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## Introduction of disability cards: A study of policy implementation and local experiences of disability in Okhaldhunga VDC, rural Nepal



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disability in Okhaldhunga VDC, rural Nepal**

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## **Abstract**

Previous studies have shown that there is significance relationship between disability and poverty. Nepal being one of the poorest countries in the world we can expect large number of person with disability. In 2008, the Nepal Government revised its disability policy of 1994 into a disability card policy. In this policy, four different categories, based on severity, are recognized: Red card (profound disability), Blue card (Severe disability), Yellow card (Moderate Disability), and White card (Mild Disability). Card holders are entitled to monthly allowances and social benefits. Until now, there is limited information available about the local implementation and reception of the policy among persons with disability. The literatures found on disability in Nepal were limited to quantitative studies of numbers and distribution. It was identified that there is a knowledge gap of the life experiences of persons with disabilities, especially in rural Nepal. Thus, this study has two main goals: to explore the everyday experiences and challenges of persons with disability in rural Nepal, and second, to analyze the local implementation of the new disability card policy in the same area.

I ask: In what ways do the disability card policies respond to the needs of people with disability in rural Nepal? How the new policy is made available to the persons with disability? How do persons with disability gain information about the cards? In which ways do they take advantage of the cards? What characterizes the local processes of accessing cards and the following benefits? I argue that without understanding the local reception of the cards and the related policies there can never be proper implementation and benefit for those who were aimed for it.

The study was carried out in Eastern part of Nepal, more precisely in Okhaldhunga VDC of Okhaldhunga district in the Sagarmatha Zone. The main methods used to collect data were in depth interviews, participant observation and focus group discussions. The study was carried out for six months. In the field, 47 people with disability participated. Among them 20 were purposively selected for repeated in-depth interviews and participant observation and further nine among them were

interviewed several times along with participant observation. However, the analysis of the study has led to the stories of seven persons with disability.

The findings in the study show that the economic improvement can improve social life. At the governmental institutional level the study shows a limited involvement of locals and particularly lack of consideration of the local context would be the main reasons for lack of a good implementation. Therefore, the findings suggest that the policy needs to take seriously the cultural and local setting and understand the needs of locally based people in order to be fully effective. Furthermore, studies on disability with nuanced analysis are required in field which will reflect the complex world of poverty and disability relations.

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## **List of Abbreviations**

CIOMS	Council for International Organizations of Medical Sciences
CWCSW	Center for women children and social welfare
DHRC	Center for Human rights for disabled
DPO	Disabled People's Organization
HI	Handicap International
ICF	International Classification of Function and disability
INGO	International Non Governmental Organization
NFDN	National Federation of Disabled Nepal
NGO	National Governmental Organization
REK	Norwegian Research Ethics Committee
UN	United Nations
UNCERD	United Nations Committee on the Elimination of All Forms Of Racial Discrimination
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNICEF	United Nations International Children's Emergency Fund
VDC	Village Development Committee
WATCH	Women Acting Together for Change
WHO	World Health Organization

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# CHAPTER ONE: INTRODUCTION

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*It is fate of my life that god gave me two sons, Suresh and Subin, 11 years and 5 years both of them cannot walk, cannot speak and cannot do the activities of daily living. People in the village think that I have done something wrong during pregnancy or there is some kind of problem with me. Even my husband thinks that there is problem with me. Sometimes, he expresses in anger that I gave birth to useless children and he wants to marry another women to have healthy children.*

*I was so happy at the thought of getting Rs.1000 for each son per month which I could use to buy soaps to clean them and wash their cloths. Perhaps will be enough to buy some nutritious food for them. But my children are so unlucky. They must have done some bad deeds in past life. After few days of receiving the Red card, VDC secretary told me that they cannot get identity card and allowance until they are 16 years. I don't know, may be my children will not live until 16 years.....*

This thesis is about poor persons with disability in rural Nepal, their experiences, and challenges. The interconnection between disability and poverty is well known. These connections have been recognized as a 'vicious cycle', in which disability and poverty both are seen to be causes and consequences of the other (Yeo, 2001; Yeo & Moore, 2003)(Elwan, 1999). With this knowledge, I found it interesting and important to focus on the issues of disability in one of the poorest countries in the world: Nepal. After the literature review it became clear that there is a lack of knowledge about persons living with disability in the rural countryside in Nepal. Moreover, as the government of Nepal has launched new disability policy, little is known about the implementations of these policies. The main goal of this study is to understand the experiences of person with disability residing in a rural area of Nepal and to understand the local implementation and reception of new disability policy at the local level.

The area chosen for the study is Okhaldhunga Village Development Committee in Central Nepal. In order to gain insights into experiences and implementations on a local level, I chose a qualitative method. The data collection method was participant observation, including repeated in-depth interviews with persons with disability, their household members, authorities and stake holders of disability identity card policy along with it; an observation was done in the domestic and public spheres of the community. In the final stage of the fieldwork focus group discussion was arranged.

The study shows that, economic position of the person with disability can have an influence in social life. The study has clearly shown the lack of implementation of policy in Okhaldhunga VDC.

## OBJECTIVES:

### Main goals

**The study has two main goals:**

- **To generate new knowledge about experiences with and perceptions of disability in rural Nepal.**
- **To explore the local reception of disability card policy in rural Nepal.**

So far nothing has been published about how the local people have perceived the idea of having a disability identity card in order to access social benefits. In order to explore this issue, solid information about people's experiences and the local perceptions of disability is crucial. These two goals are therefore directly interconnected. I ask: In what way does disability card policy respond to the needs of people with disability in rural Nepal? How the new policy is made available to the persons with disability? How do persons with disability gain information about the cards? In which ways do they take advantage of the cards? What characterizes the local processes of accessing cards and the following benefits? Without understanding the local reception of the cards and the related policies there can never be proper implementation and benefit for those who were aimed for it.

## Sub goals

- **To explore anticipated goals and aims of the disability card policy in Nepal.**

The anticipated goals and the aims of disability card, is not known as there is nothing written on it. So, without knowing the aims and goals of this new policy of disability card, we cannot know the effective implementation of disability card. This study will add value for clearer understanding of goals and aims of disability card policy.

- **To understand how the disability identity cards and its benefits are accessed by the locals (person with disability) and implemented from a rural perspective.**

The process of accessing card and benefits are not transparent, further disability card has been in the policy in 2008, but there is no information on how has it benefitted the people with disability in the rural areas of Nepal, and there is no information on how far the policy has been implemented. Without such information the results will be of value in overcoming the challenges of implication in the rural areas and also provides information on the effectiveness of the policy.

## THEORETICAL FRAMEWORK:

The theoretical framework of study has been inspired by anthropological studies due to the relatively strong focus on the individual; a discipline which to large extent focus on socio-cultural and environmental factors. The characteristic of the anthropological perspective can be said to be “its holism”, and the advantage of the anthropological perspective is that it aims to encompass diversified and pluralistic understandings of a phenomena (Greenhalgh, 1995, pp. 3-28) .

### Anthropological perspectives in disability studies

Disability studies are informed by various disciplines, such as sociology, social policy studies, law, in addition to health disciplines. Many persons with disabilities have

also been actively involved and dominated parts of disability studies (Shakespeare, 2006, pp. 7-68).

One of the disciplines that have gained influence in disability studies the last two decades is anthropology. The publication of Ingstad and Whyte's anthology *Disability and Culture* in 1995 introduces a perspective in which cultural contexts were seriously taken into the analyses of experiences and perceptions of disability.

Various attempts were made to define disability to fit universally, but Ingstad and Whyte argued that the perception of disability depends on what is valued most in particular context. Therefore, they told, we must take into consideration the cultural and social context. Definitions, meanings and attitudes vary, with different cultures and societies. It may vary from discrimination, acceptance to seeing disability as possessing supernatural powers (Ingstad & Whyte, 2007).

Discrimination and stigma are one of the major concerns related to disability and hold a central place in disability studies. In many societies, very often people with different physical shapes, sizes, and bodily functions are stigmatized as well as discriminated. Stigma varies from society to society and sometimes very different things are included in the very definition of disability. Ingstad and Whyte give us several examples of definitions of disabilities that strongly differ from what we know from WHO's categories, including old age, ugliness, or excessive freckles, protruding naval, deafness, absentmindedness, flabby and small buttock.

However, there are communities where forms of disability are accepted without discrimination and stigma, and where persons with disabilities are believed to have supernatural powers and as such play a full role in their community. One common example is the perception of blind people possessing a special sight, what in ancient Korea was called "a sight of mind", for which at many places they were given roles as diviners who acts as fortune tellers, select sites for buildings and graves, pray for rain and place curses (Levinson & Gaccione, 1997, pp. 102-4).

Gender is also a recurrent issue in disability studies, as it plays an important role in the discrimination and acceptance of people with disability. Again, the meaning of gender varies in different cultures and societies. For instance, in North-America, disabled women are less likely to get married because of high value on their appearance and fitness, while disabled men are less likely to get married in China because of the expectance of them being the bread winners (Kohrmann, 2005). Another example is from Uganda, where blind women may have children even if they are single and can depend on them, while blind men cannot achieve parenthood. Here, in these countries women and men with disability have different prospects (Sentumbwe, 1995, pp. 159-173).

As Nepal is overwhelmingly rural and so few studies have already been done about disability in the countryside, selecting a study site was rather open. Two things were important: that the area was classified as poor, and I had some contacts that would be able to introduce me to the community. Through contacts working in the Missionary Hospital in the area, I choose Okhaldhunga VDC.

### **Disability and poverty**

As mentioned, disability and poverty are inextricably linked to each other and lead to what is often termed a 'vicious cycle'. Worldwide 50% of cases of disability are directly linked to poverty. The links between poverty and disability can be multiple and complex including local and geographical factors, unhealthy or insufficient food, lack of health services or lack of access, social exclusion, stigma, unemployment, illiteracy etc. (Elwan, 1999). The vicious cycle of poverty and disability helps to explain the reasons of disproportionately higher rates of poverty among the people with disability. People with disability face widespread discrimination since their birth or the moment of their disablement. This cycle constitutes the two important phenomena: First, the high rates of poverty among disabled people, and second, the high rates of impairment and disability among the poorest. High rates of poverty among people with disability is seen due to institutional discrimination, lack of suitable physical environment, early lack of investment in children with disability, and finally lack of income opportunities and employment. Here, institutional discrimination means that the people with disability have always been marginalized by established

laws, customs or practices. Likewise, lack of appropriate physical environment also inhibits people with disability to participate equally in the society. For example, inaccessible buildings with only stairs, public transports, lack of information on Braille or audio-taped and sign language. Lack of early investment in children with disability often means that these children are less likely to be sent to school due to various reasons, one of the reasons being poverty itself. Also, the fears of child not being able to cope, fears of disclosure leading to stigmatization of the family are reasons for denied education. All these have an impact on adults as they will lack income generating opportunities. This is due to the early and on-going discrimination which again leads to poverty and therefore, finds it difficult to break out of poverty. Another reason leading to poverty is due to high financial cost of treatment and equipments (Yeo, 2001).

Moreover, the high rates of impairment and disability among the poorest are often explained due to the facts that people living in poverty have limited access to food, health services, education, shelter and employment. Therefore this leads them to adapt to hazardous living and working conditions, which increases the risk of illness, injury and impairment. This again leads to marginalization, exclusion, disablement and poverty. So, the above two phenomena clearly shows the cycle and linkages between disability and poverty (Yeo, 2001).

## **Outline of chapters**

In chapter two I have described about Nepal and its policy on disability, Chapter three describes methods and ethics, Chapter four describes marriage patterns and its relationship to organize social life, Chapter four shows the life experiences two persons who struggle to establish life, Chapter five focuses on disability policy and how it is being received both at the governmental and local level and also shows challenges in accessing the disability identity card and benefits withholding it followed with discussion. Lastly, Chapter seven has concluded study with recommendations.



# CHAPTER TWO: DISABILITY IN NEPAL

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Disability has been understood in many different ways. At the present the World Health Organization defines disability in the following way:

“Disability is a broad term, covering impairments, activity limitations and participation restrictions. Impairment is a problem in body function or structure; activity limitation is a difficulty encountered by an individual in executing a task or action; while participation restriction is a problem experienced by an individual in involvement in life situations” (World health organization).

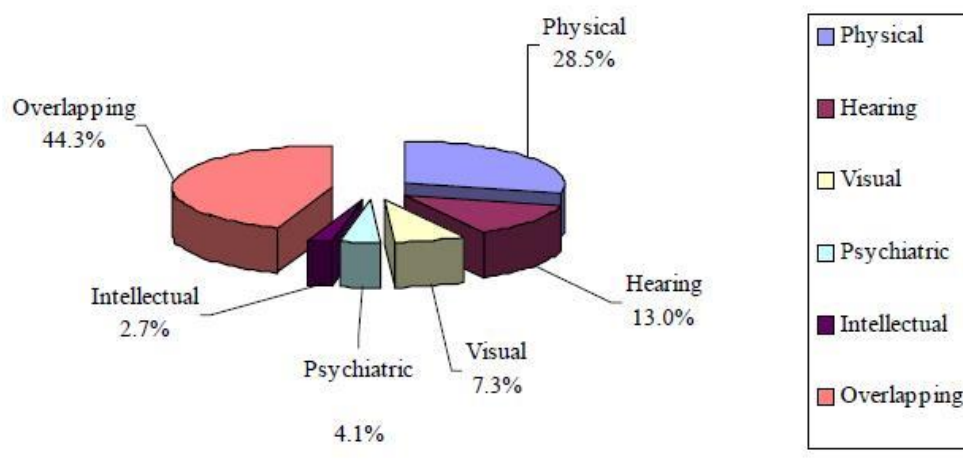
This definition includes both the medical (impairment) and social (participation) aspects of disability, thus combining the two main models of understanding disability: the medical and the social model. The medical model is a charitable approach to disability which focuses on the disabled individual, rather than on the need for societal change. Medical and technical interventions are offered by “experts” to alleviate some impairment. In this model disabled are pitied and helped but the important issues like inclusion and right of participation are not addressed.

Social model, on the other hand, defines disability as the loss or limitation of opportunities to take equal participation on the activities of daily living in a community on the equal level due to physical and social barriers. It states that impairment need not lead to exclusion and inequality if inclusive policies are implemented (Yeo & Moore, 2003). In this thesis, I follow the definition of WHO, but emphasize the social aspects of disability, focusing on participation and barriers in the local community.

## **DISABILITY IN NEPAL**

There is limited data on people with disabilities in Nepal, including how many adults and children are living with disabilities, their specific housing, education, healthcare needs, and what factors promote or hinder their equal membership in Nepali society. The available statistics are wide-ranging, from 0.45 percent (in the 2001 National Census) to 1.63 percent. Based on a 2001, Situation Analysis on Disability carried out by the Nepal National Planning Commission and UNICEF, more than 25 percent of prevalence on disability in Nepal (in a household survey conducted by the Social Science Research Foundation) (Pradhan & Shrestha, 2005). According to the World Health Organization (WHO), more than 15 percent of the world's population is living with a significant physical or mental disability (World health organization).

As, already mentioned above, there are limited data available in disability, below is the only recently available data on type and percent of person with certain disability. The data is from 2002. The data is specific data on 5 types of disability, physical, hearing, visual, psychiatric, and intellectual whereas the new definition has now categorized it into seven types.



The few existing reports from Nepal describe a widespread discrimination and negative attitudes towards people with disability thus making them passive victims (Thaneswor, 2006). Moreover, the challenges mentioned are the various social and physical barriers, violation of human rights and lack of basic support, as well as lack of awareness, understanding and lack of involvement in public debates (Shrestha, Shrestha, & Deepak, 2009).

### Disability policy in Nepal

The hardship of persons with disabilities is gaining recognition in Nepal, which is also starting to show in policy development. The first legislation related specifically to disabled people in Nepal was the Disabled Persons Protection and Welfare Act

introduced already in 1982, but the rules on how to implement this legislation were not produced for another twelve years. So, it was not until 1994 that the government produced how these rules can be exercised (The protection and welfare of the disabled persons rules 2051 (1994)). This legislation can be considered as the first movement towards a focus on disability. It also indicates that the people with disability in Nepal are not without legislative context. However, the main focus of this legislation was on the provision of facilities rather than on inclusive society and equal rights. It is not very surprising because when the act for people with disability was written, Nepal was not a democratic country. The legislation focused more on provisions or facilities on education, health, employment, self employment, transport, and social welfare. For example, it suggested free education, reserved seats for people with disability in government organization for vocational trainings and moreover an assistance from the government for private organizations providing education and training for people with disability. Disabled relief fund was also established in 1981 to allocate scholarships to disabled students (The protection and welfare of the disabled persons rules 2051 (1994)). These legislations appear to provide accessibility to education, health services, employment and social support. However, the government has only stated in the policy and it is easier for authorities to reject certain proposals on the grounds that there is lack of resources. These legislations can easily remain a written commitment which bears little relationship to the reality of people's lives and is without a clear implementation plan.

However, the above mentioned concern does not mean that nothing has been done in the development of disability welfare act and its implementation. Many NGOs and organizations including the disabled people's organizations are creating awareness about disability, making it a rising issue in Nepal. In last few years, there are some good achievements in policy and practices of government for promoting the rights of disabled people, in which a fundamental change is seen in the introduction of a new definition and classification of disability Revised by government of Nepal. This new definition of disability focuses on participation:

“Disability is the condition of difficulty in carrying out daily activities normally and in taking part in social life due to problems in parts of the body and the physical system as well as obstacles created by physical, social, cultural environment and by communication.”

It marks a change from the previous definition of disability that was based on the medical model and was more specific on the type of disability like physical and mental whereas other types of disability was not mentioned. In the old definition, negative words were used and were more described as a disease than a condition. So, this new definition has brought revolution for the people with disability.

In addition, Nepal government signed and ratified United Nations Convention on Rights of People with Disability on 7<sup>th</sup> May, 2010 (UNCRPD).\_Awareness work was launched in 2009, through radio programs. This seems to have had some positive results, and some individuals have been able to claim their rights to education and health care services. Moreover, human rights activist groups have tried one case in Supreme Court which was successful in the endorsement of free education to disabled students (Government, 1994).

In 2008, the government of Nepal developed a new policy that has the potential of being very effective for the improvement of disability rights, based on the use of disability identity cards. This policy is the focus on this project. This disability identity card policy has been categorized on the basis of severity and they are 1. Red Disability Identity Card for Profound Disability, 2. Blue Disability Identity Card for Severe Disability, 3. Yellow Disability Identity Card for Moderate Disability and 4. White Disability Identity Card for mild disability (Definition of disability and classification of disability in Nepal, 2006)

For the person holding disability identity card, the central Government of Nepal has allocated Disability Allowances Rs 1000 (€ 9) per month for Persons having Profound Disabilities and increased Rs 300 (€ 2.7) for severe disabilities. Government of Nepal has announced 100% tax free for those specially accommodated scooters which are used as need of disabled people for their private

mobility. There is 45% discount in the fare of public transport and 50% discount in air fare in domestic flight for PWDs.

### **Institutions involved**

Institutions involved in disability policy in Nepal are several and different at local and central level. At the central level, in Kathmandu, Ministry of Women, Children and Social Welfare is the main centre for distributing the information about disability identity cards, regulating policy in other parts of the country, and also distributing disability identity cards.

The disabled people's organization, the National Federation of Disabled People's Nepal (NFDN) is working towards the disability specific issues and policies. Likewise, the Human Rights Center for Disabled People in Kathmandu (DHRC) is also working towards the achieving the basic rights and issues related to disability and disabled people.

At the local level, the Village Development Committee (VDC) and the Center for Women, Children and Social Welfare (CWCSW) are playing major roles in the implementation of the disability policies. I will return to the issue of local implementation in the last chapter.

## **THE CURRENT KNOWLEDGE GAP IN NEPAL: DISABILITY POLICY IN NEPAL**

According to 2001 report authored jointly by UNICEF and the National planning commission, there were 400,000 people with disabilities in Nepal. But, the concern towards people with disability is negligible. Very few studies on disability had been done in Nepal. Available studies are mostly on the prevalence and demography of disability. None of the studies were found which has explored the experiences of living with disability in rural Nepal.

Disability studies are important in a country like Nepal where more than 60 % (31% according to the government data) of the population lives in abject poverty, which

affects different human development indices (Shrestha, Shrestha, & Deepak, 2009). According to Yeo 2001, vicious cycle of poverty and disability continues with one being the consequence of other. Therefore, to eliminate the poverty, disability should be one of the major concerns in the development. But, the attention towards disability is not enough, due to lack of awareness and knowledge. Awareness and knowledge can be spread with this kind of studies and can be the basis for further studies in disability.

As already stated, in 2008, Nepal government developed a new policy that has the potential of being very effective for the improvement of disability rights, based on the use of disability identity cards. Rather recently launched, the implications of this disability card policy are unknown and there are no information on clear implementation plan and no studies been published on how the implementation is on progress or is being implemented.

## **DISABILITY IN NEPAL: REVIEW ON PREVIOUS STUDIES**

The few previous studies of disability in Nepal have been predominated by quantitative methods. In a study conducted by Shrestha, Shrestha, & Deepak, 2009 they have assessed poverty and disability among specific rural population groups in Nepal. The study area were varied, including different geographical regions, i.e. high mountains, hills and plains (Terai), covering a total of 19,210 persons in 3,397 households of persons belonging to women's self-help groups organized under different village development committees (VDCs), in three geographical areas of the country. The methods used in the study are questionnaire and focused group discussion. Person above 41 and children below 5 are excluded in the study.

The findings of the study shows that the prevalence and gender distribution of person with disabilities is in 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 shown highest in the Terai region (2.19%) and lowest in the hills region (1.20%).

The analysis in the study also shows that the age distribution, 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.

In the total survey population wealth ranking was done and was shown that, 6.15 % to 9.74 % of population (overall 8.43 %) has been identified as “poorest of the poor”, and among them wealth ranking done for persons with disabilities was shown about 64 to 80% of them (overall 75.7 %) and are considered as “poorest of the poor”. 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%) had any access to the different disability related services.

The conclusion of the study was that person with disabilities has formed a disproportionately large part of those defined as poorest, by their own poor communities. The survey done on the study also showed that a majority of persons with disabilities from the surveyed population do not have access to any services including rehabilitation services.

The term disability has a wide ranging concept and an estimate of disability prevalence is difficult to measure. However, information about the prevalence and demography and literacy related information is essential for preventive, rehabilitative, social inclusion and equal right policies for a better quality of life.

According to my understanding, to study the wealth ranking, the focus group discussion among the community women’s group member can be considered best because it ensures that the information collected is meaningful to communities in relation to their local context. Moreover, it has an advantage of creating awareness among the community members.



In this study, to obtain the non descriptive information on age, sex, numbers, questionnaire is the right choice of method. To study prevalence can be the first step in understanding the degree of need to study disability but however may not necessary lead to solution unless the challenges of daily living and experiences of living with disability is not understood. It may lead to provision rather than the equal rights for people with disability.

Another similar study was conducted by Shrestha, Yadav, Chakravarty, & Shrestha, 2008 on the prevalence and characteristics of disability in Eastern Nepal. The method used in the study is cross-sectional house to house census by means of structured questionnaire. The aim of the study was to access the self reported prevalence of disability in terms of age, sex, types, cause and age of onset. In the study, each head of the household (or next senior most if not present) was asked “is there any disabled member (specifying the five categories they had) in your household?” If yes, then a set of structured questionnaire was asked to either person with disability or to the next most senior person if the person with disability is unable to respond. The result shown in the study was that, total of 31160 (4.87%) were found disabled out of total of 640259 individuals. The most common type of disability shown in the findings was physical disability affecting limbs, hearing and vision. Therefore the study has concluded that 4.87% was the self reported disability with inborn syndrome was the prevalence of disability in Sunsari district (Eastern Terai region of Nepal).

My argument here is that the definition of disability in local context has been overlooked; without understanding the local meaning and perception towards disability may have biased the study. Moreover, stigma should be one of the considerations while conducting such research.

However, this study cannot be generalized, since disability cannot be totally self reported due to various factors such as person with mental disabilities may not be able to self report their disability or women with disability may not move out in the public space due to stigma. These factors associated with disability have been biased in the study.

The above two studies are exclusively quantitative. However, qualitative research done by Dhungana, 2006, in the Kathmandu valley about the lives of women with disability who are vulnerable without support.

The studies has used in-depth interview, participant observation focus group discussion, interviews with several key informants and visiting several organization for collecting data with 30 women with physical disability residing in the Kathmandu valley. The study has addressed the issues on the reality of the state of disabled women due to several social and political reasons. It identifies the lack of family support for the women with disability, lack of community support, gender discrimination and also the failure of the government to address the needs of persons with disability to have an inclusive environment and lack of implementation of social security policies for the person with disability. Further, it points to dynamics that has pushed the females with disability into the cycle of poverty.

This study has impressively addressed the main and the complex issues around the disability and gender discrimination thereby exposing the vulnerability of the women with disability in the society. It is highly relevant to my study. (But the study was carried out exclusively in Kathmandu valley, which is the capital and urban area of Nepal)

## **RESEARCH GAP**

The literatures found on disability in Nepal were very limited with limited knowledge about disability in rural Nepal. There is little qualitative research done on disability in Nepal as most of the research is done on the primary health care, identifying the numbers and type of impairments. There is a lack of information about the implementation of the disability policy and lack of knowledge on reception of the policy by the locals.

# CHAPTER THREE: METHODS AND RESEARCH DESIGN

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The methodology of a study and the methods used within this frame are decided by its purpose. As the aim of this study was to assess the local experiences of person with disability, to understand local reception of new policy of disability identity cards, and to understand the implementation of new policy in Okhaldhunga, participant observation was chosen to be the best methodological approach for the study. This chapter describes the premises for data collection, the practicalities of fieldwork and considers the values and limitations of the methods chosen.

## STUDY SETTING (OKHALDHUNGA VDC)



As Nepal is overwhelmingly rural and very few studies have already been done about disability in the countryside, selecting a study site was rather open. Two things were important: that the area was classified as poor, and that I had some contacts that would be able to introduce me to the community. Through contacts working in the

Missionary Hospital in the area, I choose Okhaldhunga VDC.

Okhaldhunga VDC is located in the Sagarmatha zone in eastern part of Nepal. The study was carried out in 9 wards of Okhaldhunga VDC, which is in Okhaldhunga district. The population of the Okhaldhunga VDC is 4360 with 171 households. The total area is 11503910 areas per sq. m. It is located 1841 meters above sea level. There are no flat lands and rivers banks in this VDC, and most of the land is steep. According to VDC profile that is yet to be published, it has 37 people who are differently able.

The fieldwork was conducted from beginning of August 2011 to the beginning of January 2012, including stays both in Katmandu and in Okhaldhunga. I stayed in Kathmandu from the beginning to the end of August, and started in Okhaldhunga from the end of August, until 1<sup>st</sup> week of January.

My initial plan was to go through the public health worker contact that I had in Okhaldhunga community hospital. However, he was on leave due when I had planned the fieldwork. While in Norway, I had made contacts with the National Federation of Disabled Nepal (NFDN) through email, and they became the main door opener to the field. They collaborated with me and recommended my name to the eastern regional office of disabled person's organization to help me with needed information. They also gave me the contact number of the regional office of DPO from where I got contact with local DPO in Okhaldhunga.

But, there was a 10 days gap between my visit to Okhaldhunga and my first meeting with the president of local DPO, because the president was from another village and she was not able to manage her time. It also gave me opportunity to move around in the village and explore the local culture, understand the local government structure and develop good rapport with the possible key informants. With conscious effort to manage my limited time, I went to CWCSW office where I introduced myself and the purpose of the visit and of the study. I was also allowed to sit there with the staffs and observe which allowed me a good introduction to the role of the institution.

In this initial period, I also met many persons with disability who came from different VDCs and also got an opportunity to talk to them and learn how and what category identity card they got. In two days of participant observation, I got chance to have conversation with one person from the Okhaldhunga VDC who has visited the office to get new disability identity cards. Next day, I visited his place which led to many visits and meeting with him which allowed me to develop good rapport with him and moreover, he became one of the key informants and he was one of the resource person.

During this period of time before the meeting with local DPO, I got an easy access to VDC secretary member. I was introduced to VDC secretary by the household member where I was staying as a paying guest. From VDC I got the list of names of person with disability that has got some kind of allowances from the VDC.

Later, after 10 days of my stay in Okhaldhunga, finally I had a meeting with Local DPO where I learned that they had also collected data of person with disabilities in the different VDC's of Okhaldhunga district. So therefore I requested them to allow me to use it. It was a form with questionnaire, where technical terms were mostly used. Although the data was collected by people with limited knowledge of the field, it was useful as it provided me with a list of names that I could contact. This also gave me opportunity to check on the data they had collected and the personal information I got from the person with disabilities.

It was my first opportunity to visit to rural area of Nepal. My lack of experience in moving around in rural areas with such geographical location and mountainous terrain was a great challenge for me to reach my informants and their household at their residence. Therefore, I asked the president to provide me someone from the community who could guide me to the homes of the potential informants. So, I got a support from local DPO who introduced me to the member of DPO, who agreed to volunteer me until I become familiar with the location. Moreover, she also gave insight to the local culture of certain ethnic group, customs and values residing in this location and gave me information on how I should approach their homes without offensive behavior. For example, among certain caste people it is not good to go directly and stand at the main entrance of the door (Which was specific with some ethnic group only). Working with a local research assistant was a very fruitful way to be introduced to the community.

## STAYING IN A HOUSEHOLD



During my fieldwork, I got an opportunity to stay in a local house which was an advantage for me to better understand cultural and social setting and moreover, was also an opportunity to get in contact with the local person who could serve as a key person in my study. During the first part of the fieldwork in Kathmandu I met a person working in an organization for Deaf and hearing impaired. As a stroke of luck, he was from Okhaldhunga. He gave me number of his personal contact in a household in at Okhaldhunga, who I called. They happily accepted my request to stay with them as part of the family.

The location of the house was very central in the district, it was meeting point from all the direction of all other VDCs. The Central VDC office was few minutes of walking, Centre for women children and social security (CWCSW) was also few minutes of walking and similarly, district office was also few minutes of walking distance, the DPO meeting place which takes place at WATCH was also at few minutes of walking distance. Moreover, shops and markets were at a distance of throwing stone.

The household had three members at present, father, mother and daughter. They belong to Dalit community. Father and mother of the house are both working as tailor; therefore they had contacts with almost all people residing in the village. He was very popular for his tailoring. And the daughter, who was about my age, was working in a government organization. That also had an advantage, because it was easier for me to reach to the people working at the government level.

The house was typical style, made up of mud and woods. They had the basic kitchen where they use fire woods to cook meal. They had total two rooms in the house. And I had shared room with the daughter of the house. My room was one floor up just below the roof, where I had local mattress on the floor. There was small television too. I lived there as a paying guest, but it was more like a family.

In the beginning, behaviors were very formal. It was also my first time in a village and the members at a house were also treating me as a guest. The best things and food in the house were given to me. This included the meat, which was regarded as the best food to offer to the guests, but since I am a vegetarian, they felt too sad and were feeling guilty whenever they were having meat. That's where I told them that I am not a guest, and I will be staying there for longer. In the evenings, after I am back from my field, I used to help them in the kitchen. Only after a week, the atmosphere changed. I became friendly with all of them. I started to help them in the kitchen, chatting with the mother and father. That is how I became, familiar with the community. Many people from around the village would come there at the tailoring shop, which became an advantage for me. I started to talk to many people. When I came back from the field, I used to share to see if they know particular person with disability. They would always response positively and would say what they know from their side.

The daughter working in an INGO collaborated with government organization became great advantage for me. It was easier way to go to the offices through her than on myself. She knew people. So she became one of the important key people in the village for me. During my stay, I became very friendly with the neighbors too.

Staying in a local household was an advantage because they provide me with the rough idea about the area and the person with disability and their household members and their community participation. Staying in a household also benefitted me because I got an opportunity to discuss some of the experiences with the person with disability and their family and I usually used to share some of my experiences and put up my confusions and questions while having dinner. They used to provide me with some relevant information and sometimes tell me about their similar experiences.

Since I am a native from Kathmandu, cultures and tradition varies. And I had never come across many ethnic groups and caste people that I really had no idea about the customs and traditions there. Moreover, even though, I can speak fluent Nepali, the words and phrases people were using while conversation became very difficult to

understand at times. Therefore, without trying to ask what it means, which would have sound, very urban, I rather asked about the meanings to my household members. Staying in a local household has therefore provided me with a lot of help and advantage.

## STUDY POPULATION AND SAMPLING

While I planned to include 20 participants with disability in the study, I was able to work with 47 participants, of which I met, with 20 of them were interviewed twice. Among 20 informants, I repeatedly interviewed nine informants several times both formal and informal and developed close rapport and at last I focused particularly on seven people, with whom I spent much time at their home and work places.

The distribution of disabled are as follow: Physical disability: 20, blind and low vision: 12, deaf and hard of hearing: ten, intellectual disability/learning disability/mental disability: eight. The 35 informants among 48 were from a low economic status which means they do not have enough farm and cattle to feed the family for three months. Out of 48 informants 28 were from indigenous, ten were from Brahmins/Chettris (high caste groups), and nine were from Dalit community (low, down trodden caste groups). But, however, according to me seven of they were the main key informants. See table below for a list of participants.

*Table 1: List of participants*

	Name of participants	Type of physical disability	characteristics	Card
1.	Sudeep,30,Male	Club foot	Single, literate	Process (at first meeting)
2.	Ajay,63, Male	Physical disability(hemiplegic)	Married, illiterate	No card
3.	Bir Bahadur, 56,Male	Hunched back	Married, illiterate	No card
4.	Phurba,62,Male	Hunched back	Married, illiterate	No card
5.	Shiva, 16,Male	Deformity of hand	Student	No card



6.	Krishna,32, Male	Amputee 4 fingers of right hand	Married, educated	White card
7.	Raman, 57 Male	Club foot (right feet)	Married, literate	No card
8.	Shyam,25,Male	Weakness of lower limb Muscles(limping)	Single, literate	No card
9.	Hari,40,Male	Hunched Back	Married, Literate	No card
10.	Umesh,55,Male	Hemiplegic--hemi paresis	Married, illiterate	No card
11.	Sanju,26 Female	Deformity 4 fingers of hand	Married, illiterate	No card
12.	Sharmila,55 Female	Hemiplegic	Widowed, illiterate	NO card
13.	Sunil, 40,Male	Hemiplegic	Married, illiterate	No card
14.	Nisan,25, Male	Polio	Married, educated	No card
15.	Som Bahadur, 59 Male	Amputee below ankle	Married, illiterate	No card
16.	Rikesh,43 Male	Hunched back	Married, literate	No card
17.	Alok,28 Male	Hip dislocation (Limb length discrepancy)	Married, illiterate	No card
18.	Sushmita,17 Female	Deformity of left hand with weakness of lower limbs	Student, Single	White card
19.	Malika,25 Female	Polio	Married, educated	No card
20.	Sita,28 Female	Low Vision	Single, illiterate	No card
21.	Dhoj Bahadur, 80 Male	Low vision	Married, illiterate	No card
22.	Geeta,45 Female	Low vision	Married, illiterate	No card
23.	Sharadha,6 Female	Low vision	Student (primary level)	White card
24.	Til Kumari, 50 Female	Low vision	Married, Illiterate	No card
25.	Anjana,15 Female	One eye Blind	Student (secondary level)	White card
26.	Saraswati,41 Female	Low vision	Married, illiterate	No card
27.	Gaurab,24 Male	Blind	Single, illiterate	No card
28.	Shyam Sundhar,43 Male	One eye blind	Married, literate	No card

29.	Saroj,39 Male	Low vision	Married, literate	No card
30.	Moti Maya, 45 Female	Hearing impairment	Married, illiterate	No card
31.	Putali,17 Female	Low vision	Student (higher secondary level)	No card
32.	Anil, 35 Male	Deaf	Married, literate	Blue card
33.	Jeevan,18 Male	Hard of hearing	Student (Secondary level)	No card
34.	Ashish,20 Male	Hard of hearing	Student (secondary level)	No card
35.	Santosh,45 Male	Deaf	Married, Literate	No card
36.	Suraj,28 Male	Hard of hearing	Married, educated	No card
37.	Shyam,24 Male	Hard of hearing	Single, literate	No card
38.	Raja,15 Male	Hard of hearing	Student (secondary level)	No card
39.	Jay Ram,15 Male	Hard of hearing	Student (secondary level)	No card
40.	Sunil,17 Male	Hard of hearing	Student (secondary level)	No card
41.	Suresh,11 Male	Mental disability	Under aged, stays home	No card
42.	Subin,5 Male	Mental disability	Under aged, stays home	No card
43.	Harka,34 Male	Mental disability	Single, illiterate	No card
44.	Bijay, 3 Male	Mental disability	Under aged, stays home	No card
45.	Kumari,26 Male	Mental /physical	Stays home	No card
46.	Himal, 12 Male	Cerebral palsy	Student (primary level)	No card
47.	Mohan, 28 Male	Learning disability	Single, illiterate	No card

Due to the fact that I received the list of names of person with disabilities from VDC and later from the local DPO, I used purposive sampling (convenient purposive sampling) and the snowball method. The names from the list were used initially to conduct interviews and later snow ball method was used to meet more participants. The names from the list were chosen purposively depending upon the accessible area and the availability of the informants.

Using both the method I had an advantage to know that the actual number varies from the number I got from VDC and DPO. They had the number of person with disability residing in Okhaldhunga VDC was 37; whereas, I found that there was 47 (although I believe there should a lot more than this).

My aim was to include all people with disability in Okhaldhunga in the study, thus the criterion for sampling was exclusively done availability of the participants with respecting the value of their time, and also depending upon their interest to spare their time.

## **DATA COLLECTION METHODS**

Family Health International described participant observation as “a qualitative method with roots of traditional ethnographic research, whose objective is to help researchers learn the perspectives held by study populations” (Mack, Woodsong, Kathleen, Guest, & Namey, 2005). Participant observation is method which is flexible, open ended and opportunistic process which allows redefining the subject constantly based on the field experience and observation.

The real meaning cannot be acquired being an outsider so with this method aim was to observe and experience the perspective of participant as an insider with the knowledge of their culture and their meaning of interaction (Jorgensen, 1989). The ultimate aim of this method is exploring the truth based on life of people with disability grounded in realities of daily existence.

The study found inspiration in what has been termed “institutional ethnography” method, i.e. “empirical investigation of linkages among local settings of everyday life, organizations, and translocal processes of administration and governance” (DeVault & McCoy, 2006). In the study, I aimed to map both the experiences of persons with disability and the local perceptions, seen in the context of a new policy. The research has followed a sequence of identifying experiences, then identifying some institutional processes that are shaping the experience, and investigate those processes to describe analytically based on grounds of experience (DeVault & McCoy, 2006). However, as Smith points out, institutions cannot be mapped out in totality but the aim of institutional research is about exploration of particular corners within a specific institution, which make the connection of an institute to the other sites visible (ibid.)

With participant observation, one generally focuses on lower number of participants compared with quantitative methods, which is also the case for this study. Without the rigid form of a questionnaire survey, participant observation is a quite flexible method that enables the researcher to explore and probe deeper, and in more nuanced ways. Moreover, it enables the researcher to develop the contents according to the situation of the research area, the participants, and also the relationship between the researcher and the participant.

## **METHODS USED IN THE FIELD**

As mentioned, I lived in a local household during the fieldwork and participated in their everyday life. I used in-depth interviews, observation and focus groups.

### **In-depth interviews**

The in-depth interviews were open-ended and throughout the interviews tape recorder were used with the consent of the informants. All the interviews were taken at their home, or in their work place. In-depth interviews are commonly used to seek deep knowledge and information about particular subject matter. It provides an in-depth information and knowledge than in surveys, informal interviews or focus groups for an example (Johnson, 2001, pp. 103-120). This method also seeks to

build an intimacy between the interviewer and participant/informant which to create friendliness and self-disclosure (ibid.). The build in intimacy and friendliness helps to dig into information which is very personal like self-reflection, lived experiences, one's ideologies, perspectives, cultural knowledge, values and decisions.

In the case of this study, in-depth interviews was used to collect information from person with disability, their households, and secretary at the Village Development Committee and the authorized women officer at Center for Women, Children and Social Welfare (CWCSW) at the local level and health assistant at health center.

And, at the central level in-depth interviews was used to collect information from the policy makers, key persons from disability person's organizations. Here the participants were interviewed more than once based on the level of information obtained from each interviewee. The interviews were open-ended and unstructured. Moreover, this method can also verify my method of participant observation which will be gained throughout participation as a member of particular household in particular cultural setting (Johnson, 2001, pp. 103-120).

With this research method I believe we will be able to explore multiple meanings of or perspectives and also the detailed information on disability card policy and its categories. The meaning and perspectives many vary within individuals as the subject matter is complex.

### **In-depth interviews in Kathmandu**

In Kathmandu, access to the Ministry of Women, Children and Social Welfare was not easy. I did manage to enter into the ministry; however, without any contacts it became difficult to get an appointment for an interview at this level. From the meeting at the ministry, I received a book describing disability identity card policy.

In addition to the government, I interviewed the president of National Federation of Disabled People (NFDN), one of the organizations that have been crucial to the developing the new policy.

### **In-depth interviews with local government officials and NGOs**

In-depth interviews with the local government were carried out at two main government offices and one at government health center. The two government offices were Local VDC and Center for Women Children and Social Welfare (CWCSW). These two government offices were mainly important for the research because VDC and CWCSW are involved in the decision-making and the distributing of disability identity card. VDC secretary officer plays an important role in recommending the person with disability with identifying disability to the CWCSW secretarial officer. The secretary officer is the main authorized person to give out the cards to those classified as disabled. Three interviews were conducted in their respective offices, providing the desired information about the cards. The interview with the health assistant became important when I learned that his recommendation letter along with diagnosis is equally important to get disability card. The majority of the villagers visit government health offices rather than community hospital. I had one in-depth interview with the main health assistant.

At the local level, I conducted an interview with the president of local DPO known as Sagarmatha Apanga Sahayoji Sanstha which means helping organization for disability and also with the officer working for WATCH. (WATCH is currently supporting local DPO to established and properly run local DPO).

### **In-depth interviews at local household level**

In the beginning of the research in-depth interviews were conducted with the person with disability and their household members at their home depending on their availability. Totally 47 informants participated, though in various degrees. With all I had conversations about their life and their experiences. Out of 47 informants, 20 participants were interviewed twice and out of 20 informants, nine informants were interviewed more than two repeated interviews were conducted. Out of these nine informants, with seven informants I developed close rapport and have spend much time in their home, and at work. I also had several informal interviews with their household members.

Repeated interviews had the most advantage to develop rapport with the informants, dig into the depth of information given, probed on issues during the repeated interview after listening to the first interview, and also allowed me to understand the circumstances that might influence the informants during their participation. Oftentimes the presence of visitors and other household members would not allow me to explore some sensitive matter in-depth (because of the lack of personal space of the individual in the community), which gave additional value to repeated interviews. Lastly, these interviews allowed me to check the validity of the data during different approach to the same question.

Interviewing was challenging. The most important challenge for me to overcome during my field was my feeling of guilt, because I was invading and opening upon their wounds, which most of the times created emotional situation for both me and the participant. This made it difficult to ask probing questions in the first phases of interview. Therefore, repeated interviews were an additional help to overcome my challenge as it also developed rapport between me and my participant, and I felt confident to be open to the participant about myself. I allowed them to ask questions about myself and my personal life which in a way acted as a compensation for my guilt to open up their wounds.

I aimed at using tape recorder during the interviews, however, most of the participants were very self-conscious when I was using tape recorder even with their consent. I noticed that tape recorder closed down the dialogue. In such condition, I just took notes during the interviews.

All interviews were done in the local language, Nepali. There were few times when I was not able to understand some of the local Nepali words, and especially during first few weeks, I had to learn and understand the meanings of some of the local words and “sayings” with the help of my household members with whom I stayed in Okhaldhunga. Later I developed better understanding of common localized words, making communication unproblematic.

### **Informal conversations**

After the first few weeks of fieldwork, I became familiar with most of the people in the village especially in four wards of the village which gave me an opportunity to have informal conversations with the informants. Informal conversations were not planned but it just happened. For example, if I happen to pass by the informant's house, and stop there for a while and chat with them which help me to dug into more information as well as develop close rapport with the family and person with disability.

### **Observation**

Observations were done at different levels of community life. Most of the observations were done at the household and public space such as market areas, health centers, government offices, DPO and NGO meetings, small tea shops and wherever it was possible. The observation was carried out without specific criteria or plan on observation, but focused on the ways in which persons with disabilities participated in the community and performed their activities of daily living.

Systematic observation was also done at CWCSW with the consent from secretary for two days. The main objective of doing participant observation was to observe the processes involved when people with disabilities tried to access a disability identity card. During this period I was seen at the office as the disability card specialist, which put me into disadvantaged stage.

The observations provided a good context for the analysis of the interview data, as well as it enabled a broader understanding of not only what people say is done, but also what is done.

### **Focus group discussions**

Focus group discussion often helps the peer groups to share and express their perspectives. This method creates an atmosphere of being secure in the group who share and experience similar feelings. Therefore, participants can freely express (Morgan & Krueger, 1993). I used focus group discussions towards the end of the field work to discuss my findings with the person with disabilities and their co-



household members. This created chance to allow my participants to express their opinions freely. This was also done to exchange the knowledge and experiences, furthermore to communicate easily among and between the individuals who were going through the same situation. This method was also to ensure them about their valuable inputs in the research and not to violate their rights.

Focus group discussion can provide clear picture of how other think and talk. This can provide the reality of people whom they are trying to reach and can also get immediate and vivid feedback and how others respond to their ideas.

All the participants were informed through phones, visiting their homes and also by asking the informants to spread it to other informants. It was carried out at WATCH office and the WATCH officer acted as an initiator. I chose staff of WATCH because, I lack experience for this type of method and more importantly, I did not want talk about the same thing which I had been talking to them for months and which I thought could be quite boring for them and they may miss out few information. Furthermore, it was also because, with new person there was probability of getting new perspectives on the same issue.

These data collected while in field has been produced in the form of notes, narrated conversations, interview recordings, transcripts, observation notes, documents. The interviews and conversations has been translated in English with conscious effort not to misinterpret, and exaggerate and more importantly, tried to portray the exact meaning.

Triangulation of the methods was used as a way to create validity of qualitative research by using different methods (Mays & Pope, 2000), including several repeated interviews, observation and focus group discussions. These approaches provided depth to the material and better understanding of the material which added validity. This multiple method gave me an opportunity to test the validity of the information at several instances and which became more visible during the analysis of findings. By triangulating with data sources and methods I was able to get a more

detailed and nuanced picture of the factors influencing people's perceptions and behavior, at the same time as I was able to identify similarities and congruencies.

## **REFLEXIVITY**

The researcher's background and position affects the choice of topic, the angle of investigation, approach and decision on appropriate method, consideration on most adequate findings and how conclusions were framed and communicated accordingly (Malterud, 2001). This process of constant and conscious evaluation is referred to as reflexivity. Reflexivity starts by identifying preconceptions of the researcher such as previous personal and professional experiences, pre-study beliefs about how things are and what is to be investigated, motivation and qualifications for exploration of the field, and perspectives and theoretical foundations related to education and interests (ibid.). Therefore, the aim of including a section on reflexivity is to understand researcher's perspective and position, which can create transparency to the readers.

### **Preconditions**

My professional background and my experience in working with persons with disability have greatly influenced my thinking and my inclination towards disability studies. After, my bachelor's degree in physiotherapy, I joined in Manipal hospital in Pokhara city, as an internee. There, for the first time, I came in contact with persons with disability who came from the rural areas. There I noticed that, those who were poorest of poor were involved in health risk occupations and which as a result cause them impairments. Most of the people were so poor, that they were never able to complete their treatment in the hospital.

After 6 months of internship, I came back to Kathmandu and worked as a volunteer in Handicap International (HI) for 14 days. People from remote areas would come to HI for treatment and the organization used to pay them to visit the place depending upon their financial situation and their location. Therefore, most of the patients would always come for follow up and all most all, 99% with whom I came across were poor. Back then, I realized that there is an association between poverty and disability. It

also allowed me to think about the government's responsibility for poor disabled people.

After 2 months, I got job as a physiotherapist in Kathmandu Model Hospital, a community hospital. There I came across and treated several patients who used to come from the rural areas and were not able to come for follow up due to lack of economic resources. I felt helpless most of the time.

But, it was not until I came to Oslo and was planning my research, when I came to know about the disability identity card policy. When I learned about it, I was impressed and sad both at the same time, because, I never knew about the disability card policy when I was working in Nepal. I never came across anyone who came to Hospital with card and utilized the benefits of the card. Therefore, this gave me an idea that certainly people with disability and also the general population of Nepal are not aware of the policy. Therefore, doing a research on this topic can create knowledge and information on this subject matter.

### **Role in the field**

When I was planning my field work, I never considered that I will be looked upon like an outsider in my own country. I was able to talk fluently in Nepali language.

But, in reality I was considered an outsider. Being native from Kathmandu and higher education in abroad became disadvantage in a way while in the field. It created distance between the locals and me. Further, western clothing regular jeans and t shirt could have created a barrier in communicating and I will always be seen as upper class in the setting. Therefore in the starting phase of fieldwork, I prepared myself enough to understand local culture, and behave as soberly as possible. Therefore, I was conscious enough to wear what the most of the locals were wearing. Moreover, staying in the basic household of the local person who are from Dalit community also gave impression of having low status, which was an advantage to connect with the people who were poor.

I could understand speak fluent Nepali, some of the words and phrases people were using became difficult to understand. During the field it was not wise to ask the literal meanings to the informants because there was possibility of looking at me like someone from high profile, which could have made it difficult to develop rapport. Therefore, with the help of my household members of Okhaldhunga, I learned some difficult words and phrases.

But in converse being from different place also gave me an advantage to probe in-depth about the situation and was allowed by the informant because I was culturally neutral person who would neither judge them nor accuse them.

My role in the field was different than I had anticipated. Rather than being perceived as a researcher from the University, people saw me as a disability card policy specialist. For instance, while I was observing in CWCSW office, in one case when there was confusion regarding the category of identity card, I was expected to decide the right color card for person with disability.

There were many people among my informants who did not have any disability identity card. There were many people who had no idea about the card and did not have knowledge about the card. Therefore, at the end of each interview I gave them information about the card and the process of getting disability identity card.

Indeed, there was expectation of help. Help in the sense, to communicate and enter into the system of bureaucrats, to get an access to card, to get the benefits withholding the cards. Of course, it was another challenge but was not possible to ignore. Although, it was not intended in the beginning of the study to help the informants, during my field it became necessary otherwise letting them know about the card and procedure makes no sense when in reality they are not able to get it. Moreover, it was only what I could give them with during my field. There was a felt responsibility where I could only help with the necessary information and help them to get it.

It was ethical to help them in my own possible way as a citizen and foremost as a human being. However, it was also my dilemma to which extent I should intervene. Therefore, every time I helped someone, was with conscious effort to not offend the authorities, my approach to them was with act of anonymity with seeking knowledge and information on the matter was the key to help those in need.

### **The dilemmas of intervening**

Suresh and Subin are siblings, 5 and 11 year old boys, and are from a Dalit community (with whom we have been introduced at the beginning of thesis). Both of them are suffering from multiple disabilities, both physical and mental types. Both of them need assistance for all kinds of daily activities. And both the parents are poor and illiterate and were making their living by daily working with breaking stones. They asked me to help them by going with them to the CWCSW office. I managed my time to go there with the mother and later they got red card. Withholding red card, they were supposed to get monthly allowance of NRs. 1000 (£ 9) each. But, VDC secretary informed them that according to policy papers it will only be possible to get allowance when they are 16 years old. But, as I was doing textual analysis during the field, I could not find anything written on the policy about the age factor withholding the red card. I was also curious to know what was it all about, where in the policy is it written about the age? So, I decided to talk to VDC secretary about an issue. There I learned that they follow a policy action plan from the central government. I got that soft copy from there and decided to read it. And what I found was completely different and was exactly what I had learned through textual analysis, namely that the age bar was for those withholding the blue card, not the red card.

The situation became difficult for me to handle. For two days, I could not decide on how to approach the matter to VDC secretary without offending his knowledge and capability. Therefore, I used the strategy of inquiry, and marked with highlighter, the statement which stated that age for blue card and the line in which there was nothing mentioned about age under the red card and went back to VDC secretary. I requested him to make me understand what it means in a very polite way. He read it twice and there was surprising look in his face. Then just in front of me, he made

call to head office and confirmed about it. He responded with happiness and also appreciated my effort. Further, he told me that my effort will help those in need. And he asked his assistant to inform parents of two kids about the allowances withholding the cards.

## **DATA ANALYSIS**

All the interviews were conducted by me and at the end of conversations summary of the story according to be was presented in a way of questioning them to make sure that I understood every well enough. The tape recorders were always kept in my personal bag when travelling whereas in the house it is safely placed inside the locker of my cup board.

Only few interviews were transcribed when in field but were listened to the tape recorder to make notes and probes several times during field. (It was especially due to lack of adequate electricity supply, I was trying to save the battery of my laptop and tape recorder as much as possible). But, however, list of informants with their basic information (name, age, sex, address) was made while in the field, including their education, occupation, relationship status, and if they have disability identity card or not (see table 1)

All the interviews were transcribed after I came back to Norway in January 2012. These transcribed interviews were read several times thoroughly. Among the informants who were interviewed several times, and had close relationship their stories were narrated using transcribed interviews, observations, re-listening to the tape recorder and also re-reading the notes made during the fieldwork. While writing the narration and transcribing the interviews in laptop, I used the real names instead of fake name, so that I can always recall and relate and create less confusion for myself.

Interview with the government authorities were also recorded and transcribe using their original position and name because anonymity was not targeted and is not possible with their position in the local government level.

## Steps of data analysis

There are different ways of systematic analysis of qualitative data (Malterud, 2001). In this study, I have selected a style to which, Malterud defines as “the researcher identifies units in the text, forming the basis for data-developed categories, which are used to re-organize the text so that its meaning can be clearly seen (Malterud, 2001)”

The process of analysis followed the four steps as below: 1) reading the entire material; 2) identifying the meaning units; 3) transformation and summarizing the content of the meaning units; 4) integrating the insights in the meaning units into a consistent description (Malterud, 1993).

In the process of analysis, I have read the entire material several times to gain the familiarity of the material and then to identify the meaning units depending upon the content of the material. Some of the meaning units were revised and new ones were created. Then the themes are noted and meaning units were identified such as access to policy, challenges and difficulties to access policy, access to community participation and perception on disability etc. Then I combined these meaning units and created broader themes to cover the important meaning units to gain an objective of the study. Then I combined the related meaning units under the broader themes and created sub headings. Then after, I summarized units of meanings into a short text and found crucial quotes to reflect the meaning. Lastly, I integrated the insights from the summarized meaning units into generalized descriptions that reflected significant factors. This work was done by me, with the discussions and suggestions sought by the supervisors.

## Strength of the study

- No information was available stating that this or similar study has been done in rural Nepal accessing the experiences and the implementation of the disability card policy.

- As, I, researcher was from the different area and from a cultural setting which has provided potential neutral arena for the person with disability and their household members to voice their experience without being judged. This resulted in thick description about the lived experiences of person with disability.
- Having done textual analysis for better understanding of the disability card policy during field work provided an access to information about the policy and the process of having card and its benefits to all the informants participated in the study.

### **Limitations of the study**

- Data collection was limited by the time, and also the season of harvesting millet where most people were busy in the farm.
- The study has only reflected the situation of persons with disability living in Okhaldhunga VDC only and similarly regarding the implementation of disability policy card has been limited only in Okhaldhunga VDC, therefore does not represent situation of entire rural areas of the Nepal and country as a whole which is composed of more complex and diverse population groups, culture and socio-economic conditions. In this regard, the findings of this study might not correspond to the entire geo-political areas of Nepal.
- The data collected from the interviews had to be transcribed from the local language to English, an exercise that was very comprehensive and tedious especially as the informants were narrating in depth their life experiences.

### **ETHICAL CONSIDERATIONS**

This study was carried out according to the principles stated in the World Medical Association Declaration of Helsinki (World Medical Association, 2008), the International Ethical Guidelines for Biomedical Research Involving Human Subjects from the Council for International Organizations of Medical Sciences (Council for International Organizations of Medical Sciences (CIOMS), 2002), the Universal



Declaration of the Human Rights (United Nations, 2007) and the UN Convention on the Rights of the Child (United Nations Convention on the Rights of the Child, 1989).

In Norway the Norwegian Research Ethics Committee (REK) evaluated the project and wrote in August 2011 that the project does not need ethical clearance from them due to its lack of use of patients' medical records. Hence, they approved the project with its ethical considerations.

In, Nepal, there was no national ethical committee but the Nepal health research council was an equivalent committee where any kind of research related to human subject must be registered with the application. The application procedure contains of submitting research protocol, approval from the affiliated institute and the recommendation letter from supervisor with the NRs. 14000 fee for Nepali students studying abroad. Later, after justification on the methods, I got ethical approval on 23<sup>rd</sup> November, 2011.

### **Informed consent**

Written informed consent was used as an ethical consideration in the study. The requirement is based on the declaration of Helsinki (World Medical Association, 2008) states, that the researcher has an obligation to ensure that the person participating in the research understands what is implied by their participation, and that such a person's consent to participate is obtained without coercion. Thus, informed consent is an important ethical consideration in any research involving human subject. Basic elements of it include: brief description of the study and its procedures, full identification of the researcher's identity, and assurance that participation is voluntary and that the respondent has the right to withdraw at any point without penalty, an assurance of confidentiality, and benefits and risks associated with participation in the study.

According to this background, as a researcher play a major role in providing the participant with the adequate knowledge, aim, purpose of study and the procedures. I allowed participation decision without influencing and without luring them with false

hopes, forced money or any other funds. The participation was on their voluntary participation on the research.

During field work, informed consent was taken in the written form translated in Nepali language in non-technical words and simple and understandable sentences were used. The written form included all the necessary information and procedures of the study including the time frame of the research and also the statement describing that how the confidentiality will be maintained. In case of illiterate participants consent was take with lot of care and was taken orally which has been described below under the heading ethical challenges.

To secure informed consent was one of the major challenges during fieldwork. There were total 47 informants and out of 47 informants 36 informants were illiterate. The main challenge with ethical consideration was illiteracy. Most of them were only able to write their own names with difficulty and those who were literate were only able to read and write but the capability of understanding the material in the consent form was low. And among nine literates, three were educated.

Therefore, to overcome the challenge of illiteracy, I read everything to the informants and their family members and tried as much possible to make them understand. And, for some participants where they have their school going daughters and sons at higher secondary level, I left the paper to them one day ahead and asked them to read it to their parents. And following next day, I tried my best to make them understand things that were not clear to them. This also benefited me to have more interested participants because one of the informants read consent form from the neighborhood and therefore showed his interest to participate in the research. They contacted me using the number which I was written in the consent form.

Respecting the rights of the participant in observation study comes under the modification of informed consent. As I was doing observation during my research I had to be careful to give my participant private space. Where practicable I obtained consent post hoc. In case of difficulty in observing some behavioral patterns, it was considered as tacit refusal for observation.

The research is to find out or get information and experience about people with disability in a community rather than finding about an individual. Therefore, I have maintained the confidentiality of the person involved in the research to protect the participant from violating their privacy. However, those involved in government institution and, thus being in public positions, related to policy of disability, has been informed about their lack of confidentiality.

Research data are not concerned with participant's identities. We must be clear about who should and who should not be able to gain access to information about identifiable individuals and what grounds are reasonable for them in doing so (DeVault & McCoy, 2006). I have been careful not to release data even to the responsible public authorities in any form that could identify participants, unless explicit consent was given by the participants and guarantees of anonymity and/or confidentiality had not been made (ibid). These data stored are kept out of reach from anyone.

Anonymity was maintained throughout the research process by using pseudonyms except those working on government organizations and NGOs and INGOs. . Participant's first name and age was used to transcribe the interviews and analyze data to help me to recapture and remember the research settings. After, the meaning analyses of the data names were replaced by pseudonyms.

However, certain sensitive information has been deleted from the material which was made to ensure the confidentiality of few participants whereas large number of participants expressed that they do not see confidentiality as problem for them as there is less value of confidentiality about the personal affairs in the study. However, only pseudonyms were used in all cases.

# CHAPTER FOUR: MARRIAGE: SHAPING RELATIONSHIP

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Marriage is a central family process in Nepal. Across all Nepali cultural groups, Marriage is considered to be social contract between clans rather than personal one between individuals (Furuta & Salway, 2006). Moreover, marriage is a way of participating in a family unit and labels stories of ways of participating to the broader community which can also be seen as an important part in organizing social life and was visible in my data where 25 among 35 persons (attained legal marriage age) were married. Therefore, having large number of married couples became an interesting factor to understand both in the process of how they got married, how disability was understood among the family members and how these couples managed to deal with disability in the family setting with responsibilities and obligations.

Focus on how marriage and person with disabilities becomes methodological issue of how to investigate disability as a relationship. For this study starting point is rather the relationships between persons within households, environment and structural aspect of policy. This means a focus upon social life in a broad sense and how life is continuous and established within the cultural setting. This opens up for studying aspect that are related to what people are concern about, in the process of establishing a social life, their struggles and concerns.

To better understand marriage among participants in this study, I have differentiated two types of marriages among disabled couple, i.e. self- initiated married couple and arranged married couple. Here, self-initiated couple refers to those who choose their partner on their individual control, love marriage whereas, arranged married couples are those arranged by the family or under the control of their family. Many aspects of marriage are changing in Nepal (Barber, 2004) and self -initiated marriage is one of them. These two patterns of marriage i.e. self-initiated and arranged marriage is

seen shaping the experiences among the married couples and their access to marriage.

Therefore in the following, I have presented three stories of a married couple in which two couples are in self- initiated marital relation whereas one couple is in arranged marriage relationship.

These stories reflect the importance of marriage and how it is perceived in the society. It has also reflected the various issues of socio-economic aspects of marriage, its importance in the cultural setting, and how it is being perceived in the patriarchal society.

### **Story 1. Confronting perceptions**

Malika is a 25 year old female, a polio survivor, and has finished her bachelor degree in accounts and management. Malika was in self initiated marital relationship with Suraj who has hearing impairment (left ear). Suraj is running business on printing and also contributing in a family economy. He has good economic background.

#### How did they meet?

Malika did her higher education in Okhaldhunga VDC and since then Suraj and Malika were friends in school. But their relationship started later when she had moved to Kathmandu to study her bachelor's degree. They gradually started talking on phone which became frequent after few months of her stay in Kathmandu. (By then Suraj had started his business)

One day, during their telephone conversation, Suraj told Malika about his hearing impairment (left ear). When he told her about it she says,

*“.....my heart fell for him when he expressed me about his hearing impairment. We were both disabled and I knew how it feels”*

Further she told me that, that is how their friendship grew deeper into love. But, they had not expressed their feelings for a year. After a year, Suraj expressed his love finally and purposed for marriage.

Malika had mixture of emotions. She was both happy and sad. She expressed that she was afraid to be in marital relation for the fear of not being able to cope with the household activity. She was aware that their relationship will not be accepted by Suraj's Family. Hence that is what happened; there was a strong disapproval from her in law's family.

She says,

*".....when my husband had proposed me for marriage.... I told him to think twice..... because I will not be able to do all the household activities..... I am weak..... I even suggested him if he wants to marry my sister....."*

But, he was so strong on his decision that he convinced her and said that

*"It does not matter because we can fulfill each other's weakness with our strengths, I can assist you in physical work and you can assist me when I cannot hear properly"*

Suraj was able to convince his mother, though it was not easy.

After, Suraj's family's approval, Malika had to take permission from her parents to allow her to marry Suraj and bless them for their happy married life. At first, her parents were reluctant due to the thought of role of daughter in law which demands physical ability to perform household chores and were concerned that she might not be able to cope up with it. But, Suraj was able to convince his parents that they will be no problem with Malika and hence he can take care of her. And finally they got married which was after they had an affair for last two years.

Marriage ceremony was held along with other two couples, i.e. Suraj's brother and his wife (Both of them did not have any kind of impairment). Malika expressed that they received gifts as their brother in law and his wife and she did not notice any partiality. Malika was afraid that she might have to face partiality and unfair behavior in relation to her sister in law. They got married at the same time and were living in the same household.

Conversation with mother in law showed that she was not happy about the marriage. (I had conversations with both Malika and her mother in law in the same day which was after two days of her arrival in Suraj home). Mother in law was worried and concerned for her son's future. Further mother in law expressed that when a woman have disability can be a problem for the whole family because, woman has to take care of household chores and family members. Therefore, she needs to be physically fit to perform household activities. Malika will also have to help her husband in his business. She thinks that it can be too much and a problem for Malika in her old age due to her physical disability and therefore can create problem for both the couples and the family. Moreover, she even thinks that it can be a problem for Malika to bear child..

She says, breaking down in tears,

*" I had opposed this wedding. She cannot walk properly and she will not be able to do households properly as well..... My son's future is ruined..... I am very much worried for their future. How will they be able to work? ..... she told me her legs hurt when the weather is cold .....Since, they are newlywed, we must take her to visit our relatives and with her leg it is so awkward for me. Do you know, if there is possibility of some kind of surgery?"*

The statement from Malika's mother in law depicts her concern towards Malika's capability to fulfill her role as a wife and daughter in law. Furthermore, it also shows an emotional distress for mother due his son's desire for his choice of disabled spouse.

After a month of their wedding, I got chance to talk to Malika in a separate room where her husband works. The conversation between me and Malika was quite friendlier than our last few meetings. During our conversation she expressed, she is doing well with her household skills in comparison to husband's brother's wife (Its very typical being compared between daughters-in-law). Moreover, the way she was talking about her in laws also changed. She told me that her in laws are supportive in household chores and never heard of any complain from her mother in law in regard to household chores. In comparison to brother in law's wife, Malika was managing the household chores skillfully and was being appreciated by the household members. It seems that the situation and perceptions of both in laws and Malika's had changed. This also shows that she had to prove to show them that she is capable to fulfill her household roles.

In Malika's story, we can address disapproval for marriage from her in laws family was due to patriarchal society where women are supposed to look good physically and be competent enough to perform her household activity. But however, the material show that norms and beliefs change according to the situations and when people get to know each other better. Bambani has stated that in developing countries women with disability have to face triple discrimination because of their disabilities, gender and economic status (Bambani, 2003). Which was similar in case of Malika, but in their case the couple managed to re- negotiate the parent's perceptions. We see that the in-law becomes significant for the containment of these values and beliefs of disability as inability that needed to be confronted, a situations where couple insisting on their choice of spouse confronting the existing norms.

Furthermore, Suraj economic independence played additional support in having individual choice of spouse, which is not very common in such cultural setting. Moreover, the couple seemed to renegotiate barriers where the common concern was that, a couple of two persons with disabilities need to struggle even more. What is re- negotiated is rather that their weakness is their strengths; this they want to acts out as a reality in life. In fact we can see that the mother in law changes her perceptions reflected in how Malika talks about her situation in the family.



In the following, I present a man who is Deaf married able bodied women, (self-initiated marriage disabled) which is then followed by a story of arranged marriage where male partner is Deaf and female, an able body. These two stories illustrate some aspects of struggle and concern in addition to well being.

## **Story 2: Coping together**

My first encounter in the field with Anil, 35 is Deaf, married to Manisha (able bodied). Together they have two children. We communicated easily together, for me it was easy to understand him; during, our first meeting he showed me the local tea shop where we had our first conversation together with his wife Manisha.

It fascinated me, how he was able to communicate with us, using his hands though it was not a “sign language” as such. Every time I met Anil, we communicated using hands, sometimes writing on a paper and showing pictures and things. And moreover, what touched me most was his social act, courtesy, how he behaved with me as a guest and offered tea. This clearly shows, how cultured he was and was aware of cultural norms though he is not able to hear or speak or easily communicate with others who are not deaf.

## **Skills of Anil**

At the age of 13, he started his first school on sign language. He has studied till 8<sup>th</sup> standard. But, after 8<sup>th</sup> years of studying, he left school because there was no any school in his village and sign language courses were run temporarily by the organizations that were from capital.

He also joined martial arts training at the age of 22, and continued for around 4 years and achieved brown belt but he was not able to continue further to get black belt (which is the highest), because he was denied admission by his trainer due to his inability to speak and hear. Although, he expressed his desire to achieve black belt in martial arts and pursue his career as a martial arts teacher and make living out of

it, he was not able to go for it. He also mentioned that he got training in painting hoarding boards and showed his certificates. But, it was of no use since he is not able to make use of training and he feels he is not competent enough in the hoarding board business. At present, he works as a cook in school and earns living for his family.

### **His marital relation**

When we talk about marriage, it was indirectly through his martial arts training that enable him to make connections with other persons to mobilize him in the circle of friends and go around and meet his friends who are from different village. Directly or indirectly, his marital art training made him accessible to approach woman for marriage, because he was quite mobile and was in company of his friends. He used to visit his friends village, where he met his wife Manisha. He fell in love with her and therefore, proposed her by writing letter. (Manisha is illiterate and letter was read for her by her friend).

Manisha knew that he was Deaf, and which was the reason she had soft corner for him. Both of them belong to different castes therefore they had to elope (run away from home and get married by themselves without families approval) to get married, because the possibility for marriage with Manisha's parent's consent was thin. But, Anil's family accepted her as a wife even though they are from different caste but Manisha's family has not yet accepted their relationship. It was only after five years of their marriage Manisha was accepted by her parents to visit them. (She was from a good economic background). Till date Anil, has not been accepted by her parents as son in law. (It is both due cultural beliefs of cross caste marriage which is very strict among certain castes, and also the fact of Anil being Deaf. This is well known fact in Nepal that cross marriages are usually not accepted. Although, perceptions about cross marriages are changing in urban areas these days, but it is still very persistent in some caste and rural areas.

Here, we can address that in self- initiated marriage, they have their own control over the choice of partner where they do not consider caste or social norms of ideal partner (without disability). However, they will have to compromise in certain aspects

of their social life, for example, Anil has not yet been accepted as son in Law in Manisha's family. The reason could be both, inter caste marriage or Anil being Deaf.

Manisha mentioned that her mother feels very sad for her, and has often expressed her that she could have had a better option than Anil. This shows that, in self-initiated marital relation, the price they paid for their choice is breaking ties with Manisha's family. (Well, here I think elopement for marriage makes it clear) which has created a vulnerable situation for Manisha without her parents support in emotional, social and financial needs.

### **Communication between couples**

I had an interview with Manisha in his presence and few questions using signs with hands, not the "sign language" as such.

*..... I do not see communication as a problem between me and Anil..... at times when I am not able to get what he is trying to say, he makes me understand somehow.....*

The above statement from his wife also portrays us, how they are able to communicate in their own way and for his wife communication with her husband Anil was never seen as a problem. The way she said and expressed me was in a very casual way, as if it was only me who think that might have a problem with communication. In one of the communication she even expressed me that Anil, shares everything with her for example if he has some problems at his work, emotions etc.

I probed her regarding her attempt to learn sign language which can give them better option to communicate effectively. She explained, that they have book on sign language (belongs to Anil). Anil had several times encouraged her to learn sign language with the help of book. But, unfortunately, Manisha is not able to understand anything using book, since she is an illiterate. Further, there are no any formal "sign language" courses in the village. The situation of Manisha sheds light on the fact that there is lack of focus on illiterates for "sign language" courses.

## Daily situation

Anil's wife says,

*....I hear people calling him "laata", scolding him, verbally abusing him, behaving rudely..... but he does not understand it.... I feel worst at that moment..... I never say anything in favor of my husband.....because it's of no use.... People will say no matter what...*

With above statement, we can identify address the pain of his wife when the word "laata" is used, she see no reason to confront the use of such words. The word "laata" if translated in English means dumb. The referred word "laata" can be associated with him as being from a low socio economic background, since those who has the same disability was not seen called "laata". We will come to it in next story. But however, at present both Anil and Manisha, are worried about their children's future and their education. Therefore, both of them are equally contributing in the household economy. Anil as already mentioned above works as a cook, whereas Manisha works in the farm and has livestock. She often helps in villager's farm to make some earning.

Manisha says,

*..... sometimes it is difficult to meet the ends.... But we are managing..... I am afraid that if anyone of us falls sick then we will not have any money to go to hospital.....*

Manisha's statement makes it obvious that although there are difficulties due to financial condition, both of them are economically supporting each other in their own possible way. Therefore we can see that Manisha became vulnerable due to poverty and lack of support from her parents due to her individual choice, a self initiated marriage. But however, it also in a way shows us that marriage is important and plays vital role in supporting household and each other.

### **Story 3: Family values and arrangement of marriage**

Santosh is 45 year old man who is Deaf. He is from family with good economic background (father was well known businessman who used to run lodge and therefore had a good earning). He is married to Kanchi (able bodied woman). Their marriage was arranged by his family and relatives.

After the marriage between Santosh and Kanchi lived with Santosh's parents and was economically dependent on Santosh's parents. But, later after around four to five years the couple moved out. Since Santosh was unemployed, his wife started to run a small restaurant to make living. Until 3-4 years, Santosh was dependent on his wife. But, after around three to four years, he traveled to capital; there he saw entrepreneur's involved in hand painting business which motivated him to learn paintings. So, at present he is well known professional and has been running his painting business and supporting his family

#### **Arrangement of marriage**

Santosh's wife was from a very remote village of Okhaldhunga district. It was an arranged marriage. The parents of Santosh arranged marriage through the connections they had in her village, which was very typical way of arranging marriage. Their marriage was held in a traditional way. There was a certainly economic and social hierarchical disparity between Santosh's family and his Kanchi's family. Santosh's father was rich and had higher social position in comparison to Kanchi's family.

#### **Story from Kanchi in her words**

*..... At first, my parents never wanted me to get married with Santosh but, there was a lot of pressure as I told you earlier. So, we had no options than to get married. My mother used to cry so much. She was also worried about my kids, because she thought my kids would be like my husband. But, thanks to god, that all my kids are normal.*

*..... I knew about him before I was married. My parents and I was against it. You know at that time, it was not like now a days. There in my village, higher*

*ranking people” Karr” (insisted) my parents to marry with him as Santosh’s parents also had some links with these higher ranking people. At that time, Santosh’s parents were also one of the well- known people in the society and they were well counted in the village.*

*At that time, his father owned a hotel, and it was big thing during those days. There used to be 1 or 2 hotels only in whole of Okhaldhunga district. And the name of this area ram bazaar was after my father in laws name. He (Santosh’s father) was such a powerful person at that time. And so, the respect for his father also reflected upon Santosh, nobody called him” laata”*

*I was afraid of my relation with Santosh, in the beginning I always wanted to run away from here (Santosh’s Village). I tried to run away several times whenever I see someone from my village. But, I never succeeded. Whenever, I wanted to meet my parents, my father in law would send someone from here with me and the same person would come and take me back. Later, the desire of going back to my parents died.*

*I never tried to communicate with Santosh in fact I never had to communicate when I was living with my in laws. They used to understand his needs. It was only later when we moved out from my in laws house, we were using hands, pictures and things to make each other understand. Most of the time, we misunderstand each other and it turns out into conflict. Therefore, even today, I avoid communicating with him; my son translates whatever I have to say using sign language.*

Kanchi-- and Santosh relating towards each other becomes visible in how they communicate. In the beginning of their marriage life they stayed together in Santosh’s family household. Kanchi explained that there was never a situation when she would really communicate with Santosh. It was not until they moved out of laws house and established separate household. She communicates using hands showing pictures and things which often make it difficult to communicate and understand each other. She never received any sign language training and could

not sign as Santosh could. It was also visible while I was observing them trying to communicate with each other where his wife often raises her voice, and the situation becomes intense.

When I probed on reasons of not learning sign language she told me that the classes for sign language course were run for three months in the Okhaldhunga VDC and the classes were rented in Santosh's house, and she got the task to make lunch for all the students and to make money out of the situations. She was not given any opportunity to learn sign language at that time. But, however, all her children got chance to learn sign language, Therefore, Santosh and his children are able to communicate easily using the sign language among them. Most of the time it is their children who would relay information between their parents.

This also makes us think over Kanchi conversation when she had mentioned that Santosh had an extra marital affair with Deaf woman when he was at Kathmandu. Santosh and his girlfriend were able to communicate using sign language. While telling me about the affair Kanchi comments and says,

*.....I was not angry at him when I learned about the affair, I felt that it was good for Santosh to have someone who could understand him after all we live life for once"*

This statement shows that she understands the necessity of being able to communicate and express feelings in a relationship.

Santosh, after several years of marriage (27 years as stated by Santosh's wife) without any formal training by his own effort learned to practice painting hoarding boards and became quite popular in the area and started to earn with the same profession. He is economically independent and is able to make living for his family.

Later, I also got an opportunity to talk to Santosh's eldest son, who is 24 years old now. Though it was just for few minutes he gave me some information.

He told me that he is able to communicate with his father easily and all her siblings as well. Sometimes there used to be bullying among friends when he was small kid, but it did not happen much and neither he bother about it much. And he says,

*..... I never felt ashamed or bad for my father. I always feel proud to be his son.... He is independent and is also raising family..... (He laughs) I have not been able to earn like him and I don't know when I will be able to earn.....*

*.....communication has never been problem.....even when we had not learned sign language .....Sometimes it was hard to understand what he is trying to say or what we were trying to say ..... but when me and my siblings learned sign language... it is very easy to communicate with him..... Until now I have never felt that he is disabled.....*

The story from Kanchi, illustrates how person with disability from a higher socio economic position can have a privilege of having able bodied wife and how family with higher socio economic can have an influence in finding a wife for their disabled member. Moreover, we can also address that the wife from a low socio economic position is compelled to support her spouse's family although in the beginning. Kanchi was reluctant in marrying Santosh. The stories also tells us about the parents of the Kanchi being against the marriage and their fear of having the children with hearing impairment, which was a challenging and un-favored situation for Santosh, but the conversation also addresses the possession of power of Santosh's parents which they had, with money. In short we can say that disparities in economic and social position between these two families played a role in this marriage. So, it is also about how one has to fulfill the needs of one another, because she was from a more rural area and poor, so in a way economically her needs were fulfilled and also she was able to contribute in household chores including farming. But however, story also reflects challenges and difficulties in adjusting and accepting. It portrays how communication barrier can create hurdles in married life. At the same time, it also shows that Santosh's desire to share his feeling and being able to connect with the other women who is able to sign as him. Furthermore, it seems that sign language are not given priorities both in the way how program address families and the need



of communication medium “sign language” between couple is reflected here and also visible in how the couple makes priorities between them. In the end it creates distant in relationship.

Further the social position reflect upon, nobody would ever call Santosh “*laata*” or ever use abusive words or have guts to tease or mock him whereas other who are less economically advantaged and less in power would face all those verbal abuses, name calling, mock and tease which was quite normal in such setting and societies, and later in this chapter in we will come across same situation in Anil’s story.

Communication without any technologies is hard for Deaf. But however, it seems they are able to manage to communicate in their own different way. They use local signs, sometimes writes on paper, shows the picture and seen trying to act as well. When I was trying to communicate with Santosh surprisingly it was not so difficult to understand, he used to write and sometimes shows me with his hands. But, of course was time consuming sometimes. Even though they are able to manage to communicate in their own different way, it cannot be denied that there are difficulties, challenges and lack of opportunities for Deaf and such situations can be talked about as a stigma. Kanchi’s experience and her stories illustrate how they are coping with their own experiences of challenges and difficulties being a wife and a household of Deaf.

### **Concluding remarks:**

In these three stories, we can identify that each individual have different circumstances and have different ways of coping due to their socio- economic status.

We can see marriage as a social organization where both the partner fulfills their role in contributing to household economy in their own way. Women are commonly seen fulfilling their role in domestic work and mobilizing the home grown vegetables and grains in the market to make earnings. Whereas men are seen working in the public space.

To point out there are several issues that can be analyzed in the stories, but however, they can address that they are one or the other way linked to socio-economic factors. For example in case of Malika and Suraj, in spite of disapproval of family, Suraj managed to marry Malika which is due to his economic independence and his contribution in the family economy. Therefore, we can address that, economic independence can have a positive attitude towards individual control of marriage, because individuals who economically independent do not require or less likely to require help in arranging and managing marriage. The mere presence of economic independence and opportunities may have an influence on an individual that she can choose her own spouse and worry less about obeying her mother in law (Barber, 2004).

Similarly, in case of Santosh, marrying was only possible due to his father's socio economic influence in the village. But, in contrast, Manisha had to compromise by breaking ties with her family in order to get married to Anil, which was both social (because it was inter caste and was deaf) and economic (he was poor) factors. Therefore the findings in the study correlates with the study done by Kohrman, 1999, in China, where he reflects in the story of man who is economically independent but is expected to compromise his choice in arrangement of his spouse. In my material, it shows that Santosh valued and follow family values, and he did not cross boundaries in his choice of spouse. Whereas, in contrast to women, in the story of Anil and Manisha, where Manisha married a man from low socio economic position and had to break ties with her family. Therefore, my findings also shows how socio economic position of men can have influence in finding partner which is a way in organizing social life and fulfilling the individual role in the society as a whole. Further, the study clearly indicates that being able to earn and make contribution in the household economy is seen more important than one's own impairment.

If we compare story of Anil and Santosh, we can also address that socio-economic position of the person can have an impact in perception and attitudes towards person with disability because nobody ever dared to call Santosh "*laata*" whereas it was common case in Anil.

Bambani addresses that the women in Nepal have to face triple discrimination because of their disability, gender and economic status. And he states that there are different yardsticks of perceiving and judging disabled men and women and so the treatment meted out to them is definitely discriminative”(Bambani, 2003) which explains Nepali society’s perception towards women with disability. But, however, story of Malika, indicates that the perception towards women with disability can change when their ability to fulfill the household chores becomes visible and their contribution in household becomes visible and appreciated.

In these stories another factor that can be addressed is the way the programs have approached the person with disability and their family. We can address that the programs have fail to identify the needs of the family to be involved in the programs. For example, In case of Santosh “sign language” course only targeted an individual (Santosh) whereas there is great importance in learning “sign language” for his wife as well. Without targeting all the members of the household, having run a “sign language” course cannot have good impact in Santosh’s life when he is not able to communicate with all the members in the household.

In contrast, we can see the difference on issues on communication between those with self –initiate and arranged Deaf couple is very different. Self-initiated does not see communication as a problem whereas arranged couple (Santosh and his wife) struggle to communication more.

Another factor that can be addressed here is the way programs/trainings that have been approached was not fruitful enough in the long run for those who are targeted. For example, Anil, in spite of having trainings in Martial arts and hoarding board painting, he is making his living as a cook. It shows that though they were reached by programs which gave them hopes, possibilities for the future but these programs lack in recognizing their scope or possibility of finding work or make living which could be due to lack of consistency of the programs and lack of knowledge on the local setting which can give better picture in the local scope, but rather these training gives them hopes which becomes hard to fulfill (Ingstad, 2007). Therefore it makes it visible that “we must shift from an individual, often standardized focus to the

understanding of the roots of disabling conditions such as poverty, failed policy and the like” (Ingstad, 2007, p. 237).

We understand that marriage becomes potential to create a unity to share a commitment to establish a social life and in a way contribute in household economy. We can also say that, if the person with disability is not able to fulfill the economic demand in the household then they will have a very low social status which ultimately can push them into the vicious cycle of poverty.

Therefore the importance of having the disability identity card and social welfare can also play equally important role in access to marriage and hence lift up the socio economic position of the person with disability which can make inclusion of person with disability in social life easier.

# CHAPTER FIVE: LIFE EXPERIENCES OF DISABILITY

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Helman has described that people with different physical shapes, sizes and bodily functions are often subject to considerable stigma and explained that these bodily differences put them in variety of social disadvantages one of them is finding a marriage partner (Helman, 2007, pp. 19-50). But, however, previous chapter shows that marriage is accessible to person with disability in Okhaldhunga to certain degree. In the study, socio-economic position is seen as one of the aspects in having an access to marriage.

This chapter deals with the issue of stigma as related to caste, disability and socio-economic position. Helman also explains socio economic position being one of the factors which has an impact on degree of stigmatization.

According to Goffman, 'The term 'stigma' originates from the Greeks and was referred to bodily signs designed to expose something unusual and bad about the moral status of this particular person'(Goffman, 1989). Today it is applied more to the disgrace itself than to the bodily evidence of it. Goffman has described three different types of stigma. First, there are various physical deformities of the body which can be perceived as abnormal. Second, the character flaws which can cause a person to be perceived in a certain and unfortunate way. Such perceptions can include: having a weak will, being domineering, having unnatural passions, having treacherous or rigid beliefs, or being dishonest. If these interfere with a known record of, for example, a mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, or radical political behavior, this leads to stigmatization. Finally there is stigma of race, nation and religion. The common social reaction for all three types of stigma is that an individual, who might have been received easily in ordinary social settings, is turned away as he or she possesses a

trait which leads to inevitable attention. The person possesses a stigma, an undesired differentness from what we had anticipated (Goffman, 1989).

In the stories presented both caste and disability has shown person with low caste and disability into double discrimination which is often believed to be determined by one's birth into a particular caste, irrespective of the faith practiced by the individual. It denotes a system of rigid social stratification which is ranked into groups defined by descent and occupation. Under various caste systems there are caste divisions which also distinct in housing, marriage, and general social interaction which are reinforced through the practice and threat of social ostracism, economic boycotts, and even physical violence. Brahmins are the higher in caste hierarchy where as Dalits are so-called untouchables of South Asia—including Nepal (Narula, 2009).

“Untouchables” may not cross the line dividing their part of the village from that occupied by higher castes. They may not use the same wells, visit the same temples, or drink from the same cups in tea stalls. Dalit children are frequently made to sit at the back of classrooms. (ibid)

As a result, Dalits can and most often excluded from Hindu temples and rituals. They are also often kept from entering hotels, shops, or homes, and are even excluded from cowsheds due to the belief that they will pollute the milking cows.

Nepal's 1998 Human Development Report revealed that development indicators closely followed a caste line which shows the lower the caste, the lower the life expectancy, the literacy rate, years of schooling, and per capita income. The life expectancy rate of Nepal's Dalits is five years short of the national average of 55.80. Children face a higher incidence of malnutrition and the general population lacks access to clean drinking water or proper health services.

In 1999, Nepal's fourteenth periodic report to CERD also clearly highlighted the economic disparities that continue to persist between low and high caste populations. (ibid)

However, in the following two stories from different caste person with similar disability shows that in spite, of their difference in caste and social hierarchy both is equally facing the social barrier. Moreover, although in the earlier stages of life both had vast differences in economic condition, both of them passed through poverty and then economic gain. Further, the gain in economic situation also changed in the perception and the impact of social barrier seemed less visible.

The two atypical stories in the local setting presented here illustrate how the stigma of disability is not dependent on caste alone. While poverty is related to caste alone on the general level, caste and disability are nevertheless not fixed entities. Both person in the story, have experienced various kinds of challenges in transition to adulthood. These two stories represent two persons from different social background, one from higher caste Brahmin and other from low caste Dalit. Both of them have faced vulnerable situation however, situation is worst in case of lower caste with disability. In spite of their vulnerability they were able to break through the poverty cycle which makes it an atypical life story. Moreover, it shows the drastic change in perception towards them after they were economically independent. I argue that with proper support, people with disability from both low and high caste, are able to limit the effects of stigma. It points again to the significance of socio economy in the participation in the local communities.

### **The life: from beggar to tailor**

The first meeting with Sudeep, 30, is a man born with congenital deformity, club foot. I meet him in the office of CWCSW, where he had come to get new disability identity card. There I approached him and introduced my purpose for visit. I got an opportunity to get his address and mobile number.

In the same week after, two days of our first meeting I visited his place, where he has tailor shop and in the same shop he also gives training to three girls from different villages. He lives there, and has two assistant who also lives in the same

building but on the upper floor. He sleeps in the shop where he has placed his bed at the edge of the room, behind his tailoring machines.

In my first meeting, I had an interview with him in the shop, where people living in the same area were staring at us and listening to our conversation, which made me and Sudeep hesitant to probe and ask more questions. Therefore, I decided to have repeated interview. I had four formal interviews with him alone in a room which lasted from min 45 min to two hours, behind his shop. I also had several informal conversations and also did participant observation.

### **Experiences from his childhood**

He was born with congenital deformity known as “clubfoot”. He is from a very poor family and belongs to Dalit community. His mother was single mother which also explains the poverty. They did not have any farm to grow food grains and vegetable, therefore, mother had to work on villager’s farm which was a source of wage based income and that was the only income source they had.

Both feet were deformed, which made him unable to stand and therefore used to crawl to move around in the village. He used to go to school, crawling and he says,

*In classroom, I had to sit at the door ..... nobody used to let me sit on the chair..... there was always mocking and teasing from my classmates.....they used to call me “dudey” [ person without limbs].....*

*.....Later I quit going to school..... I could not pass my first standard for 3 years..... when my classmates who were poor in studies...who did not knew how to write alphabets were passing...but me when I knew all the alphabets and my course book was failing all the time..... What could be the reason? (He asks scornfully)*

Here he said that he was not allowed to sit on the bench with other classmates was precisely due to the fact that he was from a Dalit community. But, when I asked him to clarify for me, he said



*.....at that time, everybody in the village used “hella garthey<sup>1</sup>” .....  
Because I am disabled and I am Dalit..... At that time it used to be  
discriminative towards people like me at every place.....*

It can be addressed that the perception towards person with disability was culturally negative and he faced more disadvantaged being Dalit.

After he quit his school, he started to move around in the village crawling and asking food from other villagers and that is how he started to beg. When asked about his mother's concern, he says,

*..... We were very poor...and in a way my mother was relieved that she did  
not have to feed me...*

He was living in his own village until the age of ten. Then, he moved to Okhaldhunga VDC, because it was the center of Okhaldhunga district. But, there was not any particular reason for moving into Okhaldhunga VDC because in the beginning he had not decided to stay in Okhaldhunga VDC. He was just moving away from his own village. But, at Okhaldhunga VDC many people were kind enough to give him food, clothes and money in comparison to his own village, which made him to stay in Okhaldhunga VDC.

He was too young to move in another village and I was surprised to hear that. Therefore, my question was, did your mother tried to look for you? He said,

*..... No... .. She must have felt relieved that I left..... she had wished that I  
leave the house.... And my brother always used to threaten me to throw away  
from the house when my mother was away.....*

This statement made it clearer on why he moved from his own village to Okhaldhunga VDC.

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1 neglect

## Experiences after he moved to Okhaldhunga VDC

He was living a life of a beggar until from the age of 10 until he was 17 years old. He used to wear slippers on his hand and crawl on his hands and knees.

*“I used to kneel and walk on my hands, like animals. It was very difficult for me, I was living as a beggar..... I used to eat whatever I get from begging around the village....*

*.....during rainy seasons it used to be very difficult due to slippery muddy roads....my whole body used to get dirty.....so during those seasons my slippers did not last longer.... But I managed somehow and later it was like a habit to move around in the village like that”*

This statement clearly shows that he felt very low of himself when he was not able to stand and walk on his feet instead he has to crawl which makes him think and compare himself with animals.

Here, it is also obvious that walking on hands and knees was certainly not easy, but it shows that it was important for him to keep moving to be able to sustain his life thereby making his living as a beggar. During several conversations with him, he has mentioned and explained his past situation comparing with an animal which crawls on the ground and that his situation was nothing better than that of an animal.

He also explains about the difficulties and challenges he has faced during his stay in Okhaldhunga VDC.

*When I was living my life as a beggar..... I had to buy food.....some people even used to refuse to sell ..... and usually if I move around in the morning....some government officers used to spit on me and say “site bigryoo” [Bad omen, which literally means that the rest of the day will go bad]*

Not selling food and saying “site bigryoo” [bad omen] is not just because he was disabled but he was also Dalit.

Again here we can see the experience of double stigma of caste (social position) and disability which has also mentioned by Bambani, 2003.

### **Exceptional change in his life**

One fine day, as he was crawling and moving around, a foreigner came to him. He told him to visit Okhaldhunga Community Hospital (mission hospital). When he went there, he was offered a treatment for his club foot, which can be possible in Kathmandu, capital, but was also told that it is not sure that the treatment is suitable since he was at the age of 17. With the help of foreigners working in community hospital, he went to capital, Kathmandu in Orthopedics hospital. His treatment and staying was all funded by the foreigner and some international organization. His treatment was successful after three surgeries. After the treatment, he was trained to walk. Moreover, he was also asked what he wants to do to sustain his life. They had given his option on training on electronics repairing, basic physiotherapy training, and tailoring. Therefore, he chose to go for tailoring.

But, unfortunately, he was not accepted for the training because he had deformity in his hands. He had lost his fine movements of his hands like picking and gripping due to walking on his hands for a long time. But, the trainer was pressured to take him by the hospital director; therefore he got an opportunity to learn stitching. It was very difficult for him to understand grasp the ideas. But however, he continued for three months and came back to Okhaldhunga. He did not had enough confidence to run a tailoring therefore, he used to spend days doing nothing much and stitching torn cloths of some villagers.

Later after almost a year, he was again asked by a foreign doctor that if he was interested to go for another better training on tailoring. He said yes and then he was funded by them and stayed in Kathmandu for six months from where he developed good skills and confidence on tailoring.

## Recent experiences

At present he has been employed as a tailor, and a trainer and has been offered a place to stay and is being paid Rs.14000 (€127) per month, which is very high in context to this setting. He says,

*I do everything by myself. I can walk around the village with the help of stick..... I order and get all the stuffs for my tailor shop... I do not see moving around in the village as a problem but it is quite difficult for me to go to my native village which takes around 6-7 hours for normal people..... I will take almost 1 day for me..... Therefore I don't go to my native village.*

He says he feels very lucky now and told me that he felt like he got a new life. And he says,

*.....My situation before the age of 17 and now is like a difference between sky and earth. Before the age of 17<sup>th</sup> people never counted me as a human..... but now everyone treats me nicely and respects me and everyone knows me for what I am now.....everyone loves me. Now, I feel really lucky.....*

*..... People even greet me and now they call me with different relations like "mama<sup>2</sup>", "dai<sup>3</sup>", "bhai<sup>4</sup>"....*

This was also observed by me, in several places. I noticed that everyone who passes by his tailoring greets him, says "Namaste", or how are you? And people call him with the relative feeling like brother and uncle. When I was moving around with him in the village, and went to several places like tea shop, and shops, where he was respected and treated well and also found that he was quite popular among the villagers. Everyone who pass by used to ask him how are you and where are you going and was greeting him. And one day, I happen to go with him to meet his relative uncle, who was operated for cataract. It was at the Red Cross office, there I

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2 Mother's brother  
3 Brother  
4 Younger brother

noticed that people know him and was even offering food and sharing place to sit with him.

But however, he also expressed that he has some difficulties and challenges.

He has difficulty in walking in the newly constructed roads where soling has been done and it becomes worst during rainy season. It becomes so slippery has he has to walk at the risk of his life. (There are no plain straight roads, it all steep up or slope down.) During several occasions, when I observe him walking with the stick it scared me because the un-graveled roads were quite steep, and sometimes felt like he almost fell but gains his balance and continues to walk as if it's just a part of walking.

He also expressed that he cannot squat sit and the toilet is Indian style toilet which makes it difficult for him to use the toilet, and he has to clean toilet every time before he use to sit down completely.

And one interesting thing he told me was that now his mother visits his every twice or thrice a month and asks for money, whenever she comes for "*hattia*<sup>5</sup>" to sell goods.

(When I told him about my interest to meet his mother several times, he did not responded to it and said I will let you know but never gave me chance. Whenever I asked him about his mother, he used to take conversation in different direction and used to say, I don't get chance to talk to my mother even when she visits me because I am usually very busy. Therefore, questions around his mother and interviewing his mother were considered as a tacit refusal.)

In his lived experience we can address that there were many challenges and difficulties which has also been shaped by the cultural and social impact. Such as, inability to complete education due to mocking and teasing as well as partiality of teacher and his classmates, spitting on him or was seen as a bad omen for day etc. Further, it also shows how social impact changed with the economic independence he gained in his later life.

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5 Weekly market

## **The experience: “apanga<sup>6</sup>” to businessman**

This story illustrates experiences of being stigmatized which shows a similar process as the previous story of Sudeep, from stigma to acceptance but this time portrays in a life of a Brahmin man.

Raman is 57 years old male who has club feet on left leg. He is holding white disability identity card after learning about it in the DPO meeting.

My first meeting with Raman was at the local DPO meeting. It was his first meeting and mine as well which was at the WATCH office. There I introduced myself and told him about my purpose to visit Okhaldhunga. There I took his phone number and address and promised to meet him later same week.

I meet him after 2 days of our first meeting. I met him at his house but, we just had conversation at the gate of his house. I had 3 interviews with him and it lasted for 45 minutes to 1 hour and during my three visits he never invited me into his house. Therefore, my observation was limited to the outside environment of his house.

He belongs to higher social caste, i.e. Brahmin, which could also be the reason for not inviting me inside his house. I did not have any chances to talk to his wife, because every time I mentioned about my interest to talk to his wife he was hesitant. Moreover, I did not have any opportunities to talk to his son who was always busy at his shop. However I got an opportunity to have an informal conversation with his daughter in law. It seemed to me that, in a way, all the household members seemed less interested in having conversation about Raman.

He has had different experiences from his childhood to the present day.

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<sup>6</sup> In Nepal the term apanga is referred to disability

## Experiences in his childhood

Until the age of seven he was confined to his room due to inability to walk and move around. At the age of ten, he gradually started to walk with the help of stick so, at the age of 11 he joined school which is where he has most of experiences of challenges and difficulties. The school was at the distance of four hours of walking and with his one leg it was even more time consuming for him, it used to take almost more than five hours to walk to school. His brothers and his classmates used to go along in groups and he had to walk alone because nobody wanted to walk him for he was slow and unable to walk on the pace with his classmates and his brother. There was also mocking and teasing in the village, in school and sometimes his own brothers used to mock and tease him. People used to call him with different names. Therefore, after 5<sup>th</sup> grade, he left school and joined another school, with the hope that things will change. But, it was also same, school mates used to mock, tease and sometimes used to beat him. And therefore, later same year he dropped out from the school even though his parents were not happy with his decision and was encouraging him to go school.

He says,

*.....my situation was painful..... “Ashu nai aanne thiyo” [pitiable condition]..... when I was in school my friends used to call me “fyanthungree” [deviated fees or hands], “dudey” [without limbs].....*

*People also used to say what can “apanga” do for living..... Do not have hope for the future.....*

After he left his school, he used to stay at home and do nothing.

## Experiences of responsibility and hard work

When he was around 25, he got married with a girl from a remote village. She was from a poor family. After marriage, she often used to say,

..... How can I have normal family life with disabled man.....? It's all in my faith.....

Raman said,

*I never said anything or scolded her for saying or expressing her sadness of being married to me.*

Later, I also learned from his daughter in law, family purposely was looking for poor family so that they would agree to get married to Raman. After 5 years of marriage, he and his wife along with the children moved out from their parent's home. That is when he started to think about making living on his own. Therefore, he worked as a cleaner in community hospital where he was treated well by his female foreigner boss. She used to help him with money by buying vegetables grown by his wife. But, later after two year things changed. The boss changed, and there was another foreigner boss who used to ask him to do odd jobs like unclogging jams in the toilet, he was never considered being disabled which became difficult for him to work. Therefore, he decided to quit his job.

Therefore, he was working only in his farm which was again difficult for him, but he had no choice, he has to make living for his family. He had responsibility of his two kids.

After about one year later, his brother suggested him to run a business and he offered him to help with the capital amount. So he decided to run a shop and sell sandals and slippers. To get the sandals and slippers he has to go to Kathmandu. He explains during those days, they had to walk for one whole day and cross river to get busses to Kathmandu. It was again challenge for him, but this time he was determined to do it. Therefore, along with other shopkeepers and his brother he decided to walk, for him it took one and half day but those who were with him walked on his pace and also helped him to cross river and so brought slippers and sandals from Kathmandu. Fortunately, his business was success and he was able to earn a lot with his business and he was successful enough to well educate both his son and daughter.



At, present, his son runs his business and he is living a life of retired person. And when asked about the behavior of villagers and friends he says,

*..... Nobody mocks or teases me anymore..... it is not like before...things were different then.....*

The perception and attitude toward him as well as other person with disability has changed and is further slowly changing with different era and he has explained his life experience living with disability.

At present he is well known as a one of the rich person in the village and own two houses at the center of Okhaldhunga.

Mocking and teasing were also seen common in the community. Both the informants have experienced the attitudinal, social and cultural barriers in their life but can also be noticed that they were coping with it which was the harsh reality of their life. Here, we can notice that both the informants were able to break through the chain of vicious cycle of poverty, which is not very common and it can be regarded as a typical story of person with disability. It was the greatest challenge for them to be able to exist and participate in the community which has again been shaped by their poverty.

The way they express their experiences show differences in how their childhood have been and how the experiences shaped their life differently. Both of them received support that enabled them to achieve better life, Raman received family support whereas Sudeep, a charity support.

### **Concluding remarks**

The two stories presented shows that surviving with disability in rural setting of Okhaldhunga to large extend depends upon the social and economical factors. I would like to refer statement by Ghai 2001, in which she states that,

“for poor families, with hand to mouth existence, the birth of a disabled child or the onset of a significant impairment in early childhood is a fate worse than death” (Ghai, 2001, p. 26) which can also relate to the story of Sudeep where he was expected by her mother to leave house which is due to poverty. It creates a situation where person with disability will have to face both social and economic barriers.

In the stories we can address how behavior such as mocking, teasing and partiality of teacher and unfair behavior of classmates had affected their educational opportunities which have remarkable effect in the later stages of their life. They were both pushed towards the cycle of poverty. Therefore at one point of life, they were forced to live a life marked by extreme helplessness which makes it appear impossible to demand more for themselves, or know what is fair and right from others.

However, it is very remarkable that both of them managed to break through poverty. Both of them had different provision in the achievement of the present status of their life.

In story of Sudeep, it is visible that the state relies on voluntary sector for provision of basic services for disabled people, which was charity based health services and training to make them able to sustain their life. However, we also understand that there was an approach for Raman which is again voluntary charity sector to improve their living condition, but medically became impossible in his case.

In case of Raman, family ties and relationship played an important role in the better standard of living at present. In his stories, the family can be seen as an agency which helped in pursuing his career in business and support his family. We can notice that despite the odds, family becomes a powerful social organization to overcome ongoing oppression. It is very often that the family provides emotional strength but emotional bonding is unexpressed, unrealized or unarticulated. In the stories we can easily address the failure of the government to reach the poor whereas the voluntary

charities and social and family bonding played an important role in the breakthrough in their cycle of poverty.

Further, at the end of the stories which is the present day of their life, the ways they both present their life experience show the changes in their socio- economic positions through life and time. Even though, they have different age (one old and one younger) they have both experienced changes in how people perceived them at present when they managed to work and receive a working position in the community.

Therefore, we can also identify how attitudes and perception towards them have changed, they are both well respected in the community, well known and there are no more mocking or teasing behaviors. The changing perception towards them also has a link with the economic status of the person because we can identify in the stories that when the person with disability is economically independent, then the perception towards person with disability has changed. However, in contrast it is also remarkable when Raman said that time has changes so as the people and their perceptions and disability is a changing concept within a different society and culture. This gives a true ring to understand disability in context to cultural and local setting which is a changing concept.

In the next chapter I will discuss about disability card and benefits of holding the disability cards and challenges in accessing it, which is the government program on improving socio- economic benefits and targeting persons with disabilities.

# CHAPTER SIX: POLICY AND IMPLEMENTATION

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## THE NEW POLICY AND ITS IMPLEMENTATION

In 2051 B.S<sup>7</sup>, i.e. 1994 AD, disability protection and welfare regulation, the rule 5 declared that disability identity card should be distributed in Nepal. In 1996, the Ministry of Women, Children and Social Welfare started distributing the first of such cards. The card was simple Identity card based on four different broad classifications of types of disability: blind, deaf, physical disability and mental disability.

In the year 2006, according to the ICF classification of disability, classification and definition of classification was also revised and broadened according to the nature of the problem and difficulty in the parts of the body and in the physical system, disability has been classified into the following seven categories.

1. Physical Disability 2. Visual Disability: a) Blind b) Partial Sighted 3. Hearing Disability a) Deaf b) Hard of Hearing 4. Deaf blind 5. Speech Disability 6. Mental Disability: a) mental illness b) Autism 7. Multiple disabilities.

In 2008, the government of Nepal revised the disability policy of 1994 and developed a new policy with four categories based on severity. These are as follows:

1. Red Disability Identity Card for Profound Disability: Person who is not physically and mentally capable to carry out their daily activities even with the assistance, person with high mental disability, blind and deaf who are incapable to carry out activities without continuous assistance lies in the category of red identity card.

2. Blue Disability Identity Card for Severe Disability: Person who needs continuous assistance in carrying out daily activities, to move, have information, can read and

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<sup>7</sup> B.S. Nepali Calendar Year

write, paralysis of lower limbs due to polio or any other diseases, those whose suffering from spinal cord injury or brain injury or musculoskeletal injury causing lower limb paralysis and is using wheel chair, amputees below arm (both upper limb) or is unable to move, amputee below waist or unable to move below waist, unable to move both lower limb and uses crutch, blind, deaf, person with mental disability and learning disability but can carry out activities of daily living, multiple disabilities who need continuous assistance lies in blue card category.

### 3. Yellow Disability Identity Card for Moderate Disability and

Person who can carry out his activities of daily living by himself using prosthesis or assistive device, polio resulting inability to move below knee, and cannot independently walk and move, not having thumb and 1<sup>st</sup> finger below hand, and below ankle amputee, problem in spinal cord causing hunch back, mental disability with slow and difficult learners, using assistive device for hearing, person who has undergone vocal cord surgery and cannot speak, highly stammering, those below the height of 3 ft, person with low vision who use spectacles and hearing device, and can read only using lens or magnifying glasses to read, are in blue card category.

### 4. White Disability Identity Card for mild disability

General problems in body parts but can do his/her activities of daily living, upper limb or lower limb length discrepancy, person with low vision who only can read large letters, having 1<sup>st</sup> finger and thumb below hand, not having parts of the toe, either using or not using hearing device can hear loud sound, those who have very less memory and has difficulty in learning are under the category of white card.

Withholding these cards, a person is entitled to different benefits and social welfare, as stated in the policy. Person withholding red disability card is entitled to monthly allowance of Rs.1000 per month which is equivalent to € 9. Person withholding blue card is entitled to monthly allowance of Rs.300 (€2.7) per month. (This has been stated in the information book on disability (second edition), 2068 BS (2011 AD), published by Women, children and social welfare ministry)

However, there are other benefits withholding disability identity card such as access to free education, five percent seats reserved in government and private sector for qualified person, free trainings by government to improve self-employment opportunities, 50% discount on public transportation (vehicle carrying more than 15 passengers), reserved seats in public transportation for person with disability, tax free on specially designed vehicles for person with disability, create barrier free environment to improve the disability friendly environment, tax free on assistive devices for person with disability, access to assistive devices as a right to person with disability which one can get from CWCSW, district education office, and different organizations working on disability, provision of land and house for those person with disability who do not have one, organizing sport and entertainment for person with disability, legal support in case of necessity, educational and awareness programs regarding person with disability on national television.

The social benefits connected to the policy are not as clear as presented above. There are different books on the working procedure of VDC by the Nepal Government where they have mentioned how and who can receive social benefit, and particularly the cash. According to social welfare working plan, of those holding a blue card only 75 persons in a district with a population of three million will get Rs.300 (€2.7) per month, while only 11 will get Rs.1000 (€9) per month among those withholding red card in a district with the same population. Therefore, only having read book on disability information published by Ministry of Women Children and Social Welfare itself does make this aspect of the policy clear. This, we'll see, complicates the local implementation process.

The main intention of identity card is not clear on the government materials but as explained by the president of NFDN, it can be understood as to organize the social welfare provided by both governmental and nongovernmental organizations so that person with disabilities can have equal and justified access and opportunities to the facilities. However, in a broad sense we can understand the provision of card and social benefits for those withholding the card help to provide equal access and opportunities to the person with disability and thereby mainstreaming people with disability in all sector of development.

In the following, I will start by describing the bureaucratic system of receiving the cards in Okhaldhunga. The local bureaucracy is important to understand in order to analyze the accessibility of the cards to persons with disability. There were different channels to go through to get disability identity card, and it became important to understand who were involved in deciding the category and giving out disability identity card.

### **LOCAL POLICY IMPLEMENTERS: THE BUREAUCRACY**

At the local level, institutions involved were VDC (Village Development Committee), CWCSW (Center for Women, Children and Social Welfare), a health officer (who can be doctor from Okhaldhunga community hospital (UN mission hospital) or health assistant from government run health centers) and DFO (Disabled people's organization).

But, the main role of VDC secretary in regard to disability card policy is to give formal letter acknowledging type of disability the person possess from his VDC. The main reason of his recommendation was explained by VDC secretary as he is one among the locals and often comes in contact and familiar with the locals residing in the VDC along with their everyday setting and life situation. After, his recommendation letter and letter from health assistant, person must go to CWCSW with his copy of citizenship card or birth certificate (those who are below 16) and two "passport size" photo which clearly shows the disability. Further, those who withholds red and blue card will receive cash at the VDC office.

### **Health professional**

The role of health professionals, who can be health assistant, medical officer, staff nurse or auxiliary nurse who is locally available, has a major role in regard to disability identity card. Health professionals are responsible for clearly identifying the type of disability and writing a letter stating the type or diagnosis of the impairment. This letter forms the basis for later decisions about the distribution of the cards, thus

the health professionals can have an impact on access to have the proper of category of the disability identity card.

### **CWCSW secretary**

The staff in the Center for Women, Children and Social Welfare (CWCSW) office travel to the 80% of their time in different remote VDCs of the Okhaldhunga district in order to give information to villagers about the social welfare policies. 80% of their time, they visit in remote VDCs. This includes informing about the disability identity card policy. They conduct meetings in groups with the VDC secretaries, political leaders, teachers etc. These meetings are not particularly about disability identity cards. If they encounter severe disability during their field visit they do send the cards out in the remote villages through the CWCSW office.

The CWCSW secretary plays the most important role in the distribution of the disability identity card. The secretary has the authority to give out the disability identity card right away if there are visible impairments. In the less clear cases, the final decision is made by the disability identity card recommendation committee, which we will come to later. According to my observation in the Okhaldhunga VDC, CWCSW secretary was seen to actively making decisions about which category of the card a person would be entitled to.

In order to apply for a disability card at the CWCSW office, the person must come to the office with the copy of his or her citizenship card, two passport size photographs in which the disability is visible, recommendation letter from VDC secretary, and a letter from health assistant or doctor stating a particular diagnosis. At the office the secretary will decide on category of the card, if any, to be given. She does this depending upon the type of diagnosis the person with disability has been given from the health officer. Further the secretary told me that in case of confusions she discusses the matter with the other staff members in the CWCSW, and if they all fail to conclude she contacts the head office in Kathmandu.



## Disabled People's Organization

The representative of the Disabled People's Organization (DPO) also has a role in the distribution of the disability identity card, although it is limited. They assist persons with severe disability who are not able to travel in person to the office. In these cases, they can give a recommendation in favor of the person with disability so that their co-household members or parents can receive the card on their behalf. However, during my study, I could not find any cases of involvement by the DPO with the disability identity card policy. For instance, they were not involved in the situations where confusions of severity of disability card arose.

The information book on disability identity card has also states that a committee known as "Disability identity card recommendation (*sifaris*) committee" should be consulted. In Okhaldhunga, this committee has five members, and they are responsible, theoretically, of examining disability identity card applications. The committee consists of:

Organizer: the assistant to chief district officer (CDO) of Okhaldhunga District office

Member: the planning secretary of the district development committee

Member: the district public health secretary

Member: the national disability federation, all organization which are registered in district administration office or in related district office who are working on disability organizations

Member secretary: the CWCSW secretary

According to the policy booklet, the committee meetings should be held minimum of six times a year and the meeting should be organized by CWCSW secretary. However, there was no meetings held by this committee during my stay in Okhaldhunga.

## **INTERPRETATION OF DISABILITY IDENTITY CARDS BY LOCAL LEADERS**

In this bureaucratic organization, the secretary of the CWCSW is very powerful in determining who will access the disability cards and not. Her interpretation of the policy is therefore crucial. During my many meetings and interviews with the secretary, I came to understand that she has only limited knowledge of the issue of disability. When asking about her understanding of the aims of the policy, she said that the main intention of disability identity card is to identify persons with disability and to know what kind of disability they have, so that people will sympathize them in the community and give them necessary assistance. Moreover, she said, at the local level they can use their card to access the benefits attached.

As we saw, the policy booklet defines the disability categories according to both degree of assistance needed and bodily impairments. The secretary, in her understanding of the categories emphasize on the latter primarily. According to her, the red card holders are those with severe disability that, she says, lies like a log on the floor and cannot do anything on their own, while the blue card holders are those whose lower part of the body are paralyzed and thus cannot do everything on own and those who use wheelchair. The yellow card holders are those who have minimum difficulty in performing any activities and uses prosthesis. In all cases I encountered during my observation in the CWCSW office, she consulted the book and used it literally and focusing on bodily impairments.

The decision about the category of the card is done using the concrete description listed for each category in the policy book. Thus, the understanding of the local everyday situation of the person is only to a very limited degree included in the consideration of each case. Moreover, because the staff has limited understanding of technical words used by the medical staffs, some decisions are made without a full comprehension of the situation of the person with disability.

For example, if the recommendation letter from the staff states “left side hemiplegic” “cerebral palsy” then it puts them in dilemma. One case can illustrate this. One child in the village was suffering from severe cerebral palsy and was not able to carry out

independent daily activities of living. The health assistant wrote a recommendation stating mental disability as diagnosis, which according to the category description would give right to a blue or yellow card. The family was given a blue card, which is not what they think they deserve, as they believe they are entitled to have red card due to their severity. The situation created a controversy. Later, the health assistant was requested to write, “child is not able to move his limbs, not able to speak and has mental disability”. Then, finally a red card was given to him.

I also observed another case (which was also from remote VDC) where a child most probably suffering from muscular dystrophy also was given a white card. I felt this was an injustice to the child and parents, but it is due both to lack of biomedical knowledge and lack of infrastructure.

During my observations in the CWCSW office, I encountered many persons with disability and their co-household members who came from far away villages, often using one full day’s travel to reach the Okhaldhunga VDC center. They came to ask for help and access to the benefits that they were entitled to through various social welfare arrangements, such as the disability card. Very often they come without sufficient documents, leading them to go back empty handed. Among those who received the disability card in the office, I observed that they were not told about the benefits and the uses of disability identity card.

This also shows how person with disability has to go through different channels. It takes a lot of time investment especially for those who come from far villages. Moreover, there is little knowledge at the local level regarding the issues of disability and situation of person with disability and the circumstances and life conditions these people are living in. In general, the decision makers seem to first and foremost take the bodily impairments into account, rather than considering the degree of severity in each case.

## **INFORMATION AND PERCEPTION ON DISABILITY IDENTITY CARD**

When I first met people with disability in Okhaldhunga, only five out of 47 persons with disability had a new disability identity card. These five persons withholding the card got access to the card due to the social connection or close relationship and relatives with those working in the government sector. Four of them were withholding white cards whereas only one person with disability was withholding a blue card. Among these people who had disability identity card, only two people had some little information about the benefits of card.

Sudeep and Krishna were two persons who have some idea regarding withholding disability identity card and both of them had different expression about the card.

Sudeep withholding white card expressed that he knew about some of the benefits withholding disability identity card, like free education, discount in transportation, and free health services, but he explains that these benefits cannot be utilized staying in rural part. Some of the reasons he mentioned were, the government schools are free of cost, and he has not heard of anyone with disability accessing free education in higher studies in Okhaldhunga, the government health center are free and there are no local transportation to make use of the discount on them. Moreover, discounts on flights are not possible due to irregular flights to Kathmandu which are usually booked by those in advance who can pay extra “below table” due to corruption. He expressed that it’s only the cash, or allowance, that can to some extent assist person with disability living in Okhaldhunga.

Krishna had quite different expression than Sudeep. He recognizes the card as a way to become a committee member in governmental organizations where one seat is reserved for person with disability withholding disability identity card. But, however, he has not got an opportunity to become a committee member yet.

Because the disability card policy was central to my study in Okhaldhunga, I spent much time informing people about the policy, the benefits and the process of accessing these cards. I met different reactions and opinions to this information. To illustrate these variations, I will here return to some of the persons we’ve met in the

earlier chapters, and present their perceptions and expectations of the policy and their involvements.

Malika, who is polio survivor, expects to get either yellow or white card. Her expectation on having card is to have an access to government jobs which are reserved for person with disability according to the policy.

Anil has a blue disability identity card but was not aware of any social welfare and benefits withholding card. His expectation on having blue disability identity card was to receive allowance of Rs.300 per month, but did not expect to have access to any other benefits.

Santosh was interested in getting a disability identity card and he is under the blue card category. Withholding it, he expects to receive the allowance of Rs.300 per month, which according to his wife, they will use for the medicines. He was processing for the disability identity card, after my first encounter with him.

Bal Kumar received white disability identity card and he expressed sadness of not being able to receive money. He also expressed that, staying in the rural area there is not much benefits of withholding disability identity card. There are no public vehicles to get discount, he is not going to school anymore to enjoy free education and he will not be competing in government jobs, and they have free health services in government health centers which makes withholding card useless.

Sudeep does not expects to get any benefits which has already been mentioned above but after recognizing all the benefits he wish to try to get provision of loan from government to open a tailoring institute in future, but he sees it almost impossible.

From the above introduced five people with disability, two person had disability identity card in my first encounter with whereas three others did not have disability identity card and did not had any required information regarding disability identity card. Among these three, only one person was able to receive card whereas other two were had not got any card until the day I left, which is due to lack of

communication and lack of knowledge in bureaucracy and another reason is their anonymity and ignorance.

In general all the other participants who were illiterate were expecting allowances rather than other benefits whereas those who are educated were expecting government jobs reserved for person with disability.

However, we can identify differences in expressions and expectation in the reception of the cards. Two persons among five, regards disability card as a potential benefit for their work opportunities whereas other three some see it as a source of receiving money. To sum up, we can address that the expectation are directly and indirectly pointing seen as a potential to improve economic status of person with disability.

## **CHALLENGES OF RECEIVING DISABILITY CARD**

There were many persons hoping to receive disability identity card and the benefits attached, however, I have encountered persons who were struggling to receive disability identity card and also there were few who withholding disability identity card could not enjoy the benefits. The bureaucratic system described above also consists of persons with different understanding of disability and how to apply and understand categories of the color system. As described above, as a disabled person he/she needs a lot of information's on how to access these cards and we see that those who knew people in the system made it easier to access these cards. From that we can focus the attention on the poverty situations and that people in rural areas needs guidance from people who can give them correct information on how to proceed into the system.

I will now turn to two stories which illustrate experiences of struggles and challenges in receiving disability identity card and experience of difficulties in receiving benefits withholding the card.

### **Story one: Challenges in process of receiving disability card**

The experience of Ajay Bahadur's wife, Fulmaya, can give an insight into difficulties faced accessing disability identity card. Ajay Bahadur is 55 years (real age, but in citizenship 61) old man with hemiplegic and hip fracture and is bed ridden. Fulmaya has faced challenges and difficulties in getting an access to disability identity card and benefits withholding the card for her husband. I encountered Fulmaya on the way to her home, and it was my second visit to their home. I had not met Fulmaya in the first visit.

Ajay Bahadur and Fulmaya are from a Dalit community, and very poor. Both of them were working as a daily based laborer in construction areas or wherever there is opportunity, such as seasonal works during the harvest. But, after Ajay Bahadur's impairment, Fulmaya had to make living for both of them which made her to move around in the village to work. Therefore, during the day Ajay Bahadur is dependent all on himself for toileting. He uses jar like plastic bottle to urinate during day and he pours the urine in the bucket which is kept at the side of the bed. But, he does not get to eat anything during the day and waits for his wife to come back in the evening to feed him.

They live in a small typical house with no room but an open space, where they cook in one corner of the house and in the other far corner they have bed. They have small window near the bed and no proper ventilation. But they do have courtyard where I had conversation with Fulmaya. At the end of conversation I asked if her husband has a disability identity card. She showed a card that was not disability card but a different type of card given to poor people who are below the defined poverty limit, senior citizen and helpless people. According to her she had been getting Rs.500 (€4.5) each month from VDC withholding the card. (Which was actually an allowance which is given to the senior citizen and according to government rules those who are from Dalit community can get it as soon as they are 60. The senior citizens are those who are 65 years and above)

Further, she told me that she has received a letter from community hospital/mission hospital, and they told her to go to the CWCSW with that letter. She believes that

with that letter she can get some kind of fund for medicines. When I looked at the letter, it was a recommendation letter from the hospital doctor stating that Ajay Bahadur is hemiplegic, and it can be used to get the disability identity card. She had misunderstood the purpose of the letter, as she thought it was for fund for medicines charges.

When asked if she had gone to the center for women children and social welfare she with sadness says,

*"It's very shameful for me to say that, I had been going there at the office and cried and told them loudly about the condition. You know what they said rudely "why can't you bring the patient here, you are in the same VDC, it's not very far" They shouted at me. I told them "madam, if I would have been able to bring him here, if he could walk, I would have brought him here so please do not ask me to bring him here".*

She says, later after few days, she carried her husband with the help of nine persons from the village to the office. But at that time, another officer asked her why did she brought him there, she should first go to VDC office.

*"the staffs at CWCSW were very rude..... therefore, I don't like to go there and talk to them again"*

She said, with tears on her eye, that she has gone there 3 times.

*"How much my heart is crying because of the situation I am going through, nobody can understand". She wipes off her tears and says, "I have even begged the clothes I am wearing. I don't understand why they can't see my problem. How can I carry such a person with me to the office? She started to cry. That's why I thought they will not give me anything. Therefore, I just kept these documents with me".*



She suddenly recalls and says,

*“Just yesterday, foreigners asked me in the mission hospital if I got anything from center for women children and social welfare. I just told them they told me to carry patient there at the office and then also go to VDC, but who will carry him” so, she said “you must tell someone who can do this”. She further said, “Even these foreigners working in mission hospital said, these officers are too proud”.*

When further asked upon the difficulties and problems she says

*“What to say, the problems are so many”.* She has sold her gold, her assets, for her husband treatments.

She says:

*“I wish for this condition, there would be nice hospital and could take him to Kathmandu and will be able to stand and walk again. But, when I think sometime what to do little money will not be enough to take him to hospital who will give from where to get. I keep thinking and always in my heart what to do... sons don't support at all.”*

With this story, we see a lack of communication strategy from the government level to the local level and also lack of transparency in access to policy to the local targeted groups. Further, the ignorance and anonymity of the person with disability and household especially of those who are from very poor back ground and illiterate has created a situation of jeopardy.

At the end of this conversation, I told her the procedure of getting the disability identity card. She requested me to take picture of her husband and I printed it out for her. She even requested me to come with her to tell the officer in the CWCSW that I have visited them and her husband cannot move from the bed and as a proof I had to show the picture in my camera.

After three weeks I met her on the way when I was going for an interview. She requested me to come with her and so therefore I had a plan to go to CWCSW to

interview the secretary. I made it look like a coincidence, because I did not want to look like as a spy or interrupter or give any negative impression at the CWCSW office. As a proof of Ajay Bahadur's severe disability she asked me to show the pictures which I had in my camera. And finally she managed to get red disability identity card for her husband. Withholding this card, her husband will get an allowance of Rs.1000 per month.

### **Story two: Challenges in accessing benefits of disability identity card**

This is a story is about 17 year old Sushmita, and her failure to access to benefits implied in the disability identity card she holds.

When I had met her first time and when I was introduced, she was planning to go for higher education i.e.11th grade. She was withholding white disability card and with it, she has the right to study for free according to disability card policy. Therefore, she expressed that she had been appealing for free higher studies to the principle of higher secondary school. But the principle disagreed to give her free admission with very rude remarks. He said that she cannot get free higher education and he does not want to see any card or disability policy. According to him, there are no any rules notified to him.

Sushmita cried and told about it to the president of the DPO to help her get an admission, because she was afraid that she will miss classes which have already started and further she might not get admission if it's too late. Therefore, the president of DPO, a member and me (upon the request of Sushmita) went to meet the school principle. But unfortunately principle was busy in some seminar therefore we were not able to meet him.

Later, after a week Sushmita paid for admission due to fear of missing classes and getting too late for admission. Moreover, one of her teacher suggested to get admission before it gets too late and told her that if she is eligible for free education she will get admission her fee back. So, she got credit from her sister's husband and got her admission.

During my meeting plan with CWCSW secretary she was interested to visit. Therefore, at the end of the interview I notified the situation of Sushmita and hence she noted down her name and assured her to talk to her principle about the matter during their meeting at the district office. After a month or so, I encountered Sushmita after our last meeting. I asked her about her right to free admission. I learned that she hasn't got it yet and don't have hopes in getting it in future too. Therefore, she decided to not to appeal it to anyone.

Understanding the policy of disability in Nepal, we understand that it has adopted the standardized international policy for equalization and integration of person with disability. But, these two stories give us a real picture of how people with disability experience difficulties in accessing the system of bureaucracy.

## **DISCUSSION**

In general this policy is not yet operative; it's too early to be fully implemented. This year, the public health workers of the UN mission hospital (Okhaldhunga community hospital) approached CWCSW secretary to work in collaboration to distribute disability identity cards by running camps in different VDC's of Okhaldhunga district along with CWCSW.

Various reasons can be identified as reasons why the disability cards and benefits have not been made available in general. One of these can be addressed as limited awareness of such policies and its benefits and utilization, which is clearly visible in the material where only two people with disability identity card of the 47 knew anything about the benefits attached.

The complex and non-transparent bureaucratic system can also be identified in the study as one of the reason for lack of good implementation because people with disability especially from lower class and illiterate were not able to understand and enter into the system in order to get disability identity card. Their anonymity can also be addressed in this matter. Similarly, nepotism can also be identified as having an

access to disability identity card and probably it may be similar in case of accessing benefits.

Low budget or resources can also be addressed in the material because the budget allocated in a district is not enough. The working plan of VDC stated that only 11 person with red card, 75 person with blue card in one district with population ranging from two to three million can get allowance on the basis of quota system if there are more than the allocated numbers. The allocated number of person with blue and red card in three million populations could not be sufficient because Nepali is one of the poorest countries in the world, indicating higher number of persons with disability. Moreover there are not any data available on this. Therefore, there might be a danger to exclude large number of people with disability which can create conflicts rather than creating socio-economic improvement. This study supports Grocea et al, 2011 findings. She states that

“there is need in identifying barriers that impeded people with disabilities from utilizing cash transfer programs for their full potential. These include low levels of funding; complex and unaccountable administrative systems, physical inaccessibility or unavailability of services; and the limited awareness of the availability of such schemes among person with disabilities themselves” (Grocea, Ketta, Langa, & Trani, 2011, p. 1493)

Another important reason that can be identified in lack of implementation is a weakness of government by providing book on disability information book rather than providing better and broader knowledge on disability issues, and as well as hiring skilled staffs as an authoritative person in disability issue. As a result, staffs at CWCSW are literary interpreting the policy. Literary interpretation of policy is one of the problems in understanding the disability.

The experiences shows there is limited understanding on different person's needs, which result in lack of understanding around disability needs, and lack of communication between the CWCSW officer and locals is also visible because the CWCSW secretary is not seen actively to ask questions about the issues of person

with disability, such as their everyday life situation. Thereby, the chances of handling out the wrong categorized card are very high which can have a huge impact on the life of a person with disability and their co-household members. It was also observed that the card holders are never provided with the information regarding the benefits of a withholding card and how to get an access to benefits. Moreover, there is a lack of identifying impact of policy on household members because in such a cultural setting, a person with disability in a family affects not only the individual person but the whole family is affected economically.

The CWCSW staffs are provided with an information book which has an indicator differentiating different categories but with low skill and practical knowledge on disability issues of the staffs it can create potential danger in misinterpreting the category based on severity. For example, those who are supposed to use a prosthesis which means they should get a yellow card but instead they may get a white card due to their inaccessibility to a prosthesis. The lack of knowledge on types and severity of mental disability among the CWCSW staff and health assistance working at the health center was also observed causing misinterpretation on defining categories for a person with mental disability. Undoubtedly, the staffs need broader knowledge around understanding disability and its related issues but it is also noticeable that there is a lack of information flow from the governmental stakeholders to local stakeholders which has led to challenges in implementation of the policy. The effort from the central government on implementation of disability policy is not visible, further there are no awareness programs in disability issues by the government media at the local level which I think can have a huge impact in implementing disability policy.

Most importantly, there is no inclusion of a person with disability from the DPO in distributing a disability identity card which is a great loss in case of implementing policy. A person with disability working towards the issue of disability can be one of the most resourceful people who can assist and suggest staffs with making a decision regarding the category of the card.

Another structural factor that can also be addressed is the constant change of CWCSW secretary and also the fact that she is not a local from Okhaldhunga district itself.

Being from elsewhere leads to a lack of understanding of the locals and their everyday situation, and more importantly the sentiments is also valuable while working in such challenging environment. For example, I can relate it to VDC secretary who is local and is highly appreciated by the villagers. His is very popular whereas CWCSW lacks popularity. Locals lack connections and lacks interests in communicating at both ends locals and CWCSW staff which can also be seen as contributing factor in lack of implementation of policy.

Lastly one of the major indicators is weakness of policy maker and stakeholders to identify and understand the real need of the person with disability. The policy also lacks targeting the corporate household unity, and there is no target on other significant relationships of person with disability such as their wife. For instance, in sign language course it was seen that person's wife was not targeted by the program. This can be recognized as the difficulties of governmental officials in understanding the problem at the primary level; household and community level. The huge gap can be identified to implement policy at local level in comparison to central level.

Many of the issues raised here are not unique to the disability sector, but rather are indicative in the implementation of many social and economic policies within challenging environments. To sum up, there is greater need in understanding cultural context and everyday living setting to properly implement program and the provisions should be made locally available and accessible. Only then there will be possibility of effectively implementing disability policy.

# CHAPTER SEVEN: CONCLUSION

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The study conducted in Okhaldhunga has clearly demonstrated how bodily impairments need to be understood as relationships of disability which depends broadly on the persons, objects, environment and material, shapes values, perception of how to understand disability. This study has aimed to show that there is real need to understand disability as a culturally significant and is changing concept, which is also visible in the material therefore; policies should be adjusted and significant in context to local socio- and cultural aspects.

This study has given us a picture on how person with disability residing in rural area of Okhaldhunga experiences disability which was done by exploring their participation in the household and community as a whole. The study has also indicated the larger degree of which is visible in the findings where larger number of person with disability are seen married. And, marriage is seen as a way of participating in family and in a society as a whole.

The study shows the experiences of living with disability and different kind of challenges and difficulties they face where access to different kind of services and basic needs and opportunities are extremely limited for the entire population. More importantly, it shows despite the challenges and difficulties how they are able to cope with it.

Moreover, study has also indicated the important relationship between poverty and disability. Therefore it can be anticipated that more knowledge on links between disability and poverty, intervention can be more effectively to make a difference in the lives of person with disabilities who today continue to struggle with poverty. However, the important finding in the study can be addressed as the fact that the economic improvement can improve social life. Similarly, the findings also suggested that although there are caste discrimination and disability, proper assistance in health and income generation can change perception and overcome social barriers.

The study has also given us an insight into the policy. With understanding the intention and social benefits withholding disability identity card has led to the conclusion that the policy might be proper help in order to overcome social barriers and improve economy. Sadly, we do not know how far it can benefit people with disability because the finding has clearly identified the various reasons for lacking implementation of policy at this time. The reasons indicated were lack of awareness among the person with disability about the policy and benefits, difficulties and challenges in accessing card and benefits withholding the card, and particularly lack of involvement and participation of DPO and person with disability in general.

Further, the study indicates that the situation of people with disabilities one of the important developments problems for Nepal, where the system established for integration of disabled persons is inadequate. Yet, around the world countries, organizations, groups and individuals are attempting to provide care to people with disabilities with the means they have. If the issue of disability is not addressed, the impact of disability on socio-economic development at all levels of society would be an enormous problem for the country in the long run.

In sum, the study shows a lack of involvement of locals and particularly lack of consideration of the local context would be the main reasons for lack of a good implementation.

## **RECOMMENDATIONS**

Policy needs to involve the cultural and local setting and understand the needs of locally based people in order to successfully implement the policy. Further, policy can only be implemented when there is co-ordinate and collaborative support from all the levels of government and nongovernment organization with equal share rather than imposing responsibility to the office of the CWCSW. Most importantly, inclusion of person with disability in all the sector of disability policy is equally important and necessary in properly implementing the policy.



Furthermore, study on disability with nuanced analysis is required in field which will reflect the complex world of poverty and disability relations. And, there is great need in consideration of age, gender, rural or urban sites, minority ethnic group or specific community variables in relation to disability. In other words, it is not simply more research on the links between disability and poverty that we need, but more research that explores what poverty means at the level of the individual, the household, the community and broader society. Finally, more research is required to investigate needs of people with disability to secure sustainable long term employment.

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# APPENDIX

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## Ethical committee response in Norway (REK)



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<b>Region:</b> REC South-East	<b>Phone number:</b> +47 22845515	<b>Our date:</b> 09.09.11 <b>Your date:</b> 15.06.11	<b>Our reference:</b> 2011/1276 <b>Your reference:</b>
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Heidi E. Fjeld  
UiO  
Institutt for Helse og Samfunn  
0318 Oslo

### Implementation of disability identity card policy in Nepal

Your application was received on the 15<sup>th</sup> of June 2011. The Committee considered the application during its meeting on the 18<sup>th</sup> of August 2011.

Chief Investigator: Dr. polit. Heidi E. Fjeld.

Institution responsible for the research: University of Oslo

#### *Objectives of the project:*

*The study is about the implementation of disability identity card policy in Nepal. The main goal of this study is to understand reception of disability identity card policy in eastern rural part of Nepal (Okhaldhunga). In this research, qualitative methods will be used, particularly participant observation and interviews, to investigate local experiences of disability, local and central interpretations of the disability card policy, and the processes of policy implementation in this area. A minimum of 5 policy makers, 5 health workers and 20 persons with disabilities will participate, however, the numbers might be higher. Consent will be obtained for all information.*

#### **Decision:**

According to the Health Research Act paragraphs 2 and 10, this project does not qualify as medical and health research, and thus falls outside the mandate for the Regional Committees for Medical and Health Research Ethics of Norway.

The Committee recommends that the personal healthdata should be collected from the relevant Health Institutions, and not the patients themselves.

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<b>Postal address:</b> Postboks 1130 Blindern 0318 Oslo Norway	<b>Phone number:</b> +47 22845511 <b>E-mail:</b> <a href="mailto:post@helseforskning.etikkom.no">post@helseforskning.etikkom.no</a> <b>Web:</b> <a href="http://helseforskning.etikkom.no">http://helseforskning.etikkom.no</a>	We request that all correspondence be submitted via our web-portal or by e-mail.
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The decision of the Committee may be appealed to the National Committee for Research Ethics in Norway. The appeal should be sent to the Regional Committee for Research Ethics in Norway, South D. The deadline for appeals is three weeks from the date on which you receive this letter.

Yours sincerely

Stein Evensen(sign.)  
professor dr. med.  
Chair of Committee

Ingrid Middelthon(sign.)  
Secretary of Committee

CC: University of Oslo

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We request that all correspondence be  
submitted via our web-portal or by  
e-mail.



Ethical response from Nepal Health Research Council (NHRC),  
Kathmandu, Nepal



**Nepal Health Research Council**

Estd. 1991

**NHRC**

Ref. No. 441

**Executive Committee**

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**Vice - Chairman**  
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Dr. Devi Gurung

**Representative**  
Ministry of Finance  
National Planning Commission  
Ministry of Health & Population  
Chief, Research Committee, IOM  
Chairman, Nepal Medical Council

28 November 2011

**Ms. Namrata Pradhan**  
Principal Investigator  
University of Oslo, Norway

Ref: Approval of Research Proposal entitled **A Study of Policy Implementation and Local Experiences Of People With Disability and Their Households in Okhaldhunga VDC in Okhaldhunga District of Eastern Rural Nepal**

**Dear Ms. Pradhan,**

It is my pleasure to inform you that the above-mentioned proposal submitted on 15 August 2011 (**Reg. no. 75/2011** please use this Reg. No. during further correspondence) has been approved by NHRC Ethical Review Board on 23 November 2011 (2068-08-07).

As per NHRC rules and regulations, the investigator has to strictly follow the protocol stipulated in the proposal. Any change in objective(s), problem statement, research question or hypothesis, methodology, implementation procedure, data management and budget that may be necessary in course of the implementation of the research proposal can only be made so and implemented after prior approval from this council. Thus, it is compulsory to submit the detail of such changes intended or desired with justification prior to actual change in the protocol.

If the researcher requires transfer of the bio samples to other countries, the investigator should apply to the NHRC for the permission.

Further, the researchers are directed to strictly abide by the National Ethical Guidelines published by NHRC during the implementation of their research proposal and submit progress report and full or summary report upon completion.

As per your research proposal, your research is self-funded and NHRC processing fee is US\$ 100.00.

If you have any questions, please contact the research section of NHRC.

Thanking you.

**Sincerely Yours,**

**Dr. Shanker Pratap Singh**  
Member Secretary

