

## Prevalence of Childhood and Adolescent Disabilities in Rural Nepal

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*The study aimed to determine the number of children and young people reported as having a disability by family members, and to classify impairments leading to disability. A Cross-sectional census was conducted of all households in 24 rural geopolitical units of Makwanpur district, Nepal. Heads of household were asked about family members under the age of 20 with disability. Such members were resident in 733 of 28,376 households, a household prevalence of 2.58%. 829 people under the age of 20 were reported as having a disability, a population prevalence of 0.95%. The commonest functional impairments reported were motor and the commonest anatomical impairments involved the limbs. More males with disability were identified than females.*

**Key words:** *Childhood, Census, Disability, Nepal.*

**L**ITTLE information is available on the prevalence of disability in developing countries. Disability is related to poverty and development(1,2) and it is inappropriate to generalise data from industrialised countries. Estimates of disability prevalence may be based on either specific impairments or functional limitations(3). The WHO 2002 classification updates the 1980s framework of impairment, disability, and handicap(4) to a functional classification of medical condition, function, and participation, known as the ICF (International Classification of Functioning Disability and Health). The use of participation as a classifying parameter reflects the need to consider disability an issue of inclusion and rights.

A previous cluster survey from Nepal estimated a population prevalence of disability of 1.6%(5). This is low compared with studies from other settings, and may reflect either poor survival or marginalisation in communities. Our study had two objectives: (a) to determine

the number of children and young people reported by family members as having a disability; (b) to classify the reported impairments associated with disability.

### Subjects and Methods

Nepal's population of 23 million covers 75 districts, three ecological zones, and over 100 ethnic groups. Eighty per cent of the population are rural and 80% have livelihoods based on agriculture(6). Despite the challenges of poverty, terrain and a current insurgency, life expectancy is 61 years(7). The total fertility rate is 4.1(8), the maternal mortality rate 539 per 100,000 live births(9) the under-five mortality rate 91 per thousand live births and the infant mortality rate 64(8). Lying in Nepal's Central Region, Makwanpur District is largely rural and covers both hill and plain. The district is divided administratively into 43 village development committees and a municipality and has a population of about 400,000.

The disability census was part of a study of interventions to improve newborn infant care. Other findings from the census have been published(10) as has the outcome of the trial(11). After excluding one village development committee because of instability, we matched the remaining 42 into 21 pairs on the basis of topography, ethnic group distribution, and population, then used a list of random numbers to select 12 pairs. The resulting 24 rural village development committees constituted the study area, in which a cross-sectional census of all households was conducted. Data were collected from September 1999 to June 2000 by a team of 91 interviewers, supervised by nine coordinators and a senior manager. Each head of household (or next most senior if not present) was invited to respond to a questionnaire including two questions about disability: (a) "Is there anyone in your household under the age of 20 who has a disability?" (b) If yes "What is the nature of the disability?" Responses to the second question were recorded verbatim in Nepali. Questionnaires were manually checked on site and centrally and the data stored in an electronic database in Microsoft SQL Server 7.0.

Information was not linked to individuals because of issues of confidentiality. Text descriptions of reported disability were translated from Nepali into English, then back translated and discussed when their implications were unclear. They were coded in two ways: by anatomy and by function. The anatomical codes located the impairment to one of eight anatomical sites (eye, nose, mouth, upper limb, lower limb, trunk, genitalia, brain). The functional classification included five codes: activities of daily living such as eating; perceptual skills such as seeing or hearing; physical skills such as sitting, walking, and standing; and psychological

problems and learning difficulties. Where multiple impairments were described, constituent problems were coded individually. Frequencies and proportions were computed in Microsoft Excel.

The trial was approved by the Nepal Health Research Council and the ethical committee of the Institute of Child Health and Great Ormond Street Hospital for Children. It was conducted in collaboration with His Majesty's Government Ministry of Health, Nepal. The aims and design of the trial were discussed at a national meeting and at meetings with the District Development Committee, the Chief District Officer, and local stakeholders. Chairpersons of the village development committees involved in the study gave signed consent on behalf of their communities. Heads of household who chose to participate gave verbal consent and were free to decline to be interviewed at any time.

## Results

The census interviewed representatives from 28,376 households with 169,776 residents, 83,355 (49.1%) residents were female and 86,421 (50.9%) male. Summary findings are presented in *Table I*. People under the age of 20 with disability lived in 733 households, a household prevalence of 2.6%. 829 people under the age of 20 were reported as having a disability; this yields a population prevalence of 0.95%. 40.9% of young people with disability were female and 59.1% male. The reported prevalence of disability varied across the 24 village development committees, from 0.4% to 6.2%. This variation was not explained by sub-analysis on the basis of topography, ethnicity or levels of poverty.

*Table II* presents a classification on the basis of reported functional impairments. Out of 1721 impairments (many people having more than one), the commonest reported

problems involved mobility (89%) and manipulation (54%). The reported prevalences of hearing impairment and learning difficulties were low. *Table III* presents a classification on the basis of reported anatomical location of impairments. More anatomical abnormalities were reported than could be interpreted in terms of functional impairment. Out of 1739 anatomical abnormalities, the commonest affected the limbs.

### Discussion

This study focused on children and adolescents. The prevalence of reported disability (around one percent) is therefore lower than previous estimates for general populations, for which publications suggest a figure between three and five percent(3). This is consistent with earlier studies from Nepal which yielded prevalence estimates from 3.4% to 4.6%(12-14). It is likely that the focus on youth excludes many disabilities acquired later in life, such as those resulting from road traffic accidents, conflict, and industrial or other accidents. It also excludes disabilities acquired in old age, particularly ocular cataract which is likely to be very common.

Our findings agree with those of the 2001 UNICEF study(5) a smaller cluster survey of 13,005 households with 75,944 residents which identified 1240 people with disability. Published data allow for disaggregation into age groups, and we present some figures in *Table I* for comparison. Moreover, both studies demonstrate gender differences in reportage. The gender breakdown for the general population in the under-20 age group is 49.5% female to 50.5% male(15) but disability was reported more often in males (59%). Although the prevalence of most disabilities is higher in male than in female children, it seems likely that the disparity reflects a lower threshold for reporting

**TABLE I**—*Reported Prevalence of Disability in People Under 20*

	Current study	UNICEF 2001(5)
Number of households	28,376	13,005
Total population	169,776	75,944
Population under 20 yrs	87,599 *	39,575
People under 20 yrs with disability (%)	829 (0.95)	428 (1.08)
Females under 20 yrs with disability (%)	339 (0.39)	197 (0.50)
Males under 20 yrs with disability (%)	490 (0.56)	231 (0.58)

\* Figure calculated on the basis of 2001 census.(15)

**TABLE II**—*Reported Functional Impairments*

Functional Impairment	Frequency (%)
1721 impairments in 829 people with disability	
Mobility	735 (88.7)
Manipulation	445 (53.7)
Speaking	186 (22.4)
Somatic problems	124 (15.0)
Vision	107 (12.9)
Hearing	65 (7.8)
Learning difficulties	52 (6.3)
Epilepsy	7 (0.8)

**TABLE III**—*Reported Anatomical Location of Impairments*

Anatomical location	Frequency (%)
1739 locations in 829 people with disability	
Lower limb	660 (79.6)
Upper Limb	445 (53.7)
Mouth and Nose	186 (22.4)
Posture Control	162 (19.5)
Eyes	107 (12.9)
Ears	65 (7.8)
Mental Problems	52 (6.3)
Somatic Problems	45 (5.4)
Genitalia	10 (1.2)
Epilepsy	7 (0.8)

### Key Message

- About one per cent of children and adolescents under 20 in a rural district of Nepal were reported by their families as having a disability.

impairments in male children rather than a true finding. This in turn implies that our figures underestimate the true prevalence, a suggestion supported by the variation in estimates across the study area. Despite intensive training and piloting, it is likely that at least some of this variation reflects differences in interview style and depth of probing. Nepal's 2001 census included a question on disability for which the reported prevalence in Makwanpur district was 818/392,604(15). Equating to a population prevalence of 0.2%, such a low figure may illustrate the problem of eliciting responses within a broad questionnaire with limited probing.

Our findings also agree broadly as regards functional impairment (*Table II*). UNICEF's disaggregated functional classification reported problems with mobility in 1.0%, manipulation in 0.1%, speaking in 0.3%, hearing in 0.07%, mentation in 0.06%, chronic mental illness in 0.07%, and epilepsy in 0.18%(5). The cerebral palsy literature would support the view that motor problems with mobility and manipulation would be the largest group of disabilities within any given population(16) a finding which is partly an issue of prevalence but also because impairments of movement are easily identified by non-specialists. Our dual classification of reported disabilities—functional and anatomical shows almost identical rank order.

The higher reported prevalence of visual problems than hearing problems is surprising. The reverse is usually found(3). One

explanation for this might be that communication difficulties are attributed to symptom rather than cause: people might report speaking problems more than hearing problems, a finding that is clearly demonstrated in *Table II* and supported by the relatively high reporting of mouth and nose problems in *Table III*. About half of people with disabilities have some form of communication disability(17,18). The reported prevalence of learning difficulties is much lower than would be expected from the literature(19). This may reflect the low literacy rate in this population, since mild and moderate learning difficulties can go unnoticed if children are not required to read and write.

Our census of over 28,000 households in a rural district of Nepal suggested a disability prevalence of about 1% of the population under 20. This is probably an underestimate. The commonest reported functional impairments were motor, followed by communication problems that were referred to speech production but may also have been the result of impairments in other areas such as hearing.

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