

# **DISABILITY AND LIVELIHOOD**

(An empirical study of the experience of people with physical disability)

A thesis

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## DECLARATION

I hereby declare that the thesis entitled **Disability and Livelihood (An empirical study of the experience of people with physical disability)** submitted to the Central Department of Sociology, Tribhuvan University, is entirely my original work prepared under the guidance and supervision of my superior. I have made due acknowledgements to all ideas and information borrowed from different sources in course of preparing this thesis. The results of this thesis have not been presented or submitted anywhere else for the award of any degree or for any other purposes. I assure that no part of the content of this thesis has been published in any form before and I shall be solely responsible if any evidence is found against my thesis.

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Ashmita Basnet

Date: June, 2022

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**FACULTY OF HUMANITIES AND SOCIAL SCIENCES**  
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**LETTER OF RECOMMENDATION**

This is to certify that Ashmita Basnet has completed the dissertation entitled **“Disability and Livelihood (An empirical study of the experience of people with physical disability)”** under my guidance and supervision, I am satisfied with her dissertation; therefore, I recommended the dissertation committee for the evaluation and approval.

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## APPROVAL LETTER

This thesis entitled “**Disability and Livelihood (An empirical study of the experience of people with physical disability)**” submitted by Ashmita Basnet in partial fulfillment of the requirements for the Master’s Degree (M.A.) in Sociology has been evaluated and approved.

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## ABBREVIATION AND ACRONYMS

<b>GBD</b>	-	Global Burden of Disease
<b>GoN</b>	-	Government of Nepal
<b>IDS</b>	-	Institute of Development Studies
<b>IRP</b>	-	International Recovery Platform
<b>NDF</b>	-	National Disabled Fund
<b>NGO</b>	-	Non-government Organization
<b>PwDs</b>	-	People with Disabilities
<b>SWC</b>	-	Social Welfare Council
<b>UN</b>	-	United Nation
<b>UNCRPD</b>	-	United Nation Convention on the Rights of Persons with Disabilities
<b>UNDP</b>	-	United Nation Development Program
<b>WHO</b>	-	World Health Organization



# Chapter 1

## INTRODUCTION

### 1.1 Background of the study

The term ‘disability’ refers to the vague situation of an individual. In general sense, disability refers to the condition where a person becomes unable to perform his/her daily activities properly like a normal person. It can be described as having functional/partial problems in carrying out day-to-day activities i.e. a ‘disabled’ person is a person unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and or social life, as a result deficiency, either congenital or not in his physical or mental capabilities. Disability is universal. It is present throughout the world, in all nations and all affects entirety of the world’s population. It is found not only in human beings but in animals as well. It is either congenital (from birth) or acquired due to accident or as the result of disease. It occurs in all ages from birth to old age. In fact, disability is a human reality (Thakur, 2005).

The term ‘disability’ has a number of different meanings and, in particular, is not seen by some as a synonym or proxy for “loss of health”. However, the Global Burden of Disease (GBD) uses the term disability to refer to loss of health, where health is conceptualized in terms of functioning capacity in a set of health domains such as mobility, cognition, hearing and vision (WHO, 2008).

The ICF defines functioning as occurring at three levels: body functioning and structures, activities and participation. For example, if an individual cannot move their legs, he/she experiences a limitation in functioning at the body function level. If an individual has difficulty walking, he/she experiences a limitation at the basic activity level, in other words difficulty combining body functions to perform a particular task. If an individual cannot work, i.e. combine a group of activities in order to fulfill a social function or role, because of environmental barriers (e.g. an inaccessible work place), then he/she is restricted at the participation level (UN, 2015).

The ICF defines disability as an umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors) (WHO, 2011).

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) (Article 1) defines disability as:

“Persons with disabilities include those who have long- term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on equal basis with others” (UNCRPD, 2006).

Of the world’s population of nearly 6.5 billion in 2004, 18.6 million (2.9%) were severely disabled and another 79.7 million (12.4%) had moderate long term disability, according to the definitions given by GBD. Disability prevalence rise strongly with age. The average global prevalence of moderate and severe disability ranges from 5% in children aged 0-14 years, to 15% in adults aged 15-59 years, and 46% in adults aged 60 years and older. At all ages, both moderate and severe levels of disability are higher in low-and middle- income countries than in higher income countries; they are also higher in Africa than in other low-and middle- income countries. Older people make up a greater proportion of the population in high-income countries, but have lower levels of disability than their counterparts in low- and middle-income countries. Disability is also more common among children in the low-and middle-income countries. Moderate disability rates are also similar for males and females in high-income countries, but females have somewhat higher rates of severe disability. In low-and middle-income countries, male and female disability rates are similar, although females aged 15-59 years tend to have higher levels of moderate disability in Africa, the Eastern Mediterranean and the Western Pacific (WHO, 2008).

Disability can be categorized into different types. The main categories of disability are physical, sensory, psychiatric, neurological, cognitive and intellectual. Also, many people with disability have multiple disabilities. The most common type of disability is physical disability followed by intellectual and sensory disabilities.

- Physical disability denotes to the disorders of the musculoskeletal, circulatory, respiratory and nervous systems.
- Sensory disability involves impairments in hearing and vision.
- Psychiatric disorders resulting in disability may include anxiety disorders, phobias or depression.

Neurological disability and cognitive disability are the acquired disabilities such as multiple sclerosis or traumatic brain injury. Intellectual disability includes intellectual and developmental disability which relate to difficulties with thought processes, learning, communicating, remembering information and using it appropriately, making judgements and solving problems. Intellectual disability is the result of interaction between developmentally attributable impairment, attitudinal and environmental barriers (Pradhan, 2017).

This research study covers people with disability as the participants for the study. Within the people with disability only those with physical disabilities are covered for the purpose of the study. Physical disabilities included in this study consists of those people with visual impairment and physical impairment. The term visual impairment is used for those persons with blindness, partially-sighted or those with low vision. I have defined physical impairment as those persons having problems in their body functions or structure like with their legs or hands, arms, spinal injuries and so on. Likewise, physical impaired persons who are wheelchair users or uses any other kind of support materials are included under the study. Also, those people with physical disability who are able to perform their daily activities with or without the use of any of the kind of assistive devices are included in the study. The term ‘disability’ is used to cover all kinds of impairments used in this study.

Livelihoods in general can be defined as a set of activities and strategies pursued by household members, by using their various assets i.e. physical, natural, human, social, financial in order to make a living. Simply, it is a way by which people live. Livelihood usually involve employment of household labor and the use of other household assets, if any, in order to live on the proceeds. For the large majority of people across all countries, the most important livelihood asset is primarily their own labor, followed by other household assets (physical, financial, social and natural) (ILO & UNDP, 2015). A livelihood encompasses income, both cash and in kind, as well as the social institutions (kin, family, compound, village and so on), gender relations, and property rights required to support and to sustain a given standard of living. A livelihood also includes access to and benefits derived from, social and public services provided by the state such as education, health services, water supplies and so on (Ellis, 1998).

A livelihood is the material means whereby one lives. Livelihood generation refers to the bundle of activities that people undertake to provide for their basic needs (or support them). For the result or outcomes of those activities the term livelihood is used. Livelihood as a concept for research and development thus includes what people do (given their resources and assets) and what they achieve by doing it (Niehof & Price, 2001).

The article in IDS (Institute of Development Studies) discussion paper by Robert Chambers and Gordon Conway offers the following definition of sustainable livelihood:

“A livelihood comprises the capabilities, assets (stores, resources, claims and access) and activities required for a means of living: a livelihood is sustainable which can cope with and recover from stress and shocks, maintain or enhance its capabilities and assets, provide sustainable livelihood opportunities for the next generation; and which contribute net benefits to other livelihoods at the local and global levels in the short and long terms” (Chamber & Conway, 1992).

Livelihood is the sum of ways and means by which individuals, households and/or communities make and sustain a living. It is a concept that encompasses practices and processes much beyond the regular income generating activities. By and large, livelihood encompasses not only the economic activities that people engage in, but also their social, institutional and organizational environment. Livelihood is a system that depends on the assets people draw upon, the strategies they develop to make a living, the context within which it is developed and finally all those factors that make a livelihood more or less vulnerable to shocks and stresses. The livelihood assets required may be tangible or intangible. These could also be categorized into groups such as human capital (skills, knowledge, health and ability to work), social capital (including informal networks, members of formalized groups and relationships of trust that facilitates co-operation and economic opportunities), natural capital (land, soil, water, forests and fisheries), physical capital (basic infrastructure, such as roads, water and sanitation, schools, ITC; and producer goods, including tools, livestock and equipment), financial capital (financial resources including savings, credit and income from employment, trade and remittance) and political capital (access to citizenship, right to vote, to participate in political affairs, legal rights) (UNDP, 2012).

Livelihoods are formed within social, economic and political contexts. Institutions, processes and policies, such as markets, social norms, and land ownership policies affect our ability to access and use assets for a favorable outcome. As these contexts change they create new livelihood obstacles or opportunities. Livelihoods are also shaped by the changing natural environment. The quality of soil, air and water; the climatic and geographic conditions; the availability of fauna and flora; and the frequency and intensity of natural hazards all influence livelihood decisions. How people access and use the assets, within the aforementioned social, economic, political and environmental contexts, form a livelihood strategy. The range and diversity of livelihood strategies are enormous. An individual may take on several activities to meet his/her needs. One or many individuals may engage in activities that contribute to a collective livelihood strategy. One important characteristic of livelihoods is their interdependence. Very few livelihoods exist in isolation. A given livelihood may rely on other livelihoods to access and exchange assets. Livelihoods also compete with each other for access to assets and markets. Thus positive and negative impacts on any given livelihood will, in turn, impact others (UNDP & IRP).

Livelihood in this research study is defined in terms of how people with disability make up for their living or say what they do to sustain their daily living. Basically here livelihood comprises the overall concern related with their living condition. The term livelihood indicates to all the activities and efforts done or means used by people with disabilities to support themselves. Apart from the livelihood activities carried out by the disabled people, livelihood supports gained which may be either from the state or from the members of the family is addressed as livelihood of the people with disabilities.

## **1.2 Statement of the problem**

Disability as a complex phenomenon is not just a health problem. The experience of disability resulting from the interaction of health conditions, personal factors and environmental factors varies. Although the experience of disability is diverse, the disabling barriers has resulted to the negative experiences by the people having disabilities. In Nepal, disability prevalence is estimated 1.94 percent of the total population with some kind of disabilities. Although there are different policies that have described about the equal rights to the people with disabilities along with other citizens, it has not been fully practiced. They face greater exposure to disadvantages. In

comparison to general population, people with disabilities experience poor level of health, lower educational attainments, poor economic participation, higher rates of poverty, low level of support and restriction, no opportunities and so on. As a result, disabled populations' livelihood is constrained with limited livelihood options. Their encounter with daily life challenges and obstacles create vulnerable situation that has profound impact on the livelihood. They face various problems for sustainable livelihood. It is seen that in the everyday life situation of PwDs, their encounter with numerous challenges have interconnection with various factors that plays significant role to determine their living. It seems that disability alone is not only the major subject for their difficult situation. Their life condition is regulated by multiple factors which have significant role in determining their situation. Such factors directly or indirectly have impact on the lives of PwDs. In Nepal, PwDs are still facing various challenges in their day to day life.

- The issues related to disability are not completely addressed by the responsible authorities.
- There is no proper implementation of formulated rules and regulations to address PwDs.
- There is no provision of long term services that are provided by government and NGOs.
- There is lack of market appropriate training programs.
- There is still lack of awareness about disability.
- Attitude towards people with disabilities are still not positive and they tend to face discrimination in the society.
- People with disabilities are still not able to exercise their legal rights.

### **1.3 Research question**

This study seeks to answer the following research question:

1. What are the factors influencing the livelihood of people with physical disability?

### **1.4 Objective of the study**

The general objective of the study is to explore the livelihood of the disabled people in Kathmandu.

Specific objective of the study is:

- To identify the factors that influences the livelihood of people with physical disability.
- To explore the real life experiences of people with physical disability.

### **1.5 Significance of the study**

Disability is a global phenomenon. The prevalence of disability is not particular to certain country or place but is worldwide. The prevalence rate of disability is higher in developing countries in comparison to developed countries and opportunities and provisions for PwDs in developing countries is yet to be advanced and improvised. Nepal is one of the developing country where individuals with disability are excluded and marginalized from the main stream of the society. Various traditional and cultural beliefs have restricted their participation in the economic activities thus resulting in their poor condition and difficulty in livelihood. Many people with disability in Nepal are still deprived of basic necessities and opportunities for living. Deeply rooted social stigma and discrimination has negative impact on their lives and hindered their livelihood opportunities. Various elements or components have direct or indirect impact on the lives of people with disability. Such elements have significant role that provides basis for or act as a primary factor to support the livelihood condition.

As the main objective of the study is concerned with the livelihood means of people with disabilities, it provides overall view regarding how disabled people are able to maintain their daily living. It gives closer insight regarding how the lives of people with disabilities are affected by various factors. It provides an overview of the living standard, situation and challenges of the people with disability. Furthermore, the study helps to provide an insight to the livelihood potentialities of people with disabilities. The results are useful to the concerned people like scholars, researchers, policy makers, etc. It helps to address the issues of people with disability and be supportive for further research.

### **1.6 Organization of the study**

This research study is organized into five chapters. They are Introduction, Literature Review, Research Methodology, Data Analysis and Presentation and Summary and Conclusion.

## **Chapter I. Introduction**

This chapter of the study has presented the brief introduction of the topic and put forward the research question along with the statement of the problem and clarified the purpose of the study.

## **Chapter II. Literature Review**

Chapter two presents the review of the related literature in the subject of the study. It includes the studies that have already been conducted on the research topic. It briefly presents the scenario of disability and provides insights to the research regarding disability in Nepalese context.

## **Chapter III. Research Methodology**

Chapter three presents the description of the methodological part that explains how the research has been conducted. It explains the research design and research methods used for the study. It also explains the data collection methods and procedure for data analysis adopted for the study.

## **Chapter IV. Data Presentation and Analysis**

Chapter four deals with the presentation and analysis of the collected information. It presents the empirical findings of the study. It explains the experiences of the respondents that has been categorized under different categories related to the research topic.

## **Chapter V. Summary and Conclusion**

Chapter five is the final chapter that presents the general discussion from the research study with respect to the analysis and provides the concluding remarks.



## **Chapter 2**

### **REVIEW OF THE LITERATURE**

#### **2.1 Disability Prevalence**

Due to the use of different approaches to measure and identify persons with disability during data exercises, there are several distinct estimates of disability prevalence. In addition, as disability is a continuum, even if the same questions are used to identify persons with disabilities different cut-off thresholds used to identify people with disabilities will lead to different estimates of disability prevalence (UN, 2015). Based on 2010 global population estimates, WHO and World Bank (2011) estimate that more than a billion people live with some form of disability which equates to 15% of the world's population. This is around 10% higher than a previous WHO estimate from the 1970s. The two sources of statistical information to estimate this global disability prevalence are the World Health Survey and the Global Burden of Disease. The World Health Survey estimates that around 785 million (15.6%) persons 15 years and older live with a disability. The Global Burden of Disease estimates a figure of around 975 million (19.4%) persons. Of these, 110 million (2.2%) have significant difficulty functioning, while 190 million (3.8%) have "severe difficulty"- the equivalent of disability inferred for conditions such as quadriplegia, severe depression, or blindness (WHO, 2011).

Obtaining an exact disability prevalence figure is complicated because of the fact that there is variations in the definition of disability across countries; the quality and methods of data collection; reliability of sources; and disclosure rates. Countries with poor service provision and where families fear stigma and isolation have lower disclosure. Figures published in national statistics can therefore be misleading and are not directly comparable and often inaccurately suggest higher prevalence of disability in developed countries than developing countries (Al Ju'beh, 2017). However, the evidence indicates higher disability prevalence in low and middle income countries in comparison to higher income countries (Mitra & Sambamoorthi, 2014). This result is due to the disability measures used in low and middle income countries that use impairment or functional limitation questions whereas high income countries tend to use activity limitation measures (Mitra & Sambamoorthi, 2014).

### **2.1.1 Prevalence in adults**

Disability is highly prevalent among adults at country and global levels with severe or extreme functional or activity limitations. Based on the analysis of World Health Survey (WHS) (2002-2004) data, Mitra and Sambamoorthi (2014) estimated the global prevalence of adults with disability at 14% for 54 countries using a different methodology. They also find the variation in the prevalence of disability across countries with lower middle income countries having higher disability prevalence at 19.9% compared to high income countries at 6.5%.

A study by Behavioral Risk Factor Surveillance System (BRFSS) in United States, 2013, found that overall 22.2% of U.S adults (53,316,677 persons) have any disability. They found that disability in mobility was the most frequently reported type (13.0%) followed by disability in cognition (10.6%), independent living (6.5%), vision (4.6%), and self-care (3.6%) (Courtney-long, et al., 2015). The prevalence of disability among adults in Malaysia based on National Health and Morbidity Survey (NHMS) 2015, was 11.8% with an estimated 2.4 million persons affected. Further study showed that the prevalence of having at least one domain scored as “some difficulty” was 25.9% with estimated more than 5 million adults in Malaysia affected, while 2.7% estimated 553,865 adults had at least one domain scored “a lot of difficulties” and 1.0% with estimated 195,924 adult population scored at least one domain with “unable to do at all” (Ahmad, et al., 2017).

### **2.1.2 Prevalence in children**

Estimating disability prevalence for children poses even greater challenges than for adults as it is difficult to differentiate between natural development delays and disabilities. Some global and country studies point to prevalence estimates around 6%, but estimates vary widely depending on the methods used (UN, 2015). Data collection becomes even more complicated due to varying nature and severity in disabilities, together with the need to apply age-specific definitions and measures. Also, the poor quality of data on child disability is the result from a limited understanding of what disability is in children, from stigma or insufficient investment in how to improve the measurement of disability. Narrow medical definitions are even more likely to result in lower estimates of disability prevalence than broader ones that take into account social barriers to functioning and participation (UNICEF, 2013).

In United Kingdom, a study pointed to 7% disability prevalence among those aged 18 or under. The prevalence was higher among boys (8.8%) than girls (5.8%) and the most commonly reported difficulties were with memory, ability to concentrate and/or learn and with communication. Reported difficulties along with difficulties in physical coordination were more commonly reported in boys than girls (Blackburn, Spencer, & Read, 2010). Similarly, in United States the prevalence of disability among children younger than 18 years who were included in the 1992-1994 National Health Interview Survey were estimated at 6.5%. Respiratory diseases and mental impairments were the most common causes of disability in children which was higher for older children boys, and children from low-income and single parent families (Newacheck & Halfon, 1998).

### **2.1.3 Prevalence among older persons**

There is a higher risk of disability among older persons (WHO, 2011). World Health Survey (2002-2004) data suggests that disability prevalence stands at 39% among the elderly aged 65 and above (Mitra & Sambamoorthi, 2014). More than 46 percent of older persons- those aged 60 years and over- have disabilities and more than 250 million older people experience moderate to severe disability. Looking ahead, the global trends in ageing populations and the higher risk of disability in older people are likely to lead to further increases in the population affected by disability (UN).

A study conducted in an urban resettlement colony in New Delhi, India showed that the prevalence of disability among elderly persons aged 60 years and above was 7.4%. Disability increased with increasing age and was higher in female sex among elderly persons in urban areas. Also, elderly persons were more prone to non-communicable and communicable diseases resulting in disability (Goswami, et al., 2019).

### **2.1.4 Prevalence by sex**

The prevalence of disability is higher for women compared to men for all adults, for the working age and the elderly. The gap in the prevalence of disability between women and men is the largest among the older population: 44.2% of older women have disability compared to 33.9% of older men. In addition, women more often than men have two or more severe or extreme difficulties: for instance, among working age individuals, the prevalence of having two or more severe or extreme difficulties stands at 4.8% for women compared to 2.4% for men. However, there is some variations

depending on disability type and context. For example, blindness and visual impairment affects more women than men (Thompson, 2017).

A systematic review and meta-analysis to global vision impairment and blindness found that globally, prevalence of blindness is 36.0 million (0.48%) of which 56% were female. In addition, the prevalence of moderate and severe visual impairment was 216.6 million (2.95%) of whom 55% were female and 188.5 million (2.57%) had mild visual impairment of whom 54% were female (Bourne, Flaxman, Tasanee, & Cicinelli, 2017). The prevalence of disabling condition is almost the same for males and females, but the major contributing causes are different. While depression is the leading cause for both males and females, the burden of depression is 50% higher for females than males. Females also have a higher burden from anxiety disorders, migraine and Alzheimer and other dementias (WHO, 2008).

## **2.2 Models of Disability**

The conceptual models of disability can be expressed in a dialectic of “medical model” versus “social model”. According to the medical model, disability is a problem existing in a person’s body due to disease, trauma or health condition. Therefore, it requires medical treatment or care by the professionals to cure the disability and help individual for normal functioning. This model views medical care as the main issue and the management of disability aims to cure or help with the individual’s adjustment with the environmental condition through behavioral change. For this model, in order to address the issue of disability at the political level should focus on modifying or reforming the health care policy. In contrast to the medical model, the social model of disability views disability as a socially constructed but not as an attribute of a person. It is a matter related to the inclusion of individuals in the society. According to this model, social environment creates complex condition that limits the participation and as a result it creates disability of individuals’. Therefore, the management of disability must be directed towards social change through collective action of the society in order to make the environment inclusive for the participation of people with disabilities in all areas of social life. It requires environmental modifications rather than individual’s adjustment to the environment and rehabilitation. Disability is thus an attitudinal or ideological problem which becomes a question of human rights (WHO, 2001).

## **2.3 Disability Classification in the context of Nepal**

The Government of Nepal (GoN, 2006) classified disability on the basis of nature and severity. According to the nature of the problem and difficulty in the parts of the body and in the physical system, disability was classified into the following seven categories:

### **1. Physical Disability**

Physical disability is the problem that arises in operation of physical parts, use and movement in a person due to problems in nerves, muscles and composition and operation activities of bones and joints. For example: polio, cerebral palsy, absence of a body part, effect of leprosy, muscular dystrophy, problem with joints and spinal cord, club feet, rickets, weakness produced due to problems related to bones etc are physical disabilities. Short and stunted also fall into this category.

### **2. Disability related to vision**

Disability related to vision is the condition where there is no knowledge about an object's figure, shape, form and color in an individual due to problems with vision.

This is of two types:

- i. **Blind:** A person who cannot see the fingers of a hand by both eyes at a distance of 10 feet despite treatment (medicine, surgery and use of glasses), or cannot read the first line of Snellen chart (3/60), is blind.
- ii. **Low vision:** If any person who cannot distinguish fingers of a hand from a 20 feet distance despite treatments like medicine, surgery and use of glasses, in other words, cannot read the letters of the fourth line of Snellen chart, then that person has low vision.

### **3. Disability related to hearing**

Problems arising in an individual related to discrimination of composition of the parts of hearing and voice, rise and fall of position, and level and quality and voice is a disability related to hearing. It is of the following two types:

- i. **Hard of hearing:** An individual who can hear only little but can hear little and cannot talk clearly, can only speak little, who needs to put hearing aids in the ear to listen is hard of hearing. An individual who can hear sound between 65 decibels and 80 decibels is hard of hearing.

- ii. Deaf: An individual who cannot hear, speak incoherently or cannot speak and who has to use sign language for communication is deaf. An individual who cannot even hear sound above 80 decibels is deaf.

#### **4. Deaf-blind**

An individual who is without both hearing and vision is a deaf-blind disabled.

#### **5. Disability related to voice and speech**

Due to difficulty produced in parts related to voice and speech and difficulty in rise and fall of voice to speak, unclear speech, repetition of word's and letters is disability related to voice and speech.

#### **6. Mental disability**

The inability to behave in accordance with age and situation and delay in intellectual learning due to problems arising in relation to implementation of intellectual activities like problems arising in the brain and mental parts and awareness, orientation, alertness, memory, language, calculation is mental disability. It is of three types:

- i. Intellectual disability/Mental retardation: An individual having difficulty in carrying out activities relative to age or environment due to absence of intellectual development before age of 18 years is intellectual disability/mental retardation.
- ii. Mental illness: Mental disability is an inability where there is difficulty in living daily life due to mental illness or weakness or deviation.
- iii. Autism: Absence by birth of normal behavior in accordance with a person's age, to show abnormal reaction, to keep on repeating one activity, to not socialize with others or to show extreme reaction is autism.

Disability based on the seriousness of weakness was classified as follows:

- a. **Total disability:** Total (complete) disability is a condition where there is difficulty in carrying out daily activities even with the continuous assistance of others.
- b. **Severe disability:** The condition of having to continuously take other people's assistance in order to carry out individual daily activities and to take part in social activities is acute (severe) disability.

- c. **Moderate disability:** The condition of being able to perform daily activities of self with or without taking others support, if the physical facilities are available, the physical environment is removed and there are opportunities of training and education is called Moderate disability.
- d. **Mild disability:** The situation where taking part in regular daily activities and social activities by self is possible if there is no social and environmental obstacle is ordinary (mild) disability.

## **2.4 Disability in the context of Nepalese society**

Nepalese society is still mostly rural, and religious beliefs have a strong influence: even those living in urban areas are likely to be affected by prevailing, traditional views. Views on disability are often inflected by religious teachings which regard it as a punishment for the prior misdeeds of the parents (Lamichhane, 2013). Prevailing illiteracy, ignorance, and negative perception on the disability in the society it is considered as the punishment of the god for some sin committed in the past life but it is not so. It occurs either congenital (by birth) or acquired due to accident or as a result of diseases or due to poverty prevailed in the society. It is a human reality that occurs in all the ages from birth to old age (Timilsana, 2018).

Within a family also it is still a common practice to use the stigmatizing tag of “disfavor” with disabled conditions of family members and most of the families in Nepal still consider disability as a punishment for all the depravities and wickedness disable persons have committed in their past lives. Besides, the burden of disability is mostly put on the mothers of disabled child (Banskota, 2015). Similarly, in Nepal people often hide their disability due to a number of socio-cultural norms, values and pressures (Thapaliya, 2016). Because of the strong social stigma accorded to disability in Nepal, disabled people are hidden in family, excluded from hub-dub of social arena. This exclusion is even more perpetuating with the belief that due to disability, disabled people cannot do anything on their own (Shrestha, 2015). People still believe that having disabled members in the house is the result of their fate. Some have superstitious beliefs and even give magical explanations for the cause of disability (NPC, New Era, & UNICEF, 2001).

Because of the pre-existing cultural beliefs in deeply rooted patriarchal Nepalese society, there are many barriers in participating in education, economic activities and

social functions as well as many life activities for people with disabilities. Due to which most of them are poor, illiterate and above all stigmatized as well as segregated from the mainstream society; thus living a miserable life. Disability and related issues are seen as one of the major responsibilities of the state towards the citizens. However, disability management has been a big problem in an economically weak and developing country like Nepal (Shrestha, 2015). People with disabilities and their families face additional barriers in accessing services due to the restriction of their own disabilities, poverty, the mountainous terrain and social stigma. Less than 2-3% of people with disabilities have received any kind of rehabilitation services. More than 70% of disabled people have not had educational opportunities. Only few disabled people have received some kind of vocational training for employment (Dhungana, 2006).

People with disabilities are disadvantaged and discriminated in every sphere of their life. It is even worse when it comes to disabled women because society treats men and women differently and mostly priority goes to men whether he is disabled or not (Timilsana, 2018). Disabled women are denied access to education, health services, vocational training and employment and welfare programs that are available for disabled men in Nepal. They receive inadequate- if any- services meant for disabled people because the very limited available resources are directed towards disabled men (Dhungana, 2006).

With the pace of time, due to change in international scenario through globalization, social concept of disability and grievance regarding individuals with disability has changed gradually in Nepalese society. These days, somehow people in the society have become sympathetic towards the cause of disability (Shrestha, 2015). In the past, medical science was insufficiently developed, so the people accepted disability as part of their fate or as the punishment of god for some sin committed in the past life and were reconciled to live with it. Now, with the advancement in science, many disabilities can either be minimized or cured (Joshi, 2004).

## **2.5 Disability Prevalence Estimation in Nepal**

In Nepal, various studies have used different models to estimate the prevalence of disability all over Nepal as well as for some specific districts of the country. However, estimation of prevalence is highly uncertain. It varies from one sample to another and



is also affected by conceptual models used to estimate the prevalence rate. Existing social stigma against disability and the lack of sufficient training necessary for enumerators to use medical model have also caused the estimation to diverge. In this regard, the census 2011 has been considered as the most representative data currently available in Nepal for persons with disabilities (Poudyal, Banskota, & Khadka, 2018).

The overall prevalence of disability as of the population census 2011 was about 2% (5,13,321) of the total population in Nepal, with 2.2% prevalence of male disability and 1.7% of female disability. The odd ratios of having a disability were 1.3 times more in males compared to females. Physical disability was the most common type of disability, which accounted for more than one third of the total disabilities. Physical disability and blindness/ low vision combined accounted for more than 50% of total disabilities. Disability in rural residents was more prevalent (2.1%) compared to disability in their urban counterparts (1.2%). The prevalence of disability was considerably higher in Mountain (3.0%) compared to Hill (2.2%) and Terai (1.6%). More than one third of the disabled are less than 30 years old and only one-fourth of disabled persons are aged 60 years or more. The percentage of persons with disability in the economically active age group (15-59 years) was higher in urban areas (59.5%) than in rural areas (56.1%). The proportion in older ages (60 and above) was higher among women (27.2%) compared to men (24.3%). Likewise, disability was significantly higher among illiterates (3.87%) compared to literates (1.25%) (CBS, 2014).

As per the case wise disabilities, physical disability covers the highest 36.3 percent of the population with 38.7% of males and 33.5% of females followed by visual disabilities which is categorized into blind and low vision. It accounts for 18.5% of total disabilities with 16.8% of males and 20.5% of females. Hearing disabilities accounts for 15.45% of total disabilities with 14.7% of males and 16.3% of females which is categorized into deaf and hard to hear disabilities. Deaf/ Blind disabilities accounts for 1.84% of total disabilities and among them 1.7% were males and 2% were females. Speech related disabilities accounts for 11.47% of total disabilities. Among them 11.8% were males and 11% were females. In mental disabilities there were 6.04% of total disabilities and this category include different groups like mental retardation, mental illness and autism with 6% males and 6.1% females. Likewise, in

intellectual disabilities there were 2.9% of total disabilities with 3% males and 2.8% females (CBS, 2014).

## **2.6 Policies and Practices to Disability**

The government of Nepal (MoWCSW, 2014) has granted facilities and rights for the people with disabilities. Some legal provisions enshrined in national legislation are as follows:

1. **Disability Identity cards:** Disabled persons are issued with identity cards by the government of Nepal according to the nature of disability. Disability identity cards are categorized into four types of red, blue, yellow and white colors which are being entitled to disabled persons. Cards can be obtained from the district office.
2. **Free education:** There is a legal provision of free higher education to people with disabilities. Educational institutions operated by the government of Nepal or local level shall provide free education to the persons with disabilities. There is also a provision of special education for disabled children with special needs. Students with visual impairment are permitted for the use of an assistant during examination and additional timing of 1 hour 30 minutes shall be given to those with physical disability if required.
3. **Scholarships:** The government of Nepal has granted educational scholarship for the students with disabilities. The government provides scholarships according to the types and severity of an individual's disabilities with 5% reserved scholarship for disabled students completing their higher studies. There is a provision of scholarships for disabled including vocational and technical trainings.
4. **Health services:** There is a provision of free medical examination facilities and medical treatment in hospitals for the disabled. There is also a provision that all hospitals with more than twenty- five beds shall reserve at least two beds for the persons with disabilities. The government of Nepal provides free medicine of certain types to disabled people from government hospitals.
5. **Employment:** The government of Nepal has reserved 5% of jobs in the civil service for disabled persons. There is a legal provision that all private sector

industries and factories employing more than 25 people should give 5% of their jobs to disabled people.

6. **Transportation:** A 50% discount for transportation applies for disabled persons. Additionally, there is a provision of reservation in public vehicles. Seats are to be reserved for disabled persons where the transportation vehicle has a capacity of 15 or more.

**Physical accessibility:** There is a provision that public buildings and places should be differently able friendly and accessible. For example hospitals, schools, campus, buses etc.

7. **Income tax and customs:** An income tax exemption applies for disabled persons in Nepal by 50%. The Government has a provision of custom-free means of transportation for disabled persons like four-wheel scooters for disabled persons. Also there is a provision of exemption from customs, tax and other fees to the assistive devices, tools or equipments to be used by the persons with disabilities.
8. **Social welfare and shelter:** The government has granted disability allowances of NPR 1000 per month for those with complete disability and NPR 300 per month for those with severe disability. The government has also put into place provisions to ensure that the disabled including mentally impaired children are able to access shelter.

## **2.7 Theoretical Framework**

### **2.7.1 Stigma theory**

Stigma is a mark of disgrace that sets a person apart from others. When a person is labelled by their illness they are no longer seen as an individual but as a part of a stereotyped group. Negative attitude and beliefs toward this group create prejudice which leads to negative actions and discrimination (Australia, 2009). A stigma is a social construct which defines people by attributing them some distinguishing characteristics. It occurs when a person is identified through attribution processes to undesirable characteristics which are discredited (Buljevac, Majdak, & Leutar, 2012). People with disabilities have been stigmatized throughout history. In many cultures, disability has been associated with curses, disease, dependence and helplessness. Disability stigma can play out in a number of ways, including:

- Social avoidance: People with disabilities may be left out of social activities, or they may find that friends become more distant after they develop a disability. People may be hesitant to make eye contact or start a conversation with someone who has a visible disability.
- Stereotyping: People with disabilities may be presumed to be helpless, unable to care for themselves, or unable to make their own decisions. People with one disability, such as a speech impairment, may be presumed to have other disabilities they don't have, such as an intellectual disability.
- Discrimination: People with disabilities may be denied jobs, housing, or other opportunities due to false assumptions or stereotypes about disabilities.
- Condescension: People with disabilities may be coddled or over-protected due to perceptions of their helplessness.
- Blaming: People may be blamed for their disability, or accused of using their disability to gain unfair benefits.
- Internalization: People with disabilities may themselves adopt negative beliefs about their disabilities and feel ashamed or embarrassed about it.
- Hate crimes and violence: People with disabilities may be targeted in hate crimes. They are more likely to be victim of physical or sexual violence than people without disabilities (Washington, 2016).

The root of contemporary perspective on stigma can be traced back to the work of Erving Goffman. In his classic book *Stigma: Notes on the Management of a Spoiled Identity* (1963) stigma is defined as an “attribute that extensively discredits an individual, reducing him or her from a whole and usual person to a tainted, discounted one” (Major & T.O'Brien, 2005). For Goffman, stigma is a general aspect of social life that complicates everyday micro-level interactions-the stigmatized may be wary of engaging with those who do not share their stigma, and those without a certain stigma may disparage, overcompensate for, or attempt to ignore stigmatized individuals (Clair, 2018).

Goffman's broader definition of stigma also incorporates three different types of attributes in the definition of stigma what he defined as “abominations of the body” (eg physical deformities), “blemishes of individual character” (eg mental disorder,

addiction, homosexuality and, imprisonment) and “tribal stigma” (eg race, religion and nation) (Clair, 2018).

Link and Phelan (2001) conceptualized stigma in terms of the relation with interrelated components of labelling, stereotyping, separating, status loss and discrimination. In their conceptualization, stigma exists when the following interrelated components converge. In the first component, people distinguish and label human differences. In the second, dominant cultural beliefs link labeled persons to undesirable characteristics- to negative stereotypes. In the third, labeled persons are placed in distinct categories so as to accomplish some degree of separation of “us” from “them”. In the fourth, labeled persons experience status loss and discrimination that lead to unequal outcomes. Finally, stigmatization is entirely contingent on access to social, economic, and political power that allows the identification of differentness, the construction of stereotypes, the separation of labeled persons into distinct categories, and the full execution of disapproval, rejection, exclusion, and discrimination. Thus, the elements of labelling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold (Link & Phelan, 2001).

Stigmatizing marks may be visible or invisible. It can also be controllable or uncontrollable. It can be linked to appearance (eg a physical deformity), behavior (eg child abuser), or group membership (eg African American). Importantly, stigma is relationship- and context- specific; it does not reside in the person but in a social context (Major & T.O'Brien, 2005). According to Shrestha, Goffman suggests that the notion of normal human being may have its origin in a medical approach or as a rationale for equal treatment by the state, but it is also very much a normative system of grading people. This categorization of system to confer a social identity exists prior to social interaction, and is established by society. It is bolstered by an ideological justification for treating those with a perceived stigma as not quite human. In everyday interaction, specific stigma term such as cripple, bastard and moron are used to demean (Shrestha, 2015).

In Nepal, disabled people are more likely to be stigmatized and excluded from every aspect of the society. Negative attitudes and perceptions towards them make them feel humiliated and lose their confidence. Stigmatization has huge impact on the lives of

disabled people. Persons experiencing a disability are more likely to experience violation of dignity including social exclusion, violence and prejudice than persons without a disability. This results in less or no opportunities for people with disabilities to make their living. They are left without any life chances or options to meet their daily requirements. In this study, the understanding of stigmatization and related elements are essential to get further insight of the challenges that people with disability come across in making their livelihood. Moreover, it helps to understand their overall livelihood concerns of disabled persons.

## **2.8 Empirical Review**

Empirical evidence shows that persons with disabilities are the vulnerable communities that get marginalized in the competition for access to assets and markets, having a huge negative impact on their social, emotional and economic well-being. In this competitive race, people with disabilities are the majority group on the peripheries with no access to human, social and financial capital and having limited or negligible control and access to physical and political capital. The negative fall-out of the same hampers their enjoyment and opportunity of economic livelihood (UNDP, 2012).

Usually, people with disabilities are socially and economically marginalized. In general, they and their families are considered the poorest of the poor and are excluded from basic opportunities and services related to health, education and employment. In developing and developed countries, this group faces higher risks of poverty and impoverishment, has higher rates of unemployment and underemployment and lower educational levels. These aspects reduce their human capital and increase their risks of being chronically poor (Roncancio, 2015).

The situation of employment of persons with disabilities is somewhat similar around the world. They are not getting enough employment opportunities and those who are employed are also paid lower wages in most cases. According to Bureau of labor Statistics in USA, only 17.5 persons with disability were employed while 65 percent of persons without disabilities were employed in 2015. Similarly, the unemployment rate of persons with disability was 10.7 percent in 2015, about twice that of those with no disability (Prasai, 2017). The research study conducted by New Era indicated that some of the economically active disabled persons (22.2%) were involved in agriculture. There were those who had worked before becoming disabled and lost their jobs due to

their disabilities. However, most of the disabled persons were economically dependent on their families (79.9%) (NPC, New Era, & UNICEF, 2001).

The study by SINTEF in Nepal, initiated in 2012, showed that the proportion of individual with paid work was more than 60% higher among non-disabled as compared to disabled. The proportion of self-employed was higher among non-disabled people. Among the total unemployed people with disabilities 24% were unemployed because of their health problem. The proportion of respondents with disability who were currently working was substantially less than the proportion of non-disabled respondents, with the difference being 22.2%. Among the employed people with disabilities 36.4% were currently working and 20.7% had worked previously but left the work. Among males and females, 47.5% males and 24.3% females were currently working. More people with disability had never been employed and 72% of respondents with disability had stopped working due to illness or disability (Eide, Neupane, & Hem, 2016).

There is ample evidence on the mitigating health circumstances that PwD face. Globally, irrespective of the economic development of a country, a significant portion of the billion of PwD have poorer health outcomes than those without disability. Studies from the high as well as the low- and- middle- income settings strongly endorse this observation. The WHO Report also emphasizes that part of the problem with the poorer health outcomes also rests with the barriers to access to health care services, which discriminate against people with disability (Gudlavalleti, 2018).

A study conducted by Eide, Neupane, & Hem reported a substantial gap in access to health services among individuals with disability, with more than 40% stating that they did not receive health services even though they needed it. Among the respondents with a disability 23.2% stated that they used any medication or traditional medicine for pain that was caused by their disability. Among the total respondents, individuals with disability report higher evidence of the different health conditions except four. The respondents with disability have lower general well-being status compared to those without disability. The current physical and mental health situation shows pronounced difference between individuals with and without disability. Disabled individuals with poor physical health is 42.4% whereas physical health of individuals without disability

is 7.6%. Similarly, disabled people with poor mental health is 26.9% and 7.2% in the case of non-disabled individuals (Eide, Neupane, & Hem, 2016).

A research study conducted by Lamichhane on the title “Disability and barriers to education: evidence from Nepal” indicates that participants with hearing impairments had the fewest years of schooling compared to those with visual and physical impairments. Participants with hearing impairments had less average years of schooling (6.9 years) compared to visual impaired (9 years) and physical impaired participants (10.9 years). Of the total participants, majority 39.8% received education through mainstream schools whereas lesser 24.8% obtained their education from special schools. Majority of visual impaired participants attended integrated schools (58.1%), majority of hearing impaired attended special school (59.1%) and majority of physical impairments attended mainstream schools. Participants with visual and physical impairments had higher rates of attendance to higher education in comparison to hearing impairments. Similarly, majority of the participants with the hearing impairments did not complete their full ten years of school education. Different factors contributed to their decisions to discontinue their education which lack of support in schools, financial difficulty, scarcity of schools, and rejections from an institution (Lamichhane, 2013).

Similarly, according to the research findings of New Era, most of the disabled persons had no education (68.2%) in comparison to the general population, where 4.8% had no education. The literacy rate was considerably lower for females than males, with 77.7% of the females and 59.6% of males having no education. It was found that only half of the disabled persons of the age group 6-20 years were enrolled in school. Most of the household heads, nearly 95% wanted their disabled children to go to school but only 56.3% of the age group 6-20 years were enrolled in school because of different physical and social barriers for schooling. It was also found that because of disability more number of girls did not attend school as compared to boys. Also, the participation of disabled persons in skill training was negligible (NPC, New Era, & UNICEF, 2001).

## **2.9 Synthesis from literature review**

From the above mentioned literatures, we come to know that the situation of people with disabilities around the world is somewhat similar. In both developed countries and developing countries, people with disabilities are vulnerable population. They are



marginalized group having limited livelihood chances. They face various problems in their daily life due to their own disabilities and as well as due to other reasons like stigma, poverty, restrictions, etc. They tend to remain invisible citizens in the mainstream society, often unconsidered in various plans and policies. They are excluded from the rest of the society. As a result, they are compelled to face lots of challenges in terms of finding jobs and better career opportunities, in terms of getting quality education, better health services and facilities, in terms of getting support and recognition, etc. Despite of the policies and provisions, people with disabilities are not able to enjoy their legal rights. After reviewing various literatures, I found that most of the studies are mainly focused on the situation and challenges of people with disabilities. However, less attention is given to incorporate the importance of various factors in the lives of people with disabilities. Less studies are found explaining how and what kind of impact does it have in the livelihood of people with disabilities. Also, there are gaps in explaining the reason behind the failure of various policy implementation in an effective way.

## **Chapter 3**

### **RESEARCH METHODS**

#### **3.1 Rationale of the site selection**

The research was conducted in Kathmandu valley which comprises the capital city of Nepal along with two other districts Lalitpur and Bhaktapur. Being the capital city of the country, large number of population reside in Kathmandu valley comprising of different ethnic groups, languages and religions. The study area consists of different groups of people ranging from very high class to middle class to the lower class people including minor and marginalized groups like people with disability. Also, Kathmandu valley is the center where opportunities for education, employment, career or better services and facilities are centralized and accessible. Thus, many people with disability choose Kathmandu valley for better opportunities whether it is for career or employment or other. In Kathmandu, disability related issues are often raised and discussed with prior importance addressing their livelihood. Many NGO's are also located in Kathmandu valley working in disability sectors and helping disabled people for their betterment. My study is focused on the experience of disabled people thus, the selection of research area is justifiable. Furthermore, I myself live in Kathmandu valley so, it is much more convenient for me to conduct my research study. The research area is also more suitable because of the availability of the disabled respondents who are the major subject for the study.

#### **3.2 Research design**

Research design is the basic plan that indicates an overview of the activities that are necessary to execute the research project. This research study is based on narrative research design. The study basically intends to explore the real life experiences of the disabled people to get closer insight of their livelihood. Hence, it follows the procedures and techniques that are used in qualitative research study. The data were gathered from qualitative and quantitative nature. Similarly, both primary and secondary data were used in the study. The research study has described the lived experiences of PwDs and intends to find their livelihood influencing factors to find out the answer to the research question. Qualitative techniques such as focus group discussion and interview will be used to collect the data and information from the field.

### **3.3 Nature and sources of data**

The research study mainly focuses on the livelihood aspect of the people with disability. For this it is very much important to capture their daily lived experiences, feelings and perspectives. Hence, to fulfill the objective of the research study and make it more fruitful and meaningful, qualitative research has been carried out for the data collection. Data were gathered in descriptive form to identify the research question. The collected data for the study will therefore be qualitative in nature. Similarly, for the purpose of the study both primary and secondary sources of data were used. Primary data for the study has been collected through field work using techniques like interview and focus group discussion whereas secondary data has been collected through various source like journal articles, reports, books, web-sites and so on.

### **3.4 Universe and sampling**

The research study is focused and related only to the people with physical disability therefore, the organization working in the field of disability in Kathmandu valley is selected as the universe for the study. For the research study, access to the respondents with physical disability was challenging due to various reasons. Thus, in order to conduct the study with the respondents firstly I had to contact with the source person of one of the organization working in the sector of disability which is NDF (National Disabled Fund). The source person had worked with the respondents so it was easy to conduct the study and easy for rapport building.

NDF (National Disabled Fund) is a humanitarian organization, under the umbrella of SWC (Social Welfare Council), established on 31 Dec 1981. As a humanitarian organization NDF has been rendering support to persons with disabilities through implementing meaningful charitable programs focusing on education vocational trainings, physical rehabilitation and enhancing a living condition of a persons with disabilities for over more than three decades.

For sampling, a certain population was required to be included in the study. I used non probability sampling in this study because of the nature of the research. Under non probability sampling, purposive sampling method is used in the study for the selection of required sample. For the purpose of the study, people with physical disability were required as my research is concerned with the real life experiences of people with

physical disabilities in their course of living a life as a disabled person and their livelihood influencing factors. It would be very challenging to include every person with disability in the study and it would not be relevant to include every person with physical disability in the study. Therefore, purposive sampling was conducted and those respondents were included who were fitted to serve the purpose of the research study. This allowed to choose the samples according to the need of the study and according to my convenience.

For the study, the source person from the organization helped me to reach out to the respondents who fitted best to my study and conduct interview directly with them. 8 individual respondents were selected for the interview process as a representation of study population of 11 such respondents in the study area on the basis of their availability and unwillingness of other respondents with physical disability for interview process. Also, focus group discussion was conducted in this study with two groups consisting of 7 and 5 respondents respectively. Altogether there were 12 participants for focus group discussion. Together with focus group discussion and in-depth interview total 20 people with physical disability were the sample size for the research study.

In the beginning of the interview process with the respondents, individual consents were taken with each respondents. The purpose of the study was well explained along with the research question. The interview process was explained in detail to each individual respondents. No interviews were taken forcefully with them without their willingness to participate for the study. Also, same condition was applied while carrying out the focus group discussion.

### **3.5 Techniques of data collection**

This research study is qualitative in nature therefore, the necessary data required for the study was obtained using qualitative data collection techniques. In-depth interview and focus group discussion was carried out as a technique of data collection with the help of different tools of data collection.

#### **3.5.1 In-depth Interview**

Interview is one of the commonly used and useful research method to carry out qualitative research. For this research study, in-depth interview was carried out with

the participants. While conducting in-depth interview, semi structured interview technique was carried out with the respondents with physical disability. Semi structured interview with the respondents was conducted with the help of questionnaire checklist consisting a set of both open ended as well as close ended questions. Interview was conducted with 8 individuals with physical disability. A checklist for interview is in annex I.

### **3.5.2 Focus Group Discussion**

In this research study, the focus group discussion was carried out with the people associated with physical disability. They were interviewed in order to get collective views regarding their daily life experiences and livelihood challenges. The discussion was conducted using focus group discussion checklist as given in annex. Unstructured interview was designed and carried out for focus group discussion. Similarly, focus group discussion was conducted with 12 participants irrespective of gender and age group. For focus group there were two groups consisting of 7 and 5 participants respectively. Participants of two groups were interviewed at different timing. The participants were asked a different set of questions however, the question format of focus group discussion is similar to the interview. A checklist for focus group discussion is in annex II.

### **3.6 Process of data analysis**

The data and the information collected through interview technique and focus group discussion was analyzed descriptively. All the information collected was rearranged, analyzed and interpreted according to the need of the study for attaining the stated objectives. The recorded interviews are transcribed into MS word document. Data collected from the field study were reduced and simplified and transformed into manageable form. Data were organized under several headings in order to make it presentable and have summaries of data under different categories. Similarly, unnecessary and insignificant data were paid less attention and thus were left behind.

### **3.7 Ethical Consideration**

As a researcher, during the process of research study ethical issues should be considered in order to protect the privacy and identity of the respondents. It is very much important to consider the norms and values, religious background of the respondents and respect

them while collecting the information and presenting data in the study. Thus,, in the present study, ethical issues are highly considered and given priority during the study. All the respondents for the research study were respected and no harm was caused to their dignity. All of them were given detailed information about the research that was being conducted. They were informed about the research objectives and question. Also, they were made clear about the purpose of their participation in the study. Before the interview with the participants, an informed consent was taken verbally. They were also free to withdraw the interview whenever they want if they no longer want to participate further in the study. The respondents were also ensured for the confidentiality of their identity and information provided by them. They were further ensured that the information gathered will be solely used for the study purpose and will not be misused.

### **3.8 Limitation of the Study**

The study reflects the livelihood condition, experiences and challenges of the people with physical disability. For the purpose of the study, the capital city Kathmandu was selected as a study area and does not cover all the part of the country. So, it does not represent the entire country where the outcome of the might be different according to the time and space. The study was conducted with the small sample size of the population based on the availability of the respondents who fitted best for the study criteria. Therefore, the conclusion is generalized based on the information given by the respondents present for the study and the information is analyzed and interpreted as per their response. The study is also generalized to overall case of the people with physical disability in Nepal which might not be similar in every case and every context. The experience might also differ which can produce different conclusion. Hence, the study is limited in its scope, study area and participants and not able to address all the issues related to people with physical disability.

## **Chapter 4**

### **DATA PRESENTATION AND ANALYSIS**

This chapter presents and analyze the data that has been collected for the study following the methodology mentioned in the chapter three. The objective of this study is to identify the factors that influences the livelihood of people with physical disability and have insight to their lived experiences. Here, I have used qualitative method of data collection to conduct the research study. I choose to use qualitative method in this research study to find out the real experiences and feeling of the people with physical disability. In order to fulfill the objectives of the study, interview with the respondents were taken who were physically disabled. Individual interview was conducted with 8 participants. The collected information from the field study has been presented and analyzed below for the systematic presentation of data.

#### **4.1 Case Description**

The statement of the respondents who participated in the interview process are presented below. There are total eight case studies of the people with physical disability conducted via interview in order to find out their life experiences in many aspects of living a life as a person with physical disability and identify the factors that influences their livelihood condition. Each case description starts with the introduction of the respondents and their family background. It is then followed by their experiences and life stories. In all cases, translated language of the respondents has been used.

##### **Case 1**

My name is Sushma Karki. I am from Kadaghari, Bhaktapur. I am 30 years old and I am physically impaired. I have lost my left arm since birth. I work in an organization which works for people with disability. I am working in the organization since last two years as a member secretary. I have a political appointment of four years in the organization. Before, I was a manager in marketing department in Buddha air. I have completed my bachelor degree and now I am studying master's in major English. I am married and have a daughter of 4 years old. I live with my in-laws and husband.

I was born in a middle class family with good economic background. I did not face any kind of difficulty during my childhood because of my disability. My parents were educated so they never denied for anything. I had good educational opportunity and

facilities. My in-laws are also very supportive so they have not denied for my higher education. I think my educational qualification provided me the opportunity of good employment. It provided me better opportunity for my career. Now I have good job and better position and income to support my living. My income is around NPR 32000-40000 per month. It is sufficient enough to fulfill my daily needs. My husband has good earning as well and we both contribute in the family to run the household errands. I do not have any financial difficulty so far as we both have good income. I also have bank balance of my own income. Mostly, I spend my income in household purpose and my personal needs.

Even though I was born with physical impairment, my physical condition did not stop me from doing whatever I want. My impairment did not pose greater problems for me. I come across some minor difficulties however, I have not faced too many hardships because of my disability so far. Personally, I never felt that I am different from other people. This might be because I was not treated differently and I was brought up in a good environment during my childhood. The economic condition of my family was good so I got all kind of facilities and opportunities. They were not over protective and rigid. They were quite open minded and not superstitious so they did not impose any restriction on me. I was treated equally with my brothers. I remember that I went swimming with my brothers to the nearby rivers and my parents never denied and stopped me. They knew I could not swim but never said I could not do it and let me tag along with my brothers. Though I could not swim I enjoyed going to the rivers and playing.

Sometimes people misjudge us from our physical appearance. They doubt on our capabilities and pass out discouraging remarks. Even if we go to places people start staring uncomfortably as if they never saw anything like that before. Some people in the society show their extreme concern making us look pathetic. These days, I come across such kind of behavior less frequently than before. Actually, for me it does not matter what others think of me or what they have to say about my condition. I am confident and capable. I am very much comfortable and satisfied with my personal life. I have no complain; I just love myself. Beside I have my family to support me so I have no worries.



I do not have any problem in accessing any kind of facilities. I have easy access to my home and workplace. I do not find extreme difficulty because of the physical infrastructure or have any issue with the environmental condition. I do not feel any discrimination in the workplace. All of my co-workers are friendly and supportive. Sometimes it is difficult to have easy access in public services like transportation. I face difficulty when there are no seats reserved for people with physical disability and have to travel standing all the way which is risky as I cannot hold onto anything for support and sometimes I do not even get discount for bus fare.

In the case of Sushma, being physically disabled did not have negative impact in her life. Her disabling condition did not stop her from doing any kind of activities and enjoying her life to the fullest. She has good job and good income to support herself. She has good educational qualification which provided her good opportunity to become independent. She has support from her family and access to various opportunities. She did not face any discrimination from her family nor ill treatment by them. She also had no problem because of the behavior of the people. Because of this she has better life and is happy with her situation. Moreover, she is satisfied with her personal life.

## **Case 2**

My name is Ramesh Lama and I am 40 years old. I live in Pepsicola, Bhaktapur. I have problem in my right leg so I have movement difficulties and cannot walk properly. I was diagnosed with polio at my early age of 3 or 4 years old. I have completed my bachelor level education and I am currently working in an organization working for the welfare of the people with disability. I am politically appointed for 4 years in the organization as a president and I have been working in the organization since last one and half year. I am married and live in a joint family.

After I completed my school level education I came to Kathmandu and studied here. I also started to work and continued my study. I did not receive any scholarship for my study during my college but back in the school days I was provided with scholarship because of my disability. Later I also received computer software training which has been very helpful to me. I think it must have been more than twenty years since I am living in Kathmandu. I completed my education and started my career here. I started working at my young age of around 19 or 20. Now I have a good job. I am in a prestigious position and have very good income. I earn NPR 50,000 per month. I have

no additional source of income and with this I am able to manage my household so far. I do save little and mostly I spend for my household needs and education of children. It was very difficult for me to find employment opportunity initially. Due to my disability could not find suitable job for myself. Private sector office refused to take me in because they were skeptical about my capabilities. I faced rejection so many times that I almost decided not to find any jobs for myself anymore.

I do not remember any harsh treatment by my family because of my disability. They are supportive and caring. I do not have any issue with their behavior nor am I discriminated by the family members. I do not feel negligence or negative attitude. However, I have experienced discrimination and humiliation by other people in the society. Back then I had limited friends who were close and friendly with me. I participated less in school activities due to my disability. People in the society negatively perceived my condition and questioned my ability. But now a days, they do not try to misjudge my ability and talk about my physical appearance because I am successful. I am respected and treated well by the people when I get back to my village. I am included in social activities and religious functions. They interact very well and are kind to me. Relatively, I find views regarding disability is more stereotyped in rural areas. Though this scenario has changed a lot from what it was before but still people are superstitious and narrow minded.

Being person with physical disability, I sometimes encounter difficulty in accessing public services and facilities. Mostly, I find challenging to get easy access in public transportation. Additionally, because of lack of disabled friendly infrastructure it is difficult to get easy access in government offices, banks, roads, market places, etc. Other than this I have access to facilities. I have easy accessibility to my workplace as my office room is in ground floor. My workplace surrounding is also disabled friendly and I have no issue with my co-workers. All of them are supportive and helpful.

Personally, I do not feel uncomfortable because of my disability however, sometimes people's judgement affects me. It makes me feel low and I lose my confidence. I feel demotivated. Other than this I do not hate myself because I am doing well so far. I also have family support and love. And that inspires me and I feel satisfied. I am also capable and independent. Although it was difficult in the past now I am happy with my situation.

Because of the physical disability Mr. Ramesh had hard time finding job opportunity. He faced rejections and negative attitude from the people in the society. He was behaved differently and faced some kind of discrimination in the society. Negative perception and attitude by the people towards him negatively impacted his feelings. Although he faced no difficulty in his workplace, he finds challenging to have access to public services and facilities. With the family support and care now he has comfortable life and he is happy with his condition.

### **Case 3**

My name is Krishna Maya Nepali from Bagbazar, Kathmandu and I am 40 years old. I was born in Tanahu in a middle class family. My parents are farmers. I became physically disabled 25 years ago due to road accident. Due to the accident my left leg was severely injured. As a result I had to cut off my leg. Now I am able to walk with the help of prosthetic leg. I am married but separated and I have two sons. I live in a rented room and make my earning by selling 'chatpate' in a cart 'thela'. It is only me and my younger son living together in a rented room. I have studied up to grade 5.

I have not studied much. I can write my name. I can read but not properly so I can read only simple terms. My parents were not educated either so they did not know the importance of education. We are five siblings so it might be difficult to manage the expenses of education for all of us. Hence they did not have problem when I left my education. It was difficult to study while having to do all the household chores. Because of this I could not focus well on my studies and neither had any interest in going to school. After studying up to grade five I did not go to school. Instead I engaged in household activities like cooking, washing, collecting firewood and feeders for cattle's, etc. Now I regret for not studying. If only I had gone to school and studied properly my life would be much better. I could get employment opportunity and earn better. At that time nobody pressurized for studying and there were no tell me about the importance of education. If only I knew that I would end up like this I would study further.

I do not know the exact year of my marriage but I was around 24 or 25 years old when I got married. After 2 or 3 years of marriage, my husband went to India for employment. He returned back only twice or thrice then never returned again. I have heard from the relatives that he is in India but I have no contact with him. It has been years I know nothing about him. I only know that he is not going to return back. Actually I felt alone

when he went India even though I was living with my in-laws. After the accident I was injured badly and had to rely on others. I felt uncomfortable with my in-laws. Initially they took care of me but later I was burden for them. As I was not healthy and active as before they disliked me. Then I returned to my parent's 'maita' and stayed there. Later I came to Kathmandu to find employment opportunity. It was very difficult to find work opportunity. I asked many of them for recommending job to me but nobody recommended any to me. After much struggle I became able earn my living through this shop 'chatpate pasal'. Now, I earn enough for myself; it's around NPR 25,000- NPR 30,000 per month. Basically, most of my income is spent for fooding. I do not spend unnecessarily rather I save some amount. So far I have been managing my living with my income.

Because of my disability I went through so many difficulties. I was totally dependent and not treated well by my in-laws. People talked nonsense about my fate. As my husband did not return back I was not liked by my in-laws and considered me unlucky. I faced discrimination and people humiliated me. I was avoided by the people of the society. Although I am aware of the government services for people like me, I have no access to it. Although I have access to facilities, I find difficult to get easy access to it. I have my disability identity card but I do not receive disability allowance. Sometime my card is useful for getting discount for bus fare. I do not find public vehicles comfortable as it is not disabled friendly. I also do not find every places disabled friendly. I struggle climbing stairs and vehicles a lot.

Ever since I started earning I felt as ease. Although I do not have luxurious life I am happy and satisfied with my situation. Now I am on my own so there is no restriction and I can do whatever, go wherever. Although it is difficult to manage everything by myself, I feel comfortable and happy. My economic situation has improved and I have easy life than before.

In the case of Krishna Maya, lack of education restricted her from getting better employment opportunities. Furthermore, ignorance and lack of awareness regarding the importance of education prevented from having educational qualification. She suffered from discrimination due to traditional thoughts and misconception. She also had no support from her in-laws. Environmental barriers contributed in the difficulty level and

she had no access to facilities. However, self-employment provided the opportunity to earn and have better economic condition. That makes her happy and satisfied.

#### **Case 4**

My name is Tara Bhandari. I am from Bagbazar, Kathmandu and I am 32 years old. I was born in Dang. In the year 2060 BS I got into road accident and my leg was severely injured. I had to cut off my leg. I am married but separated. I have a daughter of 14 years old who is studying in grade 9 in a private boarding school. We live in a rented room and I make a living by selling clothing items and accessories in the street. I have studied up to grade 7 from government school.

I was keen to study but I could not complete my schooling due to lack of opportunity. It was difficult to manage time for study because of all the household chores. Not many friends of mine have completed their schooling. My parents were not strict about my education. They thought it would be fine without much education. They did not know much about education and focused more on my engagement in household activities. I had less time to study and could not go to school so I left my school after completing grade 7. My parents were not interested to send me to school either and said that I had studied enough. Since I had to be busy with all the household chores I did not think much about my education and gradually lost interest to study. I got married at the age of 20 or 2. I did not know about the behavior of my husband before marriage. After marriage, he did not behave well. He would drink every day and beat me up. He was not employed as well. My in-laws were good but I did not feel good because of my husband. I was always worried as he would always drink and go crazy. It was difficult to stay with him so I returned to my parents and stayed with them.

Later I came to Kathmandu and began to live here. Initially, it was very difficult because I had no work and no income. I tried finding work for myself but I was not educated enough and had no academic qualification so I could not find one. I had no skills and could do nothing because of my disability. I had no one to rely on. After much struggle now I am able to do something. I am able to make some money. I no longer need to depend on other and ask for help. My condition has improved over years but not so much. I do not have any property of my own except some savings from my income. I earn around NPR 30,000 per month. It is not much because my shop is small and I do not sell many items like other normal clothing shops would do. As I decided to live

separately I did not get any help from my in-laws. Though they were good, they did not support me. I remember going through a lot of hardships. I feel that if had better education I could get good employment opportunity and earn good. I could have better lifestyle.

I feel difficult to manage a household alone sometimes. It is hard to explain how tired I feel to manage everything on my own. I have faced discrimination and humiliation because of my disability. People had negative thought about my condition. They complained about my appearance and capability. I felt low and hopeless. I lost my confidence and motivation to work. I do not have my disability identity card nor have I received any vocational trainings. I have no access to any governmental services and facilities but I have no problem to get other facilities. It is very difficult to get easy access to transportation facilities and some other places due to lack of disabled friendly infrastructure. However, nowadays I can adjust to it because I am used to it and I have no other option. Other than this I must say I am quite satisfied with my living condition because now I have good income and my economic condition is lot better than before. I have more economic support and comfort than in the past.

The traditional thought and practices that guided the belief system of Tara's parents prevented her from educational opportunity. This further restricted her from getting better employment opportunity. Despite her interest in studies, she was compelled to engage more in household works that provided less time to study. This indicates deeply rooted gender inequality that forces girls to engage more in household chores and participate less in other activities. She also suffered from violence and could not stay in her husband's home due to his behavior. She had no support and people misjudged her for her physical appearance. Their attitude towards affected her emotional well-being. She finds challenging to have access to facilities like transportation. She also do not have her identity card. Her improved economic condition and better lifestyle however has provided satisfaction and comfort to her.

## **Case 5**

My name is Milan Kharel and I am from Putalisadak, Kathmandu. I am now 27 years old. I am unmarried and I am currently studying Master's Degree in social work. I work in an organization working for people with disability in administration department. It has already been 12 years since I have been involving in the social organization and

working in the field of disability. I live with my parents and younger sister. I became physically disabled due to the illness. In medical term my illness is called congenital kypho-scoliosis which is a spinal deformity.

I belong to a middle class family. My father was a teacher and we have good economic background, cultural background and educational background. My family is well educated so regarding my education I never faced any kind of discrimination. I got good educational opportunity and also received computer training. I have good employment opportunity as well. I am very much satisfied with my income level. I earn quite well. My income per month is above NPR 25,000. So far it is enough for my living. I do save some amount and make expenses for some personal use. Mostly, I spend my income for my health and education. I have a bank balance from my saving. Though I have good income and good job now it was very difficult to find employment opportunity initially. Because of my disability people were not ready to hire me for work. I faced so many difficulties and rejections. Wherever I applied for jobs I was rejected because of my disability. I appeared for many interviews but later was refused for the position. People said I could not perform well.

Although my health condition makes me difficult to perform activities like lifting weights, standing I do not think it has restricted me from doing regular activities. I can perform my daily routine without any kind of assistance at all. But many people still think of me as helpless. I find that many people still views disability negatively. People complained about my capabilities and treated me in a different way. That affected me very much in the past. I felt discouraged and ashamed of myself. Though I felt uncomfortable because of the behavior of the people in the society, I was not treated differently by my friends and family. I have many good friends who are very supportive and kind. There is also any discrimination and ill treatment in my workplace. My seniors are supportive and I get to learn so many things from them. I find my workplace environment good. I get equal opportunity to participate in training programs and workshop organized by my office. I have no problem in accessing any kind of facilities in my workplace. Everyone has easy access to office rooms. So far I do not have any complains related to my work life.

As a person with physical disability I find difficult and challenging to get easy access to facilities and services. Mainly there are no any disabled friendly means of

transportation which makes me difficult to travel on a daily basis. Although there is a provision of free health services I have no access to it. I have even experienced discrimination in the hospital. It is somewhat easy to get health services now a days while I compare with my past experiences. However, sometimes it is difficult. I also do not think every places are disabled friendly. I have to adjust with it despite difficulty. For me it does not matter what other people think of me or how they treat me. What matters is my confidence and my family support. I have both of it. Also I am able to live happily and freely so I am satisfied with my situation. Even though it is challenging to live as a disabled person I do not want to complain much about my life.

The opportunity to employment and education has positive impact on the living condition of Milan. Employment opportunity and good income from work contributed in the capacity to fulfill the requirements. Despite of the rejections he is now independent and manages his expenses on his own. Support and friendly behavior from friends and family positively influenced his emotional well-being. It provided encouragement to overcome daily life challenges and provided satisfaction. Accessible workplace environment and inclusion in various programs provided him the opportunity to increase the capability. Even though accessibility to facilities and services is quite challenging to him, friendly behavior of staff members, support from seniors, family and friends give him satisfaction and motivation.

## **Case 6**

My name is Ram Bahadur Thapa from Chakupat, Lalitpur and I am 38 years old. I became physically disabled at the age of 7 due to accident. I fell from the roof of a building which caused severe injuries in my leg. As a result my left limb is shorter and I have difficulty walking. I have completed my bachelor level education. I am a prosthetist and orthotist and I work in a physical rehabilitation center. I am involved in this occupation since last 17 years. I am married and have three children.

I know that many people like me are deprived of employment opportunity but for me it was not so difficult to find the opportunity. It might be because I studied related to my profession and there is opportunity in this profession. I have good earnings from my work. I earn around NPR 50,000 per month. Though it is good amount it is not always enough for me. Sometimes I find difficult to manage the expenses. I need to manage for the education of my children, manage for fooding, clothing, rent, etc. As a bread



winner of the family it is quite difficult but there is no choice left and so far I am doing well. I do not spend much for myself rather I spend for my children. I feel that I need to be careful in spending money.

I should say that my parents are good to me and supportive. They provided me with all the facilities and did not denied for any kind of request. They allowed me to make my own decisions. I do not feel any discrimination or inequality in the behavior of my family. I do not feel the same when it comes to the behavior of other people. Although people now a days are more aware about disability and do not act inappropriately, not everyone are kind and have positive thinking. I myself have experienced negative behavior in the society. People had negative thoughts and they considered me incapable for doing things. Some also related my disability with the punishment and fate. I was not allowed to participate in social functions as they believed that I am not capable enough to handle things. But I do not remember anything bad about my relation with my friends. Everyone were kind to me.

I find common that people like me are ill-treated and misbehaved. I do not understand why people have negative impression about us. Back then I was denied for my admission in engineering college because of my disability. Though I cleared my entrance exam, I was denied during the admission. I felt bad as I could not enroll myself for engineering. I wanted to become an engineer but could not get the opportunity.

As I cannot walk properly it is difficult for me to get easy access in many places. Although I have not experienced any discrimination in accessing facilities and services, I can tell that it is very difficult to get easy access in public vehicles. I think everyone agrees with me regarding this matter. It is also difficult to get access because of the physical infrastructure of many places. Not every places are disabled friendly. However, I have easy accessibility to my work place and home. I also have access to other facilities. There is no issue with the surroundings as my work space is located in the ground floor. I feel good about my work place environment because it is disabled friendly and comfortable. Everyone at my work place are also friendly and supportive. Because of all the support and kindness, because of my capability and my better condition I feel very satisfied and comfortable.

Although employment opportunity and education influenced the life of Ram Bahadur positively, he became a victim of traditional thought and religious beliefs. He faced discrimination in terms of getting higher educational opportunity. He was denied for his enrollment in engineering college. As a result he could not study according to his interest. He has easy accessibility to his work place and home and also he does not find difficult to have access to other facilities and services. However, it is difficult for him to get easy access in public transportation. Behavior and attitude of his friends and family towards him makes him comfortable and happy. But, societal attitude and behavior was negative towards him. Their behavior and perception restricted him from his right to participate and get equal opportunity.

### **Case 7**

My name is Chhultim Sherpa from Chabahil, Kathmandu and I am 55 years old. I became physically disabled at the age of 4 because of polio. I am a businessman and a social worker. I have completed my Master's Degree in Business Administration. I am married and I live in a joint family with my father, mother, wife and son. I have difficulty in walking so I use crutches for support.

For person with physical disability like me, I think it is difficult to get employment opportunity due to various circumstances. In some cases even if a person has good qualification I think it is difficult to get good job and good position. It has been 6 years since I started involving in a business. Before I was a job holder in a private company. It was not so difficult to find job but I was always interested to my own work. So I decided to quit and started my career as a social worker and later involved myself in the family business. Though I did not work in the company for many years I found difficult working because of my physical condition. I earn quit well from my business. It is around NPR 25,000-NPR 30,000 per month. With this I am able to manage my household so far. I also own 2 ropani of land which I have rented and I have ownership to my house and a four wheeler scooter.

I do not feel that my physical condition has ever posed a great problem in my life. It is common to face some difficulties and challenges however, I do not feel that my disability has ever restricted me from achieving my goal. Even though I am physically disabled I do not feel like a disabled person. I have not faced too many difficulties due to support from my family and friends. I have no experience of discrimination or ill

treatment by my family members. They provided me with all the facilities and love. It is not the same when it comes to social behavior. It is hard to explain because it is not once or twice but mostly I faced negative attitude from the people. It is kind of disturbing. Their rude behavior made me feel sad and lose confidence. But over a period of time I have learned to adjust and face them. Now a days I do not face such behavior as before and that feels good.

These days there are not many challenges or difficulties to have access to various facilities and services. I have access to health facilities and banking facilities. I do not face much problem with transportation facilities because I have my own four wheeler scooter. But, I find that not every places or infrastructures disabled friendly. Mainly I find difficulty to have easy access in public places like roads, market places, banks, etc. Not many buildings are disabled friendly. I have my disability card which is blue in color and I receive disability allowance that is being provided by the government of Nepal. I do not have problem in getting access to my home and surroundings. Although not every places are in my locality are disability friendly I have access to it.

In the case of Chhultim, work opportunity, education, accessibility, positive attitude and behavior has positive impact in his living condition. He is satisfied with his situation because of all the opportunities and facilities. He is independent and more capable that enabled him to live comfortable life and get better opportunities.

### **Case 8**

My name is Ramesh Ghimire from Dolakha and I am 35 years old. I am physically disabled. In the year 2069 BS I got into road accident which caused damage in the nerves of my leg. Since then I have problem in both of my legs and have movement difficulties. I have studied up to +2 level education and now I am working in a municipal office as a computer operator. I am married and live with my wife and son.

After I completed my +2 I wanted to go abroad to work. I wanted to go to Qatar or Dubai and make money. I was also unemployed here. Therefore, I decided to go abroad as a labor migrant. Unfortunately I got into accident. After the incident I had no choice but to earn my living here in Nepal. I tried to find job for myself but it was difficult than I expected. I did not have higher qualification so, I could not get any job opportunity. If only I studied further or completed my bachelor it could be easier to find

job. After much effort I was recommended for the position in the office. Now I earn myself for my living. My income per month is between NPR 21,000-NPR 25,000. I find it enough to make a living for my family. I do receive disability allowance which is of great help to me. I spent it on my medicine. I do not have any ownership to land but I have one four wheeler scooter.

I think very few people like me are able to enjoy their life without any discrimination. It is very obvious that I find myself being discriminated and offended. People try to dominate with their attitude. Some are rude and use offensive language. I felt the change in the behavior of the people who were kind to me. But, I do not have bad experience with my family. There is no difference in their behavior before and after my disability. Their love and support always encouraged me. It helped to get back my confidence. After my accident their care and support helped me to adjust with my condition. They were the one to motivate me.

Because of my disability it is difficult to perform daily activities but I can manage with it. I have easy access to my work place however, I find difficult because of the physical infrastructure in most of the places like roads, banks, market place, etc. I have access to facilities and services. I have received computer training from NGO and I have my disability card provided by the government. It is helpful to get discount and access to some services like transportation, hospital service, etc. It is quite difficult to get easy access to public transportation because it is not disabled friendly at all. Sometimes it is even challenging to get seats as there are no seats reserved for people like me. It is very difficult for me especially when I have to come to Kathmandu to get health services. Despite difficulties I am living well so far. Now I am employed and have good income. I am able to fulfill my needs and I have support from my family and friends. Everything is good so far and that makes me happy. So I must say I am satisfied with my living.

For Ramesh, employment opportunity provided him the support for living. Although he could not go abroad to work he got the opportunity to employment. Even though he experienced negative behavior from the people, his family support motivated him. Their love and care helped him to adjust to his disability and be confident. He finds difficult to get easy access to various services and facilities due to various circumstances but he has access to government services including other kind of facilities. He is also happy and satisfied because of his improved status.

## **4.2 Analyzing the cases**

The analysis of eight cases in the research study identified some commonalities and differences in the cases. Common to all the cases is that their economic status have more impact on their living condition. It is likely to be the most essential factor to regulate their daily life activities. All the participants in the study do work and their work is important to them. Involvement in some kind of income generating activities or jobs have positive impact on their life. Because of the working status they are economically and emotionally satisfied. Their financial stability and independency have added comfort to the daily living. Moreover, sound economic condition have provided them social recognition in the community and society. It has helped them to be confident and courageous. Likewise, another commonalities between the cases is the influence of socio-cultural factors in their lives. They all expressed the feeling of being discriminated in one or the other way that lead to negative consequences. Although the level of discrimination varied, the impact of discrimination had similar kind of outcomes in their lives; that is they felt less confident because of their disability.

In the study it was identified that the educational qualification of the participants did not have the same level of impact to all. Despite of the positive influence and importance of education it was found that not everyone with higher education had same experience in terms of finding opportunities; especially in terms of getting job opportunities. Even though some of them had perceived higher education degree, they expressed difficulties in finding job opportunities whereas some expressed no difficulties in finding one for themselves. In fact, they consider that their educational qualification made easy for them to find better employment opportunity.

While analyzing the cases of people with physical disabilities, it is found that their livelihood condition is very much determined by four major factors such as economic, education, socio- culture and environment. All these factors basically have some prominent role to influence the livelihood of the participants. In the study, participants with physical disability seem to agree with the fact that they are satisfied with the economic situation because of their employment, but they have mixed experience in terms of finding employment opportunities. Some had hard time finding employment opportunity due to various circumstances whereas some got the opportunity without any difficulty. The employment status determined their living condition and quality of

life. Involvement in income generating activities contributed in the well-being increasing the capacity to satisfy their needs. Employment opportunity reduced their livelihood vulnerabilities and enhanced the capacity of earning and achieving financial independency. Their employment status further promoted the economic situation enhancing future financial security. For them, their major source of income is income from work which is enough to fulfill their daily requirements.

While employment opportunity provided better living condition for people with physical disability, their likelihood of being employed was determined by the level of education. Higher educational level positively influenced the likelihood of getting better job opportunities, level of income, type of job and higher position. It provided opportunities to prestigious job sectors easily in comparison to those with low level of education or less years of schooling. Case 3 and 4 clearly illustrates that low level of education affected the opportunity to get job in different sectors. Likewise, some kind of skill development trainings increased the capabilities and knowledge. Some kind of vocational training helped in the work life (in case 2, 5, 6 and 8).

The case studies confirmed that religious beliefs had a strong influence in the life of people with physical disability. Traditional thoughts and practices prevented them from having access to opportunities. In case 4 traditional thought guided the belief system of her parents which restricted from getting educational opportunity. Also, in case 3 illiteracy and ignorance guided the perception which affected educational opportunity. Likewise, negative perception and religious teachings influenced the behavior of the people that resulted in discrimination and ill treatment (in all cases). The attitude and behavior of the people excluded them from the mainstream society. They were excluded from social participation and many other life activities. Case 3 and 4 also clearly illustrates gender discrimination where girls are forced to involve themselves more in household activities and have less opportunities, some even became a victim of domestic violence (case 4). However, family behavior and attitude towards them played significant role in their lives. Positive attitude from family members, care and support provided comfort and better life. It contributed in the emotional well-being and helped to overcome the challenges. Their support helped to develop the feeling of confidence with one's physical condition.

While analyzing the influence of environmental condition, all of them agreed that not every places are disabled friendly. They reported struggle due to lack of disabled friendly surroundings. Variations in the geographical structure created barriers in easy access to facilities and services and also created adjustment problem. Some reported accessible work place environment and disabled friendly infrastructures. This indicates the influence of environmental condition in their daily living. Addition to the physical environment of the work place, social environment seemed to have impact on the work life. A good relationship with the co-workers and staff members revealed good work life condition and satisfaction from work.

However, in terms of getting easy access to various kinds of facilities and services seemed very challenging to them. It seemed common for all of them to face difficulties to have easy access in public services. For them, accessibility to various kind of services and facilities like health services, education, sanitation, etc is quite difficult due to various reasons. All of them except one (case 4) have disability identity card and among them two of them (case 7 and 8) received disability allowance according to the categorization of disability. In terms of the accessibility to various kinds of training, some received vocational training of some kind whereas some did not receive any kind of trainings. This indicates unequal access to the public services and facilities by the people with disability. It seems work opportunity and support from family contributed in the emotional well-being providing satisfaction with their condition for almost all the cases.

In general, better access to employment opportunity, education, income, favorable environment, support positively influenced the living condition whereas negative attitude and behavior, lack of accessibility to facilities, traditional beliefs and cultural practices had negative impact on the livelihood. Hence, it could be concluded that for people with physical disability their living condition is determined by the economic status, educational status, accessibility, environmental condition, socio-cultural background and behavioral factor. All of these have impact on the livelihood aspects. Thus, economic factor, educational factor, environmental factor, socio-cultural factor and behavioral factor strongly influence the livelihood of people with physical disability.

### **4.3 Analysis from Focus Group Discussion**

Focus group discussion was conducted with two groups consisting of the participants with physical disability. There were all together 12 participants for focus group discussion irrespective of gender and age group. Group discussion was carried out with the help of guideline focusing on the collective views regarding their challenges and livelihood perspectives. Furthermore, it focused on the views of the participants related to disability issues.

Participants in the discussion revealed that people with physical disability come across various challenges in their day to day life. Life opportunities for them is constrained due to their physical condition and limited provisions that could facilitate the situation. They agree with the fact that change and development in the global scenario brought gradual change in the concept of disability. Perception regarding disability and attitude towards people with disability seems liberal to some extent in these days however, involvement of government in promoting living condition of people with disability is still limited as a result there still lacks proper plans to address the issues of disability. Participants in the discussion stated about their awareness about the government policies and provisions for people with disability but, the accessibility to the mentioned provisions are stated to be out of reach of many of them.

As per the discussion, government interventions to ensure better opportunity and better living condition for people with physical disability remains ineffective. Provisions for various kinds of facility and service seems inadequate. Efforts of various organizations and NGO's to provide skill development trainings focusing persons with different types of disability with poor economic condition and rare possibility of career seems effective but not adequate and long term. The government of Nepal has taken only few initiatives to such activities as a result, despite being aware about the provisions and policies, many are beyond the reach of services and facilities. Many continue to suffer because of lack of proper implementation of legal provisions enshrined in the legislation.

The focus group discussion confirms that people with physical disability at present context have more opportunities to livelihood and more participation in public sphere. They seem to be satisfied with the economic condition and consider economic aspect to be the most important to regulate their daily living and improve the condition. In the case of person with visual impairment, they encounter more challenges and have limited



career opportunities. For them, it is a challenge to gain independency to encounter everyday life situation. People with physical disability mostly come across environmental barriers due to lack of disabled friendly infrastructures. Furthermore, they face prejudice behavior and negative attitude.

When it comes to the opportunity to participate in income generating activities, many of them with less year of schooling or rare possibility of education and career have participation in self-employment activities. In general, employment is equally important to all whether it be self-employment or job. Many of them agreed with the fact that livelihood opportunity improved their condition over years. But, it was difficult for them to find the opportunity for themselves due to various limitations. They still find difficult to overcome the daily life challenges and struggle to adjust with the situation. According to them, lack of effective planning to empower persons with physical disability is the reason behind the failure of state to address the issue of disability. They recommend for the decentralization of facilities and services and effective monitoring of the provisions that are being provided to the persons with physical disability. Also there is a need for trainings that are effective according to the market demand and need of continuous help from the government.

It can be concluded that people with physical disability continue to struggle with their condition. Their efforts to earn the livelihood and overcome the challenges are limited or restricted due to various circumstances. Their efforts to find the opportunities are constrained by the inadequate and ineffective programs to empower them. They also continue to suffer because of the lack of practice and commitment of the responsible authorities.

## **Chapter 5**

### **SUMMARY AND CONCLUSION**

#### **5.1 Summary**

This research study has attempted to describe and analyze the experiences of individuals with physical disabilities in many aspects of living a life as a disabled person. The main purpose of the study is to identify the factors influencing the livelihood of people with physical disability and get insight to their lived experiences. This research study has been carried out by using qualitative research methodology. The data and information for the study has been collected using both primary and secondary source of information. This research study has carried out total eight case studies and two focus group discussion using interview technique as the tools for data collection and the collected information has been analyzed in descriptive form.

The analysis of the experiences of the participants' revealed that the livelihood condition of people with physical disability is determined by various factors. The interplay of those factors determine the quality of life and standard of living of people with physical disability. Factors like economic factor, educational factor, socio cultural factor and environmental factor determines the livelihood opportunity and accessibility to different means and resources. All these factors therefore influences the livelihood of people with physical disability. It regulates the daily life activities and plays significant role to shape the condition of people with physical disability.

In the study economic factor is identified as one of the major factor affecting the livelihood of people with physical disability. For people with physical disability, their economic condition has determined their livelihood. It provided accessibility to various necessities for survival. Basically, involvement in some kind of income generating activities, financial condition, source of income and opportunity to employment determined their economic status. Opportunity to employment reduced their economic crisis contributing in the improvement of economic condition. In general, the improved economic situation contributed in the access to food, child education, material needs, facilities and health services. It improved the life style providing more comfort and support to increase the capacity to satisfy human needs. It further provided social prestige and economic independency reducing livelihood vulnerabilities. In the study it is found that being employed was very important for them to earn the living and support

themselves as well as their family members. But, it was not easy for them to get the opportunities.

Another factor which is seen to be influencing the livelihood of people with physical disability is educational factor. In the study it is found that education is the key for expanding the life chances for people with physical disability. It is the source for strengthening economic aspect of life. Opportunity to education provided better opportunities for livelihood. It is found that those with higher educational qualification had better access to employment opportunity compared to those with low level of education. This indicated that educational status is more likely to influence the livelihood opportunities by empowering them. It enhanced the capabilities and increased the knowledge. Also, some kind of skill development programs or trainings helped to gain knowledge and increase the capabilities for earning livelihood.

Socio cultural factor is seen as another important factor that influences the livelihood of people with physical disability. It is found that views regarding disability is strongly guided by various socio cultural norms and values, practices, religious beliefs and traditions which regard disability in a negative way. Religious teachings regard disability as a punishment for evil deeds. This kind of belief and teaching have strong influence upon the people of the society. As a result, their behavior is strongly guided by such beliefs. People with physical disability are therefore found to be discriminated and misbehaved due to which they struggle to adjust to the social life. They are also considered incapable and inactive. Furthermore, traditional thought and ignorance restricted various life opportunities affecting the livelihood condition. However, it is seen that positive attitude and behavior played significant role to improve their condition. It influenced the well- being and provided emotional satisfaction.

The experiences of the participants' in the study also indicated environmental factor as one of the factor that have influence on their livelihood. For people with physical disability, accessibility to disability friendly surroundings is important to make easy adjustment in their daily life and carry out the life activities. However, lack of disabled friendly surroundings created barriers for accessing various kinds of facilities to regulate their life activities. Inaccessible physical infrastructures is more likely to be seen as creating difficulties in daily life. It is also seen that people with physical disabilities mostly face difficulties to get easy access to their physical environment like

roads, market places, buildings, etc. But, in the study they reported that accessibility to their work place surrounding is made easy and barrier free that has helped them to work freely without any kind of difficulties. Almost all of them reported good social environment in the workplace because of the supportive and friendly nature of the co-workers. This helped them to achieve work life satisfaction and feel motivated.

Apart from all the above mentioned factors, other factors like accessibility to facilities and services, social participation and personal perspective towards their disability are identified that have significant role to influence the livelihood of people with physical disability. Accessibility to various kinds of facilities and services are found to be difficult for people with physical disability. Most of the services and facilities meant for them are beyond their reach. Very few have access to government services like free health services, scholarships and vocational trainings. They face challenges in easy access to public services and facilities like transportation, government offices and hospitals. Social participation and work place inclusion seemed to contribute to their social life and recognition as well as their career growth. It provided better opportunities and made them more capable and active. Likewise, their satisfaction with the personal condition made them more confident and happy.

## **5.2 Conclusion**

This research study presents insight to the livelihood of people with physical disability. The attempt to explore the experience of the participants in the study identified that livelihood of people with physical disability is determined by various factors that plays significant role in their everyday life. Such factors regulate the life activities and function either directly or indirectly to determine the living condition. In the study it is found that the opportunity to employment and education, the environmental context, accessibility, religious beliefs and traditions, practices, attitude and behavior of the people have some kind of impact on the lives of people with physical disability. All these are seen to be associated with the living condition determining the capabilities and potentialities to cope up with the vulnerable situations and survive. Therefore, it can be said that factors such as economic, education, socio cultural and environment have influences on the livelihood of people with physical disability.

The present scenario of disability from the study indicates that social concept regarding disability has changed gradually in the society with the pace of time. This has allowed

people with disability to have accessibility to various kind of opportunities to keep up with their livelihood. However, people with disability have greater exposure to livelihood vulnerabilities. Their experience reflect challenges and continuous effort to keep up with their livelihood. Not every people with disabilities seems to have similar kind of experiences of being disabled. The factors that determine their livelihood condition may have varying impact on their daily activities. For people with physical disability, the basic needs for survival such as food, clothing, shelter, education and health are determined by their economic condition. Addition to these basic needs accessibility to other kinds of requirement for living is also associated with the economic aspect. The opportunity to employment provides them the capacity to improve the economic condition in order to fulfill the necessities for living. It provides support in covering the expenditures for living and break out of dependency and poverty. It adds to future security by providing support to build up the assets and savings. This indicates that economic factor influences the overall condition of life as it is the basis for livelihood.

Education is another factor that influences the livelihood of people with disability. It empowers them and enhances their capabilities for better opportunity. It is the key for expanding life chances that promotes sustainable livelihood. Similarly, socio cultural factor have significant impact on the lives of people with physical disability. It helps to determine the social life and opportunity. Various belief systems of the society, tradition, and religion have strong influence on the people that guides their behavior. The behavior of the people towards them have impact on their well- being. Perception of the people regarding disability affects the possibility to various opportunity for them. Environmental factor also have impact on the lives of people with physical disability. Both physical environment as well as social environment is likely to have some impact on the accessibility to various kinds of facilities and livelihood opportunities. It seems that favorable environment or accessible surroundings makes daily activities easy that reduces extra challenges to perform the activities and vice versa.

Apart from all the above mentioned factors, the livelihood of people with physical disability is also influenced by access to various services and facilities, their participation and inclusion and their level of satisfaction. Accessibility to various services and facilities seemed to ease their condition by providing comfort in the daily life situation. Their participation in social life and work life expanded the opportunity

for better standard of living. It provided social recognition and increased the connection with social networks. Their inclusion enhances the accessibility to various means and resources. Likewise, satisfaction with one's condition has positive influence in their lives. It has provided comfort and better quality of life.

While analyzing the diverse experiences of people with physical disabilities by comparing it with the theoretical framework, the evidence from empirical findings clearly indicates the negative attitude towards people with disabilities. The theory of social stigma explains how people with disabilities are perceived and how they are behaved by other people. As explained by Goffman, the existence of stigma takes place when a person with differences is evaluated by others in a negative way or say when the differences is evaluated as negative. Furthermore, he explains that stigmatization occurs when an individual's fails to meet the normative expectation of the society or fails to meet the notion of normal human identity. This study identified that social stigma exist because of power relation between people to create the hierarchy and discrimination related to social stigma create barriers in the lives of people with disabilities. In the study participants expressed their experiences of being ignored and discriminated due to stigma of being different from other normal people. They are labelled as useless, weak, incapable, etc. This kind of remarks from other people make them feel discriminated leading to perceive oneself as useless and different from other. This has impact on their development and living condition. Thus, it can be said that the theoretical perspective of stigma theory explained by Goffman is implacable, real and practical.

To conclude it can be said that this study identified that for people with physical disability, their livelihood is influenced by economic factor, educational factor, socio cultural factor and environmental factor. Along with these factors, accessibility to various services and facilities, their opportunity to participate and their personal perspective regarding disability also plays significant role in their livelihood. All these factors significantly serve for promoting the social life. It is a key for survival. It can be said that for enhancing the livelihood of people with physical disability it is necessary to give equal importance to every factors that helps to determine the quality of life and enhance capabilities to minimize the possible risks. Furthermore, from the findings it can be concluded that improving the livelihood condition of people with disabilities require more than improving the economic aspect of life.

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## **Annex- I**

### **Interview Checklist for Participants**

#### **General Information**

Name of the participant:

Age:

Gender

- i. Male
- ii. Female
- iii. Other

Address:

Marital Status

- i. Married
- ii. Unmarried
- iii. Divorced/ Separated

Education Level:

Family structure

- i. Nuclear
- ii. Joint

**Q1.** What is the cause of your disability?

**Q2.** Do you use any kind of assistive device for your daily activities? If yes, what do you use?

**Q 3.** What do you do for living?

**Q 4.** Do you think that being employed is important to you? Why?

**Q 5.** How easy or difficult was it for you to get employed? Why?

**Q 6.** What is your income per month from your work? (If employed)

- i. 0- 5,000
- ii. 6,000-10,000
- iii. 11,000-15,000
- iv. 16,000-20,000
- v. 21,000-25,000
- vi. More than 25,000

**Q 7.** In general how much do you spend per month from your income?

- Q 8.** Is your earning enough for your living? If no, how do you manage it?
- Q 9.** Do you have ownership to any kind of property?
- Q 10.** Do you participate in decision making in your family regarding household affairs? If yes, how often do you participate?
- Q 11.** What kind of challenges or difficulties have you faced during your study? (If any)
- Q 12.** Did you get free education?
- Q 13.** Did you wish for higher education? If yes, why did you not pursue it? (If no or low level education)
- Q 14.** Have you received any kind of vocational trainings?
- Q 15.** Have you ever experienced any kind of violence due to your disability? (eg being scolded or beaten) If yes, what kind?
- Q 16.** Have you ever experienced any discrimination in your society or family? If yes, what kind?
- Q 17.** Have you ever experienced discrimination in any of the public services? (eg banks, hospitals, bus stops, etc) If yes, what kind?
- Q 18.** Do you find difficulties in accessing any kind of services or facilities?
- Q 19.** Does your physical condition affect your daily activities?
- Q 20.** Are you receiving any treatment for your physical condition?
- Q 21.** How do you perceive your disability?
- Q 22.** What do you find about other people's attitude and behavior towards you?
- Q 23.** Did other people's behavior towards you ever posed a problem?
- Q 24.** What kind of difficulties do you face because of your disability?
- Q 25.** Do you participate in social activities? If yes, what kind?
- Q 26.** Are you allowed to participate in any programs or activities in your workplace or institution?
- Q 27.** Are you aware of the government policies and practices for people with disabilities?
- Q 28.** Are you receiving any allowance that is being provided for disabled people?
- Q 29.** Are you involved in any organization or group? If yes, what kind of organization or group?
- Q 30.** Is your surrounding where you live or work disabled friendly? If no, how do you manage with it?

**Q 31.** Is there any special provision or modification made by your institution for the people with disability like you?

**Q 32.** Do you have any suggestions to improve the livelihood of physically challenged people?

**THANK YOU**

## **Annex- II**

### **Interview checklist for Focus Group Discussion**

- Q1.** How much do you know about the provisions and policies made by the government for the welfare of the people with disabilities and do you have access to any kind?
- Q2.** What kind of major challenges do you mostly encounter?
- Q3.** How do you overcome those challenges?
- Q4.** According to you what do you think is the most essential factor that has impact on your daily livelihood?
- Q5.** Would you like to share any of your experience as a person with physical disability if you have any?
- Q6.** Do you like to recommend any suggestions to improve the livelihood of people with disability to the government of Nepal?
- Q7.** Do you find any kind of changes or improvements in the living condition of people with disability?
- Q8.** How satisfied are you with your livelihood condition?

**THANK YOU**