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MASTER THESIS

CHALLENGES IN THE INCLUSION OF PEOPLE WITH DISABILITY IN NEPALESE SOCIETY

*An empirical study of the experience of social inclusion of
people with disability*

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For My Mother Sun Kumari Shrestha

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ABSTRACT

The purpose of this study is to understand the challenges experienced by the people with disabilities in the course of their inclusion in the society. The specific context is to understand the social inclusion the people with disabilities through their participation in employment. In-depth interviews were conducted with eight people with disabilities irrespective to gender, ethnicity and age that were educated and employed as well and a focus group with five participants having similar attributes was also conducted for overall understanding the issues of social inclusion in detail. In addition to this literature on experiences of people with disabilities were referred to and the theory of social inclusion/exclusion, social stigma and social identity theory were as conceptual models to analyse the experiences of people with disabilities in regards to their inclusion in the society.

The results highlights that the severity of impairment of an individual determines the degree of acceptance of during the interaction with various power relations in the society. Findings include that higher education assists the people with disabilities to pursue better employment opportunities and involvement in disability based organizations open them the chances to strengthen social networks and grow self confidence. Due to the lack of proper financial resources, there is difficulties in the implementation of state promulgated laws for the inclusion of people with disabilities as a result gap is found between national policies and experiences of the people with disabilities in the course of social inclusion.

Key Words:

People with disabilities, social inclusion/exclusion, national policies, employment, education

CHAPTER 1 INTRODUCTION

1.1 Background

As the extent of disability increases in society, there is an increasing need to understand related consequences in many aspects of social inclusion. For example, one aspect that has received particular attention in recent years is the negative association between disability and poverty. There is an ongoing shift in thinking about the definition of disability from the older medical model towards a social model (WHO, 1999), and there is an increased endeavour for greater integration of disabled people into society. The traditional medical form perceived individuals with disabilities as having an impairment that did not allow them to partake in mainstream social activities. The 1980 International Classification of Impairment, Disability and Handicap (ICIDH-1) proposed by the World Health Organisation (WHO) is a prime example of disability defined in medical terms. On the other hand, the social theory of disability stresses the discriminatory barriers in society. Disability is therefore an outcome of social attitudes and structures, and the interaction between the person and environmental factors. This was the approach adopted in 1999 by the WHO in the 1999 ICIDH-2 classification. In 2001, the International Classification of Functioning, Disability and Health was approved by the WHO—this highlighted the interaction between the individual and the environment.

History is replete with examples of disabled people worldwide being ridiculed, killed and abandoned to die or condemned to permanent exclusion in asylums (Pritchard, 1963). Global estimates of disability prevalence vary widely. The UN estimates a rate of 10% while the United Nations Development Programme (UNDP) estimates a more conservative 5% global average. The Salamanca Framework for Action and the UN Convention on the Rights of the Child have created an international culture for inclusion by arguing that all forms of segregation are ‘ethically unacceptable’ (O’Hanlon, 2003). With a total population of about 27 million, Nepal has an estimated total disabled population of about 0.6 million (MOHP, 2011). The resulting socio-political transformation process after the Peace Agreement in 2006 put social inclusion and human rights at the top of the political and development agenda of Nepal, promoting rights of women, Dalits, Janjati and Madeshi. However, disability has not

yet strongly come up in the political and development discourse of Nepal, probably because it was not seen as one of the conflict triggers (NORAD, 2012).

Disablement has been conceptualised as a reflection of stigmatisation rather than a fixed state of disadvantage. Gleeson (1998; 130) refers to this phenomenon as ‘disability oppression’, the unique kind of social injustice surrounding the everyday lives of people with disabilities. Such kind of oppression derives from the ‘process of ableism’, the ‘internalization or self-loathing which devalues disablement’ (Campbell, 2009; 23). Viewing disability through this lens focuses largely on disabled people’s negative experiences, and thereby produces a pathological and paternalistic discourse to describe their condition. It is this argument that implicitly keeps them in a position of subordination. To go beyond a deficit-based view of disability, a theoretical shift has been initiated by the so-called social model of disabilities, which focuses on the social determinants underlying the definition of disability (Oliver, 1990). According to such model, impairment is determined by the nature of the functional limitations that strike a person’s body, whereas disability is the product of discriminatory social categorisations. The view of well known scholar in disability studies; Tom Shakespeare would also be remarkable. Shakespeare (2006; 55) opines that, “The approach to disability which I propose to adopt suggests that disability is always an interaction between individual and structural factors. Rather than getting fixated on defining disability either as a deficit or a structural disadvantage, a holistic understanding is required. The experience of a disabled person results from the relationship between factors intrinsic to the individual, and extrinsic factors arising from the wider context in which she finds herself.” However, as argued by Anastasiou and Kauffman (2013; 451), researchers should overcome this dichotomy in order to take into account the multiple aspects of disabled people’s experience (physical, psychological and social).

1.2 Disability in the context of Nepalese Society

Of the estimated 650 million persons with disabilities worldwide, 80% live in developing countries and are denied access to basic health, education, and support services (WHO, 2005). The majority of this populace is isolated and discriminated against, facing significant challenges to participating in 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). Due to lack of awareness, majority of the people see disability as a result of the sin in the past life. In this context in Nepal, disabled people are seen as ill omen. Majority of people still misperceive disability as the result of various supernatural factors such as fate, punishment of gods, evil eye curses or punishment for parents' sins (NPC /UNICEF, 2001). 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. So, the issue of social inclusion of disability is important aspect to consider.

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. 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.

Realizing the duty, the state is gradually taking steps to improve the situations of people with disability in the country by formulating the acts and laws for the protection of the welfare of individuals with disabilities, bringing out the new policies for integrating them in the mainstream society and systematizing the surroundings disability friendly. Enactment of Disabled Peoples' Welfare Act -1982 (DPWA) is one of the major outcomes of the subsequent change towards the support for the people with disabilities by the state after celebrating the International Year of Disabled People (IYDP) in 1981. The DPWA is considered as a comprehensive legal framework which incorporates the provisions that are

essential for the enhancement of lives of Persons with Disabilities. There are legal provisions addressing the disability rights such as, Special Children Act-1992, Disabled Protection and Welfare Rules (DPWR) - 1993, Special Education Policy - 1996, Disabled Service National Policy - 1996, Local Self-Governance Act - 1999, Labor Act -1999, Education Act Seventh Amendment – 2002 and National Policy and Plan of Action on Disability - 2006 have addressed the concerned issues of Persons with Disabilities (DRPI-Canada, 2013).

1.3 Debate of Inclusion versus Exclusion

Inclusion has been variously conceptualised as a process of reconstruction and reform to increase access and participation (Mittler, 2000); a process of increasing participation and decreasing exclusion from mainstream settings and communities (Booth & Ainscow, 1998); about respect, equality and collective belonging (Thomas & Loxley, 2001) and positive responses to diversity (Barton, 1997). Such concepts of inclusion tend to “transcend the concept of normalisation by using language that emphasises participation over normalcy” (Florian, 1998). Inclusion is increasingly seen as about race, gender, poverty and transcending traditional boundaries between those with and without a disability through a focus on the actions and responsibilities of everyone and not just on those of the disadvantaged, disabled or previously marginalised (Culham and Nind, 2003). In fact, the concept of inclusion advocates for the acceptance of people regardless of their differences by accepting that each person has a contribution to make in society irrespective of medical need, disability, race or gender (Dattilo, 2002).

In general, exclusion is considered as the opposite term to define inclusion. In this regards social exclusion can be understood as the mechanism or phenomenon which prevents the disadvantaged individual or group from the full enjoyment of all the rights, benefits as well as basic life requirements as the advantaged are supposed to do. “Social exclusion as a process can involve the systematic denial of entitlements to resources and services, and the denial of the right to participate on equal terms in social relationships in economic, social, cultural or political arenas. Exclusionary processes can occur at various levels – within and between households, villages, cities, states, and globally” (Khan, 2012). There are various understandings of social exclusion which emphasise different aspects: the groups at risk of

being excluded; what people are excluded from, e.g. employment, education, citizenship, respect; the problems associated with the impact of social exclusion, e.g. low income, poor housing; the processes driving exclusion; and the agents and actors involved (Ibid).

In the present day world, the essence of living a life with full dignity in regards to the respect of human rights and human values is the major concern. As a result the debate of inclusion versus exclusion is to be considered sensitively which in return will help to address some of the key questions such as “Do barriers apply generally, or are they concentrated at specific points? How is participation restricted, by whom and on what (institutional or ideological) grounds? Are there key gatekeepers who facilitate participatory or, alternatively, orchestrate exclusionary practices? Are the processes overt and direct? Are these strategies directed at people with disabilities in general or targeted at (impairment specific and other) subgroups? How far is the significance of the division between disabled and non-disabled people exacerbated or diminished across subgroups?” (Barnes & Mercer, 2003;43).

The debate of inclusion versus exclusion has produced very impressive ideas in the empirical studies. However, it is uncertain that how well the conceptualization of social inclusion will be practiced in different culture based societies in the world. Therefore, it is my interest to explore in this thesis how well the concepts of social inclusion are translated into local policy and practices as well as how people with disabilities reflect their experiences in terms of their inclusion in the society.

1.4 Choice of topic and Research problem

Scholars perceive and defend their view regarding disability on the basis of different model such as medical model or social model as appropriate to them. But, the absolute fact is that individuals with disabilities are the most marginalized, socially deprived, economically downtrodden and least prioritized group in the society. Due to cultural diversification in different societies, people with disabilities are perceived as ‘unfortunate’, ‘tragic’, ‘different’ or ‘sick’. Often, people consider individuals with disabilities as ‘useless’ which is directed by their lack of participation in mainstream economic activities. The reactions of people guided

by different cultural beliefs and social understandings make the life of people with disabilities hard. With the advent of debate of social inclusion and exclusion, the United Nations Organization (UNO) has addressed in the favour of people with disabilities and the member countries have promised for the management of necessary laws, policies and practices to integrate people with disabilities in the mainstream society. However, the progress in the life situation of people with disabilities in different parts of the world is not seen proportionately due to various factors.

I was born in Nepal and grew up in the society where people with disabilities are considered unfortunate and are kept away from others as far as possible. The harshness of the treatment varies for people with different impairments in Nepalese society. My knowledge and understanding of disability comes from my experience of growing in the society where the exclusionary practices are carried out for individuals with disabilities. During my stay in Norway as a student surprised me to know about the life of people with disabilities and their involvement in various activities socially, economically and culturally. I am well aware about the differences in resources and opportunities in Norway and Nepal but my Norwegian experience left me to challenge the cultural notion of disability in Nepalese context.

Nepal has ratified almost all the UN conventions regarding disability and other related issues. Similarly, several laws, policies have been promulgated by the state for ensuring the rights of people with disabilities but still the implementation of these laws and provisions in the acts has not been taken seriously. It may be due to serious lacking of economic resources in the country as well as lacking of making obligatory to follow the provisions mentioned in the acts and laws related to disability management. It is not that there is no any progress in the life situation of people with disabilities but it is not being as expected. This situation has made me grow an idea to do a research on social inclusion of people with disabilities in Nepal. With my interest in the study of involvement of individuals with disabilities in inclusive activities, I found my research question which is defined as: **What are the challenges that people with disabilities facing in their efforts to be included in Nepalese society?**

This is further supported by sub-questions such as:

- How do they react on, and explain the matters that are excluding them from participating in the mainstream society?
- How do the laws, policies and plans formulated by the state impact their everyday life and successful inclusion in the society?

Normally, the state promulgated laws and rules are obligatory to be followed by the citizens. Since, the laws, acts and policies for the protection of rights of people with disabilities are supposed to make the effort of inclusion easier for them. The study will further explore the gap between the policies and the real life experiences of the people with disabilities in their effort to be included in the society. In this study, I would like to explore how participants interpret the reality of living a life with disability in everyday life which will contribute to a deeper understanding of socio-cultural issues of the particular context.

1.5 Organization of the Thesis

The remaining part of this study is structured in the following way: chapter 2 is literature review including the studies that have already been conducted on disability and the social inclusion of people with disabilities in global context and in the context of Nepal as well. Theoretical framework on which this study is based will be presented in chapter 3. The theories include theory of social inclusion and exclusion which is the main concept of this study, social stigma theory, social identity theory and the empowerment approach. Chapter 4 contains the description of methodology which explains how the research has been conducted and analyzed.

Chapter 5 and 6 are the empirical chapters in this study. In chapter 5 the findings of the empirical study are presented. This chapter explains about the experience and the meaning of disability in the life of the participants. This chapter also explains the participants' experience in regards to their inclusion in the society. Chapter 6 presents the discussions of the findings explained in chapter 5. With the help of the theoretical framework the analytical discussions are made to understand meaning of inclusion in the life of people with disabilities and challenges they face in their effort to be included are also explored through the participants' interpretation. Chapter 7 which is the final one in the study presents the conclusion and the general discussion from the study in terms of theoretical framework with respect to analysis.

CHAPTER 2 LITERATURE REVIEW

This chapter intends to provide an understanding on disability as a whole and its inclusion as well as exclusion in terms of various social and cultural norms. In Nepal disability is one of the least studied disciplines. Thus, literatures on disability as a whole are seriously lacking. Above all, literatures regarding the experiences of people with disabilities are still to be explored in broader aspect. Existing literatures are mainly from the researches focused to disability and the integration of people with disabilities in education as well as community rehabilitation. Studies conducted from UN organizations and Western countries are taken account as literatures for this study as the information from these studies are however relevant to provide the understanding to this study. I have organized this literature review into two parts for easy understanding of the topic. The first part focuses on global perspective of disability and its inclusion whereas second part looks upon the accounts of previous works in the context of Nepal.

2.1 Global Studies

People with disabilities have been treated cruelly and negatively understood for very long historical time. They have always been present in our society being hidden or even in enigmatic form sometimes but due to various reasons they have become more visible in the present days. It is always difficult but important to define disability and there are many definitions available of which each one is valid with its own purpose. Definition of disability can be considered from medical or social models and also from the one which includes people with disability to society to the one which excludes as well as segregate them. People with disabilities are tend to be labelled as handicapped, disabled or impaired because they look different from the rest of society on account of their appearance, behaviour or capacity to learn (Baquer & Sharma, 1997). “The individual’s impairment or abnormality necessitates dependence on family, friends and welfare services, with many segregated in specialized institutions. In short, disability amounts to a ‘personal tragedy’ and a social problem or ‘burden’ for the rest of society” (Barnes& Mercer, 2003).

Twentieth -century social theory typically followed medical judgements in identifying disabled people as those individuals with physical, sensory and cognitive impairments as

‘less-than –whole’ and hence unable to perform valued social roles and obligations (Dartington et al. 1981). Such incapability of an individual has left the person dependent on the others. These and other negative associations meant that disability was perceived as a ‘personal tragedy’; an approach in which the individual is regarded as a victim, and as someone who is in need of ‘care and attention’, and dependent on others – a perspective which has been at the heart of contemporary social welfare policies designed to help people with disabilities cope with their disability (Oliver, 1983). The individual medical model of disability basically concerns to diagnose the bodily or sensory abnormalities and provide suggestions for appropriate treatment required. There is an associated administrative and policy interest in translating the individual’s disability into specific needs – for welfare benefits and services (Albrecht, 1976).

“During the 1970s and 1980s, disabled activists and their organizations voiced increasing criticism of the individual, medical model of disability. In developing what became known as a social approach to disability, disabled people with impairments, and therefore any meaningful solution must be directed at societal change rather than adjustment and rehabilitation” (Barnes et al. 1999). The Union of Physically Impaired Against Segregation (UPIAS), a strong critic of individual medical model argued to put the responsibility of disability completely on the failure of society. UPIAS (1976) argues that “in our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. People with disability are therefore an oppressed group in society.”

Similarly, Finkelstein (1980) describes disability as the outcome of an oppressive relationship between people with impairments and the rest of society. “once defined as a disabled person, the individual is stigmatized, and social expectations about how a person with disability should behave, or what they are capable of doing, exert an influence independent of their impairment. The assumption is that the form of disability – that is, social oppression – is universal is rejected by those following a social approach who point to the cultural and historical variation which characterizes disability” (Barnes et al. 1999). The social concept of disability explains the individual’s experience of disability in the context of the overall biography as the interconnected social relationships and life history. As a result, when the

circumstances of disabling barriers and attitudes in society get wider, the impact of state policies and welfare support system becomes weaker. There are several evidences of marginalization of individuals who possesses the lower hierarchy in the power relationship in the society. People with disability have been effectively marginalized and excluded from the mainstream of social life; and this aspect of disabling society needs to be explored in the context of unequal power and social resources (Barnes et al. 1999).

In the present social concept, disability has been tried to be understood in terms of social oppression and social exclusion which has led the debate of inclusion versus exclusion in the broader dimension. Social oppression concerns the restrictions imposed on social groups such as people with disabilities which keeps them from participating in everyday social activities; to the extent that such social exclusion is practised, people with disabilities have fewer possibilities to advance and defend their interest within society (Barnes & Mercer, 2003).

We can find several practices as social exclusion which restricts the engagement of people with disabilities from education, employment, leisure, transportation and so on. There can be seen the provision of special schools for children with disabilities established to combat the social exclusion which limits the access of education for the people with disabilities. The conventional explanation is that segregated schools emerged as a philanthropic response to the special needs of those unable to cope in the mainstream sector (Warnock, 1978). An alternative conflict perspective attributes their growth to the generalized interest in controlling potentially disruptive social problems, such as uneducable or troublesome children (Oliver, 1990).

In the discourse of disability studies, segregated schools for children with disabilities have long been preferred option ahead of mainstream schools. However, the recent concepts of social inclusion clearly criticize the segregated schools for special groups in the society. Critics of special education argue that removing children with disabilities from family, peer and the local community has wide-ranging negative effects (Morris, 1997). It has been criticized that residential and segregated schools have restricted the opportunities of children with disabilities from growing the social network with their non-disabled counterparts.

Instead of segregated institutions, inclusive education system is advised to be preferred for overall inclusion of people with disabilities in the mainstream society. As an illustration, the Salamanca Statement and Framework for Action on Special Needs Education was endorsed by 92 governments. It is unequivocal in declaring that ‘the integration of children and youth with special needs is best achieved within inclusive schools that serve all children within a community’ (UNESCO, 1994).

“In most industrialized countries paid work is a significant criterion in categorizing people in terms of class, status and power. This means that people on the margins of the labour market encounter a variety of economic, political and social deprivations. This form of distributive injustice is widely experienced by people with disabilities.” (Barnes et al. 1999). People with disabilities are particularly under-represented in the professions and management, where there are higher earnings and greater job security and opportunities for promotion; conversely, people with disabilities are over-represented in low-skilled, poorly paid, less secure jobs (Roulstone, 1998).

Studies looking at the wide range of countries document the very different ways in which different cultures perceive impairments and body –mind variations (Ingstad and Whyte, 1995). Different societies are comprised of different cultural beliefs and these cultural beliefs are guided by the existing religions followed by people. “It is widely argued that religious ideas and teachings are the main determinants of what is socially acceptable in non-Western contexts, which means that the role of material factors in the creation of disability is largely overlooked” (Barnes & Mercer, 2003). In societies where these religions claim wide popular allegiance, perceived impairments are significant for people’s life chances, because they are widely regarded as misfortunes, sent by deity, karma, fate; often associated with parental sin (Miles, 1995). These religions like Christianity also tend to emphasize ways of understanding and responding to misfortune through individual acceptance as a means of spiritual salvation (Charlton, 1998). However, most social research in poorer countries has concentrated on responses to impairment in small-scale, rural-based groups, where religious beliefs may exert a stronger impact than they do on those living in urban environments (Ingstad and Whyte, 1995).

Disability and poverty are interrelated terms. So, goals of development overcoming the existing poverty cannot be achieved without addressing the proper management of disability inclusion in the society. The studies on disability show that an individual with disability often lives in the poverty and because of his inability to participate in economic activities properly; his economic situation becomes poorer. Similarly, poverty of an individual cannot earn the good medical facility which later on may lead to impairment. Thus, disability and poverty has vicious cycle running continuously. It is true that for people who cannot afford enough food to eat, the presence of a member in a family with impairment can have devastating effects. A combination of desperate economic circumstances, lack of other support, cultural considerations and/or ignorance can result in families hiding or abandoning their disabled offspring (Ingstad, 2001).

2.2 Nepalese Studies

Prevalence and conditions of disability in Nepal are shown differently by different reports. A 2001 study conducted by NPC/UNICEF reported a 1.63 per cent prevalence rate, whereas various district level studies indicate 3–5 per cent. WHO estimates 7–10 per cent prevalence in underdeveloped countries overall, including Nepal. The major causes of disability are poverty, malnutrition, polio, communicable diseases, consanguinity, and accidents (Dhungana and Kusakabe, 2010). NPC/UNICEF (2001) noted that “approximately 70 per cent of persons with disabilities in Nepal lack education. Furthermore, 85 per cent of people with disabilities have no access to health facilities related to their impairment; 77.8 per cent of people with disabilities are not engaged in any income-generating activity, and some 69 per cent of people with disabilities depend on their families, which poses an economic problem for the household.”

Most people in the rural and semi-urban areas of Nepal view disability as a penance for sins committed in previous lives. Even in towns and cities, where people are better educated, they are influenced by such belief systems and hold strong prejudices against people with disabilities (NPC/UNICEF, 2001). Calcraft’s research (2006) on leprosy (Hansen’s Disease) in the Terai area of south-east Nepal found that disability is regarded as a result of divine punishment, and that people are not aware of its bacterial cause. Cases were found where

leprosy-affected people lost their employment for fear of contagion. NPC/UNICEF (2001) indicates that 70.1 per cent of people with disabilities in Nepal face stigma and lack self-respect within the community. Despite the recent efforts of disabled people's organisations, many People with disabilities still face the stigma related to their impairment, as most people are ignorant of the different causes, types, and cures for disability (Dhungana and Kusakabe, 2010).

Nepalese society assigns tightly defined gender roles to men as breadwinners and women as homemakers where marriage is seen as the most acceptable (economic) option for women, as it offers the best way for them to gain access – through their husbands – to the property and land that can secure their livelihood (UNICEF, 2006). However, women with disabilities are less likely to marry than are men with disabilities, as they are considered incapable of reproductive work (Dhungana, 2006).

It is true that men with disabilities also face similar problems in establishing family life as that of women with disabilities but their chances of marriage are higher, due to their entitlement to family property and also the greater likelihood of getting jobs (Thomas and Thomas 2002). Dhital (2005) in Dhungana and Kusakabe (2006), argues that there are fewer social constraints on men with disabilities seeking marriage; and surprisingly, even those men with disabilities prefer not to marry women with disabilities, fearing that they will not be able to fulfil their traditional roles or satisfy their husband's sexual wishes.

The life situation of people with disabilities in Nepal is not found satisfactory by several studies which indicate that they live in extreme poverty with lack of facilities of basic requirement, proper medication, education and lack participation in income generating activities. "While there are multiple reasons behind poverty among people with disabilities in developing countries like Nepal, poor access to education or employment stands out as one of the major factors. Several studies have concluded that education is an advantage in the labour market and it has been found that better-educated individuals earn higher wages, experience less unemployment, and tend to work in occupations with higher status and greater job security than their less educated counterparts" (Lamichhane & Okubo, 2014).

CHAPTER 3 THEORITICAL FRAMEWORK

This study of disability inclusion has made use of several theoretical perspectives such as theory of inclusion and exclusion, stigma and labelling theory, social selves and construction of reality theory and empowerment approach which I believe can provide good understanding to view the interaction of various societal structures with lived experiences of inclusion/exclusion. This study utilizes the works from the authors such as Goffman (1963), Burkitt (2008), Burger and Luckman (1966), Mead (1993), Rimmerman (2013), Healy (2005), Saleeby (2006), Oliver (1990) and others.

The use of different theoretical framework not only delivers the necessary knowledge base to understand the issues of disability in detail but also contributes in understanding and analyzing the findings. As this study intends to explore the experiences of inclusion and exclusion by the people with disabilities, the theory of inclusion and exclusion is considered as the main theory which is supported by social stigma theory and social identity theory. This chapter aims at shedding light briefly on the outline of the theory and approaches used in this study and the purposes they serve.

3.1 Theory of Social Inclusion and Exclusion

While performing the everyday activities in the social world, sometimes one is welcomed or recognized by the mainstream whereas in other cases one is ignored or denied. In both, the outcome is considered as social practices. These social practices result from the interaction between friends, colleagues, families, kinships, communities or even whole society.

Fredericks (2010) suggests that belongingness as experienced in everyday relations constructs the kinds of sentiments on which societies of exclusion and inclusion are based. Rimmerman (2013) argues that social exclusion is a complex concept that expresses disadvantages in relation to certain norms of social, economic or political activity related to individuals, households, spatial areas or population group. Thus, social exclusion can be understood as the process through which individuals or groups are wholly or partially excluded from full participation in the society within which they live (Francis,2002 cited in Rawal, 2008).

Aasland and Flotten (2000), consider social exclusion as multidimensional phenomena and have considered several important living condition variables such as exclusion from formal citizenship rights, exclusion from labour market, exclusion from participation in civil society and exclusion from social arenas as proxies for social exclusion. Francis (2002) in Rawal, (2008) locates the strength of social exclusion as a concept in its attempt to capture the multifaceted character of social deprivation, especially its institutional and cultural aspects. This conception of social exclusion has been labeled as multidimensional concept of exclusion which broadens out the notion of material poverty and identifies social problems and then labels them as aspects of social exclusion (Geddes and Benington, 2001 cited in Rawal, 2008). Sen (2000) associates idea of social exclusion to capability perspective on poverty as: “I would suggest that it is useful to investigate the literature on “social exclusion” using this broadly Aristotelian approach. The connections are immediate. First, we have good reason to value not being excluded from social relations, and in this sense, social exclusion may be directly a part of capability poverty. Second, being excluded from social relations can lead to other deprivations as well, thereby further limiting our living opportunities. For example, being excluded from the opportunity to be employed or to receive credit may lead to economic impoverishment that may, in turn, lead to other deprivations (such as undernourishment or homelessness). Social exclusion can thus, be constitutively a part of capability deprivation as well as instrumentally a cause of diverse capability failures. The case for seeing social exclusion as an approach to poverty is easy enough to establish within the general perspective of poverty as capability failure (Sen, 2000:4-5)”.

Inclusion is viewed as a desirable outcome or as a strategy to combat social exclusion, whereas exclusion is viewed as an expression of poor social cohesion (Rimmerman, 2013). Repper and Perkins (2003), furthermore defines social inclusion exclusively as a desired goal that requires equality of opportunity and participation in the rudimentary and fundamental functions of society (Repper and Perkins, 2003 in Rimmerman, 2013). The dimension of social inclusion varies from strategy to desired goal in our understanding. Therefore, in most of the social science literature, social inclusion is termed as being opposite of social exclusion. Dunn(1999), made a descriptive distinction between the two terms by claiming that social inclusion must come down to somewhere to live, something to do, someone to love. Social exclusion has been interpreted as a compound process that operates in all areas of

life – daily living, work and training, and access to services including health, insurance, consumer and leisure services (Ibid.).

Based on different notions of social integration, the three paradigms of social exclusion as described by Silver (1994), such as solidarity, specialization and monopoly attribute exclusion to a different cause and are grounded in a different political philosophy and provide an explanation of multiple forms of social disadvantage. Solidarity refers to social relations and the effort to create a cohesive society. In this case, social exclusion is perceived as a lack of solidarity or crisis in shared values and rights. Specialization is consonant with pluralism and public choice; therefore, exclusion occurs when there are core barriers to the flow of exchanges between individuals or among groups. Monopoly is usually associated with Marxism and social exclusion with oppression of the needy or poor (Rimmerman, 2013: 36).

While conceptualizing social exclusion and inclusion, it is equally important to understand the dimensions of social exclusion. Percy-Smith (2000), argues that social exclusion may relate to economic, political and spatial exclusion, as well as lack of access to specific areas such as information, medical provision, housing, policing and security which are seen to be interrelated and reinforce each other and as being associated with participation in full citizenship. Rimmerman (2013), highlights that social exclusion has been interpreted in terms of social and civic participation and has included consumption, saving, production, political and social activity. An individual's ability to participate in these activities will be affected by a range of interconnected factors including personal experience and life history, the characteristics of the area in which they live and the social, civil and political institutions with which they have to interact.

Burchardt et al. (1999) clarifies that social exclusion cannot be conceptualized separately from economic, social, political, neighbourhood and spatial, individual and group factors. Rimmerman (2013:37), sheds light on these dimensions as the economic factor is defined in terms of lack of an adequate income and unemployment, in addition to macro changes in the economy and labour market whereas the social aspect is defined as a breakdown of social norms and is expressed in the ability of people to participate in or make decisions that affect

their lives. Similarly, the political dimension is reflected in the ability of people to participate in or make decisions that affect their lives. The neighbourhood and spatial dimension of social exclusion presents the inability of local support networks to provide decent housing and services associated with combating neglect and decaying conditions. Finally, the group dimension of social exclusion is reflected in being different in some way from the dominant population or being marginalized in terms of social status.

Rimmerman (2013), argues that the history of disability demonstrates that people with disabilities lived on the margin of society, excluded from opportunities like housing, employment, healthcare, civic engagement, democratic participation and due process and entire human rights. Thus, if disabled people are characterized by their separation from the 'normal' population, specific representations of disability may be both contested and contradictory (Barne et al., 1999). In the context of unequal power and social resources, people with disability have been effectively marginalized and thus, excluded from the mainstream of social life. To normalize the disabling consequences of their illness or impairment and achieve some degree of social reintegration, doctors and other therapeutic personnel work with people with disability (Ibid.). However, the experience of many people with disability is that they are treated more as objects than as active participants in the treatment process and manipulated against their wishes into an 'abnormal' lifestyle (Albrecht, 1992).

In the name of combating social exclusion of people with disability when the inclusive strategies in the form of administrative system of welfare, employment and social security are implemented, sometimes, affects negatively keeping the people with disability largely at the margin. Blaxter (1976), offers considerable evidence that structural factors adversely affect people with disability ranging from a lack of technical aids and adaptations and poor housing to the reliance of social services on the informal voluntary support of female relatives. Locker (1983), stresses that barriers must be negotiated, consuming reserves of time, money and energy or where the effort is such the person decides not to bother and retreats into an enforced passivity. It is also handicapping to the extent it leaves the individual with no option but to rely on the help of others.

Interaction between people with disability and able bodied people in relation of day to day activities need to answer the queries in regards to their inclusion. People with disability are set apart from the ordinary in ways which see them as posing a direct challenge to commonly held societal values by appearing as unfortunate, useless, different, oppressed and sick (Hunt, 1996). For Hunt, people with disability are perceived as unfortunate because it is assumed that they are unable to enjoy the social and material benefits of modern living. These include the opportunity for marriage, parenthood, social status, independence and freedom, employment, a house and plenty more denied us (Barnes et al.,1999). People with disability are viewed as ‘useless’ because they are deemed unable to contribute to the economic good of the community. This marks them out as ‘abnormal’ and ‘different’ or members of a minority group. Moreover, people’s shocked reactions to the ‘obvious deviant’ stimulates their own deepest fears and difficulties, their failure to accept themselves as they really are and the other person simply as other (Ibid.)

Disability can also be understood as a form of social oppression. The works of Abberley (1987) and Young (1990) represent some of the most sophisticated discussion of what this might entail. Abberley (1987) argues that oppression is an all-inclusive concept which is located in hierarchical social relations and divisions and indeed, for many people with disability the biological difference is itself a part of the oppression. Because of the physical impairments associated with people, their activities are very often restricted. Thus, people with disability are oppressed because they are denied full participation in social life (Ibid.). Young (1990), states that the isolation and exclusion associated with marginalization form central elements in the experience of people with disability which is the most dangerous form of oppression because of the risk of their removal from social life through their education and accommodation in special institutions.

The experience of being excluded is often associated with negative emotions and feelings and a sense of sadness, loneliness, anger, shame and anxiety (Leary,2001). Rimmerman (2013), argues that rejection of an entire group of people, such as people with disabilities, can have negative effects, particularly when it results in social avoidance or isolation. Exclusion is therefore basically a disassociation process that ends with stigmatization, when a shared characteristic of a category of people like those associated with disability becomes consensually regarded as a basis for dissociating from (that is, avoiding, excluding,

ostracising, or otherwise minimizing interaction with) individuals who are perceived to be members of that category (Leary et al., 1998).

3.2 Social Stigma Theory

Stigma can be understood as an adverse reaction to the perception of a negatively evaluated difference (Susman 1994). As such, it is not an attribute of the individual who bears the difference but rather resides in interactions between the person with the difference and others who evaluate that difference in negative terms (Goffman 1963). While defining the term stigma, the work of Goffman (1963) is worth mentioning. According to him, “stigma is an attribute that is deeply discrediting and that reduces the bearer from a whole and usual person to a tainted, discounted one” (Goffman, 1963: 3). Goffman argues that the stigmatized self arises when there is an undesirable discrepancy between one’s virtual social identity (what society expects from him/her in a given situation at a given point of time) and actual identity (what the person actually is). Thus, the stigma makes a person less desirable and different from the ones who are normal (Ibid: 5).

Goffman argues that although a social intercourse between a normal and stigmatized person can happen at various points spread across a time span, he delves largely on ‘mixed contacts’, that is, immediate social contact of a normal person with a stigmatized one in the same social situation (Goffman, 1963: 12). Stigma is broadly defined to include abominations of the body – the various physical deformities, blemishes of individual character and the tribal stigma of race, nation and religion (Ibid.: 14). In each case, undesired differentness from the normal ones provides the basis for the stigma (Barnes et al., 1999). Thus, Goffman (1963) argues that, “the standards the person with stigma has incorporated from the wider society equip him to be intimately alive to what others see as his failing; inevitable causing him to agree that he does indeed fall short of what he really ought to be. Shame becomes a central possibility, arising from the individual’s perception of one of his own attitudes as being defiling things to process, and one he can readily see himself not possessing” (Goffman, 1963: 7).

Goffman suggests that the notion of normal human being may have its origins 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 system to confer a social identity exists prior to social interaction, and is established by society (Ibid.:11). It is bolstered by an ideological justification for treating those with a perceived stigma as not quite human (Ibid.:15). In everyday interaction, specific stigma terms such as cripple, bastard and moron are used to demean (Ibid.: 15). Most controversially, he presumes a value consensus which unites both normal ones and the stigmatized in recognizing who is normal human being and who is not (Barnes et al., 1999).

Link and Phelan (2001) argue that stigma can only be directly enacted upon individuals when there is a power differential between those with the trait and those without— when those who have the negatively evaluated difference have less power than those who do not. Thus, the stigmatization of individuals with disabilities is a complex process which involves individual biological differences, the negative evaluation of those differences by others, adverse reactions of others and negative social and emotional outcomes for individuals with disabilities (Ibid).

Link and Phelan (2001), advocates for the conceptualization of stigma in relation with interrelated components of labelling, stereotyping, separating, emotional reactions, 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 labelled persons to undesirable characteristics—to negative stereotypes. In the third, labelled persons are placed in distinct categories so as to accomplish some degree of separation of “us” from “them.” In the fourth, labelled 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 labelled 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” (Ibid.: 367).

In understanding different aspects of stigma it is also important to look closely its linkage with discrimination. Corrigan and Kleinlein (2005), perceive stigma as comprising of two components such as stereotype and prejudice which lead to discrimination. According to

them, Stereotype is seen as the collective concepts of groups which allow people to make quick generalizations about others and on the other hand, prejudice occurs when people agree with existing stereotypes and develop emotional reactions towards them (Ibid). The stereotype associated due to undesired difference in the case of people with disability is quite contagious so that close family and friends acquire stigma and in many cases they try avoiding the contact of the person with disability (Goffman, 1963:44). Such exposition on stigma, stereotype and prejudice are crucial to this study get insight into the aspects of Nepalese culture which considers the people with disabilities are disqualified to participate in social functions. Thus, the discriminatory attitude related with stigma makes the inclusion of people with disabilities in society difficult.

“Nevertheless, there remains considerable scope for uncertainty in encounters between normal ones and stigmatized ones and Goffman pays considerable attention to the ways in which stigmatized individuals attempt to manage their spoiled identity” (Barnes et al.,1999: 44). This can very well be reflected in the case of people with disabilities. For the management of spoiled identity Goffman puts forwards three strategies namely passing, covering and withdrawal. Passing is the management of undisclosed discrediting information about self (Goffman, 1963:58). Covering is a dilemma of the discredited with tension to manage and similarly withdrawal entails removal from social activities with normal ones together (Ibid:125). For the stigmatized to adjust to their predicament presumes an attempt: first to make the best of things and cultivate a cheerful outgoing manner, second not to go too far in normalization lest these efforts embarrass normal ones or be construed as an attempt to deny differentness and third to avoid self pity or resentment (Barnes et al., 1999).

“It appears that the process of exclusion and stigmatization is evolutionary in nature and represents the rejection of groups like people with disability that appear to be a burden on society” (Rimmerman, 2013: 41). It is understandable that stigma operates in relation to what others perceive about a person with disability and it is closely associated with feelings based on social interactions with others or in anticipation with how others react upon it.

3.3 Social Identity Theory

Social identity is regarded as a person's sense of 'who I am' based on his/her membership in a group in which he/she belongs. By selecting an identity, the individual is associated with attributes that determine what is viewed as negative or positive. Berger and Luckman (1966:194) states that identity is central to subjective reality and concerns with the dialectical relationship with society. Accordingly, identity is created during the social processes. On this view, identity is also seen as a phenomenon emerging from a dialectic relationship between the individual and society. Furthermore, Giddens (1991) argues that self identity is a routinely created phenomenon which sustains through the reflexive activities of the individual. In this sense, individuals are expected to develop a self identity in response to their social context since their childhood (Mead, 1993).

Mead (1993), opines that, individuals are a product of their society and views about the "self" are shaped by the societies they encounter. Furthermore, Mead (1993), differentiated between the "I" and the 'me' to explain how the self is constructed through interaction with others. Social experiences and activities are seen as key elements in the process of developing self identity. As a result people are tended to look upon other people to see the image of the self identity which will be reflected back in terms of words, attitudes, expressions and actions (Burkitt, 2008). The idea of self identity implies that what the individuals becomes is to a large extent depends upon their reconstructive efforts.

Burkitt (2008:3) argues that every individual is associated with a society composed of social relations that bear the imprint of a power structure, including a hierarchy of social classes or other groupings according to rank and status, along with a culture with its beliefs and values, such as religion, or other bodies of knowledge like science. The factors such as family, neighbourhood, social contacts, social class, gender, ethnicity, and the beliefs and values influence the way individuals develop their self. With different social relations individuals are continuously judged by the people around them and in return individuals try to create their self image in many different ways being guided by these judgements. When individuals seek to discover who they are, they often search for their hidden identity in the given social setting. Therefore, the formation of self depends on what people do and how do they share ideas with others and perform joint activities.

Burkitt (2008) further states that self identity is in many aspects related to social class and power relations within a given social structure. The individuals' understandings on pride and shame or both are very much depended on the capitals including material, cultural, social and symbolic. Through the social interaction of different power relations in the societal setting of Nepal how do people with disability perceive their self identity will help me to understand the challenges of their inclusion in Nepalese society.

3.4 Empowerment Approach

Payne (2005) argues that empowerment is seen as a means of enabling people to overcome barriers, to achieve life objectives and to gain access to services. Saleebey (2006) has defined empowerment as a process of assisting individuals, groups, families and communities to discover the resources and tools within and around them. This also means that empowerment is achieved by ensuring people with resources, opportunities, vocabulary, knowledge and skills needed to increase their capacity (Tesoriero, 2010). The conceptual framework of empowerment approach proposes professional purpose, values, principles, knowledge base, and methodology to working with individuals, families, small groups, and communities that face poverty and oppression (Lee, 2001).

In social work literature, Adams (1996) makes an interesting observation as “the antecedents to empowerment are a combination of traditions of mutual aid, self-help, and, more recently, movements of liberation, rights and social activism, strengthened by anti-racism, feminism, critiques of inequalities and oppressions arising from social class, age, disability, sexuality, religion and other differences” (Adams, 1996: 2). The main idea of empowerment is to overcome contradictions between independence and dependence, independence and guardianship, and civil rights and the government. Particularly, empowerment focuses on enabling representation for groups suffering from discrimination (Borodkina et al., 2013). This serves best for the purpose of developing the life management skills of people with disability and their capacity for independent living.

Saleebey (2002), argues that empowerment can be defined as “the intent to, and the process of, assisting individuals, groups, families, and communities to discover and expend the resources and tools within and around them” (Saleebey, 2002: 9). This study intends to

explore the challenges of people with disability in the course to their inclusion in the mainstream society in Nepal. Therefore, empowerment of people with disability is tried to be understood in the account of the definition proposed by Hansenfeld (1987). According to Hansenfeld (1987), empowerment is “a process through which clients obtain resources personal, organizational, and community that enable them to gain greater control over their environment and to attain their aspirations” (Ibid, 478–479).

Empowerment approach makes connections between inadequate social policies and programs, personal vulnerabilities, and the need for a fair start in obtaining vital internal and external resources (Lee, 2001). In social work discourse, different theories are used to practice the empowerment approach. Among them I will make use of Strengths Perspective and Anti- Oppressive theory as they provide relevant frameworks and insights for delivering support and advocacy services (Healy, 2005).

3.4.1 Strengths Perspective

The strengths perspective focuses on the capacities and potentialities of individuals. It concentrates on enabling individuals and communities to articulate, and work towards, their hopes for the future, rather than seeking to remedy the problem of the past or even the present (Healy, 2005: 152). According to Saleebey (1997: 4), the strengths perspective formula is simple: “Mobilize clients’ strengths (talent, knowledge, capacities) in the service of achieving their goals and visions and the clients will have a better quality of life on their terms”.

Strengths perspective gives emphasis to focus on the individuals’ strengths and capacities rather concentrating on personal pathology. According to Reynolds (1951) “recognition of what a client has to work with, in himself, is a better starting point than an attempt to make him accept his failure, and, building him up as a person makes him more ready, rather less so, to go on to further growth and accomplishment” (Reynolds, 1951 in Healy, 2005: 155).

While practicing, on the basis of strengths perspective, social workers turn their attention to the capacities and assets of service users and their communities, and use service users’ hopes and dreams, however unrealistic they may seem, as the guide (Healy, 2005: 154).

The strength perspective has recognized and focused on the strengths and capacities of service users to respond to the problems facing them, view service provision as a mutual learning process for service provider, seek to depersonalize the problems facing the service user (Healy, 2005). In practicing social work, a social worker creates a language of strength, hope and movement. Instead of asking family members what their problems are, a social worker can ask what strengths they bring to the family and what they think are the strengths of other family members. In fact, people are more motivated to change when their strengths are supported (Healy, 2005).

Healy (2005), argues that a strengths-oriented approach suggests that the process of identifying and reinforcing service users' capacities, of itself, contributes to positive change as it reveals existing strengths that might otherwise be overlooked and while doing so they would seek out strengths, not only within the individual, but also within their formal and informal networks (Ibid.). The strengths perspective also encourages the social work practitioners to focus on the social, as well as the individual, context of service user concerns. In contrast to the individualistic orientation of the dominant discourses shaping social work practice, the strengths perspective draws the attention of social work practitioners to how the resources within the service users' informal and formal networks can be used, or developed, to assist them achieve their hopes and dreams (Ibid.: 167).

Saleebey (2006) states that strength perspective is strongly aligned with solution-focused and empowerment approaches which honour the innate wisdom of the human spirit and makes contribution in the inherent capacity for transformation of even the most humbled and abused ones. On this view the use of strength perspective is also important in the study to address how the challenges faced by the people with disability can be assessed so as to their successful inclusion in the society.

CHAPTER 4 METHODOLOGY

Methodology can be defined as the choices we make about cases to study, methods of data gathering and forms of data analysis in planning and executing a research study (Silverman, 2006:15). In other words, methodology can be understood as a set of strategic methods developed to gather evidence from the real world about specific social phenomena (Mason, 1996).

Silverman (2010) have argued that, in the field of social research, no single methodology is better than the other. However, given the complexities of the real world, it is important to choose a methodology that is relevant to the research problem at hand as it defines how one will go about studying any phenomenon (Silverman, 2010). Here, I will mention about what I did throughout the conduction of this research project. Thus, as suggested by Berg (2009), I will emphasize not only what the data consists of and the process how I collected data but also the method how the data is organized and analyzed later on. Cooper (1984) has highlighted that a researcher needs to focus on methods that will be used in research and these methods should be argued with relevance to their strength and weaknesses taking into consideration the importance of choosing some methods over others.

Since this study is supposed to explore the experience of inclusion and exclusion by Nepalese people with disability, it can therefore be argued that the study is looked through the lens of interpretive paradigm and thus, explorative in nature. Interpretive studies attempt to demonstrate the expression of people and their actions in narrative or descriptive ways by presenting situations as closely as possible to the experience of people (Merriam, 2009). In regards to this, this study seeks to explain the challenges that People with disabilities are facing in their effort to be included in Nepalese society. Thus, the above mentioned concept has influenced my choice of methods employed and how the study is carried out up to large extent.

4.1 Research Method: Why Qualitative?

The method adopted in research becomes significant only when it provides the basis for framing of the study and examines the numerous terms to describe the perspective in detail. So, the selection of research method is based on the nature of the research question posed as

well as the preferences of the researchers (Strauss & Corbin, 1998). This study aims at finding the answer of the research question as what are the challenges that Nepalese people with disability facing in their effort to be included in the society. To understand and examine closely the lived experiences of people with disability, I adopt qualitative method as a technique of research in this study. Qualitative methods make sense when it is meaningful to understand and interpret human behaviours and the reason that controls these activities. The qualitative research methods have therefore the ability to investigate not just the questions of what, where and when but also why and how which are fundamental to understanding phenomena being investigated (Silverman, 2006). Berg (2009), argues that the meanings that we give to events and things come from their qualities therefore qualitative research is necessary when one wants to understand lives.

The qualitative research enters into the world of participants, to see the world from their perspective and in doing so make discoveries that will contribute to the development of empirical knowledge (Strauss & Corbin 2008). Indeed, seeing research participants' lives from the inside often gives a researcher otherwise unobtainable view and later during the time of analysis the flexibility of qualitative research permits you to follow leads that emerge (Charmaz , 2006). Charmaz (ibid) further adds that qualitative research is like a camera with many lenses, first we view a broad sweep of landscape and subsequently, we change our lens several times to bring scenes closer and closer into view. The choice of other technique i.e. quantitative rather qualitative method would demand high amount of quantifiable data and in return would not allow me the flexibility to analyze the data collected for drawing conclusion in different direction than afore predicted.

In my study qualitative research fits more suitable because my focus is on what the people are experiencing in their social life in the course of their inclusion with other people. In this study there is a clear indication of why I am using qualitative study because my focus is on capturing the experiences of the people who have practiced in this process and what this means to them, the challenges that they have experienced in due course and how they feel about it. Thus according to Berg (2009) this study is looking for concepts, characteristics and the description of events, hereby related to the social inclusion of people with disability.

4.2 Research Area and My Role as a Researcher

From the very beginning I was keenly interested in disability studies as I have seen from very near and have been closely in contact with people associated with disability. In the context where I grew up, people with disability were not treated with respect and most of them lived in poor economical as well as social situation. It is somehow easier to understand that the reason of their poverty was their lack of employment. Although in the later days few people with disability were seen to be employed, it was still challenging for them to live with respect. Being a social work student, I seek to conduct an empirical study about people with disability and their employment.

The research was conducted in Kathmandu valley which comprises the capital city Kathmandu and two other major districts Lalitpur and Bhaktapur. Kathmandu valley is relatively large with population nearly 2.6 million (CBS, 2012). The population of the study area is the mixture of different ethnicities and socio-economically diversified as well as containing marginalized and downtrodden groups. People with disabilities are one of the marginalized groups in Nepalese society. Being the capital of the country, Kathmandu valley is the major employment centre. My study is focused on the employment related experiences by people with disability, thus, the selection of research area is justifiable. As this study is very specialized and related only to the people with disability who are employed, the access to them is equally challenging. Therefore, the first contact, the so called gatekeeper, of the study was the source person of one NGO, NFDN (National Federation of Disabled Nepal) closely working with them.

NFDN is an umbrella organization of number of other associations working for people with disability such as Nepal Association of the Blind (NAB), National Deaf Federation (NDFN), National Association of Physical Disability (NAPD), Nepal Disabled Women Association (NDWA), Nepal Disabled Human Rights Centre (DHRC), National Association of Deaf and Hard of Hearing (NADH), National Rehabilitation Centre for Disability NRCD) etc. At the outset, the gatekeeper (Source person) was requested to help in selection of the samples. The source person made contact with number of people with disability who are employed and were employed but became unemployed recently and managed two well trained enumerators working as field worker later when I faced difficulties conducting interviews with the selected people. The source person organized the venue and time for the interviews with

employed people with disability. The interviews were conducted at the office of NFDN for the convenience and easy accessibility. 8 in-depth interviews and one focus group discussion with 5 people were conducted during the field work which was organized in December, 2014.

I had a cousin named Rita (now deceased) who was very different from other children and always kept indoors. As a result from the early days, I was very curious to know why she was not taken out to play with other children like us. I was told that she was sick and nobody would like to play with her. Moreover, whenever she was taken out, people stared at her and asked many questions which made her parents and other family members feel embarrassed. So, she was kept out of public view being completely ignored in sorry situation. Later I came to know that she was associated with intellectual disability. Whenever I see people who look and behave different like my late cousin, I feel sad due to which I grew interest to know why people behave differently to the people with disability and led me to conduct this study. My familiarity with the topic of this research put me in the position to cope easily during my field work and at the same time left the chance that any result that I draw would be affected by my pre-occupied concept. But it was very challenging to conduct interviews with people associated with disability as they were not very willing to participate in the study being conducted by a person without having disability like me. Due to the failure attempt for the conduction of interviews a couple of times, the enumerators who are also associated with disability were appointed and the entire interview and focus group discussion were conducted by them in the close presence of me. During that time, although I didn't ask any questions to the participants, I got ample opportunity to observe their body language and reaction for the questions posed to them.

4.3 Sampling

The logic of using a sample of subjects is to make interferences about some larger population from a smaller one (Berg, 2012). As Kathmandu valley is a densely populated large area, it is very challenging to go through every case so, I had to sample a certain population to be included in this study.

Berg (2012), states that, in non-probability sampling the investigator does not base his or her sample selection on probability theory and its advantage is that non probability samples offer

the benefits of not requiring a list of all possible elements in a full population. I used non probability sampling in this study because of the nature of the research.

Purposive sampling is used in this study for the reason I can use my special knowledge or expertise about some group to select subjects who represent this population. Not only this but I can also select samples after field investigations on some groups in order to ensure that certain types of individuals or persons displaying certain attributes are included in the study. Silverman (2006), opines that purposive sampling allows us to choose a case because it illustrates some features or process in which we are interested and furthermore, purposive sampling demands that we think critically about the parameters of the population we are interested in and choose our sample case carefully on this basis.

In my study I was looking for the people with disability who are educated and employed or recently became unemployed despite the gender and ethnicity as my research is focused on the experiences of people with disabilities in their course of inclusion in the society. I felt that it would be time consuming to ask every person with disability whether he or she is employed or not and if not they would not be relevant to my study. For the solution of this problem, the source person became very handy as the detailed information and special attribute in regards to the interest of my study was easily available which fitted best in my study so that I could go and conduct interview directly. 10 individuals were selected at first for the in-depth interview but because of failure in rapport development and unwillingness of the informants towards a person without disability like me I had to conduct interviews with only 8 individuals by the help of enumerators.

According to Krueger and Casey (2009), the intent of focus group is not to infer but to understand and not to make statements about population but to provide insights about how people in the groups perceive a situation. Therefore, people associated with disability were selected randomly to eliminate the biasness of selection. Krueger and Casey (Ibid.), also highlights that a smaller group with four or six participants are easier to recruit and host and are more comfortable for participants. As a result 5 people with disability were recruited for focus group discussion in this study. Together with a focus group discussion of 5 individuals, 13 people with disability were interviewed in total.

4.4 Data Collection Tools

The study made use of both primary as well as secondary data. The aim of this study is to explore the challenges experienced by the people with disability in the course of their inclusion during employment. So, it would be more beneficial to talk with people and hear their voices. Thus, interviews have been the main source for primary data whereas study of documents provided secondary data in this research. The study used two kinds of interviews such as un-standardized interview and focus group discussion. The following part sheds some light regarding how these were conducted.

4.4.1 Interviews

Interview is generally known as an interaction or a conversation between the interviewer and interviewee where both the parties create and construct narrative version of social world; interviewer asks question and interviewee provides answers. Interview has become the strength of qualitative research because of its ability to directly access the world of other person. It does not involve extra ordinary skill; it involves just trying to understand their experience, opinion and ideas (Silverman, 2006). The use of interview is very important in this study as I was looking for what kind of challenges people with disability faced during their inclusion in employment and what actually inclusion means for them.

Rubin & Rubin (2005) suggested that through qualitative interviews one can understand experiences and reconstruct events in which we did not participate. So, it can be opined that qualitative interview provides an open-ended, in-depth explanation of an aspect of life about which the interviewee has substantial experience, often combined with considerable insight (Charmaz, 2006). In addition to this Charmaz (2006), adds that interviewing is a flexible, emergent technique where ideas and issues emerge during the interview and interviewers can immediately pursue these leads.

Rapley (2004), has argued that compared to other methods, interviews are relatively economical both in terms of time and resources. Due to limited time for data collection, I found that the use of interviews is the best way that fitted what I was looking for. The use of

interviews has also allowed me as a researcher to control over act of questioning and direct my conversation towards the lead revealed by the informants. This took me in the position so that I could explore on what I was interested in.

4.4.2 Un-standardized Interviews

In this study my focus is to explore voices and experiences which have been believed to be ignored, misrepresented or suppressed in the society. Due to this nature of the study, I assumed that it would be useful to use open-ended and flexible questions instead of closed questions and formal questionnaire. Silverman (2006) argues that open-ended and flexible questions are more likely to get a more considered response than closed questions and therefore provide better access to interviewees' views, interpretation of events, understandings, experiences and opinions. In addition to this Charmaz (2006), highlights that most essentially, an un-standardized interviewing permits an in-depth exploration of a particular topic or experience and, thus is a useful method for interpretive inquiry.

The un-standardized interviews were conducted with people associated with disability who were closely connected with employment to understand their experiences regarding the challenges they faced during their inclusion in employment. During this process, I experienced as Charmaz (2006) has opined that the in-depth nature of un-standardized interview has fostered eliciting each participant's interpretation of his or her experience. To conduct the interviews, I made use of interview guide with a loose set of questions but these were not strictly followed. The use of interview guide allowed me to be sure that all the relevant topics were discussed. This was done to make conversations more exploratory and participatory which was found appropriate as the research has focus on lived experiences.

Berg (2012) suggests that with the use of un-standardized interview, an interviewer needs to develop, adapt and generate questions and follow up probes appropriate to each given situation and the central purpose of the investigation. Prior to the field work, my assumption was that people with disability always feel oppressed, discriminated and are paid very less in the work places. But when I conducted the field work I discovered that not every people with

disability thinks that he or she is stigmatized in the work place, treated differently and not only people without disability but the people with similar situations also perform the oppressive behaviour. Furthermore, the interviewees were able to express their true knowledge, attitude and experiences without being influenced in any certain way by the researcher.

4.4.3 Focus Group Discussion

Wilkinson (2004), argues that focus group is an informal discussion among a group of selected individuals about a particular topic. Indeed, focus groups are used to gather opinions where participants are selected for the reason they have certain characteristics in common that relate to the topic of the focus group. The discussions are relaxed, and often participants enjoy sharing their ideas and perceptions. Thus, a focus group study is a carefully planned series of discussions designed to obtain perceptions on a defined area of interest in a permissive, nonthreatening environment (Krueger and Casey, 2009).

In this research, the focus group discussion was conducted with people associated with disability in order to get the collective view in response to the inclusion of people with disability in employment. Focus group methodology is useful in exploring and examining what people think, how they think, and why they think the way they do about the issues of importance to them without pressuring them into making decisions or reaching a consensus (Liamputtong, 2011 in Krueger and Casey, 2009). Kitzinger (2005) also highlights that the focus group method is an ideal approach for examining the stories, experiences, point of views, beliefs, needs and concerns of individuals. A focus group study comprises of people possessing certain characteristics participate in a focussed discussion and thus provide qualitative data to help understand the topic of interest (Krueger and Casey, 2009).

In total there were five informants irrespective of gender and age group participated in the discussion. In the focus group discussion, the participants were asked a different set of questions which was slightly different from the one asked to the individual informants but the format of focus group discussion is also similar to that of the un-standardized interviews with

the individuals where participants were allowed to take their lead in the conversation. The chief intention of focus group discussion is not only to collect more data but also to allow a free conversation among the participants. My decision of using focus group together with unstandardized in-depth interview seems to be justifiable because it is a faster way of obtaining information when our goal is to understand various points of views and although in focus group discussion conversations take long time, we have an advantage of observing how individuals respond to others in a group and perceive others views in the same context (Krueger and Casey, 2009).

4.5 Ethical Issues in the Study

During the conduction of social science research, a researcher encounters with a number of ethical issues as it involves very close contact with people who could be harmed by what they say or do. Hence, the consideration of research ethics is very important in social research. Being a researcher as we anticipate data collection, we need to respect participants and their identity. Generally, anonymity to the participants is ensured to deal with this ethical issue. For the respect and protection of anonymity of participants and any events they mention at the time of interview, I have assigned pseudonyms so that the information generated could be kept confidential.

The next ethical consideration was to ensure that I do not put any participants at risk in anyway. For this, an informed consent was given to all the participants at the beginning of every interview. The participants were given full information about what the study entails through the informed consent which acknowledged that the participants' rights will be protected fully during data collection. The form also gave option to the participants to opt out whenever they felt necessary. The participants were asked to sign or stamp the form but in some cases the content of the form was read to some of the participants and consent was taken verbally.

Likewise, the consent was also taken for using the tape recorder at the beginning of interview. I respected participants' decision not to record the interview. At the outset of the interview the participants were clarified that the information provided by them will be used only for academic purpose and it shall not be leaked to any organization. The participants were also made assured that the information and other all the conversation will be highly confidential.

4.6 Limitations of the Study

This study is meant to reflect upon the challenges faced by people with disability in their inclusion in employment. It is not only in Kathmandu valley but in many other parts of the country people with disability are involved in employment. The availability of employment is not similar in other parts of the country in comparison to the study area. Apart from this the attitude of people in regards to disability and inclusive practises are somehow different in the rest parts of the country leaving the study area. This might make the generalization of the study difficult as it does not represent the situation of the entire country where the experiences might be different than what the result reflects.

The study was based on the small sample of the population based on the availability of the participants who fitted best in the study criteria. Therefore, the result might not be as comprehensive as it could be thus, leaving sample as another limitation. The enumerators were appointed while conducting the interviews due to difficulty in establishing good conversation with the participants. Although I was present at the time of interview, being a researcher I lacked the direct contact with the interviewees. Due to this, in some cases I could not conduct the interview as per my expectation and the information collected was limited for drawing results. This creates the limitation in availability of information.

All the interviews were conducted in Nepali language due to which while translating in English; it was difficult to get exactly the same. As a result there might be chance of linguistic misinterpretation in gaining the precise understanding from the study.

4.7 Reliability and Validity of the Research

The trustworthiness of a research report lies at the heart of issues conventionally discussed as reliability and validity (Seale, 1999). Silverman (2006) argues that reliability refers to the degree of consistency with which instances are assigned to the same category by different observers or by same observer on different occasions. This means that to be reliable it has to be consistent from one measurement to another. For ensuring the reliability, I documented the interviews and steps of the entire process. I also used secondary sources of data so that the reliability of the study would increase through different perspective on the phenomenon of social inclusion.

Together with reliability, validity is another important factor which a researcher should consider in the research design as it determines whether the research truly measured what it was intended to measure (Patton, 2002). So, validity is based on determining whether the findings are accurate from the stand point of the researcher, the participant or the readers of an account (Creswell & Miller, 2000). In this study the triangulation of data collection through interview helped me to ensure validity and assured credibility of the data derived so far. Berg (2009) has highlighted that while interviewing for peoples' experiences it is important to make sure that interviewees are comfortable and this is the best way to ensure validity and reliability in interviews.

4.8 A Brief Presentation of the Participants

In the present study there were 8 informants who were conducted with individual interviews and 4 other informants involved in a focus group discussion. All the informants were people associated with disability who were related with employment. All of them were educated at least up to secondary school and were associated with support groups related to disability. Pseudonyms are provided to all the participants to make the information clear.

Sabita suffered from spinal cord injury when she was 10 years old. Now at the age of 24 she is living a life of physical impairment. She likes to represent herself as a basketball player and has many experiences of playing in competitive matches. She lives in a girls' hostel with

her younger sister after living with her friends for many years. She is studying at Masters Level in a university. Apart from this, she is employed as a computer operator in an office despite her lack of interest in being employed.

Goma became visually impaired when she was 6 years old. She completed her study up to Bachelor Level but could not study further. She is now, 33 years old and has one son. Her husband lives somewhere in Terai leaving her and their son. She works in a city hospital as a telephone operator where she has bitter experience of abandonment, oppression and lack of cooperation. She had very difficult time when her son was small.

39 years old **Rajesh** developed his visual impairment at the age of 16. So, he could not study beyond secondary school. He is unmarried and lives in a rented room with his friend who is also visually impaired. He tried many jobs to earn his living but the earning was hardly sufficient which compelled him to learn music. Now he works in a restaurant as a musician and earns a good amount of living. While working in a restaurant some time before, He encountered with robbers who stole his musical instrument and left him without job but only after several months he got employed.

Ashok is associated with physical impairment. He suffered from spinal cord injury in an accident when he was 3 years old. He has completed his Bachelor Level study. He is 25 years old now and is unmarried. He works in a NGO as a consultant. He is voluntarily involved in other associations which work for the people associated with disability. So, he likes to call himself as an activist. He lives alone in a rented house.

Garima has completed Bachelor Level of her study. She is 25 years old and physically impaired. She started searching for job when she was studying at the final year of her Bachelor program but could not get success anywhere despite her intensive search. Finally, she got job in an office and she is working in the reception of the office these days. She has been living in a hostel for last five years.

Kamala is 28 years old. She is visually impaired. She developed her impairment since her birth. She has completed her study of Master level. Unlike many others she lives with her family in her own home. Despite her high qualification and skills, she suffered many troubles in finding her job. These days, she is working as a telephone operator in an aviation office.

Rama is 33 years old visually impaired woman. She lost her vision at the age of 4 due to measles. She has studied up to Bachelor level. She is living with her daughter being

abandoned by her husband some years ago in a rented house. She left her job because of the ill treatment and harassment in her work place. These days, she is involved actively in a disability support group and works part time in a massage parlour.

Hari is a 42 years old man. He has hearing impairment. He developed this impairment at the age of 12. After passing SLC he couldn't study further. He feels sorry for his association with impairment when time and again people underestimate his ability. He has long experience of misbehaviour and discouragement. Currently, he works as a symbolic language instructor.

4.8.1 Focus Group Discussion

For the purpose of the collective challenges and experiences of inclusion in employment, focus group discussion was conducted with 5 people with disability among them 3 were male and 2 were female. All the participants were of age group 20 to 30 years. The type of impairment associated with them was also different.

4.9 Data Analysis

When data is collected from field, it is first stored and then reduced as well as transformed, organized and displayed in such a way that conclusions can be drawn from the meanings ascribed in it by taking consideration of theoretical implications. The entire process is in fact regarded as data analysis. Berg (2012) argues that data analysis is a process consisting of three concurrent flows of action: data reduction, data display and conclusions and verification.

As this study is purely based on qualitative paradigm, it is necessary to reduce and transform or code the data so that it becomes readily accessible, understandable and therefore the task of drawing out various meanings and patterns for the discussion becomes easy. The literatures on social science research display various methods of data analysis such as conversation analysis, narrative analysis, grounded theory, content analysis and discourse analysis. I have decided to use content analysis technique for the qualitative purpose of this

study. According to Creswell (2009), content analysis consists of organising data, reducing the data into themes through a process of coding and representing the data in figures, tables or a discussion.

During my data analysis, I first transcribed all the recorded interviews including the focus group discussion as well into an MS Word document. The chunks of raw data were reduced by focusing, simplifying and transforming into more manageable form. While doing so, several themes were identified and data were organized under the themes. Further for analysis, I categorized the information obtained from interviews into four broad topics such as Experiences of being disabled, Dignity and autonomy, Participation, inclusion and accessibility, and Non-discrimination and equality. This allowed me to have summaries of data under various categories and the emerging themes were managed so as to construct the structure of the analysis. The summarised information were read and re-read to construct the validity.

CHAPTER 5 EMPIRICAL FINDINGS

This chapter and the following empirical chapter will present and discuss the findings of the study and reflect upon the data collected. The first empirical chapter will present the findings regarding the experiences of the people with disability focusing in terms of their employment; issues regarding discrimination, dignity and accessibility; participation and inclusion of people with disabilities.

This chapter will put forward the findings from the data and will shed light on the challenges faced by them in the course of their inclusion in employment and other life events. This chapter is divided into several headings for the clear organization of the findings. The findings of this chapter will later be discussed in the light of appropriate theoretical framework and social work perspective in the next chapter.

5.1 Experiences of being Disabled

People experience differently and in many aspects of living a life with disability. For easy understanding this heading has been categorised into smaller divisions as follows:

5.1.1 Family Experience

The role of family is always important for every kind of support to the people with disabilities and makes them easy to be included either in any particular field or in the main stream society. In many cases, family members develop stigma because of their association with people with disabilities due to which people with disabilities are very often denied, hated and marginalized even in families. Living somewhere away from families by majority of the respondents in this study may indicate the poor family support to people with disabilities. The respondents in this study are living either separately with friends, younger sister with disability or together with their families. The failure to offer complete facility of education by the families led people with disabilities to pursue their education by living separately from their families managed by some organizations working for people with disabilities.

The majority of respondents experienced marginalization and some different treatments in their families whereas some respondents experienced very supportive environment in their families. Despite lack of some disability friendly infrastructures at their homes, they were living in better condition than many other people with disabilities. In the case of some of the respondents, to support the people with disability, the family members changed their structures at homes and learned disability friendly behaviours so that they could feel easy to live in family. In some of the cases, people with disabilities experience that family members seem to be very supportive and happy for their living away from their home.

People with disabilities face many difficulties and lack of support when they live alone and separately but when they live in a hostel or some other communal places they experience supportive environment and friendly behaviour from others. Some of the respondents have experienced that such behaviour and attitude of the people nearby them have helped them to

develop self confidence so that they do not perceive their impairment as their disability. The respondents in this study have mixed experience of family as support and denial.

5.1.2 Employment Experience

The respondents in this study have viewed that the types of jobs are segregated in terms of the disability associated by the person such as visually impaired people are offered jobs in teaching sector and most of the capable visually impaired people are employed in teaching profession. Likewise, people with physical impairment are mostly employed in NGO sector or other private offices. However, despite their good academic qualification and other capabilities, people with disabilities face difficulties in finding jobs. Most of the respondents in this study have faced that they were given less priority and very often discouraged to get employed. Whenever asked about their denial from employment, they are often answered with the physical and structural difficulties of the place where they have to work. The experience of Sabita reflects this picture:

Whomever I asked for recommending job for me, they answered that, “There is a job but it is in upper floor. You have to go up to work but you use wheelchair and you can’t reach there. So, you can’t do this job.” I was discouraged every time when I asked about my employment. Several times I was rejected from jobs that I searched. I don’t think my disability is the only reason why I was not selected for the job even after the interview.

The narration of Garima shows that for people with disabilities, it is very hard to get employed although they are well trained and highly qualified.

....most painful thing is that we are well trained and have enough skills but we are not given opportunities to utilize them. It is very sad that due to poor economic condition, we have no links with people holding higher positions and no money to offer them. That’s why we are rejected time and again although we are qualified and skilful. May be they want somebody their near and dear ones.

Being a person with disability, it is equally challenging to be employed and continue the profession. Throughout the interviews and the focus group, the participants shared that most of the offices where they are employed are not fully disability friendly. It is very difficult for them to move here and there as well as up and down as some where offices are not in ground floors. Sometimes, they have to crawl on the floor to reach at the upper floor where there is the office or they have to rely on others so that people would carry them to their places. These all incidents indicate the physical and structural challenges for the people with disabilities in their employment.

The behaviour of colleagues, seniors and other members of the organizations or offices play vital role in the inclusion of the people with disabilities in the case of their employment. Some of the participants expressed that their colleagues at their work were very friendly and supportive to them. They never faced any kind of partiality and discouragement from their counterparts. They were behaved well and made participating in every possible activity conducted in the offices.

In contrast to this, some participants shared harsh treatment shown by their colleagues. They have bitter experiences of lack of cooperation, alienation and verbal abuse even. In many cases, people with disabilities were paid lesser, offered fewer facilities and faced more work load than their colleagues who are not associated with disabilities. In their work places, people with disabilities were treated as if they were from different planets by the people without disabilities. Sometimes, due to their difficulties in movement, they can't entertain all the facilities that other people are enjoying, leaving them less benefitted. The following statement of Goma makes it clear:

.....thinking that these visually impaired people have more memory power, we are made memorizing every detail and everything. Sometimes, I tell them that are we computers? Because of our impairment our reception office is separately kept inside, may be they are trying to hide us from others. People at my office never considered us as their colleagues. They never helped us and did not make us participating in the activities being conducted in the hospital although we have been working together for several years. Their unhealthy behaviour towards us is

often influenced by the stereotype of the caste system in Nepal. Most of the staffs belong to Newar caste and we from the reception belong to other caste. They speak their own language and often communicate in their language with each other which make us feel that we do not belong there. They address people from their caste as “Haamra maanchhe” (our people, our staffs) and treat them well but they call us “Hey, you!, O’ phoneka maanchheharu” (O’ people in telephone). Such offensive behaviour from colleagues disheartened me but now I just don’t care.

The environment of the work place plays vital role in the successful inclusion of the people with disabilities in employment. The above experience represents the challenges being faced by people with disabilities when they are trying to be included in employment. Some of the participants have experienced very discouraging and unsupportive environment in their working place. They have experienced that the situation in the office is so disheartening that not only a particular group of people but also all the new comers whether with or without disability get suffered.

The participants of the interviews as well as focus group have expressed that employment is very important for them to be self confident, independent and further more earn the living for them as well as the others who are dependent on them. They believe their involvement in the employment has made their life somehow easy. However, there are many challenges they face in performing their responsibilities related to employment. They feel the allocation of quota system in different government and non government organizations for the employment of people with disabilities is very much encouraging but the trend of giving priority to the near and dear ones despite the better qualification and skills of others make them sad.

5.1.3 Experience of Particular Time and Event

The experience of particular time and event shared by the participants in this study very important to understand various aspects such as poverty, role of gender, education in the life of people with disabilities. Particular experience of people with disabilities simply because of being male or female makes us clear about the role of gender in their lives. The difference in

life experiences being a woman with disability from the experience of a man with disability can no doubt shed light in my analysis regarding the social inclusion of people with disabilities. Similarly, the particular experience of people with disabilities due to their poor economic condition is vital in understanding the vicious cycle of disability and poverty. The meaning and role of education in their lives can be understood from the specific experience of event or time faced by the people with disabilities.

According to the participants of interviews and focus group, most of them were supported by some organizations working in the field of disability to complete their education and fulfil some basic life needs. Had they been left with their poor economic situation, they would never ever be able to complete their education and become confident in their lives. Some of the respondents have developed the impairment simply because their family could not afford the timely medication they needed at that time. Due to the impairment in the body, some of the respondents have to undergo through various medication and treatment several times which demands more money. As a result their economic situation remains poor and often they cannot afford. For the people with physical disabilities, wheelchairs and special scooters which are very expensive are necessary to move here and there. Due to the lack of proper space for wheelchairs in the public vehicles in Nepal, they are compelled to use private transportation of which fare is high. The active life style of people with disabilities in Nepal costs high due to which most of the people with disabilities do not have sound economic situation.

As the economic situation of most of the participants in this study is not sound, they have the experience of discrimination as well as marginalization and denial from the people without disabilities in their everyday life. The narration of Rama makes it clear.

People in my community know that I have left working at NGO and massage centre is also not popular. Last week when I went to nearby shop and asked for 5kg rice, the shopkeeper refused to give me in credit. These days I have no earning that's why he said so. This thing touched my heart badly because when I used to work in big organization, he used to show me product of Rs 40 when I had asked of Rs 10. The person who used to offer me costly goods does not give me 5 kg rice of worth

Rs 320. Why? It's simply because of my poverty. Isn't it? People think that I do not have any income and I cannot pay. I am neglected and discriminated very often.

In Nepalese society, different treatment on the basis of gender is not new. Women often experience marginalization, disparity and discrimination from men. In such context the participants of this study expressed that women with disabilities face more challenges than their male counterparts. The female participants of this study expressed that living a life with disability being a woman is double disability. They perceive that women with disabilities are the most unfortunate as well as underprivileged group in the society. They also view that people take advantage of inability and helplessness of women with disability in every possible occasions. They have the experience that people in general do not believe on their performance and capabilities as a result women with disabilities are often viewed through the eyes of disbelief.

Some of the respondents informed that women with disabilities do not have many companions and they cannot express their desire for intimate relationships. Thinking that, men approach them and try to take advantage by flirting with them. Such people also perceive that women with disabilities will not and cannot complain against them. There are many cases of abuse and exploitation of women with disabilities by men. According to the respondents of this study, men willing to take advantage of inability of women with disabilities approach them being kind with nice words and showing respect to them and in the name of lending helping hands they hold and touch in different parts of body.

Women with disabilities expressed that people take them negatively so that they are often neglected. They remain unheard no matter how hard they raise their voice among the people without disabilities. They also indicated that not only men without disabilities but also men with disabilities perceive them negatively. According to them, men with disabilities are occupied with the concept that only they are capable to do different things despite their association with disabilities; women with disabilities do not have confidence, capacity and courage to fight against the difficulties as they do. Driven by such thoughts not only men without disabilities but men with disabilities also discourage, discriminate and side line the

women with disabilities.

The participants of interviews and focus group also have bad experience related to their security. Some of the respondents have shared that due to the impairment associated in their bodies they are at the risk of being robbed on the way. There are also chances to fall down in the ditches on the roads and getting injured while attempting to get in the public vehicles as well. Sometimes, these incidents faced by people with disabilities are life threatening. There is no clear indications and information to aware the people regarding the changes on the roads. Moreover, people with disabilities have experience that they are often neglected and unheard when complained about their problems.

5.2 Dignity and Autonomy

People with disabilities encounter with several life incidents which make them feel ignored, disrespectful and even unworthy to live at times. They easily get annoyed and heart broken by the offensive addresses made by people towards them. Many of the respondents informed that they get discouraged by the rejection and refusal from the jobs they are seeking for. When people ignore their skills and capabilities and select others, they are marginalized. They feel that people do not respect their request as well as inquisitiveness by others and let alone offended. Because of the impairment in the body when they cannot hold excreta and release publicly anywhere irrespective to place and people, people with disabilities feel insulted. In such circumstances, people with disabilities start feeling that their life is unworthy; they are of no use and get disheartened in such a way that they perceive it would be better if they end their lives.

Some of the respondents expressed that these days many people are aware that they should help people with disabilities and help in performing their several jobs. It might be the love, care and support offered by others to the people with disabilities but in return they might be feeling insulted. In many cases, people with disabilities feel insulted as well as disparity when other people carry their goods although they are capable of doing themselves. Although the government of Nepal has promulgated the law for the protection of seats for people with

disabilities in public vehicles, either these vehicles do not stop for them and do not intend to get them in or they do not get the protected seats in case they get inside the vehicles. People in the protected seats for people with disabilities just pretend as if they have not known. In such situations, people with disabilities are ignored and unheard despite their request made to bus staffs.

According to the respondents of this study, offensive words used by people in public places like cinema halls, markets, bus stations etc. towards the people with disabilities make them feel that they are not respected. The narration of Ashok highlights this.

They think that people with disabilities using wheelchair are sick. While travelling by taxi, the drivers say that they don't take much money to the sick people. At cinema hall, the guard calls us sick people. Their behaviours are motivated by the feelings of inequality. There is prevalence of discrimination in many places. We face much odd behaviour when we go from one place to others.

From the interviews with people with disabilities it has been found that other people underestimate the capability of people with disabilities and often perceive that they have got job; that's their biggest achievement; apart from that they cannot do anything. Even in the same working place as well, colleagues develop the stereotype of lower level staff for the people with disabilities and hence behave sarcastically.

5.3 Participation, Inclusion and Accessibility

Whenever asked about the participation, inclusion and accessibility about the people with disabilities, many of the respondents informed that they were given less chances to participate in the place where they work. Despite being a staff of the same institution, they rarely get opportunity to participate in several programs organized among the staffs. The seniors and colleagues often do not ask the people with disabilities working as staff in the organization to participate in the programs. Instead of encouraging them to participate in the programs, the other colleagues make them engaged in other responsibilities as well. Sometimes, there are

the incidents that people with disabilities are invited to participate in the annual meetings of the organizations.

In many cases, people do not construct disability friendly structures and do not modify the existing structures so that people with disabilities would get easy accessibility due to which they can also participate actively in different activities in the work place. People, often pretend to be unfamiliar with the difficulties of people with disabilities thus restricting the accessibility of people with disabilities to participate which finally exclude them from the rest of the group. Many of the respondents feel that they are isolated in their offices by other colleagues as they do not get help from others. The statement of Goma clarifies it more.

There are lots of programs, conferences, meetings organized but we can never attain. There are other staffs in reception too but they never told us that they would look after our work so that we could go to the program. There are so many trainings. They never encourage us that even we have to participate. In the letter it is often written whole counter staff. They go themselves but never ask us to go. They don't care that we have been working together for several years and simply pretend that we are not present around them.

Lack of participation restricts the accessibility of people with disabilities and finally excludes them from the rest of the entire team in the organization. Sometimes, the colleagues do not make the people with disabilities joining together to have lunch or just to chat. This experience of some of the respondents of this study indicates to the denial of their participation which does not make them included socially.

In contrast to the above mentioned statement some of the respondents have shared different experience regarding their participation, inclusion and accessibility. They get participated easily in various campaigns; programs and very interestingly they organize the programs in some occasions as well. Their working places are easily accessible to the people with disabilities and there are no any difficulties in moving around the office. They are made participating actively in every activities organized in the organization. This provides the

example of the good participation of people with disabilities by providing them accessible environment so that they can be included socially.

The common thing among all the participants of interviews and focus group as well is that they all belong to some organizations or groups of and for people with disabilities. The association of people with disabilities in the particular groups and organizations have made them participating in every possible activities organized among them. In the organizations where they relate, both people with and without disabilities are involved. The participation of people with disabilities in various activities has given them the opportunities to make friends so that they could share their matters with each others; they could suggest the best solution to tackle the problem they are facing and additionally they could enjoy the leisurely activities which are very important aspects of their social inclusion.

5.4 Non- Discrimination and Equality

Some respondents informed that they do not face any form of discrimination in the place where they are employed. They are behaved well and provided with similar facilities as that of the other people without disabilities maintaining the equality among the staffs. However, they also face discriminatory behaviour from other people in regards to their associated disability. They have experienced discrimination in bus stations, markets, roads etc. Bus staffs of public vehicles rarely stop the vehicles for people with disabilities. According to individuals with disabilities, perhaps those bus staffs think that people associated with disabilities cannot afford the fare and if taken them inside they should be offered free ride which the vehicle staffs don't like. Similarly, people perceive that people with disabilities are unable to answer when asked about some information due to which they are often ignored by people without disabilities. The narration of Ashok highlights it:

When I go out they think me as if I am a sick person. When I go out with friends, people think that I can't speak and they ask about me with my friends. We face such discriminatory behaviour often in many places.

Some respondents have shared that people with disabilities are paid lesser salary than the other counterparts working together. Not only in salary but also in every facilities people with disabilities are provided differently thus discriminating them from others. There are cases that people ignore the complaints of unequal facilities and discrimination to the people with disabilities and in return advice them to remain quiet.

According to some respondents, people with disabilities are discriminated severely by their colleagues as if they are from different planet and are different than human beings. People with disabilities are not helped by their colleagues without disabilities no matter how difficult is the situation they are in. Although they are paid equally, there is no equality in work load and distribution of other facilities apart from salary. People in the organization discriminate people with disabilities by not including them in various activities conducted among the staffs thus restricting their participation. The narration of Goma reflects the similar picture:

They don't have friendly behaviour with us. They think us differently. They feel odd to walk, seat and eat together with us and speak shortly from far distance if compelled to do. They try to avoid us as far as possible. I get very upset and surprised at the same time that they don't drink water from the water jug if they see us drinking. How negative and narrow is their concept regarding people with disabilities. They do not have social behaviour.

These findings from the data collected are discussed and analysed through the relevant theoretical framework which is presented in the next chapter.

CHAPTER 6 UNDERSTANDING DISABILITY AND EMPLOYMENT FROM THE VIEW OF PEOPLE WITH DISABILITY IN NEPAL

In the first empirical chapter I have already discussed on the experiences of the people with disability focusing in terms of their employment. This chapter will discuss how people with disability perceive disability in their lives; what is the importance of being employed for

them. This chapter will also try to shed light on the challenges faced by them in the course of their employment and will discuss about their inclusion in the employment sector. This chapter will critically analyze the appropriateness of the policies and laws for the successful inclusion of the people with disability.

It will be very wise to understand closely how the debate of inclusion versus exclusion fits well in the life of people with disabilities and the meaning of inclusion as well as exclusion while living the life with disability can provide the ample opportunity to formulate the plans and policies for the equitable society. This chapter is organized in smaller topics for clear discussion and better understanding of the debate of inclusion versus exclusion. The topics in this chapter will be discussed through the reflection of different forms of capital like social, economic, cultural, symbolic etc.

6.1 Perception of Living a Life with Disability

The predominant Hindu culture in Nepalese society views disability as punishments of sins in the past life thus leaving the life of people with disability particularly harsh. It is also true that in a country where people are needed as economic assets within the family, and where it is assumed that people with disability are incapable of making such a contribution, the person with disability will inevitably suffer from low status, rejection and marginalization. Due to social stigma, very often, people with disabilities are kept hidden from the rest of the world. This study is supposed to explore the situation of social inclusion of such people with disabilities in the society. Therefore, it is very important to understand first that how people with disability perceive their disability in the respective lives.

In Nepalese deeply rooted cultural societies, it is not unfair to view things from the others eyes and accept the perceived ideas. During the study what I found is that although the people with disabilities try to compete with others in various aspects being encouraged and motivated through their educational status, they somehow feel whatever the shortcomings they experience in different aspects are due to their disabilities in life. They feel their life is burden to others as well as for themselves too. The following narration of Sabita gives an example of how they perceive their life with disability:

The buildings are not disability friendly like we have said. If I could come here easily by myself, it would not be trouble to you as well as not to me and even I did not have to wait. I'd easily come here. Spinal cord injury is that type of disability where people do not have regularities in toilet. So many times I'll not know but I'll be defecating, I've faced such situations sometimes even in examination hall. At that time, I feel very humiliated. In such situation, I feel that it would be better if I had died earlier rather living a life with this disability.

This shows that the people with disability get stigmatized due to their spoiled identity as mentioned by Goffman (1963). Because of this, they lack confidence in them and try to hide themselves from the rest of the world. In Nepal, disability is still viewed in terms of a “tragedy” with a “better dead than disabled” approach, the idea being that it is not possible for disabled people to be happy or enjoy a good quality of life. It has also been seen that people tend to accept their own disability as something which has resulted from their past karma or due to God’s will and thus often show low motivation to overcome the limitations (Berry and Dalal,1996).

As argued by Burkitt (2008) the self identity of an individual is in many aspects related to social class and power relations within a given social structure. The individuals’ understanding on pride and shame or both are very much depended on the capitals including material, cultural, social and symbolic. In Nepalese society, every individual is expected to look after his/her family, earn living for self as well as others and contribute socially and culturally whenever necessary. For this reason an individual is supposed to be of sound body without any forms of impairment. As a result, people with disabilities are given lowest rank in the social power relation and hence are often regarded as of no use to fulfil the social as well as cultural demands and are left with limited social network and friends. The disability discourse in the society regards that people with disabilities are socially deficient, culturally deprived and lack the social and behavioural skills to be successful in one’s life.

In the above mentioned Sabita’s experience, her feeling of shame is constructed on the basis of her social self perceived as poor and negative. This creation of her social self is based on

the perception of others as how they take her in performing day to day activities in the society. In fact the construction of her poor self has triggered her to be excluded socially. When an individual enters in the stage of life where the person is supposed to contribute the family or society as a whole through the involvement in income generating activities, social participations or cultural celebrations, most of the people with disabilities in Nepalese society perceive that their life is unworthy; their life is burden to others so its better to die rather living such heinous life.

The feeling of low esteem often keeps the people with disabilities hidden away from other people in the society. Their dislike of exposing themselves to others leaves them with limited social networks which finally becomes evident enough to exclude them in greater terms. It seems that people with disabilities possess poor social capital and lack self confidence to empower themselves so that they could better be included.

But sometimes, in contrast to the above mentioned perception, the attained disability is perceived as boon by people with disability. They feel that they get easy contact with people due to their association with disability and thus, assisted to get their fame. The statement of Ashok provides an illustration:

When I started modelling, media persons came to me for interviews and I got chance to explore myself and I started participating in fashion shows. My relation with media was strengthened, social network was widened. Similarly, when I started conducting campaigns for disability rights, media supported me very much. I was helped by my seniors, friends and others as a whole group. We continued organizing campaigns and different rallies time and again. I believe I was different than others because of my disability and this uniqueness helped me in getting support from others quite easily and my voice was paid attention at least for some moment.

The bodily differences between people with disabilities and other people draw attention in the society whenever people with disabilities are exposed. Often people with disabilities remain hidden from other people as a result they develop negative perception of people with

disabilities and consider these people as strange as well as odd in the societal setting. It is another matter that often this difference is perceived negative but sometimes it is considered significant enough to be paid attention with.

In Nepalese societies people with disabilities often remain hidden from rest of the community. Other people rarely see them and know very little about their situation and capabilities. Whenever exposed, people don't like the presence of people with disabilities and end up discriminating as well as discouraging them from public exposure. The above mentioned narration of Ashok proves that when taken the chance of challenging the exclusive behaviour of community, people with disabilities are paid attention and in return, they are encouraged to live as they are despite their inability to perform some customary activities. This encouragement makes them to accept their perceived difference from other people and helps them to realise their special capabilities as well as to have faith upon. It has been found that the acceptance of people with disabilities as normal increases with the increase in their continuous contact with other people.

Likewise, some people with disability perceive their disability as their part of life and accept it as it is normal. At the early stages of their life, they used to feel strange as if they were from different planet but with time they become habitual with the disability associated with them and do not feel different to get stigmatized. The following statement of Garima supports this :

Yes, I used to think bad and different during my childhood but now I understand that people look at us because they might not have seen any other people with disability. We see very few people with disability walking out on the street. Not everyone but few of them stare at people with disability continuously because they might not have seen people with disability very often. I didn't used to go out alone in my childhood because people stared at me continuously due to which I used to feel shy and thought why they were looking me in such way. For that reason, I used to go outside with my brothers or sisters.

The prevailing culture in Nepalese society promotes for performing various social activities collectively. These activities in return contribute in strengthening the social network of an individual. So, it is very common to make friend and do the usual activities together for people in Nepalese society but people with disabilities lack companions for such activities to perform. The experience of segregation among the colleagues makes them feel discriminated and helpless. It can also be seen that through the change of time and attained academic knowledge, people with disabilities achieve the empowerment to be self confident and face the people in the society which has made them easy to be familiar with others. Similarly, with the regular exposure of people with disabilities, common people in the society slowly start to accept disability of people as normal and remain willing to assist them in their needs. Most of the participants in this study opined that the specific group of people in the society for example young people are very well aware about the consequences of disability and accept normally as a part of life of people. The narrative of Goma sheds light on it.

People have different concepts regarding disability and people with disabilities. Their behaviour towards the people with disabilities is guided by their attitude which does not make me feel bad these days. Some people help us on the ways while crossing the roads, in riding the vehicles as well whereas some are quite adamant that they ignore us. Some people think that how long will they be assisting us at least we should learn to live on ourselves and do not help us. They feel that we should make the group of people with disabilities and perform our activities without associating with other people without disabilities. It is their thinking and I have no complaints regarding this. People are different. Some do not help and like us but some are very helpful. Some people especially young ones help us in many activities. I have experienced that they don't feel any difficulties to accompany us. They are always nice to us and we really appreciate their deeds.

The practise of making the people with disabilities participating in various activities together with other people without disabilities is the example of inclusion of this group in the society. The continuous exposure of people with disabilities among the other people decreases the risk of exclusion and thus improves the chances of inclusion in the main stream society.

People with disabilities perceive that living a life with disabilities often becomes difficult when they have to live with discrimination and no respect for the difference from the people who are not associated with disabilities. The verbal abuse through absurd words from the able bodied counterparts make people with disabilities feel discouraged and painful to live the life being associated with disability. On the streets and similar public places, usually, other people stare the people with disabilities in unusual way and sometimes provide wrong information as well as shout loudly in strange manner due to which they lose confidence and encounter with various difficulties at times. Such practises are the clear indication of exclusion of people with disabilities. The lack of respect for difference and belief that people with disabilities are capable of accomplishing the provided task leaves them far behind from the inclusion in the employment as well. The experience of Rama is the clear evidence of the exclusion of people with disabilities in the employment sector.

My seniors and colleagues do not call me by nick names or any labels but I feel hurt when they doubt upon my capacity to do the job at the office. They often think that I am not able to perform the job with demanded perfection. When the task is accomplished, they ask repeatedly whether I have done it and check it with other staffs for the confirmation. The disbelief of people at my office regarding my job performance shows that they lack the respect for difference in me and them.

The increase in the involvement of people with disabilities in employment can be seen in Nepalese society recently because of the formulation of laws to protect the welfare of people with disabilities by the government of Nepal. We can find some other inclusive strategies practised by the government as well as private sector for the people with disabilities. However, people with disabilities face number of challenges during their inclusion in employment. Sometimes, people think that it is charitable to provide employment opportunities to the people with disabilities and also perceive that they have offered much more for these people. Although, people with disabilities are included in the employment sector, it can be found that they are paid lesser than their other counterparts who do not associate with disabilities.

Some of the participants in the interviews and focus group have the experience that they are paid lesser than other staffs that do not associate with disabilities whereas many of them informed that they are paid equally as other staffs and there is no disparity in any other facilities and benefits of their employment. The equal treatment of people with disabilities with other staffs is the clear indication of the inclusion of people with disabilities which has made them easier to be included in the greater extent thus negating the chances of exclusion. It is also common that although people with disabilities experience unequal treatment in their employment, they rarely complain to the concerned authority. It can be understood that people do not complain because of the fear that they may lose their job due to their complaint. In case, if complained, they are ignored and unheard in many cases or they are advised to remain quiet. The narration of Rajesh supports this case.

Despite our better performance we are paid lesser than other staffs that do not associate with disabilities. It makes me sad but I can do nothing about it. Several times, I thought to make a complaint against this treatment but thinking that I am employed in private sector and I may lose my job when I complain I halted. So, in the fear of losing job, I remained quiet and suffered this disparity.

One of the participants has the experience of the advice to remain quiet. It highlights the challenges of people with disabilities in employment.

Yes, there used to be several projects and many people are involved as it is an NGO. I was paid lesser than my colleagues although we are appointed in same post. Not only in salary but also in other benefits and facilities I was discriminated. When I complained about this discrimination, my colleagues only listened to me but did not support me but I kept complaining. One day, one of my seniors told me that it was true that I was paid less but my contract was left for few days to be over. She advised me that due to me they are facing problem in the office and asked me stop giving pressure so that there will not be any trouble in the office. Finally, I remained quiet and my contract was over.

The involvement of all the participants in this study in some groups or associations related to people with disabilities shows that there is a very appreciable effort made to empower people with disabilities so that they would be included in the main stream society. In these groups and associations, people with disabilities gather together, share their experiences with each other and suggest and advice to those who face trouble and seek help from others. Not only they are made aware about the rights to protect the welfare of people with disabilities but also encouraged to participate more openly in different activities and raise voice against any form of discrimination and disparity. The people without disabilities associated in such groups and associations help to make acceptable environment for the inclusion of people with disabilities in the society.

Bourdieu (1986), argues that the value of one's social capital is contingent on the size of one's social networks and the value of economic, cultural and symbolic capital one possesses. The participation of people with disabilities in different groups and associations construct the social capital of people with disabilities. Through these, they get opportunities to expand their social networks and can perform various activities which could generate some income strengthening their economic capital as well. Collectively, people with disabilities can conduct several activities together with people without disabilities so that it could recognize their cultural capital in return.

Various forms of capital take account in making the inclusion of people with disabilities in the main stream society. The dynamics of the relationship of social capital to inclusive achievement becomes vital to understand while analyzing different dimensions of social inclusion and exclusion. For the same, we should consider the nonmaterial resources of cultural capital related with social capital. Bourdieu (1986) suggests that both social and economic capital can be converted into/enabled by cultural capital. Cultural capital is manifested in three states: embodied, objectified and institutionalized. Dixon-Roman (2012) clarifies that “ the embodied state of cultural capital is the embodiment of cultural capital in a scheme of socially structured dispositions and externalized practices. The objectified state is the material forms of culture such as books, magazines, arts or music. The institutionalized state refers to the degrees or certifications conferred upon by dominant institutions of

schooling. Each state of cultural capital is situated in social structures, socially distributed and socially structured.”

In Nepalese society people with disabilities are considered as worthless and burden to the people, and are not supposed to make any contribution in the family as a whole. Under such cultural scenario, people with disabilities also perceive themselves as useless and non-contributory reflecting the identities set by the society as explained by Berger and Luckman (1966). Here, we can see a complex process of stigmatization of individuals with disabilities which involves, as suggested by Link and Phelan (2001), individual biological differences, the negative evaluation of those differences by others, adverse reactions of others and negative social and emotional outcomes for individuals with disabilities.

The development of trend of assembling people with disabilities in groups; sharing their experiences to others through widening social network and working collectively for better inclusion in the main stream society strengthened their cultural capital. The involvement of individuals with disabilities in employment and earning their living as well as contributing the respective families are the good examples of changing cultural capital embedded with economic and social capital. The social capital of individuals with disabilities in the form of groups and associations for people with disabilities have empowered them to avoid self pity or resentment and in return manipulate them to be included in the society through boosting their self confidence.

These are the noticeable efforts made in terms of social inclusion of individuals with disabilities. However, the material barriers like lack of disability friendly structures limit their possibility of inclusion in the main stream society. In the context where many people with disabilities are not accessible with proper resources, the delay and lack of seriousness in the implementation of state promulgated laws and policies for the protection of welfare to people with disabilities make them suffer thus keeping at large extent excluded from the society.

According to Eide and Ingstad (2011), Individuals' interpretation and understanding of their subjective experiences and situations should be understood deeply to obtain a more complete understanding on how it is to live with a disability in the given different contexts. Without this perspective we may run the danger of generating knowledge that may represent poor guidance for changes at policy level. A culture-sensitive approach to disability and poverty quite simply requires an understanding of individuals' values, interpretations and understanding, as these are fundamental aspects to influence, utilise and /or incorporate for any suitable change to take place.

6.2 Family Perception: Support or Denial

In academic writings about people with disabilities in poor countries it has often been claimed, by academics as well as aid workers, that these people are hidden, neglected and sometimes even killed by their families, and that such behaviour has to do with attitudes and culture (Helander,1993). Such activities are carried out to overcome the contagious stigma as explained by Goffman (1963), due to undesired differences and association of stereotype with the people with disabilities.

In the context of Nepalese society, support of the family is essential to get recognition of one's identity by an individual in the society. The activities of hiding or neglect can be explained by the life situation of the family who are responsible for the care of the person with disability. The condition becomes worst and critical when there is subsequent increase in the crisis of not only economy but also the family structure. The following narration of Rama highlights the picture of adverse family support for the people with disability:

When I was a child my father brought step mother that added pain in the lives of my mother and we children. As I grew up it was not difficult to understand that there was no support from my father and mother. How could one study without support from the family? In this case I found myself lucky not because of the support from family but from other source. With the recommendation of other villagers, I got opportunity to study in scholarship of NAWB (National Association

of Welfare for Blinds) in a school living in a hostel. After my admission in the school, my parents never paid their visit in the school. They never came to take me home during holidays. I still remember even to pay a small amount of bus fare, by holding the leg of bus staff, my father pleaded for free bus ride. He told that I was not his daughter; he was having pity on me and was trying to take me to my parents. Oh, how shameful it was! I could not understand at that time but when I recall it now days, it pinches me a lot. When NAWB supported me only for the hostel fee, it grew more crises in my family. My father used to drink alcohol and beat my mother and me as well. He used to scold me very explicitly. He frequently used to say that “Tan andhi, marna nasakeki! Tanlai ta aajai maardiu jasto”(you blind! Why could not you die? I wish I could kill you right now). It was very painful but also we had to tolerate that. There was no support from my step mother as well. I used to get scolding while going home repeatedly.

There are many cases that family perceives disability as shame and burden. As a result the members in a family ignore, marginalize and try to avoid the person with disability and most of the times prioritize very less among the other members. It is also seen that family members feel stigmatized because of the presence of a person with disability in their family. There are cases such that people are abandoned by their family after developing disability in their life and sometimes, people get married despite the knowledge of association of disability, live together for some time and later carelessly without feeling of any responsibility leave the person with disability to suffer.

Stress experienced by the families is influenced by child specific variables like age, sex and severity of the problem; socio-demographic variables such as social class, family income and domicile; and family coping resources and strategies like acceptance of the child's diagnosis and perception of stigma associated with the disorder (Beresford, 1994).

Cultural beliefs about disability play an important role in determining the way in which the family perceives disability and the kind of measures it takes for prevention, treatment and rehabilitation (Sen, 1988). Existing studies reveal that very often the parents have a negative

attitude towards their children with disabilities. The parents are plagued with feelings of pessimism, hostility, and shame (Rangaswami, 1995). Denial, projection of blame, guilt, grief, withdrawal, rejection, and acceptance are the usual parental reactions (Drew et al., 1984). Some parents also experience helplessness, feelings of inadequacy, anger, shock and guilt whereas others go through periods of disbelief, depression, and self-blame. The siblings also experience feelings of guilt, shame, and embarrassment (Frude, 1992).

A negative attitude towards disability from the family members, relatives, friends and/or the society, not only impacts the child directly, but also adds on to the existing stress levels of the family. Lack of public awareness about the potential of disabled people, often acts as a barrier to their acceptance and participation of the disabled (Gupta and Singhal, 2004). Studies have shown that the discrimination and ill treatment of people with disabilities by their families particularly depends on the severity of their impairment. It has also been seen in Nepalese society that people with comparatively less severity of impairment are accepted easily than those with mental disabilities.

Most of the participants in this study are not associated with severe disabilities. It has already been mentioned that the degree of stigmatization faced by the family members depends on the severity of the impairment in the body. Thus, it can be understood that the family members of the respondents have not faced social stigma in greater extent. However, in the cultural Nepalese society where disability is considered as punishment of the committed sin in the past life, individuals with disabilities are taken as impure and unworthy. In comparison to individuals with intellectual disabilities, people with physical impairment and other forms of disabilities can have more accessibility due to which they are more exposed to other people as a result they are less unacceptable in the society.

In Nepalese society with less severity of impairment, people feel sorry about the unpleasant tragedy of an individual with disability and thus express their pity together with members of family. The denial of several services and love as well as affection to the individual with disabilities from the members in the family draws the obstacles for them on their way of social inclusion. There are clear evidences that acceptance of an individual with disability by the society grows high when family considers the person as the integral part and without feeling any sort of stigma, exposes to the society.

In the form of cultural capital, every member in the family is supposed to make contributions in various aspects. At number of times, the denial of people with disability by the family is due to their failure in making any sort of contribution. In contrast, when an individual is able to contribute in the family despite the disability, the acceptance becomes easier. The debate of inclusion versus exclusion largely depends upon the support and denial from the family.

Sometimes, people with disabilities experience positive environment in their family and are supported well by them. Some of the participants in the interviews and focus group have the experience of very supportive family in contrast to the stereotyped denial. The following narration of Kamala illustrates the same:

My family is very supportive to me. My parents never discriminated me with my siblings. They fulfilled all my needs as far as possible. Because of their support I could achieve higher education and grew confidence to do something for the sake of the society. They always have encouraged me not to tolerate the unfair behaviour shown by others towards me. In my family, everybody consider me as they are and ask help whenever they need. I feel very happy at that time when I am able to help others.

The above mentioned experience shows the acceptance of an individual with disability by the family due to the contribution being made at times. It seems that the person is included well in the family as well as it might have made easier to be included in the society. The support from the family makes a person with disability more confident and empowered to perform his/her activities without feeling stigma.

Similarly, the statement of Hari also depicts the positive attitude of family towards disability:

I have hearing impairment but my family is very happy and satisfied with me. I live with my mother, wife and two children. I am the only one with disability in the family but I don't feel any difficulties to communicate with them as they have learnt symbolic language to communicate with me. I feel very proud of my family for the support they have shown to me.

Sometimes, living in the care homes reduces the stigmatization of family members and improves the chances of easy inclusion of individuals with disabilities. Although, the homely environment in such care homes or hostels establishes the relationships like a family, there are very limited chances of being stigmatized as that of the actual family. Some of the participants who are living in the hostel for longer periods have shared the inclusive experience as:

I lost my parents in a bus accident when I was only three years old. Since then I am living in a care home and I consider members there as my family. There I have never experienced any form of discrimination from any one. Due to the support from them I am able to become what I am today. I am always encouraged to participate in gatherings, every possible leisure activities as well as several programs conducted in the institution. I believe I am empowered by the support of my family so that I feel I am not excluded in the society.

The support and denial from the family to the individuals with disabilities influence largely to the debate of inclusion versus exclusion of people with disabilities in the society. In Nepalese society the relationship of an individual with family is given high emphasis. The existence of joint family system provides them better social networks. Thus, an individual with disabilities gets empowered from the support of the family. In this case, with the improvement of social as well as cultural capital, the chance of inclusion of an individual with disabilities gets high negating the fear of exclusion in the society.

Although in most of the cases, parental expectations from their child with disability are mostly negative and unrealistic; some people with disabilities get caring and supportive treatment from their family. With the growing concern of education and disability awareness, slowly the fatalistic attitudes of many families are changing so that they do not perceive the disability of their people as inability thus provides respect and opportunity.

6.3 Interconnection of Disability and Poverty

In low income countries like Nepal, people with disabilities are among the most vulnerable. “They are often the first to die when sanitary and food conditions become critical. They do not get to the hospital because transportation cannot be paid for. They are the last to get jobs when employment is scarce.” (Eide and Ingstad, 2011). Different studies on disability have revealed that when a poor person associates with disability, the condition becomes more critical as the associated disability drives the person further deeper into poverty.

Eide and Ingstad (2011), argue that with often limited access to education and physical barriers to overcome, people with disabilities are most often severely disadvantaged on the employment market and, if employed at all, often get low-paid jobs and even lower salaries than their non-disabled colleagues. In this study also it has been found that despite their high education and capabilities, people with disabilities are offered lower level jobs like telephone operator, musician etc. The following statement of Garima illustrates the same:

Most painful thing is that I am well educated, highly trained and have enough skills but unfortunately I don't have any platform to utilize these all. I asked too many people for seeking job. None of them supported me but finally I got appointed in reception in an office. Due to my poor economic condition, I accepted the job although I am eligible for higher job than that one. I have no good link with people in high authorities and have no money to offer to fulfil their demand for managing job.

However, it is less obvious but sometimes, poverty influences or creates disability. Different studies have shown that being poor may delay people in seeking help with health problems that are normally curable which leads them to disability. The story of Goma reflects the similar incident.

I developed visual impairment at the age of four due to measles. The economic condition of my parents was very poor. If they could afford for my medical treatment, I would not suffer from disability.

Because of the poor economic condition of people with disability, they do not get many options to earn their living. As a result they are pushed further in poverty. In the context of Nepal, lack of proper welfare system and absence of strong social security policy have increased the need of employment for the people with disabilities. In many cases, to search more employment opportunities, they are compelled to live separately from their family. The narration of Goma highlights it:

Our economic condition is poor. Living together in the same place limited our employment chances. So, my husband went to Terai (In the southern part of the country) to be employed as a teacher. Although we are employed and living differently, we still are not able to manage all the necessities for our daughter.

Many literatures in disability have shown poverty as a cause and consequence of disability. In fact, disability and poverty support each other. An individual with disability often faces social marginalization and has less chances of accessing education, health care or employment. This leads the person to poverty which in return results in poor housing, nutrition and so on. The vicious circle of disability and poverty affects not only the individual but also the family as a whole. Many families in Nepalese society with a member associated with disability adds trauma in the family and drives it further towards poverty. When a member with disability is present in the family, frequent attention has to be paid to the person which limits the access of family members to the income generating activities. Finally, the poverty grows deeper.

Dixon-Roman (2012), argues that although economic capital is an indicator of a family's social position which also indicates the family's social distance from the social and cultural norms of dominant institutions of schooling- the taken for granted assumptions that are associated with the discursive constructions of their disabilities produce different treatments. The severity of the impairment associated by an individual determines the ways of acceptance or refusal of the person with disabilities. Most of the participants in this study do not have severe impairment due to which it was possible for them to be employed otherwise the individuals with sever impairments are not likely to be employed for the generation of economy.

The illustrations of experiences of people with disabilities in getting employed has contributed in their economic capital, however, their economic status has not been changed drastically. For combating the associated poverty in the situation where they lack resources, people with disabilities badly need the income generating activities. For the same being employed in government or non-government offices, private institutions or service centres is one of the options together with self employment.

In Nepalese society, self employment is not popular among people with disabilities as there are many barriers such as social, cultural, economic etc. The evidences of employment for the individuals with disabilities show the inclusion of people with disabilities with other people in the society. The lack of good social network as well as social recognition, poor economic background and denial from family are the excluding factors to break the vicious cycle of poverty and disability.

Although individuals with disabilities are employed, due to challenges like unequal payment and benefits, low access to the facilities and more workloads create barriers in their successful inclusion. This has given very limited opportunity to combat their constrained poverty. In Nepalese society people with disabilities are considered as the most marginalized and socially deprived group. There are the formulation of provision of low interest loans and management of several subsidies in operating income generating activities; the implementation of these all policies is very weak so that people with disabilities are not benefitted as supposed.

Poverty and disability are closely interconnected and this vicious relationship is caused by social, cultural, political and structural phenomena. However, not all individuals with disabilities in the low-income countries like Nepal are poor, and there are some fascinating examples of individuals with disabilities who have been able to break the poverty-disability circle and even been able to utilise their disability status as basis for their success (Eide and Ingstad, 2011).

6.4 Being a Woman with Disability is Double Disability

Nepalese society is predominately patriarchal, governed by Hinduism as a strong ideological force. Women are never equal to men and occupy second-degree citizenship and are taken as living tools for performing certain roles at home. The condition of women is strictly controlled by patriarchal norms of the society (Acharya, 1994). In such scenario, women are supposed not to entertain equal opportunities that are available for men. Therefore, many of the issues faced by women in Nepalese society also have an impact on women with disabilities.

Nepal being a traditional society, there are different yardsticks for perceiving and judging disabled men and women and the treatment meted out to them is definitely discriminatory. Family, community and even government authority more or less accept boys and men with disabilities (Dhungana, 2006). This encourages them to grab any opportunities that are available to disabled people. They also have property rights (NPC/UNICEF/New Era, 2001). In most of the cases, disability does not restrict a man from anything unless the impairment is severe but the situation is quite opposite for women with disabilities. In this regards, they face double discrimination due to their association with disability as well as gender. As Boylan (1991) remarked, this double discrimination is the root cause of the inferior status of women with disabilities, making them one of the world's most disadvantaged groups.

The case of women with disabilities in Nepal seems strange as they continue to remain as invisible citizens in mainstream policy, often unconsidered in disability affairs as well as in women's affairs (Dhungana, 2006). Berry & Dalal (1996), argue that women may be born with disabilities or acquire them through disease, accidents or violence; society then adds to the negative experience of disability, making it more difficult for them to escape from the entrapments of physical/mental and socio-cultural inadequacies As a result they are casted down, stigmatized and excluded from the rest of society.

From the very beginning the qualities of shame, fear, passivity and dependence on others are instilled in disabled girls and women. The natural human qualities of being active, courageous, curious and conscious and the mental make-up of disabled women are suppressed by the society (Bhambani, 2003).

In Nepalese society, if any services are meant for people with disabilities, women with disabilities receive inadequate as very limited resources are directed towards even men with disabilities. Maqbool (2003), argues that restricted to their homes by inaccessible environments, lack of mobility aids or transportation, and family overprotection and shame caused by cultural biases, disabled women are often isolated and unaware of their options which has often led to unnecessary and undue hardships, and even to tragedy.

Women with disabilities encounter further discrimination as they are denied opportunities to marriage and family life. As long as a disabled man earns a living his chances of getting married and having a family life are much higher than those of a disabled woman (Thomas, n.d. in Dhungana, 2006). There is an attitude that marriage is not for disabled women. Men do not prefer to marry disabled women because they are considered incapable of looking after family life. They are denied access to reproductive health services by cultural attitudes, physical barriers, and financial constraints (Maqbool, 2003). The following narration of Sabita indicates the similar situation:

Men do not feel shy like we do due to which they can make many friends. In case of marriage also, very few wheelchair user females get married in comparison to wheelchair user males. Those who got married also developed impairment later after their marriage. They said we would bring misfortune to their homes if they marry us. You know, it is very difficult for us.

Women in Nepalese society are considered as male dependent. So, they are not supposed to live independently without the company of men. Due to such constrained norm, marriage is very important for women. In contrast, men in the society are free to live independently without marriage. People with disabilities are considered dirty, unworthy and inappropriate in the developing societies like in Nepal. In this constricted societal settings, women with disabilities are stigmatized heavily. Thus, they lack social contacts severely and lose social recognition as well. It is the great challenge for a woman with disability to come forward in the society and expose herself to be engaged in several customary activities.

Women with disabilities face not only difficulties in getting marriage but also there are cases of violence and finally rejection even after marriage. Life of a woman becomes critical when she develops impairment after marriage. Very often it has been found that the women who

associate with disabilities after marriage are alienated, humiliated, denied even from basic human rights and subsequently rejected from their families. For women with disabilities, it is very difficult to get married and in case, if they got married, it is equally challenging to continue their married life. Narration of Rama illustrates:

My husband left me when my daughter was two months old. He started to misbehave me from the time he knew that I was pregnant. It has been four years I have not heard anything from him. I don't know where he is now a days.

People perceive women with disabilities as weak, voiceless and support less. They think that these women with disabilities cannot protest against anything. As a result, others try to take advantage of their weakness and abuse them or even exploit sexually. Sometimes people develop the perceptions like a woman with disability does not have any peers, has sexual desire and seeks a company of man in her life. Therefore, thinking that she would not complain people with ill intention flirt with her and try to touch in her different parts of body. Such disgusting attitudes of men lead women with disabilities suffer violence in many cases.

Many incidents can be found in Nepalese society where in the name of helping women with disabilities, men misguide them and take advantage. The statement of Kamala reflects the similar picture:

When I was crossing the road, a man came and told me that he would help me. At first he caught my hand, I thought he was helping me but I was shocked when he held me tightly. I was afraid and pushed him away. His intention was bad. Next day again, he came and started talking with me in disguise of other voice but I recognized him. Time and again he tried to touch in my body. I was very afraid that what he would do to me. He followed me wherever I went and saying there was vehicle or ditch, he tried to catch my hand. I shouted for help but nobody came to me for rescue. At that time, I was holding an umbrella. I hit him with that umbrella and started shouting very loudly going nearby the other people. Seeing me very panic, when other people came closer to me, he ran away. I was very scared at that time. Anything could happen to me on that day. The remembrance of that incident terrifies me even these days as well. I am a woman with disability due to which he could dare to commit such activity to me. If only I could see or if only I

am not disabled, I would teach him a lesson for his ill treatment. To live being a woman with disability is very hard.

The gender as symbolic capital is interconnected with social capital as well as cultural capital. In general, women are expected to remain hidden at homes performing household chores and fulfilling the needs of family. This constrained concept of symbolic capital has restricted women in having social networks, social interactions and at least conduct some activities which could make her least dependent on men. Women with disabilities are the highly underprivileged group in the society. They are discriminated, largely ignored and extremely marginalized not only by people without disabilities but also by men with disabilities. In every aspect, women with disabilities are considered negatively. Collectively, these all contribute in excluding a woman with disability at the greater extent.

Similarly, health needs of women are given less priority than men's. Studies have shown that the proportion of men with disabilities getting treatment and other necessary appliances is almost double that of women with disabilities. According to the CBR Manager (June, 2003) in Dhungana (2006), parents seem very concerned about boys' treatment and try to bring them on time for follow-up, but follow-up for girls is often missed. Actually, sex bias in healthcare has been well documented in Nepal and the gender discrimination in health has also increased the rates of disability among women (UNICEF, 1996).

A woman with disability is often considered unfortunate and perceived negatively. Therefore, she is discriminated, humiliated and exposed to violence at number of occasions. It is not new that women with disabilities are ill treated by their male counterparts associated without disabilities. My attention was dragged by the statements of most of the women with disabilities in this study. They have shared that they received negative treatment not only from men without disabilities but also from men with disabilities. We can understand it from the narration of Goma:

Although we belong to the same category, we are perceived negatively by men with disabilities. I have experienced discrimination and bad words from them. They behaved me negatively because may be they thought that I am uneducated and cannot do anything by myself. I wonder why they don't try to understand that we are from same category and our difficulties as well as sufferings are similar.

It is necessary to analyse the reason of discrimination of women with disabilities by men associated with disabilities although both represent the same marginalized and downtrodden group of the society. Due to the existing concept of gender, men consider themselves superior than women. In the case of people with disabilities as well men with disabilities are driven by the same existing stereotyped concept of gender which recognizes women as weak, dependent and less smart. Sometimes, men with disabilities are overwhelmed by considering that only they are capable to perform various activities despite their disability and only they can be included successfully leaving the women with disabilities far behind.

Women with disabilities are negatively perceived, rejected and excluded from families, and thus are positioned at the lowest social level. They have been prevented from accessing entitlements available to men with disabilities showing that men with disabilities have better privileges than their female counterparts. Despite international standards and the passage and partial implementation of exemplary training and employment legislation, policies and practices in Nepal, women with disabilities are disproportionately undereducated, untrained, unemployed, underemployed and remain the poorest of the poor (Dhungana, 2006).

6.5 Employment and Level of Education

O'Day and Killeen (2002) in Lamichhane (2012), have argued that some of the crucial social functions employment can facilitate are 'financial independence and integration into the community. It also improves social status, provides social support, enables workers to make a contribution, and increases self-worth. In this regards, employment is very crucial in the life of people with disabilities for their successful inclusion in the main stream society. However, the access to employment for the people with disabilities is very limited in the developing countries like Nepal.

Lamichhane (2012), reveals in his study that people with hearing, physical or visual impairments often dominated a particular employment sector. People with physical impairments dominated the non-governmental organization (NGO) sector; people with hearing impairments overwhelmingly worked in restaurants; and people with visual impairments often worked in local schools. It can also be found that the opportunity of employment is highly anticipated by people with disabilities in the country. Apart from

economic independence, employment has several benefits for people with disabilities in Nepal including increased confidence, gaining respect in the family and society, and the discovery of new abilities (Ibid).

Employment status and education of a person can be correlated as more educated people are less likely to be unemployed and it seems to be true in the case of people with disabilities as well. The participants in this study are educated and employed as well. Most of the participants are highly educated whereas some of the participants have the educational qualification of secondary school only. Those who have higher qualification are employed in administrative as well as secretarial jobs and those who have comparatively less qualification are employed as musician or some related jobs in restaurant and other places.

It is also true that despite having high qualification people with disabilities are getting jobs irrelevant to their qualification. The respondents of this study are able to be employed because of their attained level of education. Most of the participants in this study have considered that being employed is very important in their lives no matter whether it is of high level or low level. They perceived that employment provides the opportunity to expand their social network and strengthen social interaction; self confident to be independent and economic benefit as well. One of the participants in focus group has shared similar experience as:

I know high education is very essential for getting better jobs. I did not search for any jobs until I completed my study of Master level. I attended most of the trainings offered to me which helped me to develop various skills necessary for the employment and to be self confident. With the achievement of high educational qualification, I was confident enough that I would be employed in a better job. My job is to accomplish the computer works which I can do continuously without being distracted by others as I am associated with hearing impairment. People at my office are very satisfied with my performance and treat me equally with others which make me feel that I am respected with my differences from others. I see many people with disabilities with good educational qualification are employed these days in NGOs and other private sectors, in education sector as teachers and some as activist as well as trainer to empower people with disabilities and

advocate for the disability rights. It makes me feel happy to know about other people with disabilities getting employed like me.

As suggested by Payne (2005), empowerment is the means of enabling people to overcome barriers, to achieve life objectives and to gain access to services. Providing education is one of the right ways to empower people with disabilities. The achievement of higher education helps to develop self awareness, self confidence and capacity to interact socially with various factors. Most importantly, high educational qualification also provides the better employment opportunities so that an individual with disabilities can be economically independent.

There is no doubt that employment provides the economic independence. Higher educational qualification provides better employment which enhances the better economic opportunities. Above all, education offers the conscience to be self reliant so that people with disabilities can ease out the stigmatization of being disabled. It also empowers the people with disabilities to be aware about their rights and helps them to support each other so that others will also be benefitted by the social, cultural as well as economic capitals.

CHAPTER 7 CONCLUDING REMARKS

7.1 Discussion of Theoretical Framework with respect to Analysis

This study is concerned with the social inclusion of people with disabilities in Nepalese society from the experiences of their involvement in employment. Discussions in this study were made on the basis of the theoretical perspectives from Rimmerman's work on social inclusion, Goffman's work on stigma, Burkitt's work on social self, Bourdieu's concept on capital. Rimmerman has described inclusion and exclusion as opposite phenomenon of each process. Social exclusion as explained by Rimmerman is a wide range of phenomena related to poverty, deprivation and hardship which encounters in relation to a wide range of categories of marginalized people in the society. When an individual or group is marginalized

from the socio-economic, socio-cultural activities and let alone suffer from economic distress, poverty as well as employment, it is considered as social exclusion.

The debate of inclusion versus exclusion in the social context not only relates to employment and poverty but also overlaps with social capital and social participation. With the development of impairment in the body, the contribution of an individual drops heavily, participation in social activities get restricted and thus marginalized with the identity as disabled which finally excludes the person from the society. Considering the concept of social exclusion and inclusion, disability of a person can be viewed as a social creation. It means that the disability of a person is more or less affected by the social circumstances. As suggested by Priestley (2003:13), “the disadvantage often associated with disability might be a social rather than an individual phenomenon, something that is not biologically determined but produced by particular social process. Crucially, this view suggests that it is not physical, cognitive or sensory impairments that cause disability, but rather the way in which societies fail to accommodate natural aspects of difference between people.” The exclusion of people with disabilities in terms of social, cultural, economic and symbolic capitals depends largely upon how the society considers the impairment of an individual as his/her inability and how the person perceives the disability in the life.

In understanding the debate of inclusion versus exclusion of people with disability, social definition of disability becomes crucial. Oliver (1996) argues that “ disability is all the things that impose restrictions on people with disabilities; ranging from individual prejudice to institutional discrimination, from inaccessible buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on. Further, the consequences of this failure do not simply and randomly fall on individuals but systematically upon people with disabilities as a group who experience this failure as discrimination institutionalized throughout society.” (Oliver, 1996: 33). From the conversation with the participants in this study what I found that they all perceive that their impairment is not the barrier for them to participate socially in several activities but the perceived social identity as disabled restricts them at large. The participants in the study agree that the constrained concept of disability perceived by society largely excludes them keeping at the margin of the society and make them suffer from discrimination, economic deprivation and poverty.

The rejection or acceptance of an individual with disabilities depends on the severity of the impairment of the person as well as it also depends largely on the construction of how size of social network by the person. The involvement of the participants in employment has definitely given them to expand their social network but it also depends on an individual's perception regarding the associated disability for the better acceptance by other people in the society. The disability friendly structure at the office and equality behaviour from the colleagues has made Ashok feel included well. It can be seen clearly that such feeling has empowered him to grow the size of his social network due to which he is able to organize awareness programs as well as different campaigns.

Similarly, the denial from the jobs by giving information as the office is in unreachable place discouraged Sabita which took her long to feel socially included until she got involved in employment. Oliver's statement is supported by this study as he opines that people with disabilities are excluded largely through social interactions of physical infrastructures, opportunities of strengthening economic capital and expanding social networks. Through the involvement of the participants of this study in the employment sector, we saw that the progress in social inclusion of people with disabilities is appreciated by all however, there are more challenges of successful inclusion.

In Nepalese society, an individual is expected to perform several cultural duties within family and publicly in society as well. In this study we saw that acceptance of an individual by society becomes easy when the person with disability is accepted well in the family giving a strong cultural capital. The association of participants in different groups and organizations has provided them opportunity to expand their social networks strengthening the social capital. Stronger social capital embedded with cultural, economic and symbolic capitals creates circumstances for successful inclusion of an individual with disabilities. This interpretation is supported by the participants' experiences which suggest that consideration of different forms of capital is inevitable for understanding the debate of inclusion versus exclusion.

Goffman explained that stigma exists in the interaction of a person with difference with the evaluation of that difference by others as negative. He furthermore explains that a person develops stigma when there occurs the undesirable conflict between what the society expects from an individual at a particular time and what actually he/she is. This study recognized social stigma and stigma related discrimination as some of the barriers for successful inclusion of people with disabilities in the mainstream society. Often stigma is also developed by people who have regular or close contacts with stigmatized individuals or groups such as people with disabilities which is as suggested by Goffman considered as stigma by association.

People with disabilities who are perceived as burden in deeply rooted Nepalese cultural society are very likely to experience rejection. Such rejection of entire group of people with disabilities has negative effects when it results in social avoidance or isolation (Rimmerman, 2013). In this study participants have experienced isolation and avoidance due to perceived stigmatization of being different from other member of family. Denial of support from the family to the people with disabilities due to associated stigma of other members limits the chances of their successful inclusion. Avoidance and isolation due to perceived stigma of belonging to different caste and associating disability as well of the people with disabilities in the employment is some of the challenges faced by the participants in their social inclusion.

Sometimes, feeling of difference by an individual may be enough to get stigmatized let alone at the margin in the society. In analysing Sabita's case, it came up that her inability to hold excreta at times and releasing publicly made her feel different. This feeling of difference led her stigmatized and made her perceive that her life is worthless to live. Together with stigma, labelling and discrimination appear in the life of individuals with disabilities. This study confirms that people with disabilities are given labels as 'sick', 'untouchable' 'useless' etc. When people address the individuals with disabilities with these derogatory labels, they feel discriminated which creates barrier between them and the group or society.

The association of participants in the groups and organization related to people with disabilities and their involvement in several activities exposed to the other people in the

society has provided them the facility of coping with the perceived stigma of disability. Supported by the participants' experiences in this study, Goffman's theoretical thinking can be concluded as real.

Burkitt explains that an individual develops the self identity through the interaction with the generalizations made by others in the form of expressions, attitudes, words etc. He further stresses that the development of self identity is largely based on the reconstructive efforts made by an individuals. It was found true that the concept explained by Burkitt as the different power structures in social relations influence development of individuals self. In this study it was found that the participants who were supported by their family experienced comparatively less discrimination and empowered to be included easily but in contrast to them some participants who had experience of family denial faced more stigma and discrimination due to which they felt more barriers in their inclusion.

The fact is that the creation of self identity through various social interactions and the judgements produced as the outcomes of these power relations contribute in forming the understanding of pride or shame. The individuals' understanding of pride and shame or both largely depends on the interactions of various capitals like social, cultural, economic, symbolic etc.

While summing up the concepts of all the theoretical frameworks, it can be concluded that the perceived difference of individuals with disabilities lead them to be discriminated and stigmatized which in fact contributes in the construction of their self identity. The socially constructed self identity provides the understanding of pride and shame or both which becomes inevitable in the process of inclusion of the individuals with disabilities in the main stream society.

7.2 Conclusion

This study has attempted to describe and analyze the experience of individuals with disabilities in the course of their inclusion in the mainstream society. The purpose of this study was to understand the challenges of people with disabilities in their attempts of inclusion through employment. At first I gathered the experiences of individuals with disabilities in regards to difficulties they faced while trying to be included in the mainstream society which later on analyzed through relevant theoretical frameworks. The debate of inclusion versus exclusion uncovered in this thesis is complex and the conclusion is drawn from the highlighted findings.

The exploration of participants' experiences revealed that the judgement of perceived disability of an individual is directed by the ties of respective family performing cultural, social and economic duties. In deeply rooted Nepalese cultural society judgement of the self of an individual with disability is largely biased which takes account from the prejudice and discrimination fairly enough for their exclusion. The severity of impairment of an individual determines the degree of acceptance during the interaction with various power relations. Family being the closest and foremost association of an individual appears to be crucial in determining the acceptance of the perceived disability. In addition to significant others and care givers, the family plays the pivotal role in providing stability, supports, socialization and opportunities for social inclusion (Rimmerman, 2013). The debate of inclusion versus exclusion looms in between the support and denial from the family of a person with disability.

Gender based oppression and violence are pervasive and entrenched in largely still patriarchal Nepalese society where being a women with disability is extremely hard, unsupportive and full of prejudice. Women with disabilities are considered weak, useless and are perceived negatively not only by the able bodied people but also by the men with disabilities. A very distracting trend has been identified that women with disabilities are given less priority in front of men with disabilities when they are trying to be included in the mainstream society through various activities.

The involvement of the participants in the groups and organizations of the people with disabilities has clearly indicated that individuals with disabilities get empowered from the association of such institutions. The groups and organizations of people with disabilities have contributed in expanding their social networks, overcoming the stigma related prejudice, identifying the strengths of each other by sharing the experiences and above all empowered to advocate collectively whenever necessary. In this regards it can be concluded that functioning of groups and organizations related to disability and the association of individuals with disabilities in such organizations contribute in their inclusion in the mainstream society.

Irrespective of the type of impairments, all the participants agreed that their level of education was a key to their employment which pushed them one step further on the way to their inclusion in the mainstream society. It is seen that good education and right employment empower people with disabilities to be included socially as citizens. The findings of this thesis suggests that if individuals with disabilities are treated based on the principle of what they can do rather than what they cannot – a strength-based approach – they can not only take care of their own livelihoods, but also contribute significantly to social progress (Lamichhane, 2012). The promulgation of laws addressing disability rights by the Nepalese government has protected the provision for reservation of employment opportunities in various institutions. It has systematized the access to employment opportunities for the people with disabilities however, it is necessary that the government should widen the affirmative action measures to the broader sectors so that many individuals with disabilities will be benefitted from the increased employment opportunities. Employment skills and career goals strengthen self-confidence, self-esteem and subsequently enhance community engagement and integration. In addition, they facilitate social interaction with co-workers and engagement in social activities outside the work place (Rimmerman, 2013).

It is unfortunate to find that in many cases people with disabilities who are employed are paid significantly lesser than their non-disabled counterparts. Moreover, they are likely to be employed in lower skilled and low-paying jobs despite their high academic qualification and other necessary skills. Apart from the inequality in payment, individuals with disabilities in employment sector face number of challenges regarding their accessibility, participation, dignity and discrimination. These challenges restrict their chances of social inclusion.

The experiences of participants have indicated that employed people with disabilities can be more significantly integrated into social activities than the unemployed. In regards of this finding I conclude that employment and active social participation may empower the people with disabilities and may serve as a promising vehicle for promoting social integration and social inclusion. It will require improved employment opportunities and the elimination of prejudice and discrimination to address the debate of inclusion versus exclusion of people with disabilities in Nepalese society.

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ANNEXES

Annex 1

Informed Consent to Collect Data for a Master Thesis in Social Work with Comparative perspective

TITLE: Challenges in the Inclusion of People with Disability in Nepalese Society

I am a Master student in social work with a comparative perspective at the Department of Social Science, University of Nordland, Bodø, Norway. I would like to request your participation in a Master thesis research about the experiences of disabled people who are being marginalized and sidelined from the main stream society. This study is an academic one and will be shared amongst my supervisor and other appropriate members related to university of Nordland. The master thesis that results from this work will be published in hard copy and will be housed at the University of Nordland, Norway. Your participation will be taken in the form of interviews which will be audio tapped in a digital recorder. This research will be conducted with a guarantee of confidentiality and will maintain the anonymity of the participants. Pseudonyms instead of your real name will be used in the thesis in order to protect your identity. In terms of possible risks to participants, there are virtually none. Your participation is voluntary and you also have the right to ask for more information about this study and to withdraw from the study any time during the interview without the need for providing any reasons and without any consequences. The data will be destroyed after finishing my thesis i.e. on 15th May 2015.

The research will be conducted fully within NESH guidelines.

I appreciate your cooperation in this study.

Thank you!

Sundar Shrestha

University of Nordland, Department of Social Science

Name of Supervisor: Asgeir Solstad

University of Nordland, Department of Social Science, 8049, Bodø, Norway

(Please sign below if you are willing to participate in the interview process for the Master thesis research outlined above.)

Signature:

Print Name:

Date

Annex 2

In-depth interview Guide

Establishing rapport with the interviewee

Greetings, followed by an introduction of myself to the interviewee and explaining the objectives of the study and the kind of information I want from them.

Asking for consent

Giving the participant the consent form and let them read or read to them if they cannot read. Explain to the participant what is in the consent form and letting them understand the consent before asking for their consent. If they consent to taking part in the study they should sign the consent form and I will proceed with the interview.

A. Personal information

- (a) Age
- (b) Sex
- (c) How would you describe your disability? (Type of disability associated)
- (d) How long have you had your disability?
- (e) Education level, did you go to school or not?
- (f) If yes, up to what level, primary, secondary or higher level?
- (g) Are you employed or do you own a business of your own where you can generate money from? Do you get paid?
- (h) Are you married?
- (i) If yes, how many children do you have?
- (j) Is there anybody in your family except you who is associated with disability?
- (k) Would you say that the area where you work is accessible for persons with disabilities?
- (l) What makes the area where you work accessible or not accessible?

B. Experiences faced by the Interviewee: (perception of living a life with disability)

- (a) Please tell me a little about your life during the past five (5) years. What things do you do? Where do you go? Who do you meet?
- (b) Please tell me also in brief about your working experience, including work-training and education and work experience, during the past five years.

Have you had a job? Have you had any interviews for work (paid or unpaid)?

Have you attended any job trainings in the past 5 years? If yes then what kind of training? Have you attended any job fairs in the past 5 years?

(c) What are the things in your life that are most satisfying?

(d) What are the most difficult barriers or challenges that you face in your life?

C. Experiences of particular time and event

1.1 Do you recall a particular time or event in the last five (5) years when you were left out or treated badly or prevented from participating because of your disability?

1.2 WHAT happened? WHERE and HOW did it happen?

1.3 Is this still happening or did it just happen once?

1.4 Are there other details that you want to share with us about this experience?

1.5 Can you describe the workplace or training environment in which this experience took place?

1.6 Have you ever experienced violence or abuse in your workplace because you are disabled or a woman? If so, what did you do? Was there any internal committee that you could approach with this issue? Did you report it to an external body? What happened after you reported the incident?

D. Dignity & Autonomy

1.7 HOW did this experience make you feel and WHY? (For example, did you feel respected/ not respected, ignored/cared for, worthy/ unworthy?)

1.8 WHAT made you feel that way?

1.9 What do you think made people treat you that way?

1.10 Did you feel that you had a choice about what happened to you?
WHY? or WHY NOT?

1.11 If you had a choice, would it have made a difference to what happened? In which way?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO CHOICE AND MAKING A DECISION YOURSELF (AUTONOMY)

(a) Did you want to make a different decision or did you want to do something else?
WHAT was the different decision or what did you want to do?

- (b) Did you have enough information to make that decision?
If not, what prevented you from having enough information?
- (c) Did you feel pressured to act the way you did?
WHO/WHAT was pressuring you? HOW did it make you feel?

E. Participation, Inclusion & Accessibility

1.12 Did people in your community who knew about or saw what happened to you in the workplace or in the training do anything about it? If Yes, Who? What did they do?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO PARTICIPATION, INCLUSION or ACCESSIBILITY

- a) Were you kept apart or left out?
- (b) Did you need a service or some assistance so that you could participate?
If YES, what service(s) or assistance did you need?
Did you receive it? If you did not receive it, HOW did that affect you?

F. Non-Discrimination & Equality

1.13 How do you think your disability affected what happened to you?

1.14 Do you think that persons without disabilities would be treated the same way you were? WHY or WHY NOT? HOW would they have been treated?

1.15 Do you think being a man or a woman affected what happened to you?

[As a woman with a disability, do you get an equal wage at par with others doing the same job as you? If not, what is the difference, and why? Have you ever asked your employer about the difference?] WHY or WHY NOT and HOW?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES of DISCRIMINATION or INEQUALITY

- (a) Do you know anyone else who was treated in the way you were?

G. Respect for Difference

1.16 Were you treated the way you were because people thought you were different?
In what ways do people see you differently?

1.17 Do you think that a person without a disability would have been treated in a similar way? If not, how do you think he/she would be treated?

1.18 Do you feel that people label you and then treat you differently because of the label? If YES, what label do they use? HOW does this label affect you?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO RESPECT FOR DIFFERENCE

(a) Would someone of a different ethnicity be treated that way? WHY? or WHY NOT?
How are people from a different ethnicity treated in your community?

(b) Would a woman be treated that way? WHY? or WHY NOT?
How women in your community are usually treated?

(c) Would a poor person be treated that way? WHY? or WHY NOT?
How are poor people treated in your community?

1.19 Did you report the experience to anyone?

(a) If you REPORTED the experience, what kind of person/organization did you report it to? How did that person react? What action was taken?

(b) If you did NOT REPORT the experience to anyone why did not you report it?

1.20 In your opinion, what action[s] should be taken to improve [or prevent] the experience in the future?

1.21 Is there anything else that you would like to tell us about that experience?

Thank you very much for your time and contribution.

Annex 3

Focus Group Interview Guide

At the beginning:

Welcoming all the participants and thanking them for coming. Participants will be asked to introduce themselves with their names. A brief explanation of the project and focus group will be given. It will also be explained why the participants were chosen and the importance of their contribution to the study and the community.

Asking for consent

Giving the participant the consent form and let them read or read to them if they cannot read. Explain to the participant what is in the consent form and letting them understand the consent before asking for their consent. If they consent to taking part in the study they should sign the consent form and I will proceed with the focus group discussion. The consent will also be taken for recording the focus group.

1. Do you have a story about a particular time or event in the last five (5) years when you felt left out or treated badly or prevented from participating because of your disability [or because you are a woman]? If yes, what would have been different if you were not a woman with a disability?
 - WHAT happened? WHERE and HOW did it happen?
 - Did you report the experience to anyone? What type of person?
Was any action taken? Why or Why not?
- (a) How did that make you feel and why?
- (b) Did you feel you had a choice about what happened to you?
- (c) Did you feel pressured to act that way?
- (d) Do you think your disability [and being a woman] affected what happened to you?
Do you think someone without a disability [or not a woman with a disability] would have been treated that way? Why or why not?

2. Can you recall cases when you were treated well and that made you feel good about yourself and respected and were equal to others? Can you tell us that story?
3. Have you had any human rights or disability rights awareness raising or training?
4. What action[s] do you think should be taken to allow you to remove the challenges and barriers that you face?

Thank you very much for your time and contribution.