

## **A REPORT ON DISABILITY IN THE WESTERN REGION OF NEPAL**

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### **ABSTRACT**

*NDUP Nepal has recently successfully carried out a research to investigate the underlying reasons for disability. The research focuses solely on the causes of disability problems but not on disability itself. Similarly, NDUP focuses its study on responsible parties for problems and possible solutions. The main objective of the study was to find out underlying reasons of disability in Nepal. A total of 97 non-disabled and 35 disabled members, plus two different focus groups were included in 8 Village Development Councils of (VDCs) Kaski, Tanahun, Syanja, and Parbat districts. Qualitative data were collected by interviewing the two different focus groups in each VDC and individual interviews. The findings of this study encourage further development of rehabilitation plans of people with disability in Nepal.*

### **INTRODUCTION**

The main purpose of the study was to identify the causes of disability in Western Nepal and to assess how the community and individuals viewed rehabilitation of disabled people in their society. The study also identified attitudes of disabled people and their participation in their society.

### **METHODS**

The study was carried out in eight VDCs of four districts, namely Kaski, Syanja, Tanahun and Parbat in Western Nepal. There were two VDCs selected for the research, Dhikurpokhari and Kaskikot VDCs in Kaski, Ward No. 1 and 2 of Putalibazaar municipality in Syanja, Jamune and Khairanitar VDCs in Tanahun, and Tilahar and Pipaltari VDCs in Parbat. Interviews were conducted to extract a range of attitudes, opinions and behaviours from 97 non-disabled individuals and 35 disabled people in the eight VDCs of the selected four districts. Of the 35 people with disabilities included in the study, about 50 % were physically impaired and others had hearing difficulties or visual impairment. Focus group discussions were conducted with two different focus groups, namely disabled people and key family members, and community leaders selected from

each VDC. About 7-10 people were invited for focus group discussions in each group. The former VDC chairperson and other executives, teachers, women leaders, and Community Based Organizations (CBOs) existing in that particular VDC were also invited for focus group discussions. One in every ten households was selected for the focus group discussion and the members for discussion were selected randomly. Consent was obtained from each member/household included in the study. It was clearly communicated that participation in the study did not carry any material benefits or any promises of further rehabilitation. Names of informants and communities were kept confidential. The period of study was from April 2003 to October 2003.

## RESULTS

**Table 1. Summary of opinions during individual interviews**

<b>Questions</b>	<b>Response of the key community leaders, parents, health workers, teachers and volunteers</b>
What do you think about disabled people, since they are part of your community?	Disabled people are different in physical appearance as compared to non-disabled people. They are unable to walk, speak, see and eat. They have difficulties in daily activities, have paralysis, deafness, dumbness and mental retardation. It is pitiful, filled with suffering and complicated. It could be due to sin, dependency, lack of appropriate health services, impairment, hereditary, accidents, being proud, lack of money, leprosy, nature's gift or mental weakness. Their condition may also be due to previous life, poor confidence or frustration.
In your opinion, what are the causes of disability?	<ul style="list-style-type: none"> <li>• Lack of self-confidence, shyness, being teased.</li> <li>• Lack of educational opportunities, encouragement, and co-operation.</li> <li>• Lack of appropriate health services, socialisation, social work and hatred.</li> <li>• Negligence of doctor, family and government.</li> <li>• Poverty, unemployment and lack of opportunities for economic development.</li> <li>• Lack of assistive devices/equipment, unfavourable environment, and physical infrastructure.</li> </ul>

	<ul style="list-style-type: none"> <li>• Poor policy and legislation.</li> <li>• Problem of accessible market, unable to learn skills and no opportunities to learn skills.</li> <li>• Poor education, attitude, forgiveness and social beliefs.</li> <li>• A stage of weakness, hesitation and poor treatment.</li> </ul>
In your opinion, who are affected by disability?	People with disabilities themselves, families, community, parents, children, poor and illiterate families, country, world, everybody, friends, teachers, Institutions, poor and unemployed.
In your opinion, who is responsible for the problem of disability?	<ul style="list-style-type: none"> <li>• People with disabilities themselves, families, community and others.</li> <li>• VDC, District Development Council (DDC) country, institutions, teachers and mothers.</li> <li>• Policy makers, parents, neighbours, doctors, lawyers, hospitals, political parties and government.</li> <li>• Poverty, illiteracy and lack of awareness.</li> </ul>
In your opinion, who is responsible to resolve the problem of disability?	<ul style="list-style-type: none"> <li>• People with disabilities themselves, families, community and institutions.</li> <li>• VDC, DDC country, international communities, political leaders and social workers.</li> <li>• Policy makers, parents, neighbours, doctors, lawyers, NGOs, CBOs and INGOs.</li> </ul>
What is the root/cause of the disability?	<ul style="list-style-type: none"> <li>• Carelessness, ignorance and lack of knowledge.</li> <li>• By birth, accident, diseases, natural disaster, hereditary, negligence of mother during pregnancy and after birth, negligence of doctor, lack of doctor, unsafe delivery and use of drugs during pregnancy.</li> <li>• Marriage with a close family member, early marriage and premature delivery, poverty, lack of health, education, social circumstances and lack of physical infrastructure.</li> <li>• Abortion.</li> <li>• Lack of nutritious food, immunisation, awareness, and lack of health services.</li> </ul>

In your opinion, especially in the context of rural communities, what are the main needs of people with disabilities?	<ul style="list-style-type: none"> <li>• Education, employment, salary and allowance, skills training and awareness about activities.</li> <li>• Affection, counselling, encouragement, human rights and dignity.</li> <li>• Economic support, referral, treatment, and concessions.</li> <li>• Business opportunities such as animal keeping, shops and skill training.</li> <li>• Opportunities according to one's age, sex, and disability.</li> <li>• Development of physical infrastructure that is barrier free.</li> <li>• Assistive devices and equipment.</li> <li>• Accessible roads, schools and hospitals</li> </ul>
Do you know of any other people with disabilities in your community? If yes, what do you think of them?	<ul style="list-style-type: none"> <li>• Yes = 89, No = 8.</li> <li>• Services provided by government are not enough, local support is essential for their development.</li> <li>• Help them when there are difficulties, needs psychosocial counselling, encourage them for confidence building.</li> <li>• Treat equally; include them in all social activities.</li> </ul>
Do you know any children with disabilities in your community who are school- going?	Only one-third of the people know that children with disabilities go to schools. It means the either the physical infrastructure in villages has severe barriers, or awareness levels about schools is low.

**Table 2: Views of persons with disabilities about their situation in comparison with their peers**

Description of the situation	How severe is the problem?	How serious is the problem for you?
A. Mobility	11	24
B. Self care	25	10
C. Learning and applying	23	12
D. General tasks and demands	24	11
E. Communication	13	22
F. Domestic life	9	26
G. Major life areas	21	14
H. Community social and civic life	21	14
I. Interpersonal interactions and relationships	23	12
J. Attitudes and concerns	18	17

Out of 35 people with disabilities, the majority have difficulties in mobility, communication and domestic life. Mobility is a major problem because the roads are not accessible for wheel chair users. Sometimes, the community does not accept disabled children and the parents stated that it was a big problem. They did not know how the disabled children would spend their life after the parent's death. They felt that other family members needed to support them.

**Table 3: Focus group discussion results**

<b>Questions</b>	<b>Response of the key community leaders, parents, health workers, teachers and volunteers</b>
As a community member what do you think of disability?	<ul style="list-style-type: none"> <li>• Disability is: hereditary, due to accidents, being proud, poverty, natural gift, being different in physical structure compared to other non-disabled people, mental weakness, lack of support from others, leprosy, difficulty to walk, speak, see and eat, return to previous life, poor confidence and frustration.</li> <li>• Disabled people do have to develop their confidence. They still need to do more about it.</li> <li>• We do know that there are some disabled people in our area, we do not know in depth what is their real situation. We also hear that they have difficulties in working in the groups.</li> </ul>
In your opinion, what are the causes of disability?	<ul style="list-style-type: none"> <li>• Poverty, unemployment, lack of opportunities for economic development.</li> <li>• Lack of assistive devices/equipment, unfavourable environment.</li> <li>• Problem of accessible market, unable to learn skills, no opportunities to learn skills.</li> <li>• Poor education, negative attitude, lack of forgiveness, social beliefs.</li> <li>• Stage of weakness, hesitation, and no treatment.</li> <li>• Poor policy and legislation.</li> </ul>
In your opinion, who are affected by disability?	<ul style="list-style-type: none"> <li>• People with disabilities themselves, families, community, parents, children, poor and illiterate families and country.</li> </ul>
In your opinion, who are responsible for problems due to disability?	<ul style="list-style-type: none"> <li>• People with disabilities themselves, families, community.</li> <li>• VDC, DDC, country.</li> <li>• Policy makers, parents, neighbours, doctors and lawyers.</li> <li>• Poverty, illiteracy and lack of awareness.</li> </ul>

<p>In your opinion, who are responsible to solve the disability problems?</p>	<ul style="list-style-type: none"> <li>• People with disabilities themselves, families, community.</li> <li>• VDC, DDC, Country, International communities.</li> <li>• Policy makers, parents, neighbours, doctors, lawyers, NGOs, CBOs and INGOs.</li> </ul>
<p>Are you aware about the root cause of disability?</p>	<ul style="list-style-type: none"> <li>• By birth, accident, diseases, natural calamities, hereditary, negligence of mother during pregnancy and after birth and negligence by doctor.</li> <li>• Lack of nutritious food, awareness, lack of health services.</li> <li>• Poverty, lack of health education, biological differences, social circumstances, lack of physical infrastructure.</li> <li>• Marriage with the nearest family relative.</li> </ul>
<p>As part of community, what do you think about the needs of the disabled people in remote villages in Nepal?</p>	<ul style="list-style-type: none"> <li>• Education, employment, skills training, awareness activities.</li> <li>• Opportunities according to their age, sex, and disabilities.</li> <li>• Development of physical infrastructure as per their disability.</li> <li>• Assistive devices and equipment.</li> <li>• Accessible roads, schools, hospitals.</li> <li>• Establishment of revolving fund fixed deposit, economic development.</li> <li>• Formulation of policies and their implementation for welfare of the disabled people, and inclusion into the mainstream society.</li> <li>• Establishment of organisations to work for people with disabilities.</li> </ul>
<p>what are the recommendations for programmes on disability?</p>	<ul style="list-style-type: none"> <li>• There is a big problem of getting clean drinking water in our village and so even more for the disabled people.</li> <li>• It would be very nice to establish a skill-training centre for the disabled people.</li> <li>• Disabled people know the problem of the disabled people better.</li> <li>• All the disabled people who live in the community should be encouraged to be included into the mainstream development of the society.</li> <li>• Disabled members should not be sidelined in any opportunities available to them.</li> <li>• Awareness-rising programmes about disability and rehabilitation must regularly be organised by the concerned organisations/offices.</li> </ul>

- Some families still hide their disabled members in their houses for fear of loosing their prestige. Therefore it is necessary to arrange a comprehensive awareness-raising programme in the community. Unless community attitudes are changed to favour disability, there will not be any holistic development in the community.
- Education, employment, skills training, awareness programmes are needed.
- Opportunities according to their age, sex, and disabilities need to be provided.
- Development of physical infrastructure as per their disability is required.
- Assistive devices and equipment are needed.
- Accessible roads, schools and hospitals are needed
- Establishment of revolving fund, fixed deposit and economic development are required.
- Formulation of policies and their implementation for the welfare of the disabled people, and inclusion into the mainstream society are required.
- Establishment of organisations to work for people with disabilities is required.

## **CONCLUSION AND SUGGESTIONS**

Supporting people with disabilities is a great concern of every individual and organisation. Hence, NDUP-Nepal initiated this research for identification of reasons of disability. Even though there are many reasons for disability, this study identified some of them that are useful for planning and inclusion of people with disabilities into the mainstream development of the society. The findings of this study can be a useful resource to planners concerned with Nepal.

Some suggestions arising from the study are:

- Physical infrastructure must be accessible for disabled people so that all disabled people can use public utilities.
- Training packages should be developed according to the age of the people. People should also be categorised according to the severity of their disability.
- Effective awareness raising programmes should be conducted for disabled people, family and community about disability and development issues before and after implementing any rehabilitation activities.

- Disabled people should be encouraged to be involved in all community development activities according to their potential.
- All disabled and non-disabled members are equally responsible to establish a discussion forum about disability.
- Community attitudes need to be changed to favour disability issues, there should be an effective awareness raising programme in the community, for existing groups, schools, volunteers, elected officials, mass meeting etc.
- Family members should be trained on how to communicate with their deaf members, how to cure wounds of disabled members, how to orient blind members and how to teach their mentally retarded members etc.
- Primary rehabilitation interventions should be available in the community. It is the responsibility of the government, NGO, NGO and the community.
- Families should be encouraged to send their disabled children to schools, community events, cultural events etc. that they can enjoy, learn and share their views.
- All the disabled members are equally responsible and have equal rights to take decisions.
- Families and communities must be informed what the real needs of disabled people are because they are the key people to help disabled people to mobilise local resources.
- Non-formal education classes should be started in the community.
- Families should be encouraged not to hide their disabled members in their houses.
- VDC, DDC and government should be made aware that solving disability issues are also part of community development. Therefore they should consider this issue as any other component of community development.
- Existing laws, acts, policies and legislation about disability and disabled people must be amended by the government and implemented. INGO/NGO should be requested to implement rehabilitation activities in the community.
- There should be an opportunity to attend schools for those who cannot pay monthly expenses of schooling.
- INGO/NGO should be transparent in all the activities and should establish a good positive relationship with the community.

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