aged children in Canada: a comprehensive review with recommendations based on the ICD-10 and ICF, *Disabil Rehabil.* 2003 Aug 19;25(16):922-39

Milaat WA, Ghabrah TM, Al-Bar HM, Abalkhail BA, Kordy MN, Population-based survey of childhood disability in eastern Jeddah using the ten questions tool *Disabil Rehabil.* 2001 Mar 20;23(5):199-203

Msall ME, Avery RC, Tremont MR, Lima JC, Rogers ML, Hogan DP (2003) Functional disability and school activity limitations in 41,300 school-age children: relationship to medical impairments, *Pediatrics.* Mar;111(3):548-53

Newacheck PW, Strickland B, Shonkoff JP, Perrin JM, McPherson M, McManus M, Lauver C, Fox H, Arango P (1998) An epidemiologic profile of children with special health care needs, *Pediatrics,* Jul;102(1 Pt 1) 137-140.

Paul TJ, Desai P, Thorburn MJ, The prevalence of childhood disability and related medical diagnoses in Clarendon, Jamaica, : *West Indian Med J.* 1992 Mar;41(1):8-11

Pongprapai S, Tayakkanonta K, Chongsuvivatwong V, Underwood P A study on disabled children in a rural community in southern Thailand, *Disabil Rehabil.* 1996 Jan;18(1):42-6.

Simpson GA, Colpe L, Greenspan S, Measuring functional developmental delay in infants and young children: prevalence rates from the NHIS-D, *Paediatr Perinat Epidemiol.* 2003 Jan;17(1):68-80

Spee-van der Wekke J, den Ouden AL, Meulmeester JF, Radder JJ. Self-reported physical disabilities in children in the Netherlands, *Disabil Rehabil.* 2000 May 10;22(7):323-9.

Weale J, Bradshaw J. Prevalence and characteristics of disabled children: findings from the 1974 General Household Survey. *J Epidemiol Community Health.* 1980 Jun;34(2):111-8

Wells T, Hogan D. Developing concise measures of childhood activity limitations, *Matern Child Health J.* 2003 Jun;7(2):115-26.

Westbom L, Kornfalt R. Chronic illness among children in a total population. An epidemiological study in a Swedish primary health care district, *Scand J Soc Med.* 1987;15(2):87-97.

Westbrook LE, Silver EJ, Stein RE Implications for estimates of disability in children: a comparison of definitional components, *Pediatrics.* 1998 Jun;101(6):1025-30.