

A COMMUNITY ASSESSMENT OF POVERTY AND DISABILITY AMONG SPECIFIC RURAL POPULATION GROUPS IN NEPAL

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ABSTRACT

A participatory survey on poverty and disability was carried out among the households of members of women's self help groups in a community development project, in three rural areas of Nepal. This survey covered a total of 19,210 persons belonging to poor and marginalised population groups.

The survey provided information about prevalence and demographic and literacy related information about persons with disabilities in the surveyed population.

It also showed that persons with disabilities form a disproportionately large part of those defined as poorest, by their own poor communities. The survey also showed that a majority of persons with disabilities from the surveyed population do not have access to any services including rehabilitation services.

The survey was used as a first step to promote awareness about disability issues in the women's self-help groups and to support setting up of community groups of persons with disabilities.

INTRODUCTION

Disability and poverty are inextricably linked and lead to a vicious cycle with one being both a cause and a consequence of the other (1). Persons with disabilities are estimated to make up to 15% to 20% of the poor persons in developing countries (2). Worldwide, as many as 50% of disabilities are directly linked to poverty (3).

The links between poverty and disability can be multiple and complex, including through local geographical factors (for example, wars, specific infections like trachoma and schistosomiasis, stress, etc.), insufficient or unhealthy food, insufficient or inaccessible health services (including physical inaccessibility as well as because of related costs), social exclusion and stigma (for example for persons affected with leprosy, for persons with epilepsy, etc.), barriers to employment, etc. (1).

POVERTY

Poverty, whether rural or urban, needs to be looked at from a range of perspectives. Poor women, men and children experience poverty in different ways, in their daily lives. It affects where they live, what they eat, how they spend their days, and above all, their general well-being. It is a multi-faceted issue (4). Absolute poverty has been defined as, “a condition of life so limited by malnutrition, illiteracy, disease, squalid surroundings, high infant mortality and low life expectancy as to be beneath any reasonable definition of human decency” (5).

Often, poverty is seen only in terms of income poverty and is measured in terms of arbitrary dividing lines such as, “persons living with less than 1 US dollar per day” (4). However, poverty is not related only to the economic aspect but is multi-dimensional. It is also related to powerlessness, to not being counted, to not being considered, to be excluded, to be unheard. Poverty is related to exploitation, oppression, victimisation and violence. It is also related to migration, forced displacement, rising urbanisation and loss of livelihoods. Among the poor, the more vulnerable are those who are dependent and who have no say in decisions regarding their lives. Therefore, criteria for measuring poverty and identifying the most vulnerable groups, need to be adapted to each single context (6).

Social and cultural traditions can negatively influence the conditions of specific population groups such as children who are victims of sexual and labour exploitation, widows, single mothers, uneducated persons, wives of alcoholics, bonded (slave) labourers, prisoners, persons belonging to lower castes (like in certain parts of South Asia), etc. Poverty has a specific gender dimension.

Poverty among the minority groups is another important aspect. Persons belonging to ethnic or religious or linguistic minorities are also vulnerable to poverty and not only to economic poverty. A variety of historical, social, political and economic processes impose vulnerability on the powerless disadvantaged communities. And, at the core of their disadvantage and powerlessness is the absence or denial of certain basic rights (7).

DISABILITY

The industrial revolution and the advances in medical sciences are linked with the development of the medical model of disability (8). The medical model locates the disability

in individuals and proposes interventions for the individuals to improve functioning and decreasing impact of the disabilities.

Over the past few decades, organisations of persons with disabilities (DPOs) have proposed a social model of disability that focusses on a collective view of disability and the role of disabling barriers (physical, social, attitudinal and cultural) created by the society and proposes interventions for a more equitable, society, that dismantles disabling barriers and respects human rights of all persons.

The social model of disability has had a profound impact on the way disability issues are understood and analysed. It has also led to the development of “International Classification of Functioning, Disability and Health” (ICF, 2001) by the World Health Organisation (WHO). In the context of health, under ICF, disability is seen as an interaction, as a complex relationship between the health condition and the contextual factors (i.e. environmental and personal factors (8)).

NEPAL

Nepal, with a population of about 29 million persons, is one of the poorest countries in the world with a per capita income of US\$ 240 per year. More than 60 % (31% according to the government data) of the population lives in abject poverty, which affects different human development indices (9). Over the past decade, life in Nepal has been marked by internal strife and civil war with suspension of civil liberties, that have been reinstated only recently. This has worsened the general situation in the country.

Geographically, Nepal can be divided into three distinct ecological zones - high mountains, hills and the plains (Tarai). These three ecological regions show differing levels of well-being and poverty, as seen by the differences in the Human Development Index (HDI) in the 3 areas - hills have highest HDI, followed by Tarai and mountains respectively (10).

Nepal is populated by 103 caste and ethnic groups and the 2001 national census recorded 106 languages and dialects. While the geographical location determines the access to resources, there are hierarchical sub-groups in the population (caste based groups and tribal or *Janjati* groups), that also experience varying degree of obstacles to resources depending upon their position on the hierarchy. The exact number of the *Dalit* population (literally

“downtrodden or crushed” denote the caste groups lowest in the social hierarchy) is not certain, but one estimate is that they constitute 12.9% of the population, of which 55% live in the hills (10).

WATCH PROJECT

WATCH (**W**omen **A**cting **T**ogether for **C**hange) is a Nepalese non-Governmental organisation based in Kathmandu, that focuses on promoting empowerment of women belonging to marginalised and poor castes and ethnic groups in rural areas of different districts of Nepal.

In each project site, WATCH stimulates and supports setting up of self-help women groups in communities, that are encouraged and facilitated to undertake a number of developmental activities and to network with other women’s groups to establish district, regional and national level women federations.

METHODOLOGY

A survey was carried out in three geographical areas of Nepal, covering a total of 19,210 persons in 3,397 households of persons belonging to women’s self-help groups organised under different village development committees (VDCs), in three geographical areas of the country, as shown in Table 1.

Table 1. Districts and households covered under the survey in 3 geographical areas of Nepal

Area	Population / Household Covered
1. High Mountains covering parts of Okhaldhunga district (total population 156,702)	In following VDCs: Bigutar, Ragadip, Jantarkhani, Barnalu, Baruneshwor, Necha Batase, Mamkha, Ratmate, Patle, Shree Chaur & Biplate with a total of 37 women’s groups covering 700 households with a total population of 4,795 persons
2. In hills covering parts of Kathmandu and Lalitpur districts (total population 1,419,630)	In following VDCs: Devichaur, Dukuchhap, Chaimale and Sisneri with a total of 41 women’s groups covering 563 households and a total population of 2,733 persons

3. In the southern plains (Tarai) covering parts of Rupendehi, Nawalparasi and Kapilvastu districts (total population 1,753,265)	In following VDCs: Motipur, Majhuwa, Kerwani, Devdaha, Siktahan, Salajhandi, Salajhansi, Saljhanda, Banganga, Dudha Raksya, Karahiya, Makrahar, Jahada, Semalar, Makar, Butwal and Sunwal with a total of 152 women's groups covering 2,674 households and a total population of 11,682 persons
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All the households covered under the survey belong to poor communities according to the national criteria of poverty, with per capita incomes less than 1 US\$ per day. Almost all of them are composed of marginalised rural groups, usually belonging to specific caste groups.

WATCH has been active in these communities since 1992, for promoting the setting up of women's self-help groups and women's group federations. History of a long standing collaboration and mutual trust built in the communities, has been a key factor in ensuring the success of this initiative.

This survey was promoted for raising the awareness among the women members of self help groups and their families, about the situation of persons with disabilities in their communities and as a first step towards promoting setting up of community self-help groups of persons with disabilities.

The three health facilitators working for WATCH in the three site offices of WATCH, attended a three weeks training course on community-based rehabilitation (CBR) during which, they learnt about conducting surveys for identifying persons with disabilities in the communities.

At the same time, in collaboration with women's federations, village volunteers and other partners, focus group discussions were started with women's groups' members on criteria for wealth ranking for identifying the poorest among them. A basic set of wealth ranking criteria including kind of house-building, any land properties, material goods owned by the family, any family debts, jewellery and other valuables owned by the family, etc. was prepared by WATCH. These criteria were adapted through participatory discussions in the communities in each of the three geographical areas, to respond to the specific local contexts.

Finally, a questionnaire was prepared for collecting information about each household represented in the women's self help groups in each of the three areas covered by the project. This questionnaire was filled by WATCH facilitators with the support of women's groups and village volunteers, and provided the following information: number of households in each women's group, total family members of the households, economic status of the family according to wealth ranking criteria for their geographical area and the presence of any person with disability in the households.

For each person with disability, another questionnaire was compiled, providing the following information: age, gender, education, number of family members, economic status of the family, time of onset of disability, cause of disability, kind of disability, access to services, attitude of the person with disability and attitude of the family.

This information was collected over a period of three months in the beginning of 2006. Completed forms from each geographical area were collected and tabulated by WATCH staff in Kathmandu. These tables have been analysed for this paper.

FINDINGS AND DISCUSSION

The survey methodology for this study was based on participatory approaches where all the women belonging to the women's groups were involved in defining different study criteria and collection of different information with support from community volunteers and WATCH staff. While the blue print for the information to be collected was prepared by WATCH staff, each community had the option of discussing and influencing the decisions about what information was to be collected and how.

This had the advantage of ensuring that the information collected was meaningful to the communities and related to their local context. For example, it was important for collecting information on wealth ranking and poverty, as it took into consideration all the different local cultural and social factors, for defining the poverty rather than looking at an arbitrary amount of income for defining poverty.

However, the participatory process can also result in adoption of different criteria and definitions in the different geographical areas and thus the information collected in different areas may not always be completely comparable.

Prevalence and gender distribution of persons with disabilities

A total of 355 (55% men and 45% women) persons with disabilities were identified among the 19,210 persons surveyed, giving an overall disability prevalence of 1.84%. The prevalence of disability was highest in the Tarai region (2.19%) and lowest in the hills region (1.20%). The prevalence of persons with disabilities in the three geographical areas sub-divided according to gender is presented in Table 2.

Table 2. Prevalence of persons with disabilities in the three geographical areas

Area	Total study Population	Total number of persons with disabilities (Prevalence %)	Persons with Disability	
			Male	Female
High Mountain	4,795	65(1.35 %)	30(46.1 %)	35(53.9 %)
Hills	2,733	33(1.20 %)	20(60.6 %)	13(39.4 %)
Plains (Tarai)	11,682	257(2.19 %)	145(56.4 %)	112(43.6 %)
Total	19,210	355(1.84 %)	195(54.9 %)	160(45.1 %)

As far as gender is concerned, in the high mountains there were more women with disabilities as compared to disabled men, while in the hills and Tarai, the percentage of men was higher.

According to a national report, persons with disabilities constitute 1.63 % of the total population in Nepal. The principal causes of disability are malnutrition, congenital, non-communicable diseases, trauma, communicable diseases, mental problems, and alcohol and substance abuse (11). This national data compares well with the data collected during the survey.

However, the data collected in this survey is not based on standard definitions of different disabilities, but rather on how different existing conditions were judged as “disabling” in different contexts of three geographical areas (Tarai, hills and high mountains) involved in the survey. Some specific disabilities such as epilepsy and psychosocial disabilities (mental illnesses) were not counted.

It is also possible, that this data does not include persons with disabilities which do not affect the daily activities of the persons. For example, persons with grade 1 disability of leprosy (loss of skin sensation in hands/feet) or persons with partial vision loss or partial hearing loss may not have been included. Thus, it is likely that actual prevalence of disabilities may be higher.

Age Distribution of Persons with Disabilities

The prevalence of persons with disabilities according to different age groups was calculated in the three areas and is presented in Table 3.

Table 3. Age distribution of persons with disabilities

	< 5 Yrs	6-15 Yrs	16-40 Yrs	> 41 Yrs	Total
Mountain	2	16	23	24	65
Hill	4	7	12	10	33
Tarai	22	70	103	62	257
Total	28 (7.88%)	93 (26.19%)	138 (38.87%)	96 (27.04%)	355(100%)

To be meaningful, this data on age distribution of different disabilities needs to be correlated to the total population in each age group. However, this information was not available for analysis. From the available data, it appears that in the surveyed population, children below 15 years, together constitute about 34 % of persons with disability.

Prevalence of different kinds of disabilities

In the three areas, the categories of different disabilities were decided after discussions with the persons participating in the survey. These categories that were decided, were different from those used in the WHO manual on community-based rehabilitation. The prevalence of different disabilities in the three geographical areas is presented in Table 4.

Table 4. Prevalence of different disabilities

Kind of disability	Mountains	Hills	Tarai	Total
Movement	36(55.4%)	19(57.6%)	146(56.8%)	201(56.6%)
Hearing and speech	15(23.1%)	4(12.1%)	45(17.5%)	64(18.2%)
Vision	4(6.1%)	2(6.1%)	27(10.5%)	33(9.3%)
Intellectual	9(13.8%)	2(6.1%)	17(6.6%)	28(7.8%)
Multiple	1(1.5%)	6(18.2%)	22(8.6%)	29(8.1%)
Total	65	33	257	355

The categories of convulsions (epilepsy), loss of sensation (leprosy) and strange behaviour (mental illness) used in the WHO's CBR manual are missing.

Age at the Onset of Disability and Cause of Disability

The survey collected information about the time of onset of disability and the cause of disability, from all the persons with disabilities identified in the three geographical zones.

An analysis of this information shows, that for persons who developed disabilities after birth, the answers about age of the person at the time of the onset of the disabilities are not precise. Therefore, the data about "age of onset of disability" can only be analysed in terms of two categories – if the persons had disability at birth or did they develop it later.

The analysis of this data shows that 41.6% of the persons with disabilities covered in this survey had disability since birth. Data on age of onset of disability is presented in Table 5.

Table 5. Age at the onset of disability

Area	Persons with disability at birth	Persons who developed disability after birth	Persons for whom Information not available	Total
Mountains	31	33	1	65
Hills	13	20	0	33
Tarai	97	145	15	257
Total	141 (41.6%)	198 (55.8%)	16 (4.5%)	355

In the literature, it has been estimated that disabilities present at birth may constitute 15 to 25% of all persons with disabilities (12). However, this contrasts with the findings from this survey, where persons with “disabilities since birth” constitute more than 40% of all persons with disabilities.

Information about the opinions of persons with disabilities and/or their family members about the causes of disability, was not collected in a uniform manner in the 3 areas. Often, the causes were mentioned in a generic way (for example, “due to a sickness” was used frequently in the answers). Thus these answers have not been analysed for this paper.

Literacy levels among persons with disabilities

Data on level of education of persons with disabilities has been collected in different ways in the three geographical areas. For some persons, the precise number of years of school education are mentioned while for others, the answers are recorded simply as “literate” and “illiterate”.

Therefore, to compile this information, all the persons who had at least one year of school education have been calculated under the column “Lit.” (persons with basic reading and writing skills) in Table 6, without specifying the number of years of schooling. Therefore, this group of persons also includes some persons who have higher literacy levels.

Persons above 41 years and children below 5 years were excluded from this analysis.

The analysis shows that overall, among the 224 persons with disabilities belonging to the age group from 6 years to 40 years, 101 persons (45%) were literate and had at least basic reading and writing skills. Information on basic literacy for persons with disabilities subdivided for gender and age, is presented in Table 6.

Table 6. Basic Literacy for persons with disabilities subdivided for gender and age

Area	Male						Female					
	6-15 yrs			16-40 yrs			6-15 yrs			16-40 yrs		
	Lit.	Illit.	NA	Lit.	Illit.	NA	Lit.	Illit.	NA	Lit.	Illit.	NA
Mountain	2	5	-	5	7	-	5	4	-	7	4	-
Hills	3	1	-	6	2	-	1	2	-	0	4	-
Tarai	18	10	7	27	27	7	17	12	6	17	23	2
Total	23	16	7	38	36	7	23	18	6	17	31	2
%	50	34.8	15.2	46.9	44.4	8.6	48.9	38.3	12.8	34	62	4

Note: Lit.: knows basic reading and writing; Illit.: no reading and writing skills; NA: not known.

Since similar data about non-disabled persons according to age and gender is not available, this data cannot be compared with the situation in the remaining surveyed population.

However, these literacy levels compare well with the average national literacy levels in the general population in Nepal, that is 48.6% (13). This can also be a reflection of a long tradition of formal and informal education activities by the women's self help groups in the last 15 years and may not reflect the general situation.

Disability and Poverty

Wealth ranking of all the persons surveyed in the three areas was a key activity of this initiative. Though according to the official definitions, all the persons included in this survey fall under the definition of "rural poor", they were asked to identify the ones they considered the poorest amongst themselves. Communities in each geographical area discussed the wealth

ranking criteria, to fine tune them so that the criteria keep an account of their local context. Information on wealth ranking of all the survey population to identify the poorest among them is presented in Table 7.

Table 7. Wealth ranking of all the survey population to identify the “poorest of the poor” persons

Area	Total Population	Very poor population	%
Mountains	4.795	295	6.15 %
Hills	2.733	187	6.84 %
Tarai	11.682	1,138	9.74 %
Total	19.210	1,620	8.43 %

The survey showed that about 6 to 10% of the surveyed population were considered as “poorest of the poor” by their own communities.

At the same time, this information provided wealth ranking data for all the persons with disabilities identified in the surveys. This was analysed separately and situation is presented in Table 8.

Table 8. Persons with disabilities among the “poorest of the poor” persons

Area	Total Persons with disability identified	Wealth ranking not done	Very poor persons(%)
Mountains	65	-	42(64.6%)
Hills	33	-	21(63.6%)
Tarai	257	17	193(80.4%)
Total	355	17	256(75.7%)

In the total survey population wealth ranking, 6.15 % to 9.74 % of population (overall 8.43 %) was identified as “poorest of the poor”, while if one looks at the wealth ranking done for

persons with disabilities, about 64 to 80% of them (overall 75.7 %) are considered as “poorest of the poor”.

This finding confirms the strong links between poverty and disability in these communities and that poverty affects a disproportionately large number of persons with disabilities as compared to the general population.

Access to Services for Persons with Disabilities

Persons with disabilities and/or their families were asked if they had ever received any specific service for disabled persons (rehabilitation services, any aids or appliances, hospital visits, any training programme, etc.) from any institution or programme. The following Table 9 presents a summary of the answers about contacts with any specific services for persons with disabilities.

Table 9. Access to specific services for persons with disabilities

Area	Total number of persons with disabilities	No information available on access to services	Persons who received at least one service once in their lives (%)
Mountains	65	-	12 (18%)
Hills	33	-	5 (15%)
Tarai	257	5	21 (8%)
Total	355	5	38 (11%)

This means that around 80% of persons with disability did not have any contact with any disability related specific centre or services. The study shows that a very small percentage of persons with disabilities (8 to 18%) has any access to the different disability related services.

Issues of actual benefit from the services, details of different services accessed, quality of services received and level of satisfaction from the services were not tackled in this survey.

The issue of access to existing health services was also not tackled. Generally speaking, most of the areas covered by the project have inadequate coverage for basic health services. For example, in the mountain areas, out of the 18 health centres “planned” for the area covered by the survey, only 8 have any staff. However, none of these 8 centres were operative through out the year - majority of them functioned for about six months per year. Considering these difficulties, specific questions on access of persons with disability to existing primary health care services were not asked, but the access to the local primary health care services were likely to be very low. Access to more specialised rehabilitation services was likely to be even lesser or almost non existent.

Transport difficulties were common in all the three geographical areas covered under this survey. In the mountains, reaching a public transport service can require 2-4 days of walking. In the hills and Tarai, the walking distances to any public transport were lesser, but still can require hours of walking. These difficulties also influence the access to different services. However, specific roles of different factors including transport, in influencing access to different services were not tackled during the survey.

Other Information Collected During the Survey

The survey also provided descriptive information about attitudes of persons with disabilities, about their lives and their possibilities and the attitudes of communities towards persons with disabilities. This descriptive information is usually expressed in very generic terms and has not been analysed for this paper.

Impact of the Survey

The information collection initiative was carried out to promote awareness about the situation of persons with disabilities among the women involved in self-help groups and women’s federations. Preliminary discussions with the women’s groups had suggested that there were not many persons with disabilities in their communities. Therefore, community surveys provided actual information about the persons with disabilities who were often hidden and were invisible, and their needs were not considered.

Following the surveys, self help groups of persons with disabilities were formed in all the three geographical zones. Two federations of self-help groups of persons with disabilities

were also constituted in Rupandehi (Tarai) and Okhaldhunga (high mountains). There have been some contacts with national level organisations of persons with disabilities (DPOs). They have been able to demand resources from local government agencies and they have been able to establish contacts with national level organisations, but they are still neglected. At the same time, this initiative has been important in promoting inclusion of persons with disabilities in the development activities carried out by women's groups, but still a lot more requires to be done. A number of initiatives including community-based rehabilitation activities are being planned.

CONCLUSION

This study involved a community participatory survey in a relatively large sample of a population group of persons belonging to specific poor and marginalised caste groups, for creating awareness about the situation of persons with disabilities and as a first step for promoting setting up of community self-help groups of persons with disabilities.

All the households involved in this survey belonged to poor families according to the national definitions of poverty, as persons living on less than one US\$ per day. The participatory survey done by the women's self help groups shows that in these poor communities, a disproportionate number of persons with disabilities are among the "poorest of the poor". The participatory survey also showed that only a small percentage of persons with disabilities from these marginalised communities had access to any specific services.

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REFERENCES

1. WHO, *Disability and Poverty - WHO Fact Sheet*, Disability and Rehabilitation team, World Health Organisation (WHO/DAR), Geneva, 2006
2. Elwan A., *Poverty & Disability: A Survey of the Literature*, World Bank, December 1999
3. DFID, *Disability, Poverty and Development*, UK Department for International Development (DFID), February 2000
4. Nayar U. S., Poverty and Identifying the Poor, in "*Poverty, Health and Development*", Health Cooperation Papers volume 17, edited by Deepak S., AIFO, Italy, 2003
5. Macnamara R. quoted in *The Oxfam Poverty Report*, Watkins K., Oxfam, UK and Ireland, 1995
6. AIFO, Final Document, in "*Poverty, Health and Development*", Health Cooperation Papers volume 17, edited by Deepak S., AIFO, Italy, 2003
7. Nayar, U. S., *Work Patterns of the Girl Child*. The Indian Journal of Social Work, Vol. LII - 1, 1991
8. Mitra S., *The Capability Approach to Disability*, papers for 3rd conference on Capability Approach, Pavia (Italy), 7-9 September 2003 (<http://cfs.unipv.it/sen/papers/Mitra.pdf>)
9. Shrestha S., Accessibility of Health Services in Nepal, in "*Poverty, Health and Development*", Health Cooperation Papers volume 17, edited by Deepak S., AIFO, Italy, 2003
10. Pradhan R. & Shrestha A., *Ethnic and caste diversity: Implications for Development*, NRM Working paper 4, Asian Development Bank, Nepal Resident Mission, June 2005
11. WHO/DAR, report of *Inter-country Workshop on Strategy for Improving Rehabilitation Services*, Kathmandu, Nepal, 26 – 30 August, 2002
12. Einar Helander, *Prejudice and Dignity* – an introduction to community based rehabilitation, 2nd edition, UNDP 1999
13. United Nations Development Programme, *Human Development Report 2007-08*, http://hdrstats.undp.org/countries/data_sheets/cty_ds_NPL.html