

A Situation Analysis of Disability in Nepal

**Executive Summary
of
Disability Sample Survey 2001**

**Carried Out by New Era
for
National Planning Commission**

A situation Analysis of Disability in Nepal 2001

Executive Summary

The study on the situation analysis on disability in Nepal was carried out under the aegis of the national planning commission secretariat and the social welfare council and was funded by UNICEF. The study was conducted by New ERA in 1999-2000. The main purpose of the study was to develop a comprehensive definition of all kinds of disabilities and to derive nation-wide data and information about the situation and services for persons with disabilities in Nepal.

1.0 The definition: Various studies conducted in Nepal in the past gave varied information on the prevalence disability in the country. This variation reflects the methods and definitions used in the surveys. The studies with high incidence include mild disability and sometimes also impairment and diseases like eye infections. The initial task of the study was to develop a working definition of disability for the survey. A team of experts comprising of technical experts in the field of medical science, social science and experts in the community based rehabilitation program met several times to discuss the definition based on the scope of the study, which was intended to be carried out by semi-skilled interviewers. Accordingly, the definition of disability was adopted for the purpose of this survey.

1.1 The definition considered a person to be disabled if the person could not perform the daily activities of life considered normal for a human being within the specified age and where the person needed special care, support and some sort of rehabilitation services. This definition focused on the priority group for services, policy and program formulation.

- 1.2 Accordingly, the study classified disabilities under four broad categories, namely, a) communication disability b) locomotion disability c) mentally related disabilities and d) complex disabilities. Communication disability included seeing, hearing and speaking disabilities. Locomotion disability included mobility and manipulation disability. The mentally related disabilities included mental retardation, chronic mental illness and epilepsy. Complex disability included more than one type of disability, which was termed multiple disabilities and included cases of cerebral palsy.
- 1.3 Seeing Disability:** A person, who, even after treatment, could not count fingers with improved eyesight (both) from a distance of ten feet (3 meters), was said to have seeing disability and was considered functionally blind.
- 1.4 Hearing disability:** A person who could not hear ordinary voice with both ears from a distance of one meter was said to have hearing disability.
- 1.5 Speaking disability:** A person who could not speak at all or a person who could not be understood outside the family was said to have speaking disability.
- 1.6 Mobility disability:** A person who was unable to perform the daily activities of life due to a physical deficiency, defect or deformity in the lower limbs was said to have mobility or walking disability.
- 1.7 Manipulation disability:** A person who was unable to perform the daily activities of life due to a physical deficiency, defect or deformity in the upper limbs was said to have working or manipulation disability.
- 1.8 Metal retardation:** A person who was unable to perform activities or to learn new tasks per the age and environment due to delayed mental development prior to the age of 18 years was said to be mentally retarded. Under this classification, two categories were included: a) persons who could manage the daily activities if life with the help of training and b) persons who could not manage daily activities like eating, dressing, speaking and going to the toilet even with training.

1.9 Epilepsy: A person who had frequent attacks of unconsciousness and showed symptoms of tongue biting, frothing from the mouth, shivering and incontinence was said to be an epileptic.

1.10 Chronic mental illness: A person who, after 18 years of age, had some kind of mental instability with symptoms of unprovoked anger or elation, crying without reason and seeking isolation was said to have some kind of mental illness.

1.11 Multiple Disabilities: A person having more than one type of disability was said to be having multiple disability.

1.12 Cerebral palsy: A person who had some damage in the immature brain leading to physical incapacity was said to have cerebral palsy. Some cases could have mental retardation.

1.13. The study was conducted in 30 districts spread over the 15 eco-development regions of the country. A sample of 13,005 households covering a population of 75,944 was considered for the study. These households were drawn from a total of 217 clusters, each cluster representing either a ward or a combination of wards or a sub-ward. Among the sample clusters, 89.4 percent were from rural areas and 10.6 percent from urban areas.

1.14 Quantitative as well as qualitative methods were used for the collection of information.

2.0 Socio-Economic Characteristics

The socio-economic characteristics of households with disabled persons and those without disabled persons were assessed. The economic parameters like landholding size, occupation and income of the survey population were taken into account. The household characteristics (literacy, sex, religion and caste) and the housing characteristics were assessed to analyze the condition of the households with disabled persons in relation to the households without disabled persons.

2.1 There was slight difference in the economic level of the households with disabled persons and those without disabled persons, though statistically the difference was not significant, at a 5% (percent)

level of significance. The households with disabled persons were found to be slightly worse off than those without disabled persons

2.2 There was, however, a significant difference in the literacy status of the household heads with disabled persons and those without disabled persons, at a 5% level of the significance. This is confirmed by a clear difference in the highest level of education attained by the household heads. The study found that 57.6% of the household heads in households with disabled members had no education, while 50.7% of the household heads of households without disabled members had no education. As the persons who are not literate usually have fewer opportunities to improve their economic states, the households with disabled person were more likely to be in a less advantageous position than those households without disabled members. It is known that poverty creates a greater risk of disability due to malnutrition and inadequate access to medical care.

2.3 A higher proportion of disabled persons was found among the Sherpa/Tamang, Magar, Tharu and occupational caste groups. There be different possible explanations for this. The higher incidence of disability among these groups could be due to their poverty, hardship and social disadvantage. It could even be because their proper caring of the disabled persons resulted in a higher survival rate.

3.0 Status of disability

3.1 Based on the definition adopted for this study, the prevalence of disability was estimated to be 1.63 percent in the total population, with estimates of 1.65 percent in the rural areas and 1.43 percent in urban areas. In the case of the ecological belts, the prevalence of disability was highest in the mountain (1.88%), followed by the hills (1.64%) and the terai (1.45%). Likewise, in case of the highest prevalence of disability, with 1.81% in the population of that region being disabled.

3.2 It was found that most of the disabled people had multiple disabilities, which accounted for 31.0% of the total disabled in the country. This indicated that the prevalence of multiple disabilities in the total population was 0.51%. Combined disabilities such as

speaking and hearing disabilities were found to be as high as 48.3% of those having multiple disabilities.

- 3.3 It was found that 17.4% of the disabled persons, including those with multiple disabilities, had mobility disability. Epilepsy accounted for 13.3% of the disabled persons. Disabilities such as mental retardation, speaking disability and chronic mental illness as single disabilities were found to be less prevalent.
- 3.4 Among the different types of disabilities in the disabled population, including multiple disabilities, it was mobility disability that was found to be the most common type, accounting for 19.5% of all types of disabilities. Speaking disability accounted for 19.4% while hearing disability accounted for 19.1% of all types of disabilities. Manipulation disability accounted for 14.8% while epilepsy accounted for 11.1% of all types of disabilities. There were fewer cases of mental retardation (5.9%), seeing disability (functionally blind) (5.6%) and chronic mental illness (4.6%).
- 3.5 Disabilities were seen more prevalent among males than female. The result of sex differentiation reduces the chance of survival among females. The reason for the lower prevalence of disabilities in women could be because their disabilities were not identified. Girls and women are often able to perform certain activities, albeit at enormous personal cost (pain and/or effort), to hide their disabilities.
- 3.6 Age specific disabilities in the population indicates that the prevalence of disability among the working age group (15-59 year) was 1.99%, which accounted for 64.3% of the total number of disabled persons.

Causes of disability:

- 3.7 It was found that 50% of different types of disabilities occurred before the age of five year. This suggests that most of these disabilities could be attributed to childhood disease and accidents.
- 3.8 The reported causes of disability varied according on the types of disabilities. Disabilities such as hearing, speaking and mental retardation were reported to occur from birth in most of the cases. As the respondents did not find obvious causes such as episodes of disease or accidents for the disabilities, the cause was reported as "being born with disability".
- 3.9 Disease played an important role in contributing towards all types of disabilities, with about 30.3% of the causes attributed to disease. Disease has been the most prevalent causes for seeing disability (62.5%) and mobility disability (36.0%), and it plays an important role in hearing disability, manipulation disability and mental retardation. Accident has been predominant in the case of manipulation disability (40.3%) and plays an important role in mobility disability (25.5%). In general 15.4% of the cases of disability were reportedly due to accidents.
- 3.10 The high incidence of onset of disability under the age of five years and the high incidence of disease indicate an urgent need for prevention initiatives. The high incidence of accidents as the cause of mobility disability and manipulation disability indicates neglected traumas or, in other words, the lack of appropriate medical treatment following the accident.

4. Attitude and perception

- 4.1 People still believe that having disabled members in the house is the result of their fate (28.4%). Some have superstitious beliefs and even give magical explanations for the cause of disability. These findings show that few people are aware about the medical causes of disability.
- 4.2 The household members encouraged the participation of disabled persons in different activities (going to school, playing with others

and going to work) though they still do not encourage the marriage of disabled persons.

- 4.3 Many of the disabled persons (49.3%) took care of themselves. However, in those cases where the disabled persons were not able to take care of themselves it was usually the task of the female household members to take care of them.
- 4.4 Most of the disabled persons (69.3%) received support from their family members. However, giving stimulation and exercises to the disabled persons to improve their condition was found to be negligible. The attempts made by the households to make household adjustments for the disabled persons by modifying the furniture and facilities were negligible in general.
- 4.5 Having a disabled person posed problems on most (90.5%) of the households. The difficulties they faced were mostly related to the inability of the disabled persons to work and taking care of the disabled persons, like teaching new tasks or having to leave the disabled persons alone.
- 4.6 All together 31.4% of the households felt that the disabled persons in the households had posed a huge economic burden, and these were mostly people with mental retardation, mobility, seeing and manipulation disabilities. The females were seen as imposing less of an economic burden, probably because they had fewer demands and expectations than males.
- 4.7 In most of the cases (68.8%) expenditures were made for treatment. Most of the families (71.5%) took their disabled members for treatment. The disabled persons were mostly taken to the doctors or health post for treatment (40.9%). A considerable number of households took the disabled persons to the faith healers for treatment (30.3%).
- 4.8 Still, nearly 30% of the disabled persons did not get any kind of treatment. This could be due to the lack of knowledge and awareness that disabilities can be treated. It could also be because the family does not have the resource, or because the health facilities do not function properly and staff does not know about disability. The assumed problem with health facilities is supported by the

findings that there are very few specialized referral services available in the rural areas.

- 4.9 In nearly half of the cases, the household members had to face humiliation within the community because of their disabled family members. It was also noticed in the focus group discussion sessions with the local leaders that the community outlook towards the disabled person varied according to the type and services of disability. Persons with mild disability could be more easily accommodated in the society than those with services types of disabilities.
- 4.10 It was stated by 70.1% of the disabled persons that it was difficult to live in the community with self-respect.
- 4.11 Though most of them (82.9%) knew that they did have rights within the framework of human rights for disabled persons, they said that they were not able to take advantage of them.
- 4.12 The participation of the disabled persons in the local organizations working for the disabled persons has been negligible.

5.0 Economic and Social Participation

- 5.1 Most of the disabled persons had no education (68.2%) as compared to the general population, where 4.8% had no education. The literacy rate was considerably lower for females than males, with 77.7% of the females and 59.6% of the males having no education.
- 5.2 While taking in to account the age group of 6-20 years, it was discovered that half of the disabled persons in this age group were enrolled in school. Though nearly 95% of the household heads wanted their disabled children to go to school, only 56.3% of the age group 6-20 years was enrolled in school, indicating that there were different physical and social barriers for schooling. Disability was a powerful reason for not attending school for all, but it figured more for girls than for boys.
- 5.3 The findings show that most of the disabled children were attending regular classes, most probably because there was no special school. It can be noted that special units may be appropriate in some cases, but

the majority still valued going to school (81.0) as they benefited from attending the classes. Not all those who had enrolled were currently attending school. For most of the dropouts (36.5%), the reason was their not being able to perform like others in the class, indicating a lack of support in school.

5.4 There were also some disabled children who did not actually benefit from school, indicating that some had difficulty in coping in the ordinary classes. The 67.6% who could not grasp what was taught require some special provisions or some sort of support within regular classes. There is a general lack of support for the disabled persons in schools as indicated by the high dropout rate.

5.5 The distance to school and the need to be there on time poses problem in general in the rural areas, but it has particular significance for all the disabled children.

5.6 It can be noted that once at school, those with locomotion disabilities and those with epilepsy performed well at school. These children in particular would clearly benefit from assistance to get to the school. The need for the teacher to be more sensitive and supportive is vital.

5.7 The non-formal education sector did not seem to be very productive for the disabled persons and requires better materials and specially trained teachers.

5.8 The participation of disabled persons in skill training was negligible, with only 27 disabled persons out of 917 disabled persons over the age of 14 getting some training. Among these, more than half did not benefit from such training even though they had acquired the skills. Some of the reasons given for this were the lack of materials, tools and market access.

5.9 Some of the economically active disabled persons (22.2%) were involved in agriculture. There were those who had worked before becoming disabled and lost their jobs due to their disabilities. However, most of the disabled persons were economically dependent on their family (79.9%).

5.10 Quite a large number of disabled persons had difficulties in joining social events, where most (84.6%) found it difficult to participate in the weekly market.

- 5.11 In general, it was also founds that disability presented obstacles to getting married.
- 5.12 Few (only four) disabled persons participated in the organizations working for the cause of disability, and even those who participated were of the opinion that they were not benefiting.
- 5.13 Disabled persons are neither integrated in to the school or in skill training or in employment development program. Education and skill training has an impact on future occupation opportunities. The employment status of disabled persons has an impact on the economic situation of the households with disabled members. Disabled girls and women participate even less in education and employment than disabled boys and men.

6.0 Services for Disabled Persons

- 6.1 There are many governmental as well as non-governmental organizations working in the field of disability in the country. The governmental agencies working for disability are the National Planning Commission Secretariat, the Ministry of Women, Children and Social Welfare, the Ministry of Education, the Ministry of Health, the Ministry of Finance, the Ministry of Local Development and the Social Welfare Council.
- 6.2 The special education unit under the Ministry of Education as been playing an important role in promoting special education for the disabled persons.
- 6.3 The National Planning Commission Secretariat does have its education unit that deals with the issue of disability and special education.
- 6.4 Recently, the national coordination committee for welfare of disabled persons has been formed with the participation of the Ministry of Women, Children and Social Welfare, the Ministry of Finance, the National Planning Commission Secretariat, the Social Welfare Council and the Nepal Industrial Development Corporation.
- 6.5 After the initiation of the Local Government Act, the Ministry of Local Development directed the District Development Committees (DDCs) as well as the Village Development Committee (VDCs) to

focus on the protection and livelihood of the disadvantaged communities, including disabled persons.

- 6.6 The Social Welfare Council, constituted under the Social Welfare Act 1992, plays a vital role in the services and development sectors undertaking welfare activities, which includes welfare of the disabled persons in the country.
- 6.7 During the study period, information was collected from about 148 non-governmental organizations working in the field of disability. A majority of the organizations were working for people with seeing disability, hearing disability, and those with mental retardation. There were also quite a number of organizations working for people with all types of disabilities. However, there were few specialized organizations working for people with disabilities such as cerebral palsy, leprosy or epilepsy.
- 6.8 Financial problem, as reported by 35 organizations (23.6%), hampered their work. Eleven organizations with financial problems had stopped functioning for this reason. Others reported the lack of government policy, lack of skilled manpower, space problems and political disturbances in the locality that made it difficult to conduct their work.
- 6.9 Besides the local NGOs, INGOs have also played an important role in the field of disability in Nepal. It was observed that the international community has initiated support for Nepal since 1964, with the voluntary services overseas (VSO) of the United Kingdom being one of the first few organizations to work here.
- 6.10 A majority of the respondents (97.9%) were aware of the availability of the health services in their particular VDCs. As the organization for the disabled persons have not reached extensive areas of the country, a majority of the respondents were not aware of such organization.
- 6.11 The respondents were mostly found to visit the health facilities for treatment of general problems and not their disabilities, as only 15.3% of those who visited the health facility went for treatment of their disability.

- 6.12 In the case of organizations for the disabled persons, only eight disabled persons received services from such organization.
- 6.13 A majority of those (83.6%) who had visited health facilities did not benefit from the services they received. This could be due to expectations that disability can be cured. Moreover, it could be due to the fact that the health posts and sub-health posts were not functioning well due to a lack of resources and staff. It could also be because the staff members themselves did not know anything about disability. This is supported by the fact that there were very few referral services.
- 6.14 The study also indicated that special aids have not been available to a large number of disabled persons.
- 6.15 The families of disabled persons should know that disability cannot be cured but that the life of the disabled people can be improved. Specialized organizations do not touch upon wider community awareness. This indicates that mainstream development organization have a substantial advantage over specialized organization. The health care staff needs to know more about disability. They need education on the referral network and appropriate services. This is especially important because appropriate services can then be offered to disabled people in local health facilities.

7.0 Required Support for Disabled Persons

- 7.1 The household heads (43.2%), the caretakers (38.7) as well as the disabled persons (37.8%) felt that medical treatment was the support most required for disabled persons.
- 7.2 The next important need as expressed by the household heads was financial support to look after the disabled family members.
- 7.3 In the case of the caretakers and the disabled persons it was the skill training that was though more important than the financial support, though they also expressed the need for financial support.
- 7.4 The expectation from the government for the disabled persons was for financial support. This suggests that the disability allowance would be an investment for some with a return to the community.

- 7.5 Some of the respondents (37.7%) felt that the disability allowance was needs for them to lead a better life.
- 7.6 Only 0.9% of the respondents (caretakers and disabled persons) mentioned that skill training would be more useful for the disabled persons than an allowance. The local leaders mentioned during the focus group discussions that the allowance was not so important and emphasized the need for training.

8.0 Legislation and Human Rights

- 8.1 Nepal recognized the human rights of person's disability in the year 1981 and celebrated The International Year of Disabled Persons (Protection and Welfare) Act, 1982 (DPWA). The DPWA and other laws give certain rights and privileges to the disabled persons but these rights are not enjoyed by them for many reasons.
- 8.2 Many development laws in Nepal, including DPWA, have remained only on paper. The law made in 1982 by the legislature' of the time for the welfare and protection of persons with disability promised to deliver many things, but in actual practice have served very little purpose during these 18 years.
- 8.3 Insufficiency of economic resource in the country may be one factor that might have caused the delayed execution of the laws. However, it is lack of the commitment of the government authorities to implement the laws that has caused the real problem. The implementation of the laws essentially requires good governance, and a powerful, progressive and committed administration. It requires strong efforts of progressive state power to implement the laws honestly and provide the legal rights and facilities to the disabled persons as granted by the law. The local government agencies should be knowledgeable about the existing policies regarding disabled persons and their responsibilities to carry out these policies.
- 8.4 Since the restoration of democracy in 1990, the persons with disability through their organizations have been continuously demanding that the government implement the laws and provide them all facilities as postulated by the law. Of late, the government under the pressure of the Disabled Persons Organizations has shown its commitment to implement the law faithfully and even to amend the law, if needed.

***Source : Report of Disability Sample Survey conducted by New Era
for national planning commission in 2001***