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**Maternal Health Care Service Access to  
Disabled and Dalit Women in Nepal**

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**A Thesis Submitted to University College London (UCL)  
For the Degree of Doctor of Philosophy**

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## **DECLARATION**

I, Hridaya Raj Devkota, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:

Date: 30/01/2017

## ABSTRACT

**Background:** The access and utilization of maternal health care services by disabled and Dalit women in Nepal has not been well studied, and yet disparities in these may result in poor health outcomes. Co-existence of caste and disability may lead Dalit women with disability to further exclusion and marginalization, preventing them to access basic human rights and opportunities such as maternal health care services. It is therefore important to understand disabled and Dalit women's access and utilization of health care service and the effect of intersectionality between their caste status and disability in the use of services. Previous efforts have focused on disability, gender and caste separately, but few studies have attempted to understand the inter-relationship between them or where they co-exist. This study explored this complex relationship and the multiple perspectives of Dalit women with and without disability about their access and utilization of maternal health care services with the assumption that all of these factors interacting together lead to exclusion and marginalization preventing their access and utilization of services. The study objectives were: (i) to compare and determine maternal health care service access and utilization patterns among disabled and non-disabled, Dalit and non-Dalit women in the Rupandehi district; (ii) to understand the attitude and behaviours of society and maternal health care providers towards disability; and (iii) to identify inhibiting and enabling factors for disabled and Dalit women with regards to access and utilization of maternal health care service.

**Methods:** The study employed a mixed methods design combining quantitative and qualitative components of data collection and analysis. Quantitative data was obtained from survey questionnaires administered to women between aged 15 - 49 years and also of their health care providers. A total 354 women, of which 79 were disabled (18 disabled Dalit and 61 disabled non-Dalit) and 275 non-disabled (133 non-disabled Dalit and 142 non-disabled non-Dalit) participated in the survey. While qualitative data was gathered from 37 in-depth interviews, six focus group discussions with women (disabled and non-disabled; Dalit and non-Dalit), and six key informant interviews with activists, community leaders and policy makers. Quantitative data was analysed using descriptive statistics, bivariate and multivariate analysis with a logistic regression model and theme content analysis was applied to the qualitative data.

**Results:** The study found inequitable utilization of maternal health care services, with disabled women having lower utilization of ANC one (83.5% vs 96.7%,  $P < 0.001$ ), HF delivery (52.6% vs 69%,  $P < 0.05$ ) and PNC (18.4% vs 32.5%,  $P < 0.05$ ) services compared to non-disabled women. Household indicators relating to education, wealth and family circumstances were the main determinants for

disabled women having less service utilization ( $P < 0.05$ ). Low utilization of postnatal care (PNC) services among all groups found due to the poor information received by women from local health providers and strong negative traditional beliefs among communities.

The study did not find differences in the utilization of maternal health care services between Dalits and non-Dalits ( $P > 0.05$ ). Rather it found that maternal health care services are not easily or equitably accessible to all social groups, preventing full utilization for disabled. Societal and health care providers' attitudes towards disability were often found to be negative, although there were positive and negative user experiences and perceptions of provider's attitude and behaviours. A further finding of the study was that the health care needs of disabled women are invisible at the policy level, which appeared to translate into unsuitable health care settings and ill-prepared health care providers to cater for them.

Women from all social groups encountered a number of barriers to access, relating to personal, socio-cultural, and policy or system factors; however, disabled women faced additional barriers. Women with disabilities from all social groups faced physical, attitudinal, socio-cultural and policy related issues, including a lack of knowledge and skills among providers were critical barriers for women with disabilities; whereas having positive providers, a favourable family environment, as well as education and information, were enabling factors for disabled women's access and utilization of care. Women with disabilities from all social groups also have higher levels of fear and perceived risks associated with pregnancy and delivery. This is primarily linked to worries about delivery complications associated with their disability and also that the baby would inherit their disability. The study did not find any compounding effect of caste and disability in access and utilization of maternal health care services.

**Conclusion:** Improving equity and maternal health care access and utilization for disabled and other marginalised women requires that policy and existing traditional strategies be re-examined, re-developed and implemented through a human rights-based lens, with programme interventions focused on addressing persistent negative attitudes and socio-cultural barriers. Women's education, social status, decision-making power and access to resources are critical factors associated with health care access and utilization among all groups of women. Significantly, women with disabilities, no matter what their social group, faced greater barriers than non-disabled women. Therefore, in order to increase access and utilization of maternal health care services across the population, holistic approaches including multi-sectoral interventions should be adopted.

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## ABBREVIATION & ACRONYMS

ADB	Asian Development Bank
AHW	Auxiliary Health Worker
AMDA	Association of Medical Doctors of Asia
ANC	Antenatal Care
ANOVA	Analysis of Variance
ANM	Auxiliary Nurse Midwife
ARROW	Asia Pacific Resource and Research Centre for Women
ATDP	Attitude Towards Disabled Person
BEOC	Basic Emergency Obstetrics Care
BLF	Big Lottery Fund
CBS	Central Bureau of Statistics
CEDAW	Convention on the Elimination of All Forms of Discrimination Against Women
CEOC	Comprehensive Emergency Obstetrics Care
CI	Confidence Interval
CPR	Contraceptive Prevalence Rate
CSDH	Commission for Social Determinants of Health
DFID	Department for International Development (UK)
DHS	Demographic Health Survey
DO	Dalit Organization
DoHS	Department of Health Service
DPHO	District Public Health Office
DPO	Disabled People's Organization
FCHV	Female Community Health Volunteer
FGD	Focus Group Discussion
FHD	Family Health Division
FP/MCH	Family Planning & Maternal Child Health
FWCW	Fourth World Conference on Women
GO	Government Organization
GoN	Government of Nepal
HA	Health Assistant
HF	Health Facility

HMGN	His Majesty's Government of Nepal
HP	Health Post
ICPD	International Convention on Population and Development
ICU	Intensive Care Unit
ILO	International Labour Organization
IMF	International Monetary Fund
IMR	Infant Mortality Rate
INGO	International Non-Government Organization
IYDP	International Year for Disabled People
KII	Key Informant's Interview
LSGA	Local Self Governance Act
MCHW	Maternal Child Health Worker
MDG	Millennium Development Goal
MMR	Maternal Mortality Rate
MNCH	Maternal, New-born and Child Health
MoHP	Ministry of Health and Population
MoWCSW	Ministry of Women Children and Social Welfare
NAB	National Association of Blind
NDHS	Nepal Demographic and Health Survey
NFDN	National Federation of the Disabled, Nepal
NFHP	Nepal Family Health Programme
NGO	Non-government Organization
NHRC	Nepal Health Research Council
NHSP IP	Nepal Health Sector Programme Implementation Plan
NPC	National Planning Commission
NRP/Rs	Nepalese Rupees
OR	Odds Ratio
PHCC	Primary Health Care Centre
PRSP	Poverty Reduction Strategic Plan
PWD	Persons/People with Disabilities
SBA	Skilled Birth Attendant
SD	Standard Deviation
SDG	Sustainable Development Goal

SDH	Social Determinants of Health
SHP	Sub-health Post
SLHP	Second Long-term Health Plan
SPSS	Statistical Package for Social Sciences
SRH	Sexual Reproductive Health
STD	Sexually Transmitted Disease
TB	Tuberculosis
UHC	Urban Health Clinic
UN	United Nations
UNCRPD	United Nations Convention on Rights of Persons with Disabilities
UNDAF	United Nations Development Assistance Framework
UNDP	United Nations Development Programme
UNESCAP	United Nations Economic and Social Commission for Asia and the Pacific
UNFPA	United Nations Population Fund
UNICEF	United Nations Children’s Fund
USAID	U.S. Agency for International Development
VDC	Village Development Committee
VHW	Village Health Worker
WHO	World Health Organization
WTO	World Trade Organization

## CHAPTER ONE: INTRODUCTION

“Of all the forms of inequality, injustice in health care is the most shocking and inhumane”.

- Dr Martin Luther King

“People with disabilities.....experience health care disparities, such as lower rates of screening and more difficulty accessing services, compared to people without disabilities. Eliminating these multifaceted disadvantages among people with disabilities should be a critical national priority.”

- Lisa I. Iezzoni

### 1.1 BACKGROUND

#### 1.1.1 Maternal Health

This study will investigate the factors and barriers that make some socially discriminated groups like disabled and Dalit women in Nepal more vulnerable to experiencing the disparities that lead to poor maternal health outcomes. Additionally, this study will look at how disability and caste interact; what are the outcomes when disabled women are also Dalit versus when disabled women are non-Dalit.

Women in low income countries are at high risk of dying during pregnancy and childbirth (Ajaegbu, 2013; Suwal, 2008). The WHO estimates that in 2013 alone, 289,000 women died due to complications of pregnancy and childbirth; of these deaths, about 99% occurred in low and middle income countries. More than half the deaths occurred in sub-Saharan Africa, and one third in South Asia (WHO, 2014). The ‘life time risk’ of maternal death during or shortly after pregnancy in sub-Sahara Africa is 1 in 38; whereas in South Asia is 1 in 200. By way of comparison, the risk in high income countries is far less, for example in Italy it is 1 in 20,000 deaths (CSDH, 2008; WHO, 2014).

In low-income countries, the most common causes of maternal death are haemorrhage (25%); infection (15%); unsafe abortion (13%); hypertension and eclampsia (12%); and obstructed and prolonged labour (8%) (Bhandari, 2012b). Almost all maternal deaths occur due to preventable obstetric complications between the third trimester and the first week after pregnancy (Bernis, Sherratt, Abouzahr, & Lerberghe, 2003; Bhandari, 2012a; Kwast, 1991; Nour, 2008).

Deaths occur mostly due to lack of access to health care, particularly emergency services, during pregnancy, delivery and immediately after childbirth (WHO, 2011). Disparities in access to health



care, delays in seeking and obtaining care and poor quality of care due to lack of skilled health professionals also contribute (ARROW, 2010; Thaddeus & Maine, 1994).

Studies in Nepal and India showed significant differences in the utilization of maternal health care services and health outcomes among social groups (Bennett, Dahal, & Govindasamy, 2008; Kumar & Gupta, 2015). The socially oppressed, such as disabled and lower caste groups (Dalit) women were less likely to utilize maternal health care services compared to non-disabled and higher caste women, (Kumar & Gupta, 2015; Morrison et al., 2014; Pandey, Dhakal, Karki, Poudel, & Pradhan, 2013; Saroha, 2007) which could lead to higher maternal mortality among these groups.

### **1.1.2 Disability**

The UN Convention on the Rights of Persons with Disabilities (2006) defines disability as “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (UN, 2006).

The chosen terminology of the disability movement varies in different cultures and languages. In the UK, the term ‘disabled people’ is favoured; in this report the terms ‘persons/ women with disabilities’ and ‘disabled people’ are used interchangeably as both terms are used by organisations supporting people with disabilities in Nepal. The Nepali word ‘*apanga*’ is a direct translation of the English word ‘disability’ and there exists similar equivalents in most regional languages within the country. However, the common use of this word usually refers to people with the most obvious and severe forms of physical and sensory disability only.

About 15% of the world’s population has some form of disability; and the prevalence among females is 61% higher than males (i.e. 12% among male and 19.2% among female) (WHO & The World Bank, 2011). Women in low income countries are particularly vulnerable to disabilities due to poor access to healthcare, poor working conditions and exposure to gender violence (ILO/USAID, 2011).

Acquiring accurate data on disability prevalence in Nepal is difficult. This is largely due to a lack of common definition and prejudice and will be discussed in more detail in this study. Data from the latest census (2011) found about 2% (n=513,321) of the population have disabilities in Nepal (GoN/NPC/CBS, 2012a). Other surveys have revealed prevalence rates ranging from 1 to 13% in Nepal (Shrestha & Nilsson, 2012). However, a recent study in Makawanpur on maternal health conducted using adapted questions from the Washington Group on Disability Statistics, found 29%

of married women with children having disabilities (Morrison et al., 2014; 2015). These wide variations in findings demonstrate the inconsistencies in current approaches to measuring disability in Nepal, as well as suggest that true figure is considerably more than the official government statistics. As a consequence of low official data, policy on disability is often inadequately informed, which ultimately influences maternal health care services and support for women with disabilities.

### 1.1.3 Caste System and Dalits

Caste is a form of social hierarchy. Berreman (1967:70) has defined the caste system as a '*system of birth-ascribed stratification, of socio-cultural pluralism, and of hierarchical interaction*'. The caste system in the Indian sub-continent including Nepal borrows the classical model consisting of four broad social classes called "**Varna**" based on **Vedic faith** that relates to Hindu religion. These are categorized in hierarchy as Brahmin, Chhetriya, Vaishya and Sudra. Caste is determined by birth; however it is also commonly associated with traditional occupations – Brahmins as priests, Chhetriya as Kings and warriors, Vaishya as merchants and traders and Sudras as labourers (Gang, Sen, & Yun, 2012; Iversen, 2008; Subedi, 2010). As a subset of Sudras, a separate category called Chandala are the last amongst all in the social order whose distinguishing characteristics are particularly the lowest level labourers and menial workers (considered polluting) as traditional occupation. These are called impure, polluted and untouchables (Gang et al., 2012; Iversen, 2008). The groups under this category are now known as Dalits and are mostly labourers such as ironworkers called **Kamis**, leather workers - **Sarkis** and tailors and musicians – **Damai** (Subedi, 2010).

Nepalese are known by castes with their surname essentially providing their identity. It effects their family life, food, dress, occupation and culture. Every individual has a caste or ethnic identity and the people in Nepal know what their ascribed identity is (Gellner, 2007).

Nepal is a diverse country with more than 10 religions and 125 different ethnic and caste groups (GoN/NPC/CBS, 2012b); of these, 28 social groups are listed as Dalits ('untouchables'), and comprise 13.6% of the total population (Gurung, 2008). 'Dalit' is a term given to a group of people who are placed at the bottom of the caste system hierarchy. The word "Dalit" literally means "oppressed" in Sanskrit. This self-chosen political name united those caste groups during the Dalit movement in India in nineteenth century. This terminology has continued to be used in Nepal after the democratic movement of 1990 (Gellner, 2007).

The caste system - and subsequent caste discrimination - is a rigid form of exploitation and oppression in South Asia that has left some groups, such as the Dalits, marginalized and vulnerable (Nohrlind, 2009). Caste is characterized by endogamy, hereditary transmission of lifestyle, occupation and rituals status in hierarchy that exists particularly in Nepal and India. '*Jaat*' is the term used for caste in Nepali. The terms '*achhut*', '*pani nachalne*', '*sano jat*' are used to refer to Dalits in Nepali and mean respectively, '*untouchables*', '*we can't use their water*' and '*low caste*' (Gurung, 2008). While the "New National Code of Nepal" abolished the practice of untouchability in 1963, making it illegal, in practice, it is still continues today.

In this report, the "Dalit" term is used to describe those considered '*untouchable*'. This is the practice of excluding a group by segregating them from the mainstream by social custom on the basis of pollution and purity – which forms the basis of the exclusion (Gurung, 2003).

Caste – and the related exclusions – has a pernicious effect on all aspects of life. For example, a World Bank/DFID study reveals Dalit women in Nepal rank lowest in the composite empowerment and inclusion Index (Lynn, 2006). The literacy rates of Dalit women is 24.2% and their life expectancy is 50.8 years compared to a national literacy rate of 43% and national life expectancy among females of 59.9 years (Acharya, 2004). Another study shows the maternal mortality ratio (MMR) among Dalit women as 273 per 100 000 live births, compared to 182 per 100 000 live births among higher caste Brahmin women (Suvedi, Pradhan, Sarah, & Mahesh, 2009). The Nepal Demographic Health Survey data shows the rates of institutional delivery for Dalit women to be 26.4% and delivery assisted by skilled birth attendant at 26.8%; whereas the figure for Brahmin women is 62.2% and 64.8% respectively (MoHP/NewEra/ICF International 2012).

These figures illustrate how Dalit women appear to face more challenges in accessing health care – particularly maternal health care - resulting in higher risk situations and poorer outcomes than women from more advantaged caste groups. Despite these poor indicators within this group, there is another group of women with characteristics that may result in even greater challenges and potential for inequity, they are Dalit women with a disability. This group of women have been facing triple discrimination being women, belonging to the lower caste group and being disabled.

Based on the above-mentioned data, it is hypothesized at the outset of this thesis that health care services may be least accessible to disabled, lower caste women due to their lower status, fear of or actual poorer treatment by health care providers. Conversely, it was speculated that in comparison, higher caste non-disabled and disabled women might have greater access to health

care services because of their higher status in the society, higher level of education, better economic status, participation and access to community resources.

#### **1.1.4 Health Inequalities**

Health inequality is the result of complex interaction between individual, cultural, economic and political factors (Acharya, 2012). If a section of society is excluded from healthcare services on the basis of race, ethnicity, gender, disability, age, caste and/or class, then disparities will inevitably result (Carter-Pokras & Baquet, 2002). Sadly, such disparities can be found almost everywhere, irrespective of how developed the country is (Acharya, 2012). Moreover, the WHO concluded from studies in over 10 countries that inequalities in health are increasing (as cited in CSDH 2008). However, the gaps and nature of health inequalities are different across low and high-income countries. Reducing these inequalities and meeting the health needs of all social groups is an issue of social justice (Marmot, 2005).

Evidence shows consistent pattern of inequalities in maternal mortality rate and disparities in health care service utilization among different social groups in Nepal. As stated above, the study found much higher maternal mortality rate among Dalits (273 per 100,000) compared to higher caste group women (182 per 100,000) (Suvedi et al., 2009). Similarly, the Nepal Demographic Health Survey (2011) reports that the utilization of maternal health care services were much lower among Dalits (e.g. 26% Health facility delivery) compared to higher caste Brahmin and Chhetri women (49%) (MoHP/NewEra/ICF International Inc, 2012; Pandey et al., 2013). Those studies consistently showed most of the health indicators at lower levels among socially discriminated and marginalized groups such as Dalits and Muslim women compared to privileged groups such as Brahmin and Chhetries. However, the literatures are silent about the causes of these differences.

Inequalities in health are reflected not only by the unfair system and unequal distribution of health resources but are also due to unfair and unequal social arrangements (Dahlgren & Whitehead, 2006). In Nepal, as in many other settings, social structures prevents women from access and utilization of maternal and health care services (Furuta et. al, 2006; Matsumura & Gubhaju, 2001).

#### **1.1.5 Public Policy to Deliver Human Rights Commitments to Health in Nepal**

The Country Code (Civil Law) 1963, Constitution of Nepal 1990, the Civil Rights Act 1995 and the Interim Constitution of Nepal 2006, all state that “No person shall, on the basis of caste be discriminated against as untouchable” (Lynn, 2006; UNDP, 2008).

The human rights treaties and UNCRPD, Article 25a state “the State must provide persons with disabilities with the same range, quality and standard of free and affordable health care services as provided to others without discrimination” (UN, 2006). Nepal has also ratified a number of relevant international human rights treaties including the International Convention on the Elimination of All Forms of Racial Discrimination (1965) (Bhattachan, Sunar, & Gauchan, 2009); Convention on Elimination of All Forms of Discrimination Against Women (CEDAW) in 1991 (HMG/N 1998, Lynn 2006); Convention on the Rights of Person’s with Disability (UNCRPD) in 2010 (Shrestha & Nilsson, 2012).

The Interim Constitution of Nepal (2006) also defines every citizen’s right to have free basic health services from the state. Considering these, Nepal has provision in its policy to provide essential health care services free of cost to ultra-poor (those living on less than \$1.25 per day), vulnerable and people with disabilities (GoN/MoHP, 2009). In addition, there is a range of laws and policies in addressing the needs and rights of persons with disabilities and Dalits that obliges the government to provide free services (education, health care) as the people’s fundamental rights. For example, the National Policy and Plan of Action on Disability (2006), has provisions for free treatment for basic healthcare for persons with disabilities (GoN/MoWCSW, 2006). However, many people with disabilities (PwDs) experience poorer levels of health; which, combined with unequal access to health care services results in unmet healthcare needs compared to the general population (HMG/NPC/UNICEF Nepal 2001).

#### **1.1.6 Maternal Health Situation in Nepal**

In Nepal, the maternal mortality ratio (MMR) declined from 850 per 100,000 live births in 1990 to 170 in 2013 (GoN/NPC, 2013). This reduction demonstrates that Nepal was well on track to achieve its MDG 5 of reducing MMR to 134 by 2015 vindicating the government’s long-term policy and fiscal commitment. Contributing factors to this dramatic reduction included the legalization of abortion (2002); provision of free delivery and maternal care (2009); financial incentives for women to deliver in health facilities with a skilled birth attendant (SBA) (2005); free primary health care; as well as the increase in contraceptive-use, from 39.3% to 49.7% over the past 10 years. These changes have led to a declining family size and a remarkable reduction in unwanted pregnancies, resulting in a total fertility rate drop from 4.1 in 1996 to 2.6, as noted in the 2011 Nepal Demographic and Health Survey (NDHS) (Hussein et al. 2011; MoHP/NewEra/ OrgMacro 2002; MoHP/NewEra/ICF International 2012). Moreover, increased household income, improved girl’s education, women’s empowerment; better access to health facilities and availability of

maternal health care services, accompanied by a rise in deliveries in public health facilities - from 9% of all births in 2001 to 26% in 2011 - have all contributed to reducing maternal mortality. Another key factor contributing to decreased MMR is the increased percentage of births attended by skilled birth attendants from 12.9% in 2001 to 36% in 2011 (MoHP/NewEra/ICF International Inc, 2012; MoHP/NewEra/OrgMacro, 2002, 2007).

However, this remarkable achievement is not evenly distributed among the population: huge differences in maternal health have been observed between social groups and those living in different geographical locations. For example, the NDHS (1996, 2011) shows considerable variability between social groups and wealth quintiles for women living in different parts of the country (Bennett et al., 2008; MoHP/NewEra/ICF International Inc, 2012; MoHP/NewEra/OrgMacro, 2007; Pandey et al., 2013).

The following section describes more about the variability and trends in maternal health care service utilization in Nepal.

#### **1.1.7 Trends in Maternal Health Care Service Utilization in Nepal**

Despite policies to redress them, disparities persist widely in maternal health care utilization (GoN/MoHP, 2010). In particular, these disparities can be observed between advantaged and disadvantaged groups of people; such as non-Dalits and Dalits, urban and rural; socio-economic and ethnic groups (MoHP/NewEra/ICF International Inc, 2012; Pandey et al., 2013).

For example, in 2001, utilization of antenatal care by urban women was reported to be more than four times higher (48.4%) than rural women (11.8%) using the WHO recommended measure of four or more visits (MoHP/NewEra/OrgMacro, 2002; WHO, 2003). Similarly, health facility delivery was more than six times higher in urban areas (44.5%) compared to rural areas (6.6%). However, it should be noted that while by 2011 utilization of health delivery had significantly increased (24%), overall it remained low and not on track to meet the national target to 40% by 2017 (HMGN/DoHS/FHD, 2002; MoHP/NewEra/ICF International Inc, 2012; MoHP/NewEra/OrgMacro, 2007). While gaps between urban and rural populations have narrowed over a decade, differences still remain; for example, women in urban areas are more than twice as likely (71%) to deliver in an institutional setting than women in rural areas (32%). The proportion of rural women who do not attend postnatal check-ups is more than twice (56.6%) that of urban women (23.9%) (MoHP/NewEra/ICF International Inc, 2012; Pandey et al., 2013). Unsurprisingly, it has been reported that maternal deaths due to pregnancy related causes are higher in rural areas (28% of total deaths) than in urban (22.2%) (Suwal, 2008).

Home deliveries are most common in rural and remote communities as well as among poor, illiterate and disadvantaged populations who do not seek care from health facilities to the same degree (Bhandari, 2012b; Wagle, Sabroe, & Nielsen, 2004). One study suggests lack of access as one of the most significant obstacles to increasing institutional deliveries (Engel, Glennie, & Samuels, 2013).

Studies in countries with similar rural geographical challenges - Vietnam and Nigeria for example - also suggest that geographical access as one of the factors affecting utilization of delivery services at the primary level in rural areas (Duong et al. 2004; Ajaegbu 2013). On the whole, the literature shows that an individual's place of residence influences the uptake of maternal health services, because of distance, availability of services and transport access.

In sum, while there is an overall positive trend in maternal health service utilization, a subsequent narrowing of disparities does not seem to be the case equally for all populations, and the situation of some groups of marginalized women, including women with disabilities, is largely unknown. There is limited data about disability within the government system and no information available specifically regarding disability and reproductive health. It is impossible to glean an accurate picture of maternal health for women with disabilities on a national basis, although few qualitative data indicates that access to maternal health services for women with disabilities is limited (Dhungana, 2006). Given the embedded nature of discrimination in Nepal, and the inequitable progress in maternal health, it is unlikely that women with disabilities or women from Dalit groups will have benefited to the same degree as other women since both groups have been facing similar nature of social oppression. But this study set out to better understand the parameters of these issues.

## **1.2 RESEARCH PROBLEM**

It is interesting to explore what maternal health care is like for Dalits and women with disabilities because it is largely unknown, and it is important to better understand how disability and caste interact with each other to affect this in access and inclusion. What influences Dalit women with disabilities to seek health care services, and what is the provision of accessible health care services to these vulnerable groups? These issues have not been explored in detail in Nepal, so this research will attempt to understand the maternal health needs of Dalit women with disabilities, their service utilization experiences and also identify the factors affecting their experiences in order to strengthen the evidence base to

advocate for more informed policy, provide recommendations for improved and more equitable services.

Existing social power structures leave Nepali women undervalued, disempowered and marginalized, with consequences that increase risks to health and exacerbate maternal mortality (Rath et al., 2007). Women with disabilities who belong to lower caste groups experience compounded marginalities (Mehrotra, 2012). While being disabled and being Dalit are different experiences, they have common social constructs, which result in subjugation. Both lead to discrimination, stigmatization, isolation, the prevention of opportunities and denial of rights (Pal, 2010). Studies from countries around the world show gaps in access to health care and health status exist between disabled and non-disabled people. People with disability are consistently more likely to have poorer health indicators compared to non-disabled people (Thierry & Dennis, 2004; Trani et al., 2011).

Dalit women with disabilities face significant difficulties as a result of long standing socio-cultural constructs that hinder their opportunity to participate equally in society and have equitable access to services, and which in turn negatively affect their well-being and survival (Stubbs & Tawake, 2009; Thomas, 2004). A UNFPA report has highlighted the fact that the sexual and reproductive health needs of women with disabilities are neglected, including access to essential health care (UNFPA, 2011). Similarly, Bhattachan et al. (2009), suggest that Dalit Nepali women experience caste based discrimination while seeking health care services. In sum, gender discrimination, the practices of caste untouchability and negative attitudes towards disability are all challenges faced by Dalit women with disabilities in Nepal. This combination of factors could be described as a 'triple burden'.

Maternal mortality remains high in Nepal compared to other low income countries (MoHP/NewEra/ICF International Inc, 2012; WHO, 2014). About 73% of all maternal deaths occur due to direct obstetric causes which could be prevented if women had access to basic health care services (Say et al., 2014). Under-utilization of maternal care services, unavailability or poor quality of services, and socio-economic and cultural factors that inhibit use of services are the main contributors to high MMR in Nepal (Shrestha 2012).

Nevertheless, despite the low maternal health care utilization, Nepal has seen a significant reduction in MMR over the past 20 years - from 850 maternal deaths per 100,000 live births in 1990 to 258 per 100,000 in 2015 (MoHP/NewEra/ICF International Inc, 2012;



MoHP/NewEra/OrgMacro, 2007; National Planning Commission, 2016). However, these improvements in mortality and other health indicators have not been equitably enjoyed across Nepal.

It has been suggested that increasing universal access to maternal health care, reducing deep-seated gender and caste based inequalities, along with health system improvements may impact positively in the lives of women with disabilities (Thomas, 2005; UNFPA, 2004). However, to date, no studies have been done that explore how maternal health care issues intersect with disability and caste as they relate to embedded societal norms, values and practices in Nepalese society. The absence of credible research in this field means that the problems remains poorly quantified and understood; evidence to support advocacy, policy and practice change remains minimal and avoidable discrimination and exclusion continues.

Maclachlan et al. (2011) suggest that as MMR can be seen as a reflection of the overall quality of health services in the country, access to health care services for people with disabilities could be a proxy indicator of equity in a health care system. Although disability and caste are emerging issues in development and political discourse in Nepal (Paudel, 2013; Rawal, 2007), the lack of sufficient data or evidence around the issues means that addressing health needs and rights of different caste groups and people with disabilities remains challenging. This study therefore seeks to contribute new evidence and understanding to the arena.

The study used a small sample of structured and semi-structured interviews with 354 women aged 15 – 49 years, with and without disabilities having pregnancy experience in the last 5 years. Of these, 79 were disabled (18 disabled Dalit and 61 disabled non-Dalit) and 275 non-disabled (133 non-disabled Dalits and 142 non-disabled non-Dalits). This was complimented by focus group discussions (FGDs) in order to address the following questions: to what extent does access and utilization of maternal healthcare services differ among different groups of women – in particular Dalit and non-Dalit, and disabled and non-disabled women? What are the factors associated with service utilization? What are the attitudes and behaviours of maternal health care providers towards disabled and Dalits? What are the enabling and inhibiting factors for disabled and Dalit women to access maternal health care services? Detailed research questions and objectives are stated in the subsequent chapter.

### **1.2.1 Rationale/Significance of the Study**

Disability overall is an under-researched area, poorly represented in social and health research; and access to health care services for women with disabilities has been even less well studied (WHO & The World Bank, 2011; Wong, 2000).

Previous efforts have been made to explore issues related to gender (Bhandari, 2012b; Furuta et al., 2006), caste (Lynn, 2006; Ravishankar, 2012) and disability (Dhungana, 2006; Gautam, 2009; Joanna Morrison et al., 2014) singly, but no studies have linked these to explore the complex inter-relationships between them. This study explored the significance of compounding factors of exclusion to explore how these intersect to affect women's access and utilization of maternal healthcare services in Nepal and other areas with similar characteristics.

The study formed part of an NGO programme on Safe Motherhood project in Nepal funded by Big Lottery Fund UK that aimed to improve maternal health, particularly of disabled and Dalit women. The information and evidence were produced to inform the existing safe motherhood project as well as future interventions.

Moreover, the study is expected to narrow the evidence gap about the maternal health of this neglected group. It is trusted that organizations and individuals who advocate for the rights of women, Dalits and persons with disabilities can use the information generated by the study. The findings may contribute to future policy development and interventions undertaken by government organizations (GO) and non-government organizations (NGOs), which lead eventually to fundamental shifts in society, including greater equity, the realization of human rights for all and relief from oppression for these specific neglected groups.

In addition, it is hoped that through the practical actions of the research (interviews, group meetings), more immediate benefits may be gained by participants, for example increased knowledge of government entitlements, as well as increased awareness and consciousness-raising about their own – and others – situations.

At the outset, it is important to declare that I (researcher) come from a higher caste Brahmin family, but from the same culture and social system as that of the study. I previously have worked for several years as a community healthcare provider at the grassroots level in rural

communities of Nepal. This perhaps has allowed me greater insight about the health care issues of disabled and lower caste groups compared to researchers coming from other background, and outside the country. Throughout the project, I was very mindful and cautious about the need to be an objective researcher, but that this may also have led to preconceptions and assumptions. I have attempted to mitigate these by ensuring that all steps are objective and transparent, seeking regular review by fellow researchers cognizant of gender, ethnicity and caste, and by regular open reflection with a peer group of social science researchers within Nepal.

Growing up in this society, I witnessed first-hand the impact that multiple levels of systemic and individual discrimination have on life opportunities, determinants, aspirations, well-being and choices of whole communities, and women in particular. Motivated to address this social injustice, I worked professionally in this field for over 20 years, and worked with the complex barriers faced in trying to address these issues.

I also witnessed the institutional apathy and the resignation resulting from what sometimes seems to be impregnable obstacles to progress and I was committed to take actions that I feel would gradually support necessary change.

Finally, it is important to situate myself within this research: I have worked in the disability sector in Nepal for over eight years and in the public health sector for over 20 years, in both governmental and non-governmental organizations. For the past six years, my involvement in development projects in the same district gave me an opportunity to be familiar with district-level project stakeholders in the area.

As stated above, the study as a part of a Safe Motherhood project that focused on women's empowerment, particularly Dalits and disabled women to increase their access to maternal health care. Thus, the study is intended to not only generate new knowledge and evidence for influencing policy but also played a crucial role for empowerment. Among the approaches applied in disability research over the years including post-positivist, interpretivist and participatory paradigms, the emancipatory research approach has been favoured (Danieli & Woodhams, 2005; McColl, Adair, Davey, & Kates, 2013). Unlike traditional academic research, this approach challenges the dominant research norms whereby knowledge, expertise and power lie exclusively with academic researchers and the researched are relegated to roles such as research objects (Barton, 2005; Oliver, 2002). It is hoped that this research

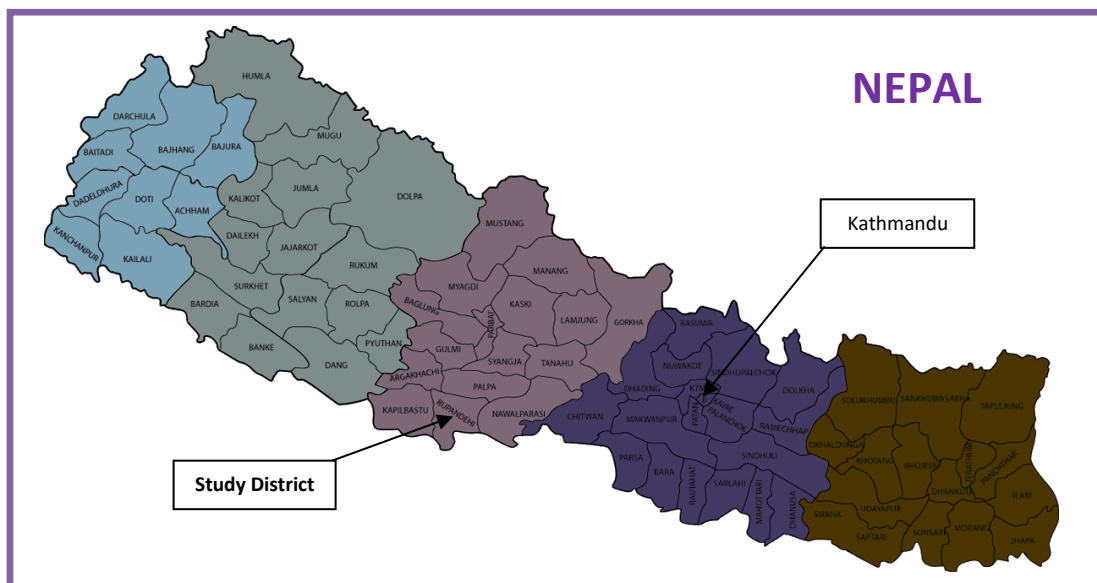
contributes to empowering women themselves providing opportunities for interaction and using the knowledge and expertise of the researcher in the process. The research successfully established trust, respect, participation and reciprocity between researchers and researched.

### 1.3 RESEARCH SETTING

The study was conducted in Rupandehi district of Nepal (Figure 1) as a part of the Rupandehi Safe Motherhood Project funded by the UK’s Big Lottery Fund (BLF) and implemented by Kidasha UK, an INGO working in Nepal. The district selection was based not only on the fact that there were on-going projects there, but can also be justified on its own merits as the district has wide geographical variation, population diversity and cultural multiplicity (GoN/NPC/CBS, 2012a).

Rupandehi district is located in the southern belt of Nepal, bordering India. The district has two municipalities and 69 Village Development Committees (VDC). VDCs are the smallest administrative geographical units within a district, which are clustered into 17 Ilakas and seven electoral constituencies.

**Figure 1: Map of Nepal showing study district**



The total population of Rupandehi is 880,196 with a 50.89% female population (GoN/NPC/CBS, 2012b). Out of 125 recorded ethnic and indigenous groups in Nepal, the study district population comprises upwards of 95 different groups of ethnic and indigenous inhabitants including 28 different groups of Dalits. The majority of people (78%) live in rural villages, though the urban population is growing fast. The majority (86.23%) of the population are Hindu; 8.22% are Muslim, and 4.60% Buddhist. In terms of caste breakdown,

in 2011, Rupandehi population was comprised of 12.03% Dalits, 24.45% Janajatis, 15.21% Brahmins and 5.62% Chhetries. The National Census reports that only 1.12% of population have a disability compared to the nationally cited figure of almost 2% (GoN/NPC/CBS, 2012b). Nevertheless, as the population of Rupandehi is large it can be assumed to have significant numbers of persons with disabilities (GoN/NPC/CBS, 2012b).

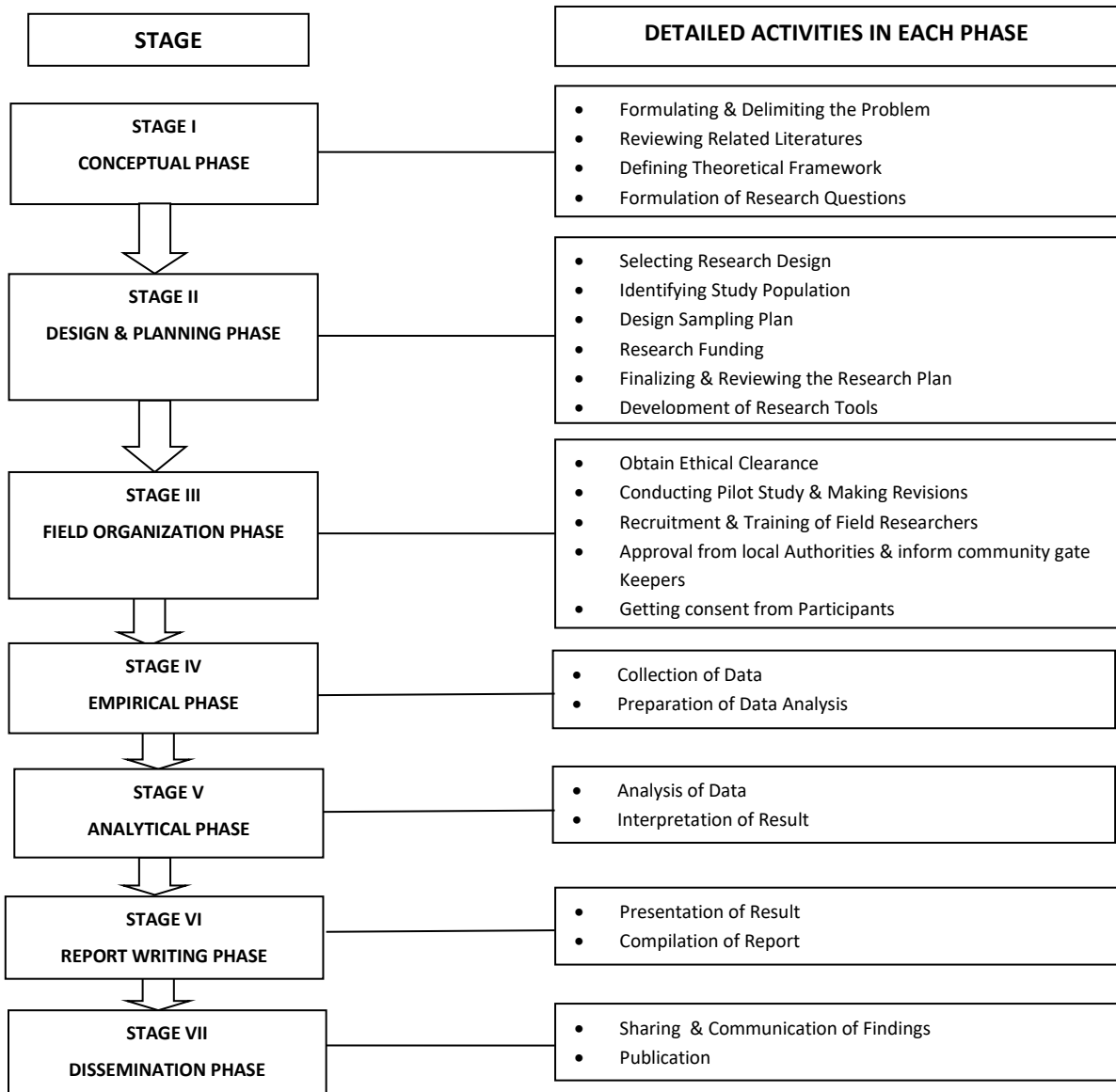
In terms of infrastructure, while all VDCs are connected by passable roads, many parts of the district are still without basic infrastructure such as electricity and public service facilities such as transport. There is a large variation in access to services and development opportunities between urban and rural areas, which poses challenges such as distribution of health services within the district. Primary healthcare services in the district are delivered through five Primary Health Care Centres (PHCC), six Urban Health Clinics (UHC), six Health Posts (HP) and 58 Sub-Health Posts (SHP). One district hospital and one zonal hospital (that covers six districts) provide secondary care services in the district (Figure 2). In addition to the government health sector, there is a wide network of NGO and private sector services providing private hospitals, nursing homes, clinics and pharmacies/drug shops (DPHO, 2012).

**Figure 2: Map of Rupandehi district showing Public Health Facilities**



## 1.4 STUDY PROCESS

The study followed the standard research process, as delineated by Polit, Beck, & Hungler, (2001) that consists of seven stages as shown in the flowchart below.



Adapted from Polit et.al., 2001

## **1.5 CHAPTER PLAN OF THE THESIS**

This thesis begins with background information on maternal health, disability, caste system and health disparities in Nepal followed by a literature review of maternal health and service utilization beginning with global and moving to local contexts, with a discussion of their complex relation with gender, disability and caste. Furthermore, in the following chapters it presents the details of research methodology, study results, analysis, and discuss the findings of research results. Finally, the key conclusions of research findings will be presented, and then research questions will be discussed in light of recommendations for future action and research.

### **Chapter 1: Introduction**

Chapter One lays out the background and context for the study, briefly describing maternal health and health inequalities, disability and caste system globally and in Nepal. The subsequent sections state the research problems, key research questions, which is followed by the rationale of the study. The chapter concludes describing briefly about study site and giving a synopsis of study process.

### **Chapter 2: Literature Review**

Chapter Two presents a review of the literature, specifically in maternal health and service utilization, disability, gender, caste, access to health care; and provides a synopsis of the global and national perspective and initiatives of maternal health followed by an overview of maternal health and policy development in Nepal. It then presents a summary of findings from available research on maternal health care utilization among different social groups and factors affecting in service access and utilization. It also elaborates research questions and outlines study objectives. The final section of this chapter presents a conceptual framework for the study that guides this research. This chapter ends defining the key concepts and terms used in this thesis.

### **Chapter 3: Methodology**

The Third chapter outlines the research methodology with philosophical assumptions that underpin this research. It gives an account of the research design including study population, sampling strategies, data collection methods and tools, process of data analysis with measurement details. The chapter concludes describing the researcher's position, study constraints and limitations.

#### **Chapter 4: Overview of Nepal's Health Care Services**

Fourth chapter briefly presents Nepal's health care services in regards to overall policy environment, status of key health indicators, health care delivery system and structure, and emergence and current status of primary health care and safe motherhood programs.

#### **Chapter 5: Maternal health care service utilization and access among Dalits and non-Dalits with and without disabilities**

This chapter presents the findings with the analysis of quantitative and qualitative interview data, addressing the first research question about maternal health care utilization status among Dalit and non-Dalit women with and without disabilities and their access to services. This chapter is organized into four sections. The first two sections present the survey results focusing on the utilization of maternal health care services among those four groups during pregnancy and childbirth, and the analysis of the factors influencing service utilization. The third section examines how accessible the maternal health care services are to disabled and Dalits, using both quantitative and qualitative data. At the end, it discusses the key findings of the results.

#### **Chapter 6: Societal and health care provider's attitude towards disability**

Chapter Six presents the results and discusses the key findings derived from qualitative and quantitative interview data analysis in relation to societal and health care provider's attitude towards disability. This chapter is organized into four sections. The first section presents the themes generated from qualitative interviews and focus group discussions on societal attitudes towards disabled women. The second section presents the result of attitude towards disability survey conducted among health care providers and the third section presents the themes generated, analysing qualitative interview data on women's experience in service use during pregnancy and childbirth. The chapter ends with the discussion on the key findings of the results.

#### **Chapter 7: Inhibiting and enabling factors in access and utilization**

Chapter Seven discusses inhibiting and enabling factors in access and utilization of maternal health care services using largely qualitative data supplemented by the quantitative data where relevant. This chapter consists of two broad sections presenting the themes on inhibiting factors in the first section, then goes on to the themes on enabling factors, which emerged from in-depth interviews and focus group discussions. Finally, the chapter ends discussing the key findings from the both sections.



## Chapter 8: Conclusion and Recommendation

Chapter Eight summarises key findings from empirical data and reviews the literature to address the research objectives and key question, which is “what, if any, are the differences in the access to, and utilization of, maternal health care services among Dalit and non-Dalit women, with and without disabilities in Nepal? If so, what are these differences and what causes these disparities”.

In addition, this chapter also discusses methodological issues, reflects upon the overall research approach, field experiences and issues that arose during the study. Finally, it outlines areas for future research and offers recommendations for policy makers, development agencies, practitioners, academics and researchers.

## **CHAPTER TWO: REVIEW OF LITERATURE**

### **2.1 CHAPTER OVERVIEW**

This chapter reviews the available literature on the study topic to identify and collate available research to test the research question against what already is known about the subject.

This review presents findings related to the key themes that emerged from the literature search. The status and influences of maternal health at the global level are presented, then followed by a closer examination of these in the Nepalese context. The specific and separate impacts and influences of gender, disability and caste, particularly in relation to their effect on service utilization, is then presented and discussed. Supply factors, socio-cultural issues, and individual and household characteristics are also examined in the context of access to appropriate and acceptable healthcare provision.

This chapter is organized into four sections. The first section describes the methodology used for the literature review, the search and selection criteria for studies included in the review; followed by the second section which is a summary of key findings from the literature. The third section formulates the research questions and objectives based on the literature review. Finally, the fourth section presents an integrated conceptual research framework based on relevant theories, models and concepts from literature.

### **2.2 REVIEW METHODS**

The literature review was undertaken using electronic databases as well as manual searches of published and unpublished research papers, reports and books. Databases used for the literature search were CINAHL Plus, EMBASE, MEDLINE, PubMed, SCOPUS, Ovid, Science Direct and Google Scholar. The key words used were 'Disability' AND 'Maternal Health' OR 'Health Service'; 'Disability' AND 'Pregnancy' OR 'Pregnant' OR 'Childbirth'; 'Maternal Health' AND 'caste' OR 'untouchability'; 'Disability' AND 'Health service access'; 'Health care access' AND 'women with disability' OR 'People with disability'; 'gender' AND 'Disability'. These terms were also used for other manual searches and searching the websites of specialist agencies.

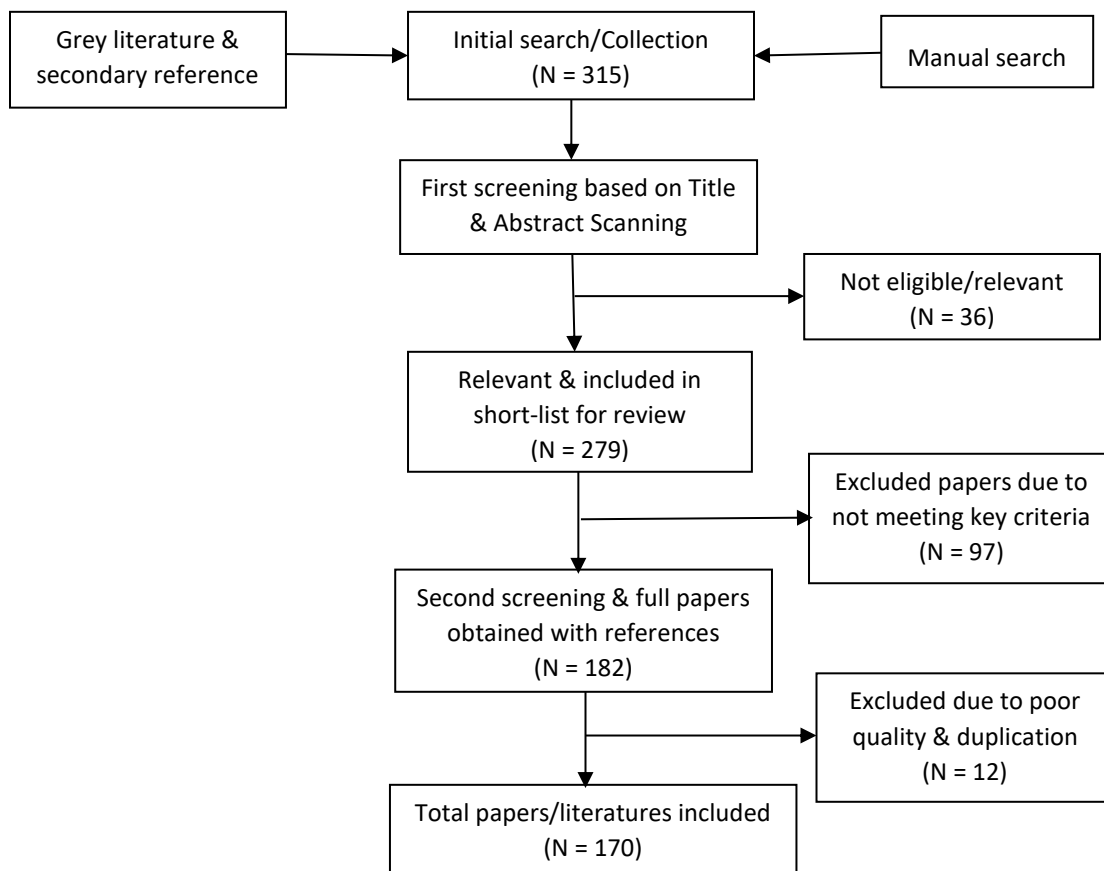
No literature was found that specifically addressed the core components of this study – specifically, disabled, Dalit women and maternal health care. Therefore, it was necessary to review a wider range of papers, that focused on two or more of the factors included in this

study. The main themes explored in literature review were maternal health and service utilisation, disability, gender, caste, access to healthcare.

A wide range of publications related to maternal health, service utilization, gender and access to health care were found in literature search, however, limited literature was found in the field of disability or caste systems and their effects in access and utilization of maternal health care services. Moreover, papers in areas like family, education and socio-economic issues as they pertain to individuals with disability and different castes were very limited in number. When looking for intersectional papers that covered MCH and within this realm, specifically looked at disability and/or caste the literature was smaller still.

The flow chart below (Figure 3) shows the literature screening and selection process for the review.

**Figure 3: Process of Selection of Papers/Literatures for Review**



In total 315 papers, documents/reports and books were identified at the initial stage while combining the search themes, 170 were included for review. In the first step, based on availability and appropriateness of fit and looking for whether the key components of the articles were discernible including theory, solid methodology, sample size, analysis and results, all identified papers were screened and chosen for further assessment. This was done by scanning the title and abstract. Specifically papers that broadly discussed issues of health or gender but did not offer insight into what theory or database they based conclusions or opinions on were excluded. Articles that were not deemed relevant to the subject matter i.e. did not address issues related to specifically to gender, maternal health, disability or caste, were also excluded.

Articles found relevant in the first screening were further assessed using the checklist for paper selection criteria (Appendix H). The assessment checklist consisted of six key elements: study approach used, study design, sampling and data collection, analysis, findings and interpretation, and implication and limitation. Each element was assessed and rated asking a number of questions. Based on the ratings, the articles were then categorised into three groups - good, medium and poor, and the papers of the first two categories were included in the review.

The selected articles were then critically appraised. Organizing the papers into a matrix, each paper was reviewed asking the questions listed in the assessment checklist above and in Appendix H. These questions included - Does the study pose relevant questions? Does the study add anything new towards understanding of the field with the population relating to disability, caste and or access to health services? Are statements and/or data supported theoretical arguments or qualitative or quantitative data? Are statements in the papers supported by credible literature citation? Does the study investigate the predefined objectives? Was the study design appropriate for research questions? Was the study performed according to the research protocol? Were the data analysis performed appropriately/correctly? Do the data justify the conclusions?

Peer review papers were given particular attention (although unpublished work and work published in the grey literature was also included if met the checklist criteria. Again, it should be noted that there is a paucity of literature available in this field – there were only a

small number of peer-reviewed papers, unpublished and grey literature also was limited in both number and scope of findings.

Quantitative data was also significantly limited in the available literature. There were a handful of papers in the peer-reviewed literature and additional studies were available only in the grey literature and unpublished reports, but these often-lacked comprehensive detail of how that data was collected or analysed. In many cases the original research details were not possible to obtain, hindering full appraisal of the findings and in these cases, the findings and conclusions reached are treated with caution. It is of note however, that the majority of papers of adequate quality relevant to this study came from qualitative studies.

Given the limited number of quantitative and qualitative studies available, there was no one domain in which a disproportionate number of papers by subject were divided. Papers on domains such as family, education, socio-economic issues and provider-focussed problems (i.e. poor facilities, transportation, in accessibility and prejudice and stigma) were identified, but for the most part, these papers, whether quantitative or qualitative in nature, attempted to review a range of different issues faced by persons with disabilities. For this reason, it is not possible to enumerate or list papers by domain.

The reviewed literature were summarised developing the themes and is presented below. The following discussion will first examine the global situation relating to maternal health in order to situate this study within the global context.

### **2.3 MATERNAL HEALTH GLOBAL PERSPECTIVES**

Maternal mortality was not a major national or international priority until the Safe Motherhood Conference in Nairobi in 1987 (Thomas, 2013). The Nairobi meeting launched a global movement for Safe Motherhood, with the aim of reducing the burden of maternal death and ill health. Since then, maternal mortality has been moving up the global development agenda (Family Care International, 2007).

A second conference – the International Cairo Conference on Population and Development (ICPD) also set a notable milestone. The ICPD Cairo (1994) Programme of Action called for maternal health services based on the concept of informed choice, prenatal care, adequate delivery assistance, post-natal care and family planning. Finally, the Fourth World Conference for Women (FWCW) in Beijing in 1995, and the Copenhagen Social Summit in the same year

both gave substantial attention to maternal mortality and reiterated the commitments made in the ICPD.

Then in 2000, the Millennium Development Goal (MDG) summit focused on a range of steps felt necessary to advance global development, with one goal specifically - MDG 5 - aimed specifically at improving maternal health. This focus increased international attention and actions that impact on maternal mortality, as well as providing mechanisms for monitoring progress (ARROW, 2010; Family Care International, 2007).

At the World Summit in 2005, world leaders committed themselves to achieving universal access to reproductive health by 2015 (UNFPA, 2005). The Launch of the UN Secretary General's 'Every Woman Every Child' campaign, its Global Strategy for Women's and Children's Health (2010) strengthened commitment.

These international commitments and priorities contributed to achieving remarkable progress globally for improvement of maternal health in general, and more specifically the reduction of maternal mortality.

However, despite these international commitments and progress, some groups such as women with disabilities and those from lower caste groups throughout the world have failed to benefit from international, regional and national legal frameworks, standards and agreements because of intersectional discrimination associated with their gender, caste and disability (Frohman, Ortoleva, & Al, 2013; Stubbs & Tawake, 2009; WHO/UNFPA, 2009). (Frohman et al., 2013). Frohman et al. (2013) argue that such women experience systematic exclusion from sexual and reproductive health care services, and systematic prejudice and discrimination result in extreme violations of their reproductive rights. Forced sterilization, forced contraception and poorly managed pregnancy and child birth are just some of the concerns that illustrate this (Groce, 1997; Tilley, Walmsley, & Earle, 2012).

No international level initiatives were found that directly support the compounded issues of women enduring gender disparities, caste discrimination and disability.

There have been numerous initiatives to support equity and inclusion of all. For example, The ICPD (1994) Principle 4 aims for the 'advancing of gender equality and equity; and empowerment of women and eradication of all forms of discrimination'. This programme of action emphasizes narrowing disparities within countries; between geographical regions,

socio-economic and ethnic groups. Principle 8 talks about the right to the enjoyment of highest attainable standard of health for everyone. It also highlights that States should take all appropriate measures to ensure universal access to health care services, including sexual and reproductive health (UNFPA, 2004; United Nations, 1995). Following this groundbreaking meeting, governments committed to address reproductive health needs for **all** as a matter of urgency, though this was not legally binding.

‘Declaration 30’ from the Fourth World Conference on Women (1995), calls for equal access to and equal treatment of women and men in health care and enhancing women’s sexual and reproductive health, as well as committing to further advancement and empowerment of women to ensure equal rights and elimination of all forms of discrimination. ‘Declaration 32’ from the same conference focuses on empowerment of women facing multiple barriers because of race, ethnicity, culture, religion and disability.

A number of sessions related to women and disability were held at the World Conference of Women 1995 in Beijing (UN, 1996) and the intersection of poverty, gender and disability is well evidenced by number of studies (Groce, Wirz, Lang, Trani, & Kett, 2011; Mitra, Posarac, & Vick, 2013; UNESCAP, 1995, 2012).

The MDG’s 3 and 5 are about promoting gender equality and women empowerment; and improving maternal health respectively. However, disability issues were missing in the MDGs and associated calls for action and declarations. Neither the goals nor the targets and indicators of the MDGs included disability issues. Amidst huge international pressure and criticism (Disabled People’s International, 2010), the annual progress reviews of the MDGs began to include disability issues in some 40 countries by 2009 (UN, 2011). Notably this lack of attention to disability issues is addressed in the new SDGs which cite disability specifically in a number of Targets and Indicators and more generally include disability throughout under the ‘leave no one behind’ statement in the introductory ‘chapter’ (United Nations, 2015).

## **2.4 MATERNAL HEALTH IN NEPAL**

Historically maternal health in Nepal has been amongst the worst in the world in terms of mortality, morbidity and access to appropriate care (Suvedi et al., 2009). This has led to significant internal policy and infrastructure development, and strategic commitment and investment from both government and the international community to address this issue. The result has been

marked with sustained improvements in maternal health at a national level and good progress towards the country achieving its MDG targets for maternal health (GoN/NPC, 2013).

However, these achievements are relative to a very low baseline and there remains a need for continued improvement. Furthermore, these improvements were achieved with 'blanket' policy interventions, which mask ongoing inequities, and many sub groups of the population, notably poorer and already marginalized groups, have not experienced the same improvement in their maternal health or access to care. These include disabled, Dalits, ethnic/religious minorities and women living in rural.

Nepal has made good progress towards achieving MDG 5 (GoN/NPC, 2013). Its policies and plans incorporate gender and caste issues to some extent, but none states an intention to address the reproductive and maternal health issues of women with disabilities despite the state's commitments to human rights treaties conventions including United Nations Convention on Rights of Persons with Disabilities (UNCRPD). The government of Nepal frequently refers to the consensus achieved at ICPD in its domestic policymaking. With the new Sustainable Development Goals, there is a renewed commitment to continuing improvements seen in Nepal under the MDGs (GoN/MoHP/PD, 2011).

The following sections examine the intersectionality of gender, disability and caste in access and utilization of maternal health care services.

## **2.5 GENDER AND MATERNAL HEALTH CARE SERVICE UTILIZATION**

Gender roles are determined by culture and social values which may be further reinforced by social and institutional structures and legal provisions (Namasivayam et al. 2012, Mumtaz et al. 2011). Gender norms and disparities restricts the social power of women keeping them in the lowest positions in family and society (Sanneving et al. 2013; Furuta et al. 2006). It therefore follows that improving women's social positions and gendered roles translates into increased use of, and better access to maternal health care (Azuh, Fayomi, & Ajayi, 2015; Baral, Lyons, Skinner, & Teijlingen, 2012; Matsumura & Gubhaju, 2001; Namasivayam et al., 2012).

Namasivayam et al. (2012) examined gender roles in women's access to reproductive healthcare in two South Asian and two Sub-Saharan countries (Namibia, Kenya, Nepal and India), and found that the extent of gender inequalities varied across and within countries and is rooted in cultural practices and gender norms. The study suggests that gender inequalities are multidimensional and



affect women's access to health care in many ways limiting their access to resources, decision-making and participation.

Gender issues and prejudiced attitudes are at the root of much Nepalese culture and society, and this has perpetuated women's lower position (Shrestha, 2012).

A meta-analysis of data from 31 developing countries found empowerment of women to be significantly associated with utilization of maternal health care services (Ahmed, Creanga, Gillespie, & Tsui, 2010). Conversely, a multi-country study conducted by Ghuman et al. (2006) shows that more restricted freedom of women, usually within their family or spousal relationship, translates into lower service utilization.

In their study, Furuta et al. (2006) found that if Nepali women had increased communication with their husbands -particularly about family planning and maternal health issues – it had a positive impact on their receiving skilled maternal care. The findings suggest that household gender inequality is an important determinant of maternal health utilization with better communication being linked to increased access.

There is no data available in the countries like Nepal about inter-spousal communication specifically between disabled women and their partners.

## **2.6 DISABILITY AND MATERNAL HEALTH CARE SERVICE UTILIZATION**

Women with disabilities face numerous barriers in accessing maternal health care services (Becker, Stuifbergen, & Tinkle, 1997; Lipson, Rogers & et.al, 2000; Redshaw, Malouf, Gao, & Gray, 2013). Issues of quality of service, cost and lack of family support have been found to be barriers to maternal health care service utilization for disabled women in Nepal (Joanna Morrison et al., 2014).

Two qualitative studies conducted in Nepal by Khanal, (2013) and Dhungana, (2006) on maternal health care and motherhood experiences of upper caste women with physical disabilities identified several attitudinal and physical barriers. Almost all participants experienced difficulties with the hospitals not having basic accessible physical infrastructural facilities for disabled people. Similarly, hearing and visually impaired mothers had trouble with communication and mobility while visiting the facilities. However, the study also highlighted factors that positively affected their experiences too, particularly the empathy demonstrated towards the women by some health professionals.

These findings from Nepal are similar to those found in other low and middle-income countries. Smith et al. (2004) found in Zambia that women with disabilities encounter social, attitudinal and physical barriers to accessing reproductive health services. Their study found misconceptions among service providers that women with disabilities were asexual; traditional beliefs that disabilities would be transferred to the child; and health workers' fears of greater delivery complications for women with disabilities. Moreover, they found disabled women faced frequent humiliation and exclusion from mainstream health services (Smith et al. 2004).

Trani et al. (2011) compared health status and access to reproductive health care services between disabled and non-disabled women in urban and peri-urban areas of Sierra Leone. While they found disparities between women with and without disabilities in access to regular government health facilities, there were no significant differences among women accessing maternal health care services. However, the study found low access for all women because of poverty.

## **2.7 CASTE AND MATERNAL HEALTH CARE SERVICE UTILIZATION**

The literature reviewed demonstrates that caste has a strong influence on maternal health care service utilization (Saroha, Altarac, & Sibley, 2008; Saxena, Vangani, Mavalankar, & Thomsen, 2013). The concept of "Untouchability" isolates 'Dalits' from other caste groups (Pal, 2010) and underpins chronic poverty in South Asia including Nepal (Mumtaz et al., 2011). Two case studies from Pakistan demonstrate how gender inequalities interact with caste and poverty to exclude women from accessing health care services, which ultimately resulted in the loss of the lives of two Pakistani women. The author argues that gender roles are sharply demarcated, with men socially constructed as providers of resources and women as consumers (Mumtaz et al., 2011). This concept can also be extrapolated to Nepal due to socio-cultural similarity considering women inferior to men.

In India, the 2007 National Family Health Survey highlighted the fact that the proportion of scheduled caste (Dalit) women who had not used any ANC was considerably higher compared to other caste groups (IIPS/Macro International, 2007). Similarly, Institutional delivery is also comparatively lower among this group of women (Nayar, 2007). Another Indian survey found that 33% of village Health Visitors refused to visit Dalit homes (Shah, Mander, et al., 2006); while another showed that a majority (94.4%) of Scheduled Caste women made only one ANC visit during their pregnancy and only 10% of them received the full recommended four ANC visits. In contrast, women in the richest wealth group received 26 times more recommended full ANC visits

compared to the poorest (Ravishankar, 2012). Mohindra et al. (2006) conducted a cross sectional study to examine the social patterning of women's self-reported health status in India and concluded that women from lower castes report a higher prevalence of poor health than women from higher caste.

Data from a variety of sources support these findings in Nepal: the NDHS (2011) demonstrate that Dalit women are far below their upper caste counterparts in almost all health indicators. For example, less than half of Dalit women gave birth at a health facility compared to upper caste women (MoHP/NewEra/ICF International Inc, 2012); another study shows women from privileged castes are significantly better positioned to access health facilities (Pandey, Lama, & Lee, 2011). But the results are mixed. Another study from Nepal shows no effect of caste in the use of health care services (Niraula, 1994). With these are contradictory findings, it can be suggested that whilst caste is a factor, caste alone may not have significance in determining women's health indicators and accessing health care services in Nepal. Other factors may influence women's health care access including disability.

The literature review found very few papers that made direct reference to the combined issues of disability and caste. Based on the available literature it can be hypothesized that gender role together with caste and disability can have a negative impact on women's maternal healthcare experiences. This may have particular implications for women in Nepal, where negative attitudes about caste, gender and disability continue, despite measures attempting to address these. The following section discuss in more detail some of these measures and their effectiveness in maternal health care service utilization.

## **2.8 SUPPLY FACTORS AND MATERNAL HEALTH CARE SERVICE UTILIZATION**

The supply aspect in health-care is characterised by service availability, involving human resources, facilities and activities (Gulliford et al., 2002). Factors relating to quality or acceptability of care and policy and systems may also be described (Ensor, 2004).

A review of 86 articles about access to Primary Health Care among persons with disabilities in rural areas (US) reveals the common failure of health care systems in rural areas to adequately address the medical needs of disabled people (Lishner et. al, 1996). Studies in Ethiopia, Nigeria, Tanzania, and Nepal reveal service supply factors such as availability of staff, opening and waiting time and community perception of quality of care and effective health system strongly influence in service

utilization (Dhakal et al., 2007; Kruk, Rockers, Mbaruku, Paczkowski, & Galea, 2010; Moore et al., 2011; Morrison et al., 2014b; Worku et al., 2013).

Women with disabilities often encounter providers who lack knowledge and skills, as well as have negative attitudes towards their disability (Morrison et al., 2014; Nosek, 2000). A study in South Korea also found supply side barriers included poor understanding of disability by health workers and the absence of care facilities (Lee, Oh, & et. al, 2005). However, research in Cameroon found some health workers with positive attitudes, or who were sympathetic or knowledgeable in offering special maternal care for women with disabilities (Bremer, Cockburn, & Ruth, 2010). Studies from the US also found women with disabilities were prevented from accessing health care services, with particular barriers for women with communication difficulties (Becker, Stuijbergen, Tinkle, et al. 1997; Turk 2004; Lipson et al. 2000).

In sum, with regard to supply and related barriers, women with disabilities face numerous common problems, while receiving services in both high and low-income countries. Provider's negative attitude towards disability, lack of access and systematic barriers, denial of services and untrained health professionals are recurring supply-side barriers faced by women with disabilities.

### **2.8.1 Cost Factors**

In the literature, women with disabilities and women from ethnic and minority groups in the communities around the world are consistently identified as being poorer on average than their non-disabled peers. Therefore, cost of health care is another area of particular concern.

Cost factors (including consultation fees, service charges) are deterrents for utilization of health services (Amnesty International, 2014; Ensor, 2004); whereas demand side financing schemes such as travel cost reimbursement have found effective to increase utilization of services (Murray, Hunter, Bisht, Ensor, & Bick, 2014). A number of studies have found other costs to service users, rather than those incurred at a facility, such as transportation costs that range between 25 – 28% of the total treatment cost (Ensor, 2004). While it would be interesting to also to present this as the difference between disabled and non-disabled, however, these statistics do not exist.

In Kenya, travel and other associated costs were cited as the main reasons for low health facility delivery (Ikamari, 2004), with similar findings in Nepal, Vietnam and Nigeria (Ajaegbu, 2013; Duong et al., 2004; Matsumura, Bina, & Al, 2001; Moore et al., 2011).

Many countries - including Nepal - have adopted free maternal health care schemes. However, travel and hidden costs threaten to undermine these. Hidden costs such as medical supplies,

under the counter charges and transportation costs prevent people from seeking care. This is not unique to Nepal – a study in Bangladesh found large hidden costs on “free” maternity care provided by the government (Nahar et. al, 1998). This discourages poor women utilizing health care service posing a cost burden on poor households – this includes poor households whether they be Dalit or non-Dalit and disabled or non-disabled.

### *2.8.2 Quality of Care and Client Satisfaction*

Quality of care and client satisfaction is another area of concern for all women including among women with disabilities and women from ethnic minority communities. Campbell et al. (2000) defines quality of care as “ability to access effective care with the aim of maximizing health benefit in relation to need” (Campbell et al. 2000). The components of quality services as defined by WHO (2006) are effective, efficient, accessible, acceptable, equitable and safe.

The decision to choose healthcare is determined in part by the quality of the services offered (Duong et al., 2004; Mawajdeh, Al-Qutob, & Raad, 1995). The research conducted in China and Nigeria (Harris et al., 2010; Moore et al. 2011) confirm the association of quality of care with maternal health service utilization.

A study in Nepal shows that pre-natal service coverage is four to six times higher in the catchment areas of high quality health facilities than in areas with low quality health facilities (Acharya & Cleland, 2000). Baral and colleagues argue that reasons for low utilization of SBA services in Nepal includes poor quality service (Baral, Lyons, Skinner, & Teijlingen, 2010), but the study conducted by Pandey et al. (2011c) found that the quality of care has no effect on use of health services. It is interesting to note that none of these studies looked specifically for disabled and Dalits.

Another recent Nepali study on women’s perception of quality of maternity services (Karkee, Lee, & Pokharel, 2014) found that the recently introduced government Birthing Centres had the lowest rating on adequacy of medical equipment, adequacy and suitability of health staff; whereas public hospitals were rated lowest in respect to adequacy of space, adequacy of water, clean environment, maintaining privacy and adequacy of information.

Even in a high-income country with comparatively well-developed services and health systems, women with disabilities do not always have positive experiences. A study in the UK of the experience of maternity care during pregnancy, labour and childbirth and the postnatal period for women with disabilities found that women having more than one identified disability or mental

health issue were least likely to report a positive experience of pregnancy and birth (Redshaw et al., 2013).

The published evidence from high and low-income settings suggests a strong but inconsistent relationship between the quality of health care services and subsequent satisfaction and utilization. Common problems reported about quality issues for both disabled and non-disabled women relate to provider's attitude and behaviours, as well as the availability of basic infrastructure. However, caste based discrimination, providing poor quality of care to lower caste women have been often reported (Thomas et al., 2012).

## **2.9 SOCIO-CULTURAL FACTORS**

### ***2.9.1 Culture, Tradition, Religion and Service Utilization***

As with the impact on gendered outcomes, religion, culture and tradition also influence maternal mortality and health outcomes (Arokiasamy & Pradhan, 2013; Basu, 1990). In addition to the gendered norms outlined above, studies outline disparities in health, healthcare provision and healthcare utilization among different religions and cultural groups (Hulton, Matthews, & Stones, 2007; Mrisho et al 2009; Atwebembeire 2011).

Seclusion of mother and babies after birth is common practice in Asian as well as in African countries. Higher maternal mortality could be explained due to the rigid cultural and traditional practices that interferes with women of post-delivery checks. In Nepal, socio-cultural beliefs play an important role in the utilization of pre- and postnatal care (Suwal 2008; Pandey, Dhakal, Karki, et al. 2013, Mesko et al. 2003). Traditionally a woman and her new-born child are considered impure for up to two weeks after childbirth. The mother and baby are secluded inside the house and often confined in a room, presenting a barrier to visiting health facilities for post-partum care.

### ***2.9.2 Women's Status***

Study carried out in Nepal have shown a significant association between decision-making and utilization of delivery care, which is of particular concern where women with disabilities routinely have diminished say in household decisions. Women with strong decision making power in the household were 2.24 times more likely to deliver their babies at a health facility compared to women with little autonomy (Matsumura et al., 2001). Women's lower status and autonomy prevents them from voicing concerns about their health needs (Shaikh, et.al, 2004). It follows that women's empowerment and autonomy are directly related to maternal health service uptake (Hou & Ma, 2013) and women's health indicators; as can be observed in the case of women from the Mongoloid ethnic group in Nepal, who are more empowered and better positioned in their

household compared to women of other ethnic groups; and have lower rates of maternal mortality (Suwal, 2008).

Thapa et al. (2013) examined Nepalese women's autonomy in four dimensions: Economic Autonomy; Domestic Decision Making; Movement Autonomy; and Intra-spousal Communication in-regards to family planning and contraceptive use. The study revealed that women were unlikely to have the final say in decisions related to large household purchases and schooling of children. They had little influence in the decision to have children and use of family planning methods. Only 39.3% women reported they could make the decision to visit a health facility themselves.

Similarly, Mistry et al. (2009), Chakrabarti & Chaudhuri (2007) and Sharan, Ahmed, & Strobino, (2005) assessed women's autonomy in India and their studies found that women's autonomy had little influence on deliveries attended by skilled birth attendants, but decision-making autonomy was associated with the use of antenatal and postnatal care.

The level of autonomy differs in different culture, religion and caste groups. Interestingly, a number of studies in Nepal reveal higher levels of autonomy among lower caste group women than in higher caste groups. Pandey, Dhakal, Karki, et al. (2013) found that lower caste women have more autonomy within their family compared to upper caste women. They found a slightly higher percentage of Hill Dalits (27.7%) make decisions about their own health compared to higher caste Hill Brahmin women (26.6%). Conversely, the proportion of lower caste women utilizing maternal health services is far below than higher caste women, so other factors such as power and social position could be influential in determining service utilization.

## **2.10 INDIVIDUAL AND HOUSEHOLD FACTORS**

### **2.10.1 Age, Parity and Previous Pregnancy Experience**

Age, parity and previous pregnancy experience are strong predictors of service utilization (Celik & Hotchkiss, 2000; Karkee et al., 2014; Paudel & Pitakmanaket, 2010; Wagle et al., 2004). Zeine et al. (2010), in their study of women in Ethiopia found maternal age to be a major predictor for ANC service utilization. Studies in Ghana, Nepal and India show mothers below 20 years of age were more likely to use antenatal services and have a hospital delivery (Appiah-kubi, 2004; Dhakal, 2007) - although another study in Tanzania found no association between women's age and delivery at a facility (Kruk et al., 2010).

A study conducted in Nigeria suggests that women with previous childbirth experience are less likely to receive ANC and have deliveries in a hospital setting compared to primigravidas (Duong et

al. 2004; Ajaegbu 2013). Another Ethiopian study found a negative association for all maternal health care utilization with higher birth numbers and in the case of unwanted pregnancies (Worku et al., 2013).

The literature from Asia and Africa frequently demonstrates associations between women's age, parity and previous experience with maternal health service utilization. Women below 20 years are more likely to use services in general and health facility delivery in particular. However, studies show that disabled women are more likely to give birth at their older age compared to non-disabled women (Lim, Lee, Park, Lee, & Oh, 2015; Redshaw et al., 2013).

### *2.10.2 Knowledge/Awareness, Information, Communication*

Studies show an association between service utilization, knowledge and awareness, with a lack of knowledge and information about reproductive health and service availability found to be the main barrier to the utilization of maternal health service (Becker et al., 1997; Bremer et al., 2010; Dhakal et al., 2007). Evidence also suggests that women who have had exposure to media have better maternal health care service utilization (Arokiasamy & Pradhan, 2013; Chakrabarti & Chaudhuri, 2007).

Rosenstock et al. (1988) illustrate through their health belief model that perceived susceptibility and severity motivates the individual to seek action. This posits the notion that the stronger the perception of vulnerability, the greater the likelihood for taking protective action. Using this model, Dhakal et al. (2007) found few Nepali women in rural areas received post-natal check-ups within 48 hours, with the main reason given by respondents for this as a lack of perceived need for PNC by the women and their families. Other studies (Choulagai et al., 2013; Hickerton, Aitken, Hodgson, & Delatycki, 2012) found women's awareness of pregnancy danger signs positively influenced their uptake of antenatal care services; and in Uganda (Atwebembeire, 2011), one of the few disability studies of this kind, found that women with a disability exposed to information utilized maternal health services three times more than those not exposed.

The literature demonstrates that disabled and Dalit women are excluded and therefore often prevented from gaining exposure to information (Morrison et al., 2014; Shah, Mandar, Thorat, Deshpande, & Baviskar, 2006), and thus may possess limited knowledge about their own reproductive health and information about services.



### *2.10.3 Education and Maternal Health Service Utilization*

Evidence suggests that maternal education levels are correlated with health service utilisation, with educated women being more likely to realize the benefits of using maternal health services (Appiah-kubi, 2004; Celik & Hotchkiss, 2000; Furuta et al., 2006; Matsumura et al., 2001; Trani, Barbou-des-Courieres, & Al, 2012). This is because as noted above, education may enhance female autonomy, boosting their household position and thereby increasing the ability to make decisions regarding their own health. Moreover, education often increases knowledge of modern healthcare, thus increasing the demand for health services (Arokiasamy & Pradhan, 2013; Hotchkiss, 2001).

A meta-analysis of the recent DHS data from 31 developing countries found education significantly associated with utilization of maternal health care services, with five times the percentage of primary educated women receiving maternal health services compared to illiterate or less educated women (Ahmed et al., 2010). Studies have also found a strong link between husband's education and maternal health care utilization (Worku et al., 2013). Ikamari (2004) in Kenya, Sharan et al. (n.d.) in India and Duong et al. (2004) in Vietnam found women's education showed significant associations with all health outcomes but regardless of educational attainment, women from a scheduled castes seem to be systematically and consistently excluded (Sanneving, Trygg, Saxena, Mavalankar, & Thomsen, 2013).

Studies in Nepal found that educated women were more likely to access services during pregnancy and child birth (Bhandari, 2012b; Choulagai et al., 2013; Khanal, Adhikari, Karkee, & Gavidia, 2014; Pandey et al., 2011; Sharma, Sawangdee, & Sirirassamee, 2007). Simkhada et al. (2006) found higher maternal mortality among illiterate women in Nepal in their study.

The literature is fairly unequivocal in demonstrating that level of education of both women and men has a strong association with maternal health and service utilization. In Nepal, women who are poor, have disabilities, and/or belonging to lower caste groups receive little education and are often illiterate. Therefore, as will be explored later in the thesis, poor Dalit women with disabilities may be more likely to have lower rates of maternal healthcare seeking and utilization, and poorer experiences if they do so.

### *2.10.4 Household Income and Service Utilization*

An association between economic inequality and use of maternal health services has been well-documented. Women from economically disadvantaged groups are less likely to use maternal health care services compared to higher income groups. A study in Rwanda reveals that women

from the lowest wealth groups are three times less likely to give birth at health facilities than wealthier mothers. Conversely, a study in Tanzania did not find any association of household wealth with facility delivery (Kruk et al., 2010).

However, studies have found both individual and family income influence seeking care and receiving care. For example, one study in China suggests the uptake rates for all maternal health services increase as income rises (Liu et al. 2013). DHS data analysis for 31 developing countries shows that in poorest wealth quintiles, the odds of having a skilled attendant at childbirth for women are 94% lower than that of highest wealth quintile (Ahmed et al., 2010); although interestingly, a study conducted in Afghanistan found no differences across wealth groups (Trani et al., 2012).

Household economic status has been found to be a strong predictor for health seeking behaviour and the utilization of maternal health services in Nepal (Hotchkiss, 2001; Paudel & Pitakmanaket, 2010; Sharma et al., 2007).

The available literature and evidence suggests that utilization of maternal health services increases with the level of household wealth. However, the literature is not wholly congruent in this and in some settings; this does not seem to be the case. In Nepal, household economic status has been found to be an important determinant, but the evidence also suggests that traditional gender roles and household decision-making are significant factors. Moreover, caste system and disability status are also well documented to be the key drivers of poverty and inequality (Groce, London, & Stein, 2014; Rao, 2010) and that may have detrimental effect on utilization of maternal health care services by disabled and Dalit women.

#### *2.10.5 Occupation/Employment and Service Utilization*

The relationship between employment, occupation and healthcare utilization is complex. In Ethiopia, a study found proportionately higher use of maternal health services by women from higher wealth quintiles and having mixed occupation (Worku et al., 2013).

Three studies undertaken in Nepal, Matsumura et al. (2001), Furuta et al. (2006) and Sharma et al. (2007) found women's employment increased their status in society; but interestingly, they found no influence on utilization of services - with one study finding a negative influence, and the other two finding that women faced with a double burden of work both inside and outside their home were prevented their uptake of maternal health services. However, household economic status was found to be significant in predicting utilization behaviour. This suggests that the relative cost

as well as competing demands on time associated with the use of health services has an impact on the decision to seek care.

In Nepal, women from richer families; those with formal employment ; and those with husbands with higher socioeconomic status report better utilization of postnatal care (Dhakal et al., 2007) – the exception to this being women and families engaged in agricultural occupations (Khanal et al., 2014). Mixed results have been found from examining the relationship between utilization of maternal health services and women’s employment and occupation.

## **2.11 ACCESS**

Aday & Andersen (1974) define access as potential or actual entry into the health system and gaining access as initiation into the process of utilizing services. Penchansky and Thomas, (1981) defined accessibility, availability, affordability, acceptability and accommodation as typologies of access. Some also consider quality and adequacy as aspects of access too (Ensor, 2004). Broadly speaking, access relates to both demand and supply side factors that influence an individual’s health service utilization.

### ***2.11.1 Geographical/Physical Access (Distance/Transportation/Infrastructure)***

Another issue of immediate concern to many women with disabilities is physical access to available health care. Difficult topography, distance to health facility, inadequate built infrastructures, roads and transportation difficulties are all found to be the main barriers that inhibit service utilization in Nepal (Wagle et al. 2004; Simkhada et al. 2006; Baral et al. 2010 & 2012; Choulagai et al. 2013). In Nepal, a study conducted by (Khanal et al., 2014) found mothers living in accessible places were more likely to attend PNC within 42 days of delivery and immediate postnatal care.

The impact of the barriers evidenced in the literature obtained from general maternal populations may be exacerbated in the target population of this study because the challenges of physical access are compounded for those with disabilities; and the ability to secure additional assistance in the absence of suitable public transport, may be less for Dalit disabled women who are likely to be poorer.

### ***2.11.2 Women with Disabilities and Access***

Access of women with disabilities on reproductive health care has been reported in countries around the world. For example, Noesek et al. (2001) found that American women with disabilities encounter serious barriers to receiving general and reproductive health care. Physical barriers were found in physicians' offices and hospitals, as well as invisible barriers such as discriminatory

policies that deny services to women, and the refusal of physicians to see women on the basis of their disability were common. Another study conducted by Thierry & Dennis (2004) supports the findings of Nosek (2000) and found additional barriers that were commonly experienced by women with communication difficulties.

Arcella et al. (2009) describes access barriers for women with disabilities as challenges regarding receiving information, inaccessible health services, and unavailability of trained health workers. A study in Uganda, conducted by Atwebembeire (2011), found a strong relationship between distance and utilization of delivery services at health facilities by disabled women, with women with a disability living more than five kilometres from a facility less likely to seek services than the women with disability living less than five kilometre distance (Atwebembeire, 2011). Another study of maternal health services in Cameroon showed that inaccessible health facilities and lack of transport made maternal health services almost impossible for women with disabilities to utilize (Bremer et al., 2010).

People with disabilities are often isolated and have fewer opportunities for social contact, which may result in them being less likely to receive appropriate sexual and reproductive health information (Becker et al., 1997). They often have little or no access to family planning or maternal health services. Evidence suggests that health service providers sometimes appeared surprised that persons with disabilities are sexually active and therefore often did not ask about contraceptive use (Thierry & Dennis 2004; Frohmader et al. 2013).

As noted before, Khanal (2013) and Dhungana (2006) found almost all their research participants experienced difficulty with hospitals in Nepal not having basic physical infrastructure accessible to disabled people.

The available literature reflects a commonality of findings and experiences of women with disabilities across high and low income countries, in their access to maternal and reproductive health care. These experiences are characterised by difficult or inaccessible facilities, poor access to maternal and reproductive health information, and a lack of understanding on the part of health workers that people with disabilities are sexually active.

## **2.12 SUMMARY**

This review found that studies specific to Nepal, other countries or in general, seem to be very limited in maternal health care issues of disabled and Dalit women, revealing an important research gaps that this study will attempt to address. It also found that health disparities exist

globally despite great efforts at national and international levels and there remains a large gap between maternal health and healthcare services in low-income and high-income countries particularly for women with disabilities. The literature shows persistent disparities whatever a country's level of development and the evidence shows that various factors influence maternal health and healthcare access depending upon the context (socio-cultural, economic, and political) as well as individual behaviour. In every society there appears to be some discriminating factors (e.g. class and caste, gender, disability, sexual orientation etc.) that significantly influences maternal health disparities. The review has shown how access to health care is shaped by societal and individual preferences about resources. Despite global and local commitments to equality in health and use of services, prejudicial attitudes and discrimination remain. The impact and effectiveness of government commitments to reduce inequality will be further explored in this study through the lens and real life experiences of women who can be said to commonly experience discrimination and inequity.

## **2.13 STUDY QUESTION AND OBJECTIVES**

This literature review suggests that in addition to the general challenges women face, particularly poor and marginalized women, there are additional inequalities and challenges for women with disabilities in accessing and using maternal health care services. The review also identifies gaps in the evidence base, particularly in relation to women with disabilities who are from the Dalit groups and therefore potentially at even greater risk of discrimination, marginalization and exclusion. This, and experience in the field of maternal and child health in Nepal, has led the researcher to propose the following key research questions.

### **2.13.1 Key Question**

Based on the evidence, what, if any, are the differences in the access to, and utilization of, maternal health care services among Dalit and non-Dalit women, with and without disabilities in Nepal? If so, what are these differences and what causes the disparities?

### **2.13.2 Research Questions**

- i. What is the service utilization status; i.e. ANC, Delivery and PNC is among disabled, Dalit and non-Dalit women? What are the factors associated with service utilization?
- ii. Are the services accessible to disabled and Dalit women? If so, are the services accessible to them equal to those received by other women?

- iii. What are the societal attitudes and behaviours towards disabled women in regards to their maternal health needs?
- iv. What are the maternal health care provider's attitudes and behaviours towards disability?
- v. What are the maternal health care service utilization experiences of disabled women?
- vi. What factors inhibit disabled and Dalit women in access and utilization of maternal health care services?
- vii. What factors enable disabled and Dalit women in access and utilization of maternal health care services?
- viii. How do disability and caste interact in accessing maternal health care services?

### **2.13.3 Study Objectives**

1. To compare and determine the maternal health care service access and utilization patterns among disabled and non-disabled, Dalit and non-Dalit women in Rupandehi district.
2. To understand the attitude and behaviours of society and maternal health care providers towards disability.
3. To identify inhibiting and enabling factors for disabled and Dalit women with regard to access and utilization of maternal health care service.

## **CHAPTER THREE: METHODOLOGY**

### **3.1 CHAPTER OVERVIEW**

This chapter discusses the methodology employed in the study. It begins by discussing the philosophical assumptions of the research that influenced the chosen methodologies, including sampling procedures, data collection, research tools and defining the variables. Procedures applied and the rationale used for the testing of data collection tools, reliability and validity; and the process of data analysis, are then discussed. The chapter concludes by outlining the researcher's positionality whilst conducting the research, as well as the constraints and limitations of the study.

Crotty, (1998) describes the research methodology as “the strategy, plan of action, process or design lying behind the choice and use of particular methods and linking the choice and use of methods to the desired outcome”. The author further explained that “as researchers, we have to devise for ourselves a research process that serves our purpose best, one that helps us more than any other to answer our research question” (Crotty, 1998). Because of the crosscutting nature of the research questions being asked regarding a hidden population of disabled women, this study employed a “mixed methodology” to ensure a pragmatic approach to inquiry, data collection and analysis that best addresses the overall objectives.

### **3.2 STUDY DESIGN**

The study design consists of four key features: the epistemology informing the research, research paradigm, the methodology itself and the techniques and procedure to collect data. A well-defined study design is crucial because it communicates and brings together the information about key features of the study that may differ for quantitative, qualitative and mixed methods.

The research design used in this study was a combination of exploratory and descriptive. An exploratory research design is often recommended when the study topic is either new or little known, whereas descriptive research is employed to describe a particular group or situation (Neuman, 2003; Tuli, 2010). Furthermore, exploratory design is employed to explore phenomena, problems or behaviours in order to gain familiarity and insight. Exploratory research examines the extent of the phenomena or problem, whereas descriptive research deals with the what, where and when of the phenomena (Driessnack, Sousa, & Mendes, 2007).

With reference to this study, the researcher intended to explore a complex socially and culturally constructed situation and multiple perspectives of disabled and Dalit women concerning their

maternal health needs, societal and health care provider's attitudes and behaviour towards their pregnancy and motherhood. Furthermore, the study aimed to describe the maternal health care situation among these groups and the factors affecting service use.

### **3.2.1 Study Approach and Method**

Positivism/post-positivism and interpretivism are the two key research paradigms that surround research. The positivistic/empiricist paradigm follows as objective reality that is primarily considered to be deductive, while the later carries a subjective worldview, in other term humanistic model and characterizes as inductive (Creswell, 2009; Guba & Lincoln, 1994; Tashakkori & Teddlie, 1998).

Mixing the two, a third model is generated that claims to be both pragmatic and appropriate for social science research. The mixed method involves combining quantitative and qualitative research components, guided by two different philosophical stances. However, both paradigms share common beliefs. The pragmatist philosophical approach understands that 'what works' in practice is what is ultimately important (Tashakkori & Teddlie, 1998). There are conflicting opinions on combining the two research methods. One of the criticisms relates to the incompatibility of the underlying paradigms. Others argue that this approach has strength, with both objective and contextual information collected in different phases of the study (Tashakkori & Teddlie, 1998). Given the complex nature of this study, it was felt that using only one data source and single method of inquiry was likely to be insufficient to best address the overall research objective. Moreover, combining quantitative and qualitative approaches offers a better understanding of problems than either approach alone (Creswell, 2003).

The study used a simultaneous mixed method approach by which the quantitative and qualitative data were collected at the same time and analysed in a complementary manner (Creswell, 2003). As described by Greene, Caracelli, & Graham, (1989), the study carried the five characteristics as strengths of a mixed methods approach: (i) triangulation, (ii) complementarities, (iii) development (iv) initiation and (v).

The study collected numerical data using a survey questionnaire (see below) to determine service utilization within the study population. Qualitative in-depth interviews and focus group discussions were conducted to understand the experience of study participants.



### **3.2.2 Study Population and Sources of Data**

In order to address the research questions outlined above, the study population identified included married and unmarried women between 15 and 49 years old who had been pregnant within the last five years (2009 – 2014). The sample was drawn from four different categories: Dalit women with disability, non-Dalit women with disability, Dalit women without disability and non-Dalit women without disability. While disabled and Dalit women are of particular interest in this study non-Dalit non-disabled women were included in the study for comparison purposes.

Due to ethical and other concerns, women with a severe intellectual disability and those with a hearing impairment with whom it was not possible to communicate by verbal and/or non-verbal means, such as Nepali Sign Language, were excluded from the study (Please refer to ethical consideration section below).

The study obtained data from primary and secondary sources. Primary data was collected using individual interviews with selected women; focus group discussions and key informant interviews. Secondary data was collected from the published literature and grey literature such as reports and records from health facilities.

### **3.2.3 Sample Size and Sampling Process**

The method chosen for this study required both qualitative and quantitative data. Qualitative inquiries typically focus on depth and use relatively small samples, while quantitative inquiries emphasize width or generalization and depend on large sample numbers. However, it is not always straightforward to estimate the sample size of invisible populations or 'hard to reach' groups, particularly for conducting large-scale quantitative studies (Bryman, 2008; Lee, 1995).

#### ***3.2.3.1 Recruitment of disabled women***

Considering the above, estimating the sample size of the disabled population fitting the inclusion criteria and then finding the required number of participants for the study was challenging. Therefore, a balanced approach to achieve the minimum number of participants required for descriptive statistics and enough participants for in-depth interviews to reach saturation level was taken. Due to the huge variance of population size among the comparison groups, the sample size for the quantitative interviews was unequal in number. Similarly, the sample selection criteria, their identification and recruitment process also differed for different groups.

Due to the unavailability of accurate data as well as smaller number of disabled verses non-disabled women in all populations, a 1:1 ratio of disabled to non-disabled on a population basis was not possible. Therefore, on the basis of initially available disability data in the district, the field research team first developed a sampling frame for people with disability and estimated the sample size at 250 for the study population for survey, comprising 50 Dalit and non-Dalit women with disabilities, 100 Dalit and 100 non-Dalit women without disabilities. By using 1:2:2 sample sizes it was expected to produce a representative numbers for quantitative analysis.

A three-stage approach was adopted for identification and recruitment of research participants. In the first stage, the researcher made preliminary contact and organized consultation meetings with Disabled People's Organizations (DPOs), Dalit organizations, Female Community Health Volunteers (FCHVs), the District Women and Children office, District Development Committee and NGOs working with Dalits and people with disabilities in the area. On the basis of references and available information from those consultation meetings, and also published sources such as district reports, a list of potential disabled participants was prepared. In the second stage, those potential disabled participants were located with the help of community gatekeepers such as FCHVs and local leaders. At the same time, those disabled women were also asked for other potential participants in the area to be added in the list. These two stages resulted in 119 women with disabilities being identified and listed in the sampling frame.

In the third stage, participants identified for inclusion were visited at home and asked to consent to their participation and screened for the interview using the Washington Group questionnaire (short set) (Madans, Loeb, & Altman, 2011) for confirming their disability. With this comprehensive process, 79 women with disabilities (66%) – 18 disabled Dalits and 61 disabled non-Dalits were included for the interview-sampling frame. Of the total 119 women initially identified, 40 women were excluded from the sample. Exclusion was done mainly (30) based on lack of home address or unable to locate, six were due to difficulties with communication due to deafness or intellectual disability, two declined to be included and two dropped out of the project after initially agreeing to be interviewed.

### *3.2.3.2 Recruitment of non-disabled women*

Similarly, a multi-stage simple random sampling method was followed for the selection of non-disabled women participants. For this purpose, the district was stratified into seven

strata on the basis of government electoral constituencies. From each constituency, one Village Development Committee (VDC) and several wards from those VDCs were chosen randomly for the selection of Dalit and non-Dalit women participants. From those wards, on the basis of 119 initially identified women with disabilities and following 1:2:2 ratios, a comprehensive list of 2,388 Dalit and non-Dalit women between 15 – 49 years old who had been pregnant within the last five years was prepared in consultation with Female Community Health Volunteers (FCHVs) and Health Facility (HF) staff. From the list, a total of 316 women (158 Dalit and 158 non-Dalit) were randomly chosen for an interview making a total of 395, including the women with disabilities.

### *3.2.3.3 Recruitment of health care providers for Attitude Survey*

In order to estimate the sample size and the proportion of health providers required to be interviewed as part of the attitude survey, a health facility-linked two-stage approach was used. In the first stage, 40 health facilities –50% of the total were selected from across the district, using criteria that included all types of public health facilities i.e. hospitals and primary level health care centres. In the second stage, 396 health providers with different jobs including female community health volunteers were selected following the criteria recommended by Turner, Angeles, Tsui, Wilkinson, & Magnani, (2001) for HF surveys. All health providers were chosen from health facilities having four staff or less, and four from the larger HFs. Similarly, six female community health volunteers linked to each selected urban health facility and five from each rural health facility were chosen randomly. All health providers approached for interview agreed to be interviewed.

### *3.2.3.4 Qualitative interview participant's recruitment*

For the qualitative data collection, based on the literature, an initial target of 30 participants (five disabled Dalits, five disabled non-Dalits, ten non-disabled Dalits and ten non-disabled non-Dalits) was set to be selected purposively for in-depth interviews. This number was as a potentially large enough number to allow identification and insight into key themes based on previous qualitative research on disability. However, number of disabled non-Dalits and non-disabled Dalit women was increased during the interview to reach the saturation. Similarly, the purposive selection of a Dalit leader, a DPO leader and two women's leader/ activists at district level; and two interviews with a policy planner and a policy implementer at MoHP/Department of Health Service level was conducted.

The focus group discussion (FGD) participants for upper caste groups and Dalit groups were also chosen purposively from different settlements in order to ensure the participation of appropriate individuals and groups.

The Table 1 below presents the number of sample participants in both quantitative and qualitative interviews and focus group discussions.

**Table 1: The detailed numbers for quantitative and qualitative interview participants**

Methods	Total Sample	Type of Participants	Number	Remarks
<b>A. QUANTITATIVE</b>				
1 Household Survey Interview (15 - 49 yrs women with U5 Child)	Estimates for interview: 361	Disabled Women	79	Dalit: 18 Non-Dalit: 61
		Non-disabled Dalit Women	133	Interviewed: 137
	Interviewed included for analysis: 354	Non-disabled Non-Dalit Women	142	Interviewed: 145
3 Attitude Survey (Health Providers)	Estimates for interview: 374	Community Health Volunteers (FCHV)	215	
	Actual interviewed & included for analysis: 396	Professionals (Dr, Nurse, ANM, HA, AHW)	181	
<b>B. QUALITATIVE</b>				
1 In-depth Interview (15 - 49 yrs women with U5 Child)	Estimates for interview: 30	Disabled Women	17	Dalit: 5 Non-Dalit: 12
		Non-disabled Dalit Women	11	
	Interviewed & included for analysis: 37	Non-disabled Non-Dalit Women	9	
2 KII	6	DPO Leader/Activist	1	
		Dalit Women Leader/Activist	1	
		Women Leader/Activist	2	
		Policy Planner & Implementer	2	
3 FGD	6	FCHVs	2	Groups
		Dalit Women	2	Groups
		Non-Dalit Women	2	Groups

### 3.2.4 Data Collection Methods and Tools

As noted above, the study used multiple methods of inquiry and data collection. Both quantitative and qualitative data collection tools were developed, tested and validated before introduction in the field. The types of tools used for quantitative data collection were structured questionnaires and attitude survey questionnaires. As discussed in greater depth below, both closed and open-ended questionnaires were developed and used for structured interviews. Semi-structured questionnaires and topic guides were used for the qualitative interviews.

#### 3.2.4.1 Survey Interviews

A series of linked qualitative and quantitative tools were developed or adopted for use as part of this study. These included the following:

1. A general survey was conducted among Dalit and non-Dalit women with and without disabilities having pregnancy experience within the last five years, using a structured questionnaire developed for this study. Because there was a need to collect information that covered demographics, maternal child health, Dalit/non-Dalit and disability since no existing survey was available. Survey development for this project was thus begun with a review of literature where surveys with relevant questions were identified and then a series of questions was adapted from these previously developed standard questions. Particular attention was given to surveys previously undertaken in Nepal, such as Nepal Demographic Health Survey (NDHS 2011).

Using these surveys as a starting point, a structured 15-page questionnaire with 95 questions was developed. The questionnaire included both closed and open-ended questions. Socio-demographic information (13 questions) and family background (13 questions) were taken from NDHS 2011 questions. The new questionnaire also included questions related to disability (11 questions), pregnancy and childbirth (23 questions), delivery and postnatal care (17 questions) as well as information related to empowerment (18 questions). The questions were developed from similar studies in the literature.

The Washington Group questions (short set) – **Appendix D** were used to identify disability (Madans et al., 2011). The questionnaire was developed in English and later translated into Nepali and then field tested among 5% of the total sample size to ensure accuracy in translation. The tool was piloted and revised three times with continual refinements made in the language and wording

after each pilot. The fourth version was adopted as the tool to be used in the study, and was used as the tool on which enumerators were trained. Please refer **Appendix B** for the detailed questionnaire.

2. An attitude survey was conducted to examine health service provider's attitudes toward people with disabilities. This tool was adapted from the widely used including Asian countries and validated "Attitudes towards Disabled Persons (ATDP) Scale". The sample tool is attached in **Appendix C**. This tool is simple, easy to administer, simple to score and has been used extensively in previous research to assess general attitudes toward disabled persons (Au & Man, 2006; Paris, 1993; Perry, 2008). The scale measures attitudes towards disabled persons in general rather than a specific disability group. The ATDP Form B consists of 30-items with a six rating Likert-type scale instrument. It was first developed and applied in 1960 by Yunker, Block, & Campbell and updated in 1970. The tool reliability coefficient range estimates 0.71 to 0.83 in Form B (Yunker, Block, & Young, 1970).

For the Attitude survey used in this study, the first part of the questionnaire records personal information, the second part consists of the ATDP Form B, and the third part includes three questions about the individual's contact or exposure to persons with disabilities and any training received about disability (**Appendix C**). The first part (personal information) and the third part (contact or exposure to Persons with Disabilities) were added to the original ATDP Form B questionnaire. Before administering the survey tools in the field, all the instruments were carefully translated into the Nepali language and checked by two bilingual speakers, and field-tested among 6% (23 providers) of the total sample size population in a similar context.

#### *3.2.4.2 Qualitative Interviews*

In-depth semi-structured or unstructured interviews are typically the foremost methods of data collection in qualitative research (Legard, Keegan, & Ward, 2003). These types of interviews are often in the form of conversation with a purpose, guided by certain topics or open-ended questions. Hutchinson (1994), stated that qualitative interviews increase self-awareness among interview participants, grants a sense of empowerment, promote healing and give voice to the voiceless. The study, having an emancipatory nature, employed qualitative interviews as key elements of data collection.

A total of 37 in-depth face-to-face individual interviews were conducted with women with and without disabilities, to understand their experiences related to pregnancy and health

service use. In addition, community leaders/activists, policy planners and implementers were also interviewed to get their opinion on pregnancy and maternal health care issues of disabled and Dalits.

The interview schedules were utilized as a guideline and are included in **Appendix B**. The topic guides and interview questions were developed by establishing the subjects to be covered in data collection based on the research questions. A broad agenda of topics and themes were identified to explore following the literature review, as well as discussions with the supervisors, team members and potential users such as community leaders, health providers and DPO members. A separate set of guidelines for each category of interviewee and FGD was developed to be able to collect as much detailed information as possible.

#### *3.2.4.3 Focus Group discussion*

Focus group discussions are a popular qualitative data collection method that are typically defined as a structured discussion on a precise topic of interest or certain issue/s, with a group of people comprising six to twelve in size (Masadeh, 2012). It is considered an efficient way of gathering large amounts of information in a short time. Focus group discussions indicate community beliefs, ideas or opinions on the issues discussed. This technique is used either as a 'standalone' or self-contained as a principal method of research, or it can be used as a supplementary source or as a part of mixed methods research (Morgan, 1996). However, it is considered an effective means when used in conjunction with other data collection methods as a form of triangulation (Bloor, Frankland, Thomas, & Robson, 2001; Krueger, 1994; McClelland, 1994; Threlfall, 1999).

In this study, focus group discussions were used in combination with other methods to generate information and understand local culture, opinions and participant's attitudes towards disabled women and their sexual/reproductive health. To capture the views from diverse perspectives, six focus group discussions were conducted with three different groups: female community health volunteers, Dalit women and non-Dalit women (general public). Each group consisted of six to twelve participants. A practice session with a different group using the topic guide/checklist was done before conducting the actual focus group discussions to ensure the questions generated were relevant, understandable and would elicit responses that are more accurate. FGD topic checklists, **Appendix B** that was developed as stated above were used.

### **3.3 ORGANIZATION OF THE STUDY**

#### **3.3.1 Field Work Preparation and Field Procedure**

##### *3.3.1.1 Ethical Consideration*

Before the study commenced, the researcher obtained ethical permission from the Nepal Health Research Council (NHRC) – Reg. no. 34/2014 and UCL ethics committee project ID: 5260/001.

Additionally, approval was received from the government district public health office in the study district (**Appendix E**).

Moreover, local health professionals and community gatekeepers were consulted and taken verbal consent at different stages of the study. Before each interview and group discussion, the participants were asked for their written or verbal consent with, after the data collectors had read out aloud the participant's information and consent sheet (**Appendix B**). In the case of participants with intellectual disability and/or those below 18 years of age, the consent of both participants and parents/guardians were sought.

After being provided with the approved ethical approval statements, including the voluntary nature of the interview and their right not to answer any questions and their right to end the interview at any time, participant's verbal consent was obtained for recording the interviews and discussions. Privacy of the participants was protected throughout the interview process, and the confidentiality of data in processing and analysis were maintained strictly. The principle of anonymity was followed in all reports. The in-depth interview and focus group discussion participants were compensated for their time with NRs 200.

##### *3.3.1.2 Field Procedure for Data Collection*

The preliminary field assessment, gathering information for the development of sampling frames was done in May and June 2014. Before the collection of data, two groups of pilot studies were undertaken, one in May and one in July/August. These were done to identify whether the data collection methods or instruments were appropriate for both participants and data collectors (Teijlingen & Vanora Hundley, 2005). The structured and semi-structured individual interview questionnaire (in-depth interview guidelines) were pre-tested with a target population in a similar context to check the sequence, the structure of questionnaire and the local meaning of the language used. Necessary changes such as sequence of the questions, wording of the language and additional possible answers in the tools and schedule were made after the pre-test. Moreover, the average time taken to complete the research



instrument was established. Similarly, key informant interview (KII) guidelines and focus group discussion (FGD) checklists were also pre-tested during a pilot FGD to confirm suitability as well as familiarise with the tool and process. Data collection, household survey and service provider's attitude surveys were all conducted between September–October 2014. The in-depth interviews, KIIs and FGDs were undertaken in February - March 2015.

#### ***3.3.1.3 Recruitment of field researchers and Training***

The field data collection started with the recruitment of field researchers and data collectors locally, training them and practicing the tools in the field. Due to cultural sensibilities, both Dalit and non-Dalit, male and female interviewers were recruited. Moreover, one of the senior female staffs working with Kidasha in the Maternal Health project was also recruited as a research assistant to work together with the researcher. Quantitative data was collected first, followed by the qualitative interviews. The field researchers and data collectors with the guidance and supervision of the lead researcher collected the quantitative data. The researcher, with the help of the female research assistant collected the qualitative data including in-depth interviews, KIIs and FGDs. Both male and female interviewers were used to collect data from health care providers, policy makers and others.

### **3.3.2 Data Quality Assurance Mechanism**

#### ***3.3.2.1 Validity***

The study made an effort to maintain all three quality assurance mechanisms commonly described – content, construct and criterion related validity. The content validity focused on whether the instruments cover all the relevant aspects of the constructs that the study claimed to measure. It was done by review of literature, comparison with existing instruments and review by the experts (supervisors). The contents and the instruments were also examined and adjusted after the interviews of potential respondents and pilot testing the draft versions. The study used an already validated existing tool for collecting quantitative data, which consisted of content and criterion related validity (ATDP Form B). Two additional tools, a semi-structured questionnaire for in-depth qualitative interviews and a structured questionnaire for survey interviews were developed by adapting standard sets of questions taking from the literature such as Nepal Demographic Health Surveys and already employed in different research in Nepal. All tools were further pre-tested in the field before administering for the data collection.

Careful consideration was given along with the expert's (supervisors) opinion while defining and operationalization of the variable of interest. Moreover, the researcher made an effort to maintain

reliability and validity by establishing a logical link between the research objectives and questionnaires (Teijlingen et al., 2004). The construct validity was assessed using known-group technique (Polit & Beck, 2010) analyzing score differences between groups.

Data consistency checks, debriefing of participants and district stakeholders, triangulation and cross checking of data with district data and published research ensured the external validity of quantitative data.

As in quantitative research, the concept of validity is equally significant in qualitative studies. However, it is approached with different terminology and measured slightly differently in qualitative than in quantitative procedure. The commonly used validation methods in qualitative studies such as constant comparative method and deviant case analysis (Glaser & Strauss, 1967), triangulation and respondent validation (Creswell, 2003; Lewis & Ritchie, 2003) were applied in this research. Not all findings of the study are generalized; participant's views and opinions are presented as lived experience that ensured the external validity.

#### **3.3.2.2 Reliability**

Reliability refers to the consistency of the measurement. The interpretation of the term reliability differs in quantitative and qualitative methods and tools. Generally it is understood as replicability or repeatability of research findings (Lewis & Ritchie, 2003). With quantitative methods, it can be predicted by correlating the scores obtained by the same respondent on different occasions. Cronbach's Alpha confirmed the correlation values among the questions on the survey instrument (ATDP).

In qualitative methods, the reliability discussion is about conformability of findings, trustworthiness and the consistency (Glaser & Strauss, 1967; Graneheim & Lundman, 2004; Guba & Lincoln, 1994; Lewis & Ritchie, 2003). Trustworthiness comprises credibility, dependability, conformability and transferability in a circular and dynamic process (Devkota, 1996).

The study used the following criteria to ensure trustworthiness.

#### **Credibility:**

Researcher and his team's intensive engagement with data (recording, notes and transcripts), transcription, translation and coding were done by two members (research assistant and staff of Kidasha), then checked carefully and any differences in coding discussed in order to make a decision. Clear links were demonstrated between data process and interpretation.

**Dependability:**

To ensure stability and consistency in the process of inquiry, precautions were taken in the research process to ensure logical, traceable, and well-recorded documentation in a reflexive way, providing supervisors with a detailed account of research process.

**Conformability:**

Conformability was enhanced by the researcher's awareness and precautions to minimize possible biases. An audit trail was implemented (supervisors checked the data analysis) and ensured that the analysis and interpretation were sound and confirmed the findings.

**Transferability:**

Transferability refers to the generalization or replicability of the findings to other setting or groups (Guba & Lincoln, 1994; Leininger, 1994). The findings could be replicable in the similar context; however, the intention of this study was to identify width and the depth of the issue and accepted local norms and trends on research issues rather than generalization of the findings.

**3.4 MEASURES****3.4.1 Outcome Measures****3.4.1.1 Pregnancy Health Care Service Utilization**

Three measures of pregnancy health care service utilization were assessed in this survey: Ante-Natal Care (ANC), Delivery and Post-Natal Care (PNC). The government of Nepal has adopted the WHO recommendations that pregnant women receive at least four antenatal and three postnatal visits/checks for each pregnancy as standards for maternal health care services in Nepal. For safe delivery and childbirth, it is recommended the delivery occur in the presence of skilled birth attendants or in a health facility (GoN/MoHP/FHD, 2009). Therefore, adequate utilization of ANC for the purposes of this study were considered to be four or more visits, compared to less than three visits during the last pregnancy (an inadequate care was considered three visits or less). As per MoHP guideline, out of three recommended postnatal check-ups, the first check-up is recommended within 24 hours of delivery, the second on the third day following delivery, and the third on the seventh day after delivery (GoN/MoHP/FHD, 2009). In addition, analysis also considered whether there was at least one postnatal care visit within a week after the delivery to assess the utilization of postnatal care service. Delivery service utilization was measured as birth given in any type of health facilities - private or public birthing centres, sub-health posts, health posts, primary health care centres and hospitals. Among women with two or more pregnancies

and childbirths in the last five years, study data referred to the most recent pregnancy or childbirth and the services used at that time.

### 3.4.1.2 Access

Access to pregnancy health care was measured by developing both objective and subjective indicators. The observable facts and figures like distance, time and cost to nearest health facility were used as objective indicators; whereas pregnant women's perception and satisfaction level on each factors obtained from interviews were used as subjective indicators. The survey questions used to assess each of these access measures are located in table below (Table 2).

**Table 2: Variables and their description measuring access dimensions**

Access dimension and definition	Indicators of measurement	Questions asked
<p><b><u>Accessibility</u></b> The location of HF is in-line with the location of clients and linked with road and transport.</p>	<p><u>Distance/Location</u> of HF <u>Road &amp; Transport</u> link to HF <u>Travel time and Cost</u></p>	<ul style="list-style-type: none"> <li>• How far is the HF from your place of residence?</li> <li>• Does the road links to HF?</li> <li>• Does the HF have access to Public transportation?</li> </ul>
<p><b><u>Availability</u></b> The existing health services and goods meet client's needs  (Volume &amp; type of existing services and resources – i.e. Adequacy of HR, facilities – hospital, clinics., Services, Drugs &amp; materials)</p>	<p><u>Resources</u>: Staff, Drugs, Beds/Material/Equipment (allocation/distribution) <u>Time spent</u> by the providers <u>Waiting time</u> in HF <u>Facilities</u>: Types &amp; provision of services <u>Information</u>: Information available about staff, services &amp; materials</p>	<ul style="list-style-type: none"> <li>• Does HF have filled all the staff positions?</li> <li>• Does HF have drugs &amp; supplies available as per standard list?</li> <li>• How much time did provider gave you for ANC check -up?</li> <li>• How long you have to wait to get the services?</li> <li>• Does HF provides all type of maternal health care services?</li> <li>• Do you know about travel cost reimbursement scheme?</li> </ul>
<p><b><u>Affordability</u></b> The prices, insurance or allowance provision for services fit the client's income and ability to pay</p>	<p><u>Cost</u>: Charges for services, Materials/supplies <u>Income</u>: Individual &amp; Family earning, allowances and reimbursement</p>	<ul style="list-style-type: none"> <li>• Did HF charge for services and supplies for your delivery?</li> <li>• What is your occupation?</li> <li>• What is your husband's occupation?</li> <li>• What is the main source of your household income?</li> <li>• Do you receive any type of allowances from govt. or any other organization?</li> <li>• Did you receive transportation allowance (cash reimbursement) from HF?</li> </ul>
<p><b><u>Acceptability</u></b> The characteristics of services, its delivery and characteristics of providers match with those of clients</p>	<p><u>Provider's sex, Age, Caste/ ethnicity</u> <u>Attitude &amp; Behaviour</u>: courtesy/respect, dignity/ privacy, kindness &amp; positive regards) <u>Procedure</u> of service delivery</p>	<ul style="list-style-type: none"> <li>• Was the provider Male or Female? If the provider was male, how did you feel to be examined by male?</li> <li>• How was the behaviour of staff/providers in HF?</li> <li>• Was your privacy maintained during check-up?</li> </ul>
<p><b><u>Accommodation</u></b> The infrastructure and organization of health care meets the client's expectation</p>	<p><u>Structure</u> of HF building <u>HF opening hours&amp; schedule</u> <u>Space &amp; internal arrangement</u> <u>Adapted beds</u> and equipment</p>	<ul style="list-style-type: none"> <li>• Is the HF building wheelchair accessible?</li> <li>• Does the HF have separate examination room, adequate waiting space for the clients?</li> <li>• Does facility has adapted beds and equipment for disabled?</li> </ul>

#### *3.4.1.3 Provider's Attitude*

Maternal health care service provider's attitude was measured using attitude toward disabled persons (ATDP) scale and the score the providers received. Items on the ATDP scale were expressed as statements with which the participant might agree or disagree. The participant's reaction in terms of a response category ranged from +3 to indicate "I agree very much" to -3 to indicate "I disagree very much". The scale did not have a neutral or zero rating point, forcing participants to make either a positive or negative responses.

The ATDP score ranged from 0 – 180 on Form B. The score interpretation is based on the individual's perceived similarity or differences of persons with and without disabilities. A higher score indicates perceiving a person with disabilities as similar to a person without disabilities and lower score indicates the respondent perceives persons with disabilities as different from persons without disabilities. Higher scores can also be interpreted as an individual displaying a more accepting (positive) attitude of persons with disabilities while lower scores reflect a rejecting or discriminatory attitude towards persons with disabilities (Yuker, H. E., & Block, 1986). There is not consensus in the literature about what threshold is regarded as a positive score. However, scores of 110 for male and 113 for female are set as thresholds (Yuker et al., 1970; p:28).

The original instrument consisted of both positively and negatively worded items. Therefore, the first step of analysis was to change the signs of the items so that a higher score indicated a more positive attitude. This was done by changing the signs of the positive items; the algebraic sum of all the item scores was obtained. The sign of the sum then reversed from +ve to -ve and vice versa. To eliminate -ve value, a constant 90 was added to convert all scores to positive. Thus, the resulting scores ranged from 0 to 180, indicating higher scores as a positive attitude.

#### *3.4.1.4 Exposures*

The exposure variables used in the study were disability and caste. The study assessed disabled versus non-disabled and Dalit versus non-Dalit.

#### *3.4.1.5 Covariates*

The covariates were used to understand the economic and socio-demographic characteristics of the respondents. These included: place of residence, age, marital status, age at marriage, parity, education of respondent, education of husband, occupation of respondent, occupation of husband, source of income, household wealth, empowerment and knowledge and awareness. The last three covariates: household wealth, empowerment, and knowledge and awareness were measured developing indices using multiple variables.

Table 3 and 4 lists the variables and the details used for quantitative analysis in the study. The indices for socio-economic status, empowerment and awareness were generated from the binary scoring method utilizing survey questions and respondent's household assets. Those scores were used as wealth quintiles, empowerment index and awareness index.

**Table 3: Variables and their description measuring maternal health care service utilization**

<b>Measure</b>	<b>Definition /Coding</b>	<b>Level of Measurement</b>
<b><i>Outcome Variables</i></b>		
ANC Visit	Most recent attendance at a health facility (HF) by a pregnant woman for antenatal care during last pregnancy (0 = <4 visit, 1 = 4+ visit)	Binary
HF Delivery	Most recent child birth at a health facility (HF) designated for safe delivery.(0 = Home delivery, 1 = HF delivery)	Binary
PNC Visit	Attendance at a HF for postnatal care by a woman within 7 days of last childbirth. (0 = No, 1 = Yes)	Binary
<b><i>Exposure Variables</i></b>		
Disability	Disability status of respondent women meeting Washington Group Questionnaire criteria. (1 = Non-disabled, 2 = disabled)	Binary
Caste/Ethnicity	Self-reported caste and ethnicity of respondent woman. (1 = Dalit, 2 = Non-Dalit)	Binary
<b><i>Covariates</i></b>		
Place of residence	At the time of survey, respondent living in VDC are considered rural and living in Municipality are urban. (1 = rural, 2 = urban)	Binary
Age	Completed age of women at the time of survey in years. (1=15 -24, 2 =25-34, 3 =35- 49)	Categorical
Marital status	Couple living together at the time of survey. (1 = married, 2 = unmarried/widowed/divorced or separated)	Binary
Age at Marriage	Completed age of women at the time of marriage in years. (1 = 5 – 18, 2 = 19 – 40)	Categorical
Parity	Number of pregnancy or childbirth in lifetime. (1=Primipara, 2 = Multipara)	Binary
Respondent's education	Number of years of school education completed by the women. (1 = Illiterate, 2 = Literate/Primary education up to class 5, 3 = Secondary education or above)	Categorical
Occupation	Occupation of respondent woman at the time of survey. (1 = Unemployed/Farmer/Daily wage, 2 = Regular employment – service/small business)	Categorical
Husband's Occupation	Occupation of respondent's husband at the time of survey (1 = Unemployed/Farmer/Daily wage, 2 = Regular employment – service/small business)	Categorical
Main source of Income	Main income source of family members at the time of survey (1 = Farming/Daily wages, 2 = Service/ employment/Small business, 3 = Others/mixed)	Categorical
Husband's Education	Number of years of school education completed by the respondent's husband (1 = Illiterate, 2 = Literate/Primary education up to class 5, 3 = Secondary education or above)	Categorical

<b><i>Covariates</i></b>		
Knowledge and awareness Index	Knowledge of danger signs spontaneously cited during pregnancy, childbirth and postpartum (An additive index). (0 = No knowledge at all, 1 = Little knowledge or low level of awareness, 2 = Enough knowledge – high level of awareness)	Ordinal
Empowerment Index	An index developed using 24 questionnaire items at individual, family and community level indicators. (1 = low, 2 = medium, 3 = high)	Ordinal
Household Wealth Index	Wealth index developed based on socio-economic indicators and household assets reported at the time of survey. (1=low, 2 = Middle, 3 = high)	Ordinal

### Household Wealth Index

The household wealth index variable was constructed using 22 indicators of household possessions having a total score of 26. The household possession or dwelling characteristics used for creating the household wealth index were chosen from the Nepal Demographic Health Survey 2011 and its standard questionnaires. The index variables are listed in Table 2 and **Appendix G**.

Except for two indicators (Roofing Materials and Source of water used by the household), all other variables were dichotomized assigning the code 0 or 1. In the case of Roofing Materials, the household was assigned the weight 1 with Natural/non-durable roofing materials (Grass/Straw/Plastic/Tent), 2 with durable roofing materials (Tin/Jasta/Tile/Khapata) and 3 for those having long durable roofing (Cement and concrete). Similarly, households using surface water/shallow well are given the score 1, those using tube well are assigned 2 and who are using piped water are given 3 score.

All others indicators were assigned with 0 or 1, with households not having the asset assigned 0 and households possessing the asset receiving 1. The scores were summed for each household; and women were ranked according to the score of the households in which they resided. The sample was then divided into quintiles from one (poorest) to five (richest). However for the purpose of analysis, the lowest two (poorest and poor) and the highest two (richest and rich) groups are collapsed making three categories (low, medium and high) of wealth ranking, since in some categories only a few cases were reported, which was not enough for analysis.

### Women's Empowerment Index

In order to construct an index for women's empowerment and autonomy, four dimensions were used that are common and widely used to measure women's empowerment: economic, socio-cultural, familial/interpersonal and political (Malhotra, Schuler, & Boender, 2002; Narayan, 2005).

These dimensions were then adapted to reflect the local context at Individual/family (micro) and community (meso) level. Six micro and meso level indicators with 24 questionnaire items (**Appendix G**) were used to derive a score. The indicator related to household leadership and domestic decision-making contained three question items; financial autonomy/access to and control over resources contained three questions; mobility/freedom of movement indicator contained eight; decision about choosing one's spouse and control over own body for health and well-being contained two; freedom from abuse and violence contained two; and rights, social and political participation consisted of six questions. All the questionnaire items were dichotomized with the code 0 if the women reported "No/other" and 1 if she reported "Yes". A composite measure was created using the sum (maximum score of 24) of the equally weighted binary input variables.

#### **Knowledge and awareness Index**

The knowledge and awareness index was created by asking the respondents two questions to assess their knowledge on danger signs of pregnancy and childbirth: (1) 'Are you aware of any problems that are potentially dangerous to the mother during pregnancy and childbirth?' and (2) 'What are the danger signs to mothers during pregnancy, childbirth and after delivery?'. Those who answered "No" for the first question were given a score of 0 and those who answered affirmatively were asked the second question. Women stating one to three danger signs while asking the second question were given a score of 1, and those who stated four or more signs were given a score of 2.



**Table 4: Variables and their description measuring health provider’s attitude survey**

<b>Measure</b>	<b>Definition/Coding</b>	<b>Level of Measurement</b>
<b><i>Outcome Variable</i></b>		
Attitude score	Total algebraic sum of the rated scores by the respondents (between 0 – 180)	Ordinal
<b><i>Background Variables</i></b>		
Respondent’s location	At the time of survey, respondent living in VDC are considered rural and living in Municipality are urban. (1 = rural, 2 = urban)	Categorical
Age	Completed age of women at the time of survey in years. (1=18 -24, 2 =25-34, 3 =35 – 44, 4 = 45 – 54, 5 = 55 - 60)	Categorical
Gender	Male or female respondent (1 = male, 2 = female)	Categorical
Caste/Ethnicity	Self-reported caste and ethnicity of respondent woman (1 = Dalit, 2 = Non-Dalit)	Categorical
Provider’s type	Classification of health care providers by their job role. (1= FCHV, 2 = ANM/Nurse, 3 = Dr/HA/AHW)	Categorical
Provider’s exposure to disability	Service/treatment given to disabled. (1 = Yes, 2 = No) Maternal health care service given to disabled women. (1 = Yes, 2 = No) Disability related training/orientation received. (1 = Yes, 2 = No)	Categorical

### **3.5 DATA MANAGEMENT AND ANALYSIS**

#### **3.5.1 Data Management**

The study followed data management procedures for quantitative data as recommended by Fink (2003) that included drafting an analysis plan; creating a codebook and establishing reliable coding; review of complete or missing data; entering data and validating entry accuracy; and cleaning data. Field survey data were checked for completeness and accuracy and the first stage data cleaning was done at the field level immediately after collection by the researcher together with the field researcher and data collectors. An analysis plan was drawn up, coding principles agreed together with the data entry clerk, and the data was then inputted into the computer using appropriate software (i.e. Epi-INFO/SPSS).

The in-depth interviews, key-informant’s interviews and FGDs were audio-recorded with the approval of participants and one of the interviewers took notes. Data obtained from the interviews and focus group discussions were crosschecked with respondents after the interview. All the qualitative data were transcribed and translated into English from the local language/ Nepali. Each transcript and translation was done by two persons and the investigator then audited those against the original audio record. The transcripts and translations were edited in consultation with the transcriber or translator where inconsistencies of the meaning found in the

process of auditing. Those data were cleaned, coded and stored in both paper and electronic form with clear numbers and identity, in a locked and secure place in the Kidasha office in Nepal where the researcher was based.

### **3.5.2 Data Analysis and Interpretation**

#### ***3.5.2.1 Quantitative data analysis***

Quantitative data analysis started by coding the variables. Then the data gathered from the field were entered into the computer in EPI-Info software version 3.4.1. After checking the accuracy and completeness against the paper records, the data were transferred into SPSS (version 16.0 for Windows) for analysis. Data was then cleaned, running frequencies and tabulation of each survey question and crosschecked for consistency, tallying with the related items.

The household survey aimed to assess utilization of maternal health care services and identify the factors influencing access and utilization of services. Survey participant's socio-demographic, empowerment and awareness characteristics were first compared across groupings of disabled Dalit and disabled non-Dalit and non-disabled Dalit and non-disabled non-Dalit, using ANOVA for continuous variables and Pearson's chi-square statistic for categorical variables. Descriptive statistics were also given separately for caste group and type of disabling impairment for disabled participants. Second, associations between the measures of utilization – Ante-Natal Care (both any check-up and frequency of check-up), Delivery (Health facility vs home delivery) and Post-natal check-up (yes/no) and disabled/Dalit status were examined using cross tabulations and chi-square tests. Factors found to be significant at 5% level,  $P < 0.05$  were then further analysed using multi-variate logistic regression to generate odds ratio (OR) and confidence interval (95% CI). Regression analysis was carried out to test whether Disabled or Dalit status was related to utilization measures once potential confounders (Place of residence, women's age, age at marriage, parity, husband's education and husband's occupation) had been taken into account. Interactions between exposures (disability, caste) and outcomes were tested by inclusion of interaction terms (i.e. women's age\*disability) in each model. For example, to test the interaction between caste and women's age, the model was fitted with caste, women's age and women's age\*caste.

#### ***3.5.2.2 Qualitative data analysis***

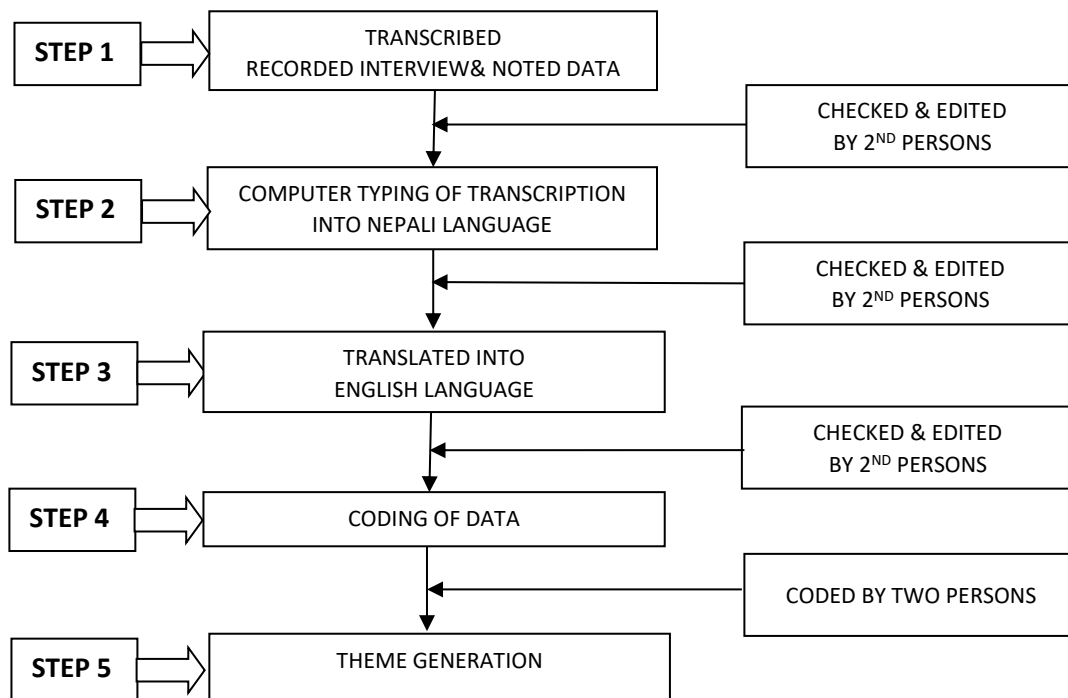
This study utilized thematic analysis using framework methods developed by Jane Ritchie & Lez Spenser adopting grounded theory approach. According to Ritchie & Spencer, (2003) framework analysis is considered a flexible method that involves five stages in the process of analysis, they are: familiarization; identifying a thematic framework; indexing; charting/mapping; and

interpretation. In the literature, a number of methods and techniques are recommended for qualitative data analysis depending upon the nature of the research and research questions. Some examples of commonly used methods are content analysis, thematic analysis, grounded theory analysis, narrative or framework analysis (Devkota, 1996).

Marshall & Rossman, (1999) states, “data analysis is a messy, ambiguous, time-consuming, creative and fascinating process”. Others point out that there is a lack of specific methods for qualitative data analysis (Spencer, Ritchie, & O’Connor, 2003), while still others argue that it can be done in many ways that vary by study type, study objectives and also by researchers (Bogdan, R.C. and Taylor, 1984). Qualitative data analysis searches for relationships between variables, looks for the patterns and generates themes for interpretation.

The qualitative data analysis in this study followed a five step process, as shown in the chart below (Figure 4) in order to generate the themes. This started with transcribing the audio-recorded interviews and field notes and then translating them into English language. The data were first analysed manually, a process in which transcripts were read and re-read several times by the researcher and two research assistants with different background – health professionals, disability and development specialists who were involved in the entire process of tool development and data collection process in the field together with the researcher. Before coding started, the team discussed the coding criteria and agreed on the parameters. Two members in the team coded the data separately. Inconsistencies and questions in this process were discussed among the research team and decisions reached by consensus. The data were coded searching the meaningful segments and units. Once meaning and the segment was identified category was developed with corresponding codes. Both an inductive and deductive process following Corbin & Strauss, (1990), that included the breaking down of the data, conceptualizing it and putting it back together in new ways to generate themes. The deductive coding was based on priory concept and constructs from the access model framework as recommended by Penchansky and Thomas (1981), whereas the inductive coding was based on meanings and constructs grounded in the data (Glaser & Strauss, 1967). In the deductive analysis, the data was sorted according to established themes (physical accessibility, availability, affordability, acceptability and accommodation) in access model and fitted into the template.

**Figure 4: Steps and Process of Qualitative Data Analysis**



The thematic analysis was done with three levels of coding: open, axial and selective coding following a grounded theory approach (Corbin & Strauss, 1990). The coding was based on the repetition of key words, phrases or statements in the transcripts. The process of open coding consisted of reading and identifying underlying concepts and clusters, naming and categorizing/classifying, then indexing and describing phenomena from the text. This involved constant comparison by asking questions and comparing meaning between interviews (transcripts) and grouping together the related concepts to generate themes. In each transcript, the important texts and the respondent's description were highlighted with different colour (colour-coding) showing the relation of the code in the margin of the transcript to retrieve easily later and also for use as quotations in the report. In the next step, we searched for the patterns, and similar concepts and constructs and the axial coding was done on the basis of their relationships and similarities to fit with attitudes, feelings or perceptions, experiences and barriers or facilitators for maternal health care utilization. Unlike open coding which broke the data into concepts and categories, axial coding involved putting these concepts back together in new way by making connections between them as categories and sub-categories. Thus, axial coding involved making the relationship between the codes and developing the main categories and their sub-categories. Finally, the selective coding formed the themes showing the causal relationships, conditions and consequences in the phenomena. To avoid bias in the analysis and adjustments of

non-repetitive words, phrases or statements that appeared in the coding were critically analysed for theme identification.

Selection of appropriate quotes that were representative of the concepts and categories identified were also selected at this point for inclusion in the text. These quotes were chosen because they either provided specific insight into identified areas of focus or because they summarized broad ideas and experiences that were felt to be representative of the issues that emerged as part of the data analysis during this thesis.

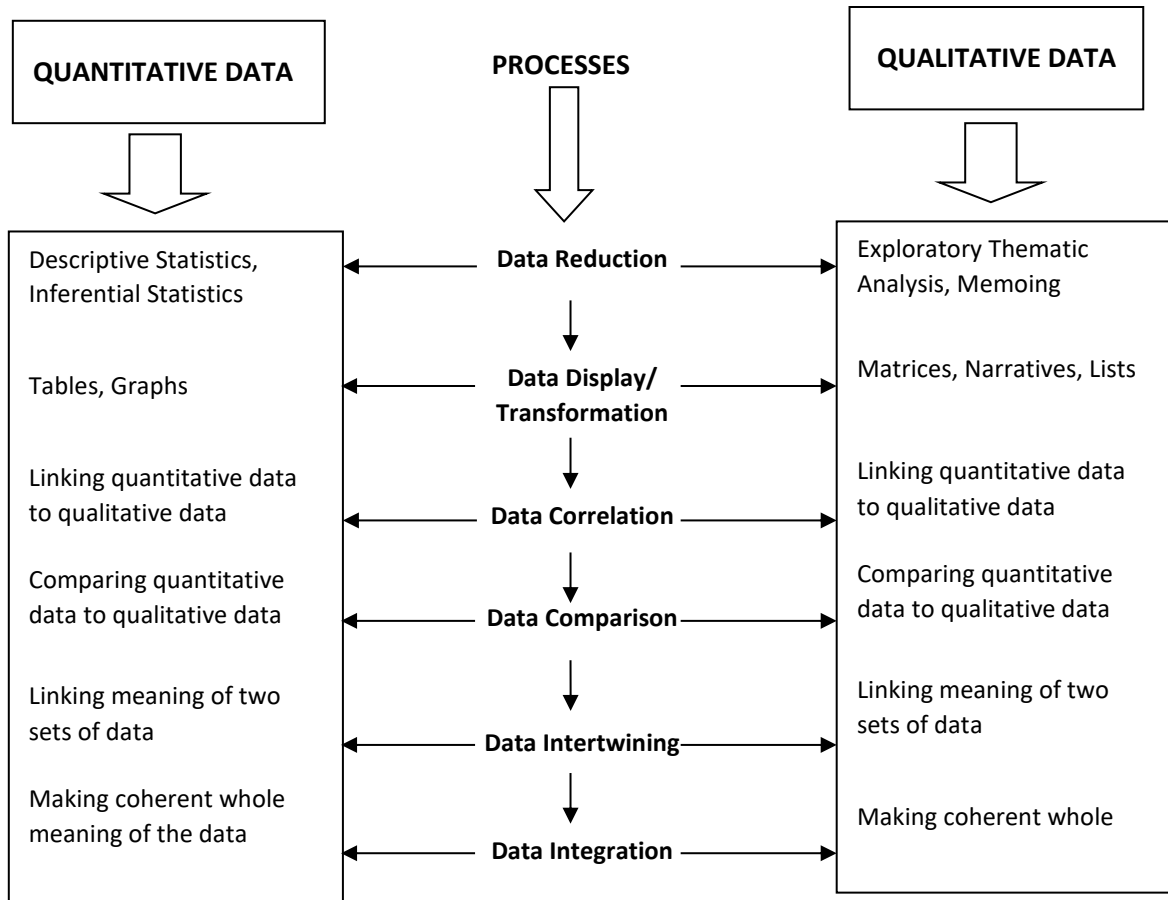
The last step in data analysis involved triangulation. Triangulation incorporates several viewpoints and methods; both quantitative and qualitative verifies the findings and increases validity of the study (Fielding, 2012; Jick, 1979; Kennedy, 2009; Kruger, 2003; Yeasmin & Rahman, 2012). The purpose of triangulation in this study was to obtain different but complimentary data to understand the complexities of human behaviour from more than one standpoint.

The literature suggests many different approaches to triangulation; however common forms of triangulation employed are: data triangulation, investigator triangulation, theoretical triangulation and methodological triangulation (Denzin, 1978; Jick, 1979). The study utilized several types of triangulation and data and viewpoints were triangulated using different methods (quantitative and qualitative, interview and focus group discussions), multiple researchers used in transcribing and coding interviews, revisiting participants and setting up a feedback loop. These were blended or married with the findings from opinions and methods, and conclusions drawn.

### *3.5.2.3 Data interpretation*

Data analysis and interpretation occurred simultaneously once quantitative and qualitative data collection was completed. Ulin, Tobbinson, & Tolley, (2005) describe data interpretation as “the act of identifying and explaining the data’s core meaning”. As recommended by Onwuegbuzie & Teddlie, (2003), the study followed the standard method of data interpretation linking quantitative and qualitative data that involved data reduction, display and transformation, correlation, comparison, intertwining, and integration (**Figure 5**).

**Figure 5: Data interpretation process**



Adapted from Jimmy-Gama, 2009

### 3.6 ROLE OF THE RESEARCHER

The role of the researcher is often limited in a traditional research. In quantitative study, the relation between researcher and participants is unequivocal and predetermined. It is guided by a positivistic paradigm and views the researcher as value free and a neutral observer, whereas in the qualitative paradigm, the researcher fosters a relationship with participants and encourages their contribution (Karnieli-miller, Strier, & Pessach, 2009).

However, the role of researcher and his team was instrumental in this research process since the study was of an emancipatory nature that contributed to the empowerment of participants transferring knowledge and power and carried an interpretive paradigm. The researcher and his team were involved intensively in the field having sustained contact with study participants and this introduced number of strategic, ethical and personal issues in research process.

### **3.6.1 Positionality**

Positionality reflects the position adopted by a researcher in relation to the subject, participants, context and the process. It is described as the researcher's identity and power relation with participants in a particular situation (Dwyer, 2009; Sultana, 2007). The literature suggests social researchers recognize their own position in order to explore research issues and its phenomena with no or little interruption and maintain neutrality. Aspects of identity such as gender, class, caste, language and social hierarchy; the researcher's long-term presence in the study area may influence interaction between 'researcher and researched' (Hopkins, 2007; Sanjari, Bahramnezhad, Fomani, Sho, & Cheraghi, 2014).

In this study, considerable effort was placed in balancing the power relationship between the researcher and the researched. It was essential to pay attention to the positionality of the researcher as insider - outsider at different stages and on occasions. Since the research population was heterogeneous, the position of researcher was as an insider in some groups due to the researcher having the same language, culture and social system, allowing the researcher to have a different type of insight compared to other researchers. Where the researcher was an outsider, because of the language, education, ethnicity, caste and culture differences between researcher and participants, it took quite some time to be engaged with some participants. However, as the research team was comprised of experienced female development professionals from the same district and had worked in maternal health care for a long time in the same area; the relationship minimizing the power hierarchy. Moreover, the researcher and the research team were fully oriented and were very mindful and cautious of the fact that both roles that may lead to preconceptions, assumptions and ethical dilemmas. However, recognizing and working with multiple positionalities needed constant negotiations at different stages of the research process in order to promote trusting relationships between the researcher and participants.

### **3.6.2 Reflexivity**

Reflexivity is an important aspect of the research process that mitigates a researcher's individual values, beliefs, culture and interests influencing research. Reflexivity involves self-reflection of a study process and seriously examines the power relationships between researchers and the researched; researcher's accountability; and ethical issues in data collection, analysis and interpretation (Sultana, 2007)

The researcher's awareness, experiences and procedural discipline helped the researcher to be cautious in the research process and to reduce biases in collecting data, analysis and interpretation. In addition, it was mitigated by ensuring all steps were objective and transparent, by regular review, by recruiting co-researchers of different gender and ethnicity, and by regular open reflection with a peer group of social science researchers within Nepal.

### **3.7 CONSTRAINTS, LIMITATION AND BIASES**

#### **3.7.1 Constraints and Limitations of Study**

The study had several constraints and limitations. This research was a part of a Safe Motherhood Project in Nepal; therefore, the study population was limited to the project district. Secondly, having a very specific 'hard to reach' population for the study with narrow inclusion criteria (i.e. Dalit and women with disability having had at least one pregnancy in the past 5 years), was limiting as the small sample size led the study to understand the depth of the issues rather than wider generalization of the findings. Furthermore, the small sample size has had implications for quantitative data analysis too, in that it forced the researcher to employ a logical collapse of the variables where possible to measure associations with other variables or outcomes. In several circumstances the tests for association was calculated with a small figure, which may have implications for accuracy.

Given the large number of comparisons made in the quantitative section, significant associations close to the 0.05 level should be interpreted with caution (as 1 in 20 tests may have a p-value below 0.05 purely due to chance). Consistent relationships were seen between disability status and maternal health care outcomes, suggesting that at least for disability status findings are robust.

Language and communication barriers were another prominent constraint in the study that was overcome by recruiting local research assistants and also using a questionnaire translated into the local languages (Nepali and Bhojpuri). The study could however not explore the experiences of women with all types of disability and all categories of Dalit caste groups.

#### **3.7.2 Biases**

Reality could be distorted by bias (Degu & Yigzaw, 2006). It is inevitable in qualitative research to have some degree of biases and the study might also have some biases since it adopts both quantitative and qualitative approach of inquiry. Nevertheless, careful design, implementation and



interpretation of collected data minimize the possible biases and maximize the validity and trustworthiness of the findings.

In this study, the probable biases in tools and instruments such as culturally inappropriate and leading questions found by pre-testing the tools were removed. Sample size and participants were clearly defined with inclusion and exclusion criteria to reduce selection bias. Most importantly, the research team was comprised of both male and female researchers from different caste groups that included Dalit, Madhesi, Janajati, Brahmin and Chhetri, who worked together in the field to minimize the personal/researcher bias and hierarchal influence while collecting data. Moreover, the bias in data collection and interpretation were handled through checking and rechecking the validity of information. In order to minimize response bias, the researcher/moderator created a comfortable and private environment for participants, explaining the questions carefully.

### **3.8 SUMMARY**

This study employed a mixed method design in order to explore and describe maternal health care access and utilization of services among disabled and Dalit women. A multi-stage random sampling method and purposive sampling method was used for participant selection for quantitative and qualitative data generation. Survey interviews, qualitative interviews and focus group discussions were conducted using structured, semi-structured questionnaires and topic guides to collect data. Data collection tools were field-tested and practiced several times before use. Careful consideration was given to validity and reliability while developing the tools, in measurements, data collection, analysis and interpretation. Quantitative and qualitative data collection was done simultaneously and followed a convergent analysis method mixing data during interpretation. Qualitative data analysis followed a grounded theory approach. Triangulation and complementation increased validity; however, it is acknowledged that the study might have been influenced by certain biases and limitation.

The study will now turns to examine the status of maternal health care service access and utilization by different groups. It will first present an overview of Nepal's status on key health indicators, health care delivery system, health resources and its distribution. This is followed by the assessment of service utilization by disabled, Dalits and non-Dalit women and the factors affecting for their service utilization.

## CHAPTER FOUR: OVERVIEW OF NEPAL'S HEALTH CARE SERVICE

### 4.1 CHAPTER OVERVIEW

This chapter presents Nepal's health policy environment, trends, status of key health indicators over the past two decades and existing health delivery structure, system and resources. The chapter also discusses the emergence of primary health care in Nepal during different planning periods and the status of the maternal and disability health care programme. Finally, a review of the emergence of maternal health care issues and the development of Safe Motherhood programme in Nepal over different periods and its current status is discussed.

### 4.2 OVERALL POLICY ENVIRONMENT

Modern health care services started 120 years ago in Nepal (Dixit, 1995; GoN, 2008).

However, the growth and development of the health service was slow before the start of the first five-year plan (1956 – 1961). During the period of the first plan, the emphasis was on expansion of curative health services with the establishment of some hospitals, a few dispensaries and *Ayurvedic Aushadhalaya* (clinics). In addition, some training programmes and malaria eradication projects were initiated (Dixit, 1995). In the 1960s, during the second five-year plan (1962 – 1965), many vertical projects such as Tuberculosis (TB) and Leprosy control programmes, Smallpox and Family Planning, and Maternal Child Health projects were implemented separately with no link to each other. By the fourth plan period (1970 – 75), Nepal saw progress in health indicators with increased life expectancy rising from 33 in 1962 to 42.3 years in 1975 when IMR also stood at 157/1000 live births (Dixit, 1995).

Nepal's first Long Term Health Plan (1975 – 1990) was formulated covering three (fifth, sixth and seventh) five year periods and focused on integrated community health development through primary health care. Nepal's participation in the Alma Ata conference in 1978 and its commitment to "Health for all" by 2000 emphasised its focus on the provision of comprehensive basic (primary) health services to rural people at community level, integrating vertical services.

Following the International Year for Disabled People (IYDP) 1981, the government of Nepal introduced the Disabled Protection and Welfare Act 1982. Then the seventh five-year plan (1985 – 1990) included a few programmes focusing to disability. These included a prevention of blindness project, a disabled rehabilitation programme and a survey and treatment programme on deafness. During the UN Decade for the disabled (1982-1993), some initiatives for people with disabilities,

including community based rehabilitation programs, were initiated and implemented in eight districts of Nepal (Dixit, 1995). However, none of the health policies and plans carried an emphasis on addressing disabled people's health needs.

The Government of Nepal formulated its first Health Policy in 1991 that created health service structures up to the village development committee (VDC) level. The policy introduced the concept of central, regional, zonal and district hospitals as secondary and tertiary care centres. It also arranged the delivery of primary health care through the provision of primary health care centres – each with three beds and a doctor in all 205 electoral constituencies; health posts for 25,000 populations covering 3 - 4 VDCs as an *Ilaka* (constituency), and a sub-health post in all 3,900 VDCs with 3 – 4 paramedics. Moreover, it aimed to recruit over 75,000 village health workers and volunteers to provide outreach health programmes across the country (Dixit, 1995; HMGN/MoHP, 1991).

In the late 1990s, the government introduced a market led corporatization of health care policy that encouraged a liberal policy on privatization in health care as in other public enterprises. However, due to the lack of political consensus and the contradictory views of political actors at the national level and also the poor performance of privatized enterprises in Nepal, the thrust of privatization was delayed (Adhikari & Adhikari, 2000). Nevertheless, external development partners and international financial institutions such as the World Bank, the IMF and the Asian Development Bank (ADB) continued pressing the government for the adoption and implementation of a privatization policy in health care as a remedy for health care improvement in Nepal (Paudel, 2006).

Nepal's health policy has been heavily influenced by external organizations such as the International Monetary Fund (IMF), the World Bank and the WTO. They forced Nepal to adopt their globalization and privatization policies in health care services. Nepal's donor dependency in health sector expenditure has increased massively in recent years; it doubled between 1994/1995 and 2007/2008 increasing from 27.6% to 50% (The World Bank, DFID & ADB, 2006; Schmidt, 2009).

In 1997, the Ministry of Health and Population (MoHP) developed the second Long Term Health Plan (1997 – 2017) that aimed to address gender issues through reducing disparities and making quality health care services equitable. This plan attempted to incorporate Nepal's commitments to the ICPD, 1994 and the Beijing Convention, 1995.

The tenth five-year health plan covering the period 2002 – 2007, focused on policy objectives to establish a decentralized health system encouraging people’s participation. Following the peace negotiation in 2006, after the end of a decade long conflict in the country, the three year interim plan 2007/2008 – 2009/2010 was developed that emphasized the rights of citizens in health care with the provision of free basic primary health care services (GoN/MoHP/DoHS, 2010, 2012; GoN/NPC, 2007).

Along with those policies and plans, the government of Nepal instigated two important steps in the health sector, starting with the implementation of the National Safe Motherhood Program (NSMP) in 1997, and the National Health Sector Program Implementation Plan (NHSP – IP) in 2004 to improve the health outcomes of women. These two programmes particularly focused on reducing inequalities in access to and utilization of health care services between caste and ethnic groups, as well as poor and rich. The NSMP was initiated with the goal of reducing the maternal mortality rate to 300/100 000 by 2009, which was at 539/100 000 live births, the highest in South Asia at that time (HMGN/MoHP, 2004; MoHP/NewEra/OrgMacro, 1997). The aim of NHSP – IP (2004 – 2009) was to make available equitable, high quality health care services in line with the Poverty Reduction Strategy Paper (PRSP) 2002 and MDG 2000 which was targeted to reduce maternal mortality ratio to 134/100,000 by 2015 from 430/100,000 in 2000 (WHO, 2014). With the significant progress of NHSP IP 2004 – 2009 demonstrated by improvement of equity of access, the Government of Nepal (GoN) developed NHSP – IP II (2010 – 2015) with the objectives of increasing utilization, reducing cultural and economic barriers and achieving universal coverage of essential health services (GoN/MoHP, 2010; HMGN/DoHS/FHD, 2002; HMGN/MoHP, 2004).

In addition, as stated in the “The Interim Constitution of Nepal 2007”, the GoN recognized basic health care services as the fundamental right of every citizen, and they subsequently introduced a free health care provision and an essential service package in 2008. Under this scheme, 22 essential drugs for sub-health posts and 32 essential drugs for health posts, PHCCs and district hospitals were made free throughout the country covering delivery and maternity care services.

The Nepal Health Sector Program (NHSP) 2004 – 2009 was underpinned by the “Health Sector Strategy; An Agenda for Reform”. The Health Sector Reform programme identified six key areas for reform. They are: (a) ensure universal access to essential health care services using cost effective interventions; (b) establishment of public-private, NGO partnerships to deliver quality health care services to people; (c) decentralization of health system for fair and efficient delivery;

(d) obtain better value for health expenditure through pre-paid alternative health financing mechanisms; (e) provide access to services outside of health care facilities; and (f) monitoring of health sector performance through logical frameworks (HMGN/MoHP, 2004).

The NHSP II 2010 – 2015 was the second sector program that aimed specifically to improve the health and nutritional status of poor and excluded people. This was principally an extension of the first program; however, it laid the emphasis on partnerships and decentralized service delivery, strengthening local governance and increasing equitable access to essential health care services (GoN/MoHP, 2010).

In sum, over the last 20 years, the GoN has made considerable efforts to provide accessible health services to all people across Nepal. The recent health policy and strategy of Nepal supports the delivery of essential health care services to the people with equitable allocation of resources, increased partnership and people's engagement through empowerment and inclusion of poor and disadvantaged segment of population (Devkota, 2008). This emphasises improvement in utilization of basic health care services and quality of care particularly in remote and underserved area.

#### **4.3 NEPAL'S STATUS OF KEY HEALTH INDICATORS**

Over the past two decades, despite intense political changes and instability, Nepal has made good progress on improving the overall health outcomes of its people. Population and Demographic Health Survey (DHS) data shows that the overall progress in key health indicators such as life expectancy, child mortality and maternal mortality are encouraging (MoHP/NewEra/ICF International Inc, 2012; MoHP/NewEra/OrgMacro, 1997, 2007).

**Table 5** below compares the basic key health indicators between 1990 and 2013. As shown in the table, life expectancy increased by 13 years, from 55 in 1990 to 68 in 2013. The proportion of underweight children decreased by half (29% in 2013 from 57% in 1990) within this period. Similarly, infant mortality and the under-five mortality rate per 1000 live births was reduced from 94 to 32 and 135 to 40 respectively. Measles immunization coverage was 88% among children aged 12 – 23 months in 2010. However, this remained stagnant in 2013 (GoN/MoHP/DoHS, 2013; MoHP/NewEra/ICF International Inc, 2012; MoHP/NewEra/OrgMacro, 1997).

Nepal Demographic Health Surveys and MoHP/DoHS Annual Reports suggest substantial increases in health service utilization over the past two decades. For example, ANC 4<sup>th</sup> visit increased to 50% in 2011, up from 14% in 2000. Moreover, institutional delivery and PNC visits within 2 days of

childbirth increased to 35.3% and 45% respectively, which is about four fold higher than that of 1996. The total fertility rate has gone down from 5.3 in 1990 to 2.6 in 2011 and contraceptive prevalence rate (CPR) doubled in the same period. However, CPR has gone down by more than 5% between 2010 - 2013 (MoHP/NewEra/ICF International Inc, 2012; MoHP/NewEra/OrgMacro, 1997). With regard to basic sanitation facilities and access to safe drinking water, the indicators show slow progress. The data in the table below suggests that the proportion of population with access to sanitation facilities and safe drinking water increased by 56% and 39% respectively between 1990 and 2013.

**Table 5: Key health indicators and its trend between 1990 and 2013**

Indicators	1990	2000	2005	2010	2013	MDG Target
Life expectancy (in Years)	55.1	60.4	63	64.1	68	NA
Male	55	60.1	63	63.6	67	NA
Female	53.5	60.7	64	64.5	69	NA
Prevalence of underweight children aged 6 – 59 months (%)	57	53	43	38.6	28.8	29
Infant mortality rate (per 1000)	108	64	48	46	32	36
Under 5 mortality rate (per 1000)	162	91	61	54	40	54
Proportion of 1-year-old children immunized against measles (%)	42	71	85	88	88.2	>90
Total fertility rate	5.3	4.1	3.1	2.6	NA	2.3
Contraceptive prevalence rate (%)	24	35.4	44.2	49.7	44	67
At least one ANC check-up (%)	15	48.5	73.7	89.9	85	100
Four or more ANC check-up (%)	NA	14	29.4	50.2	50.1	80
Delivery attended by SBA (%)	7	11	19	36	50	60
Health facility delivery (%)	6	9	18	35	50	NA
PNC for mother within 2 days (%)	NA	17.1	33	45	NA	NA
Maternal mortality ratio	850	430	281	229	170	213
Access to clean drinking water (%)	46	73	81	80.4	85	73
Access to improved sanitation (%)	6	30	39	43	62	80

Source: (GoN/MoHP/DoHS, 2013; GoN/NPC, 2013; MoHP/NewEra/ICF International Inc, 2012; MoHP/NewEra/OrgMacro, 1997, 2007; WHO, 2014)

As the **Table 5** shows a number of indicators, for example contraceptive prevalence rate and percentage of women visiting ANC, seem stagnant, and are even worsening. Moreover, despite the policy efforts outlined above to redress them, significant equity gaps in health care service and health outcomes persist. A wide range of variations in health service distribution, utilization and health status across different socio-economic and geographical population groups have been

observed. For example, Nepal DHS (2011) data shows under-five mortality rate of 75/1000 for the poorest wealth groups while it was reported as 36/1000 for the wealthiest groups. Similarly, an infant mortality rate of 69 and 65/1000 among the minority and marginalized groups of Muslims and Dalit respectively was reported in comparison to 45 for privileged groups such as Brahmin/Chhetri. The surveys also reported better health indicators for urban populations than rural residents (MoHP/NewEra/ICF International Inc, 2012).

The following section describes the health care delivery system, its development at different plan periods and the current structures that deliver the services at community to national level.

#### **4.4 HEALTH CARE DELIVERY SYSTEM IN NEPAL**

Nepal's health care service is largely delivered by government. The private sector contributes a small portion concentrating to curative services to the urban population. As reported by MoHP/DoHS, about 70% of the people in Nepal utilized public health services in 2013/2014. About 9% of the people received services from higher level health facilities such as hospitals and primary health care centres, whereas 91% received services from health posts and sub-health posts (GoN/MoHP/DoHS, 2014).

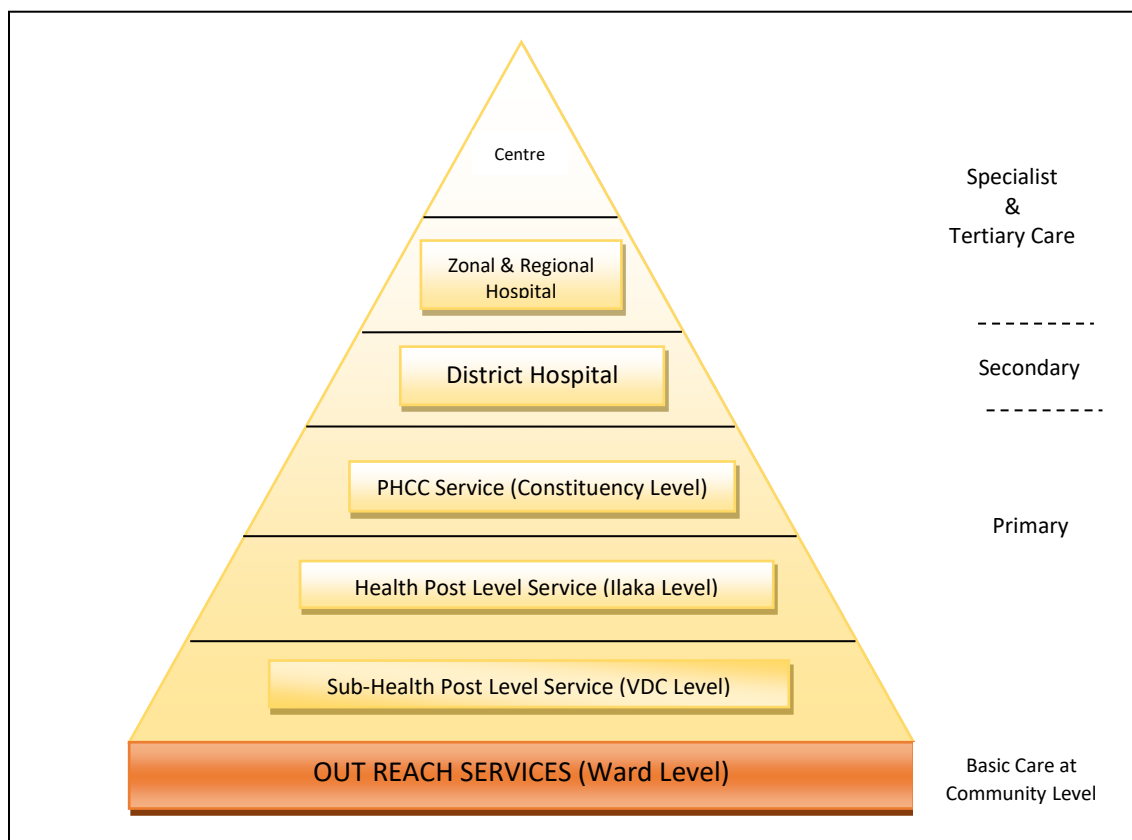
The health system is the combination of resources, organization, financing and administration that ends in health services offered to the public (Roemer, 1991); and according to the WHO, a health system consists of all the activities whose primary purpose is to promote, restore or maintain the health of the people (WHO, 2007).

Nepal's health system often faces challenges due to financial resource constraints, scarcity of trained human resources and poor and inefficient management of available resources (Onta et al., 2014). Despite these limitations, the annual reports released by Ministry of Health and Population state that the system and facilities have been developed and expanded gradually over time (GoN/MoHP/DoHS, 2010, 2012, 2013, 2014).

As outlined in the policies above, the GoN adopts a decentralized health care delivery model (GoN/MoHP, 2004) providing services at four different levels: community level health facilities; Sub-health Posts, Health Posts and Primary Health Care Centres (PHCC), which primarily focus on delivery of basic primary healthcare through preventive, promotive and curative services. This structure can best be illustrated as a triangle (**Figure 6**). At the bottom are the 51,470 Female Community Health Volunteers (FCHV) at the community level who work together as the key in the front line for maternal and child health. These are followed by PHCC, health post and sub-health

post, staffed by nurses and Auxiliary Nurse Midwives (ANM). The Sub-health Posts (2,247) and Health Posts (1,559) are distributed in each Village Development Committee (VDC), followed by 208 PHCC at the electoral constituency level, which are headed by an Auxiliary Health Worker (AHW), Health Assistant (HA) and Medical Officer (MO) respectively, and offer basic services at community level (GoN/MoHP/DoHS, 2014).

**Figure 6: Health Care Delivery Model in Nepal**



Source: National Health Policy 1991

At the district level, 78 hospitals (at least one per district) provide secondary level care including basic emergency obstetric care (BEOC) and comprehensive emergency obstetric care (CEOC). Normally, a senior medical officer leads the district level hospital. The Zonal, Regional and Central level Hospitals provide tertiary level specialist care.

As directed by the second long term health plan (1997 – 2017) and the policy for decentralization, MoHP started health sector decentralization in 2001/2002, making peripheral health facilities autonomous. The MoHP started handing over of management of local health facilities to management committees in 2002, under the self-governance Act (LGSA) 1997. In 2002/2003, the MOHP handed over 1,433 health facilities to local health

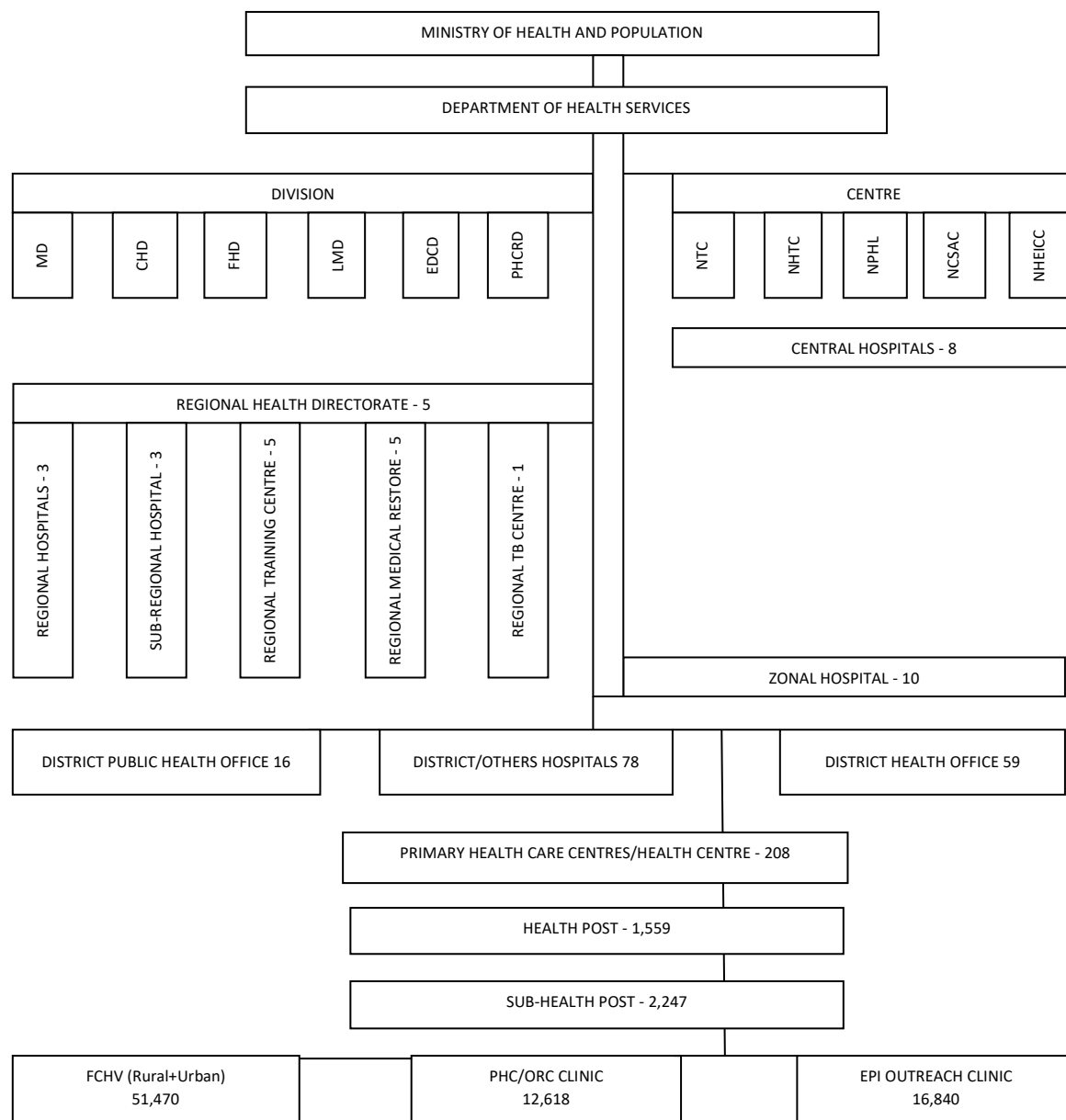


facility management committees (USAID, 2003). However, the structure and governance remained poor and unchanged due to the changing political context and in the absence of local elected bodies subsequently.

Responsibility for the provision of health care service delivery and its management lies with Ministry of Health through the Department of Health Services (DoHS). MoHP administers services through Regional Directorates and District Offices. Principally, health management boards and committees at different levels are responsible for the management of health facilities. However, coordination and monitoring of disability related services including health care lies with National Disability Coordination Committee under Ministry of Women, Children and Social Welfare at central and district level. Due to the capacity as well as technical constraints, the role of this committee providing policy inputs and monitoring of disability related services has not found effective at both national and district level. Moreover, the existing Health Management Information System (HMIS) under DoHS/MoHP do not collect and analyse disability related data. Because of data was not collected on this topic, health service delivery and utilization status by disabled women in Nepal is largely unknown.

The following diagram (**Figure 7**) shows the current health system structure of the Department of Health service and the distribution of health facilities (GoN/MoHP/DoHS, 2014).

**Figure 7: Organogram of Department of Health Services (DoHS)**



Source: DoHS, Annual Report 2070/71 (2013/2014)

#### **4.5 HEALTH CARE STRUCTURE AND HUMAN RESOURCES**

While distributed at different levels of health facilities (national, regional, zonal, districts and community level), the actual distribution of health facilities and the health care work force are inequitable – for example, in the 20 year period between 1991 and 2010, the number of health facilities increased more than fivefold in primary care, secondary level and above. But the overall increase was focused in the private sector; and in secondary and tertiary care facilities in urban and cities. The increase of government health facilities were more focused to lower level facilities,

mainly in rural areas. Private sector health facilities providing specialist services increased more than ten-fold, almost all concentrated in urban cities whereas the increase of government's specialist health facilities remained at 24% in the same period.

Table 6 shows the distribution of health facilities in 1991 and 2010 and hospital beds in 2010.

**Table 6: Hospitals and Beds**

Health Facility	1991	2010	2010
	Number	Number	Available beds
Public Hospitals	77	95	7,637
Private Hospitals	11	105	4,621
Medical Colleges	1	20	10,576
Mission Hospitals	8	8	612
Primary Health Care Centres (PHCC)	-	214	642
Health Posts/Sub-Health Posts	834	3,806	-
<b>Total</b>	<b>931</b>	<b>4,248</b>	<b>24,088</b>

Source: Annual Report, Department of Health Service (GoN/MoHP/DoHS, 2010)

In 2010, the hospital to population ratio was reported at 0.4 hospitals per 100,000 populations while this ratio was 0.2/100,000 in Bangladesh and 0.6/100,000 in Pakistan. Similarly, hospital bed to population ratio between 2005 and 2012 in Nepal was reported at 50 beds per 10,000 populations whereas this was reported 6/10,000 in Bangladesh and 9/10,000 in India in the same period (WHO, 2013)

In countries like Nepal, community health workers and volunteers are also very important human resources for health. These volunteers are the backbone for the delivery of basic health care services at the community level, as demonstrated in the MoHP commitment to community level healthcare in its policies and approaches.

However, while the population has increased by more than 30% since 1991, the number of healthcare workers in the public sector has only increased by 3.4% despite health service delivery in Nepal being largely led by the public sector (Sherchand, 2013). Moreover, despite the increased number of medical institutions and production of human resources for health, the healthcare worker population ratio is still very low. The DHS (2011) shows the number of physicians and nurses (including midwives) to be at 0.17 and 0.51 per 1000 population respectively - which is far

below the global average and that recommended by WHO<sup>1</sup> (MoHP/NewEra/ICF International Inc, 2012; WHO, 2006a).

Table 7 shows the status of key healthcare staff working in public health facilities in 2010. Overall, more than 11% of health care positions are vacant throughout Nepal. Also of note is the high proportion of vacancies for medical doctors (23%) followed by paramedics (13%) and nursing staff (11%), whereas the rate of vacancies for junior and support health staff is comparatively low, at about 7%.

**Table 7: Human resources under MoHP in Nepal 2010**

Position	Sanctioned	Filled	Vacant	Vacant %
Medical doctor	1,062	816	246	23.16
Nursing staff (including ANM)	5,935	5307	628	10.58
Paramedics	10,642	9,212	1,430	13.44
Other	6,838	6,394	444	6.49
<b>Total</b>	<b>24,477</b>	<b>21,729</b>	<b>2,748</b>	<b>11.23</b>

Source: Annual Report, Department of Health Service (GoN/MoHP/DoHS, 2010)

Nepal produces 1,074 doctors annually; however, only 600 find employment with the government. A small number of others are absorbed by the private sector; some are unemployed or migrate to developed countries. There are no records or accurate data about Nepali health worker migration patterns; however, it is estimated that 500 – 700 medical trained doctors have migrated to other countries in the last decade (Dixit & Marahatta, 2008). Another study shows that more than half of all medical professionals in Nepal planned to go abroad for work (Lakhey, Lakhey, Niraula, Jha, & Pant, 2009).

Similarly, the data shows the annual production of Staff Nurses and Auxiliary Nurse Midwives (ANM) as 1,451 and 1,133 respectively, but very few of them find employment in Nepal. In addition, most health workers do not show interest in working outside of cities due to insecurity, less income opportunities and harder living conditions (Gupta et al., 2013). Despite the increased production of human resources in health in recent years, there is a gap in the supply side of the health system in Nepal.

<sup>1</sup> The World Health Report (2006) pointed out the need for a minimum of 2 – 3 health workers per 1,000 populations to meet health related MDGs.

#### **4.6 SUMMARY**

Nepal has experienced remarkable improvements in health indicators over the past two decades. As a signatory of several health and population-related conventions as discussed above, Nepal has committed to improving the health of its people with a particular focus on the most excluded and marginalized populations, applying the primary health care approach (Dixit, 1995; United Nations, 1995). The approach is espoused in key national health policies, strategies and plans. For example: The Second Long Term Health Plan 1997 – 2017, Health Policy 1991, Health Sector Strategy 2004, Nepal Health Sector Program Implementation Plan (NHSP IP) 2004 – 2009 and NHSP IP II 2010 – 2015. However, due to donor dependency in health sector expenditures, external organizations (donors) such as the IMF, the World Bank and the WTO have influenced Nepal's health policy heavily (The World Bank, DFID & ADB, 2006; Schmidt, 2009).

The government's continued commitment twenty years on from the introduction of National Health Policy in 1991, has led to improved health in Nepal. Those improvements were observed particularly in the reduction of child and maternal mortality and the increased life expectancy of Nepalese people. The majority of health-related MDGs were already achieved by 2013 (GoN/NPC & UNDP, 2013).

As has been outlined above, the government has introduced free health care services in all facilities below district level. Moreover, at the current critical juncture of changed political contexts and the country entering into the federal system, Nepal's health care policy seems to be at a crossroads between a state-led and state-facilitated model of health care delivery. Critical challenges and failures in regulation faced by the government have resulted in overproduction of medical doctors and nurses in one hand and poor utilization and distribution of their skilled resource on the other. Health facilities in rural and remote areas always face challenges of under staffing.

In conclusion, access to and utilization of health care services in Nepal has increased gradually. It has impacted on people's lives and this has been reflected in the improvement of health indicators, particularly the decrease in maternal mortality and child mortality. However, the improvement has been inequitable among different groups and geographical regions. Policies and plans have been trying to address the maternal health needs of Nepalese women in general, but none of the policies and plans specifically address the issues of marginalized women with special needs such as women with disabilities. There is a need to better understand the determinants of

maternal health disparities in order to improve access to health care services for disadvantaged groups.

The following chapter will examine the maternal health care access and utilization status among Dalit and non-Dalit women with and without disabilities by comparing the service uptakes (ANC, health facility delivery and PNC) among those groups. The chapter will also identify factors associated with service utilization and discuss how accessible these services are for disabled women and Dalits. The accessibility of services are assessed on widely accepted five dimensions of access, they are - accessibility, availability, affordability, acceptability and accommodation.

# **CHAPTER FIVE: MATERNAL HEALTH CARE SERVICE ACCESS AND UTILIZATION AMONG DALITS AND NON-DALITS WITH AND WITHOUT DISABILITIES**

## **5.1 CHAPTER OVERVIEW**

This chapter uses fieldwork data to assess and discuss maternal health care service access and utilization among four distinct groups of women in Nepal – women with disabilities and without disabilities, Dalit women and non-Dalit women - to identify what, if any, association there is with socio-economic and demographic factors influencing their utilization of maternal health services.

The study used both descriptive and inferential statistics where possible. The analysis and the results in this chapter is divided in four sections aimed at assessing whether disabled and Dalit Nepalese women experience maternal health care services differently from non-disabled and non-Dalit. The first section presents findings of a survey conducted among women 15 – 49 years, focusing on the utilization of all three maternal health care services; ANC, Delivery and PNC for disabled, non-disabled, Dalits and non-Dalits women during their last pregnancy and childbirth. Data includes comparative demographic and socio-economic characteristics of the survey participants and maternal health care service utilization amongst the four different groups.

The second section then goes on to analyse the association between each independent variables and outcome variables and identify factors influencing service utilization. The third section examines how accessible maternal health care services are for these groups. The results include an analysis of data gathered from semi-structured interviews with women between 15 – 49; key informant interviews and in-depth interviews of purposively selected participants. Finally, the chapter ends discussing on the key findings of the results from those sections.

## **5.2 RESULTS**

### **5.2.1 MATERNAL HEALTH CARE SERVICE UTILIZATION AMONG DISABLED, DALIT AND NON-DALIT WOMEN**

#### *5.2.1.1 Demographic and Socio-economic Characteristics of survey participants*

Table 8 shows selected characteristics of survey respondents. A total of 354 women aged between 15 – 49 years were included in the survey. Of the total, almost 43% were Dalits, more than one out of five were disabled women and one in twenty were disabled-Dalit women. Approximately half of the respondents (49%) were in the 25 – 34 age groups, 38% were 15 – 24 years old and the

remaining small percent were between 35 – 49 years of age. More than 90% of non-disabled Dalits and Non Dalits reported their age between 15 – 34. In comparison, more than 82% of disabled women reported were between 25 – 49 years, indicating that disabled women in general give birth at older ages than non-disabled women.

All disabled Dalits and non-disabled Dalits reported being married and living with their spouse, whereas one in ten disabled non-Dalit women were unmarried, widow or separated. Four out of five Dalits married at the age of 18 or below, compared to two out of three non-Dalits and just over half of the disabled Dalit and non-Dalit respondents. However, approximately three out of four disabled women reported having more than one child, compared to over half of Dalits and less than one-third of non-Dalits.

More than 80% of the total respondents lived in rural areas, with a higher proportion of disabled (91.1%), compared to non-disabled Dalit (76.7%) and non-disabled non-Dalit (77.5%), residing in rural areas. However, none of the disabled-Dalit participants lived in urban areas (p-value=0.430). The education status of the respondents was that roughly one-third of the total number of respondents were illiterate, and the same proportion had primary and secondary education or above. There was a higher degree of illiteracy among disabled women (40.5%), with the highest among disabled-Dalits (55.6%), compared to 36.1% among disabled non-Dalit. The illiteracy percentage was 31.6% and 29.6% for non-disabled Dalit and non-disabled non-Dalit women respectively. The average employment rate was 15.8% overall for all women, with the lowest rate of employment (12%) among Dalits and nearly equal among disabled and non-disabled women. The group differences in some variables, specifically education, marital status, age at marriage and parity are statistically significant (P<0.05) (Table 8).

**Table 8: Distribution of respondents (15 – 49 years women) by selected characteristics**

Individual Background Characteristics	Disabled Dalit	Disabled non-Dalit	Non-disabled Dalit	Non-disabled non- Dalit	Total	P-Value
<b>Place of Residence</b>	n = 18 (5.1%)	n = 61 (17.2%)	n = 133 (37.6%)	n = 142 (40.1%)	n = 354 (100%)	P=0.430
Rural	18 (100%)	54 (88.5%)	102 (76.7%)	110 (77.5%)	284 (80.2%)	
Urban	0 (0%)	7 (11.5%)	31 (23.3%)	32 (22.5%)	70 (19.8%)	



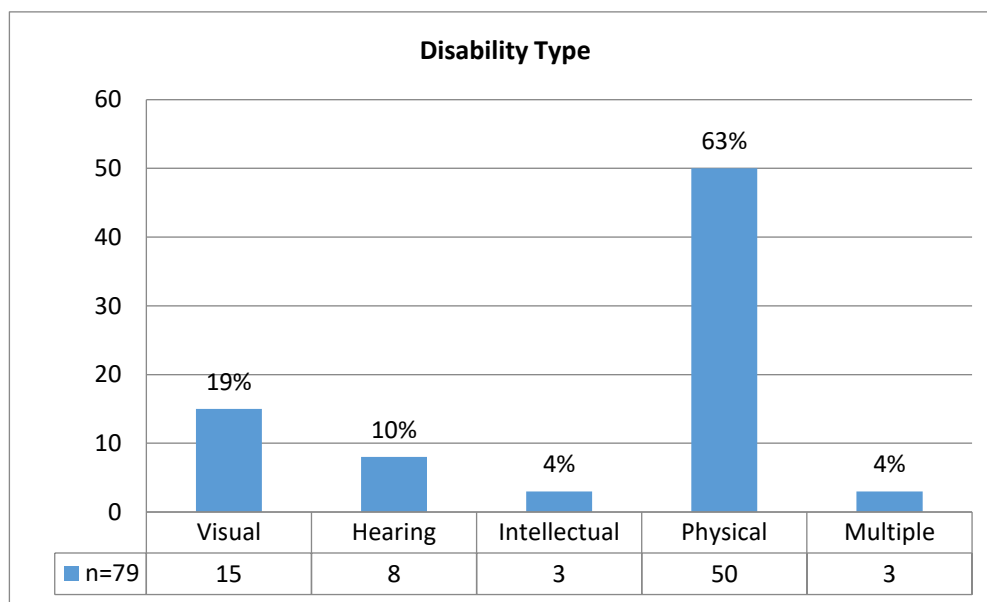
Individual Background Characteristics	Disabled Dalit	Disabled non-Dalit	Non-disabled Dalit	Non-disabled non- Dalit	Total	P-Value
<b>Respondent's Age</b>	n = 18 (5.1%)	n = 61 (17.2%)	n = 133 (37.6%)	n = 142 (40.1%)	n = 354 (100%)	
15 – 24 Years	4 (22.2%)	10 (16.4%)	60 (45.1%)	60 (42.3%)	134 (37.9%)	P=0.317
25 – 34 Years	8 (44.4%)	29 (47.5%)	60 (45.1%)	75 (52.8%)	172 (48.6%)	
35 – 49 Years	6 (33.3%)	22 (36.1%)	13 (9.8%)	7 (4.9%)	48 (13.6%)	
<b>Education</b>	n = 18 (5.1%)	n = 61 (17.2%)	n = 133 (37.6%)	n = 142 (40.1%)	n = 354 (100%)	
Illiterate	10 (55.6%)	22 (36.1%)	42 (31.6%)	42 (29.6%)	116 (32.8%)	P=0.002
Literate/Primary Education (up to 5 Class)	3 (16.7%)	16 (26.2%)	59 (44.4%)	39 (27.5%)	117 (33.1%)	
Secondary Education (6 class & above)	5 (27.8%)	23 (37.7%)	32 (24.1%)	61 (43%)	121 (34.2%)	
<b>Occupation</b>	n = 18 (5.1%)	n = 61 (17.2%)	n = 133 (37.6%)	n = 142 (40.1%)	n = 354 (100%)	
Unemployed/Farmer	15 (83.3%)	50 (82%)	117 (88%)	116 (81.7%)	298 (84.2%)	P=0.150
Employed (Service/ Business)	3 (16.7%)	11 (18%)	16 (12%)	26 (18.3%)	56 (15.8%)	
<b>Marital Status</b>	n = 18 (5.1%)	n = 61 (17.2%)	n = 133 (37.6%)	n = 142 (40.1%)	n = 354 (100%)	
Married	18 (100%)	55 (90.2%)	133 (100%)	142 (100%)	348 (98.3%)	P=0.034
Single (Unmarried/ Widowed/ Separated)	0 (0%)	6 (9.8%)	0 (0%)	0 (0%)	6 (1.7%)	
<b>Age at Marriage</b>	n = 18 (5.1%)	n = 59 (16.8%)	n = 133 (37.8%)	n = 142 (40.3%)	n = 352 (100%)	
5 – 18 Years	10 (55.6%)	30 (50.8%)	104 (78.2%)	92 (64.8%)	236 (67%)	P=0.002
19 – 40 Years	8 (44.4%)	29 (49.2%)	29 (21.8%)	50 (35.2%)	116 (33%)	
<b>Parity</b>	n = 18 (5.1%)	n = 61 (17.2%)	n = 133 (37.6%)	n = 142 (40.1%)	n = 354 (100%)	
Primipara	6 (33.0%)	28 (45.9%)	65 (48.9%)	99 (69.7%)	198 (55.9%)	P=0.003
Multipara	12 (66.7%)	33 (54.1%)	68 (51.1%)	43 (30.3%)	156 (44.1%)	

Pearson Chi-square test of significance

### 5.2.1.2 Distribution of disabled participants by their Impairment (disability) type

Among the 79 women with disabilities surveyed, 23% were disabled Dalits and 77% disabled non-Dalits. Of the total, 63.3% had physical impairment, whereas 19% and 10% had visual and hearing impairment respectively (as defined by UN Washington Group questionnaire). The intellectual and multiple impairments were 3.8% for each group (Figure 8).

**Figure 8: Distribution of disabled participants by type**



Over half acquired their disability after birth while about 47% were born with a disability. One out of four became disabled between the ages of 5 – 12 years; and for nearly 14% the age of onset was under five years; with a similar percentage aged 13 and above at onset.

### 5.2.1.3 Family Background Characteristics

Table 9 indicates that roughly 17% (n=352) of respondents reported their husbands as illiterate and over half (55%) reported their husbands as having secondary education or above. Two out of five disabled Dalits and one out of three disabled non-Dalit women reported their husbands as illiterate, whereas this proportion was only one in ten among non-Dalits. Compared to other three groups, a higher proportion of Dalit women (35%) reported that their husband having primary level education only, while this proportion was 27% and 23% for disabled and Non-Dalit respectively. Two-thirds of non-Dalits, half of Dalits, more than two-fifth disabled non-Dalits and one-third disabled Dalit women reported their husband with secondary education or above.

The highest proportion of disabled Dalit (38.9%) and lowest proportion of disabled non-Dalit women (33.9%) reported their husband as unemployed whereas this proportion as almost equal

(36%) among non-disabled Dalits and non-disabled non-Dalits. Over half of the interviewed women reported having mixed sources of family income, and approximately 19% said service or employment was their main source of income. None of the variables in family background were found to be statistically different for disabled, non-disabled, Dalit and non-Dalit women ( $P>0.05$ ) (Table 9).

**Table 9: Distribution of Respondents by their Family Background**

A. Family Background	Disabled Dalit	Disabled non-Dalit	Non-disabled Dalit	Non-disabled non-Dalit	Total	P-Value
<b>Husband's Education</b>	n = 18 (5.1%)	n = 59 (16.8%)	n = 133 (37.8%)	n = 142 (40.3%)	n = 352 (100%)	
Illiterate	7 (38.9%)	18 (30.5%)	19 (14.3%)	15 (10.6%)	59 (16.8%)	
Literate/Primary Education (up to 5 Class)	5 (27.8%)	16 (27.1%)	46 (34.6%)	32 (22.5%)	99 (28.1%)	P=0.090
Secondary Education (6 class & above)	6 (33.3%)	25 (42.4%)	68 (51.1%)	95 (66.9%)	194 (55.1%)	
<b>Husband's Occupation</b>	n = 18 (5.1%)	n = 59 (16.8%)	n = 133 (37.8%)	n = 142 (40.3%)	n = 352 (100%)	
Unemployed/farmer	7 (38.9%)	20 (33.9%)	49 (36.8%)	51 (35.9%)	127 (36.1%)	
Employed (Service/Small Business)	11 (61.1%)	39 (66.1%)	84 (63.2%)	91 (64.1%)	225 (63.9%)	P=0.873
<b>Main source of Family Income</b>	n = 18 (5.1%)	n = 61 (17.2%)	n = 133 (37.6%)	n = 142 (40.1%)	n = 354 (100%)	
Farming & Daily wages	7 (38.9%)	21 (34.4%)	36 (27.1%)	33 (23.2%)	97 (27.4%)	
Service/Employment (Service, small business)	2 (11.1%)	9 (14.8%)	20 (15.0%)	36 (25.4%)	67 (18.9%)	P=0.194
Others (Mixed source of income)	9 (50%)	31 (50.8%)	77 (57.9%)	73 (51.4%)	190 (53.7%)	

Pearson Chi-square test of significance

#### 5.2.1.4 Household Wealth, Level of Empowerment (Autonomy) and Knowledge & Awareness

Table 10 illustrates that two-third of disabled-Dalit, more than one-third disabled non-Dalit, about one-fourth (24.1%) of non-disabled Dalit respondents belong to low wealth ranking whereas this figure is far less (10.6%) for non-disabled non-Dalit women. In contrast, none of the disabled Dalits and only one in ten disabled non-Dalit women are in the high wealth group whereas, one in six non-disabled Dalit and one in four non-disabled non-Dalits belong to this group. Household wealth is found statistically significant among groups ( $P>0.05$ ) (Table 10).

The empowerment index shows that nearly 22% of all women reported low empowerment or autonomy. However, interestingly this low level of empowerment/autonomy is found proportionately highest among disabled Dalit women (33.3%) compared to disabled non-Dalits (24.6%), non-disabled Dalit (18.8%) and non-disabled non-Dalit women (21.8%). Fewer than 20% of all respondents had a high level of empowerment and approximately 59% had a medium level. The percentage of non-disabled Dalit respondents was higher (63.2%) in medium level empowerment/autonomy followed by disabled Dalits (61.1%). compared to non-disabled non-Dalit (54.9%) and disabled non-Dalits (57.4%). However, a higher percentage of high-level empowerment (23.2%) was observed among non-Dalit women than the other three groups. Nonetheless these differences are not statistically significant ( $P>0.05$ ) (Table 10).

Questions about pregnancy danger signs were asked to gain an understanding of the respondent's knowledge and awareness levels. Over 20% of respondents reported not having any knowledge about danger signs in pregnancy. This percentage was much higher for disabled women (27.8%). Little knowledge and awareness was found among 39% of respondents, with not much difference between disabled non-Dalits, non-disabled Dalit and non-disabled non-Dalits. This proportion was much higher among disabled Dalit women (55.6%). However, 45.9% of non-disabled Dalits, followed by 43.0% of non-disabled non-Dalits reported having enough knowledge about danger signs. This percentage is far below that for disabled Dalits and disabled non-Dalits, 16.7% and 32.8% respectively. Importantly however, all these differences in knowledge and awareness were not statistically significant ( $P>0.05$ ) (Table 10).

**Table 10: Distribution of Respondents by Household Wealth, Level of Empowerment & Awareness**

A. Index	Disabled Dalit	Disabled non-Dalit	Non-disabled Dalit	Non-disabled non- Dalit	Total	P-Value
<b>Household Wealth Index</b>	n = 18 (5.1%)	n = 61 (17.2%)	n = 133 (37.6%)	n = 142 (40.1%)	n = 354 (100%)	
Low (<40% in ranking)	12 (66.7%)	22 (36.1%)	32 (24.1%)	15 (10.6%)	81 (22.9%)	P=0.024
Middle (40 – 60% in ranking)	6 (33.3%)	31 (50.8%)	77 (57.9%)	86 (60.6%)	200 (56.5%)	
High (>60% in ranking)	0 (0%)	8 (13.1%)	24 (18.0%)	41 (28.9%)	73 (20.6%)	
<b>Women Empowerment (Autonomy) Index</b>	n = 18 (5.1%)	n = 61 (17.2%)	n = 133 (37.6%)	n = 142 (40.1%)	n = 354 (100%)	
Low	6 (33.3%)	15 (24.6%)	25 (18.8%)	31 (21.8%)	77 (21.8%)	P=0.347
Medium	11 (61.1%)	35 (57.4%)	84 (63.2%)	78 (54.9%)	208 (58.8%)	
High	1 (5.6%)	11 (18%)	24 (18.0%)	33 (23.2%)	69 (19.5%)	
<b>Knowledge &amp; Awareness on Pregnancy Danger Sign</b>	n = 18 (5.1%)	n = 61 (17.2%)	n = 133 (37.6%)	n = 142 (40.1%)	n = 354 (100%)	
No Knowledge at All	5 (27.8%)	17 (27.9%)	21 (15.8%)	28 (19.7%)	71 (20.1%)	P=0.516
Little Knowledge (Low level of Awareness)	10 (55.6%)	24 (39.3%)	51 (38.3%)	53 (37.3%)	138 (39.0%)	
Enough Knowledge (High level of Awareness)	3 (16.7%)	20 (32.8%)	61 (45.9%)	61 (43.0%)	145 (41.0%)	

Pearson Chi-square test of significance

#### 5.2.1.5 Maternal Health Care Service Utilization

Almost 94% of women attended at least one ANC visit and 78% attended the recommended four or more ANC visits in their last pregnancy. Among the four groups, non-disabled Dalit women reported the highest percentage of having one ANC check-up (97.7%) followed by non-disabled non-Dalits (95.8%). Disabled women utilized services the least (83.5%). Among the disabled as well, more Dalits (88.9%) utilized one ANC than non-Dalits (82%). However, non-Dalit women reported the higher percentage of recommended four or more ANC check-up than that of Dalits among both non-disabled and disabled groups (Table 11).

The percentage of health facility (HF) delivery and postnatal check-ups were also reported higher for non-disabled non-Dalit among the four groups. The lowest health care utilization was by

disabled women, with only approximately one in two delivering in a health facility and one in five receiving postnatal check-ups. Interestingly, the percentage of disabled Dalits using postnatal service was remarkably higher than disabled non-Dalit (27.8% vs 15.5%). The differences between groups in utilization of services are statistically significant ( $P < 0.05$ ) except in recommended ANC 4+ visits ( $P > 0.05$ ) (Table 11).

**Table 11: Maternal Health Care Service Utilization by different groups of study participants**

Outcome Variables	Disabled Dalit	Disabled non-Dalit	Non-disabled Dalit	Non-disabled non-Dalit	Total	P - Value
	n = 18	n = 61	n = 133	n = 142	n = 354	
Utilization of at least one ANC	16 (88.9%)	50 (82%)	130 (97.7%)	136 (95.8%)	322 (93.8%)	0.000
	n = 16	n = 50	n = 130	n = 136	n = 332	
Utilization of 4+ ANC	10 (62.5%)	37 (74%)	101 (77.7%)	111 (81.6%)	259 (78%)	0.136
	n = 18	n = 58	n = 132	n = 142	n = 350	
Health Facility Delivery	9 (50%)	31 (53.4%)	84 (63.6%)	105 (73.9%)	229 (65.4%)	0.008
	n = 18	n = 58	n = 132	n = 142	n = 350	
Utilization of PNC services	5 (27.8%)	9 (15.5%)	40 (30.3%)	49 (34.5%)	103 (29.4%)	0.017

Pearson Chi-square test of significance

Table 12 below shows that a significantly higher percentage of non-disabled than disabled women utilized all care services. Those proportions was 96.7% vs 83.5% for at least one ANC visits ( $P < 0.001$ ), 79.7% vs 71.2% for four and more ANC check-ups ( $P > 0.05$ ), 69% vs 52.6% for health facility delivery ( $P < 0.05$ ), and 32.5% vs 18.4% for postnatal check-up ( $P < 0.05$ ).

**Table 12: Maternal Health care services utilization among disabled and non-disabled women**

Type of Service	Disabled	Non-disabled	Total	P-Value
<b>ANC Check up</b>	n = 79 (22.3%)	n = 275 (77.7%)	n = 354 (100%)	
Yes	66 (83.5%)	266 (96.7%)	332 (93.8%)	P=0.000
No	13 (16.5%)	9 (3.3%)	22 (6.2%)	
<b>Frequency of ANC Check Up</b>	n = 66 (19.9%)	n = 266 (80.1%)	n = 332 (100%)	
1 - 3 time	19 (28.8%)	54 (20.3%)	73 (22%)	P=0.095
4 + time	47 (71.2%)	212 (79.7%)	259 (78%)	
<b>Delivery</b>	n = 76 (21.7%)	n = 274 (78.3%)	n = 350 (100%)	
HF Delivery	40 (52.6%)	189 (69%)	229 (65.4%)	P=0.008
Home/Outside HF Delivery	36 (47.4%)	85 (31%)	121 (34.6%)	
<b>PNC Check Up</b>	n = 76 (21.7%)	n = 274 (78.3%)	n = 350 (100%)	
Yes	14 (18.4%)	89 (32.5%)	103 (29.4%)	P=0.017
No	62 (81.6%)	185 (67.5%)	247 (70.6%)	

Pearson Chi-square test of significance

Table 13 below shows that higher percentage of Dalits compared to non-Dalits had at least one ANC check (96.7% vs 91.6%) and postnatal care visit (30% vs 29%). Contrarily, a higher percentage of non-Dalits compared to Dalits reported using recommended four or more ANC visits (79.6% vs 76%) and HF delivery (68% vs 62%). However, except one ANC visit ( $P < 0.05$ ), none of these differences were statistically significant ( $P > 0.05$ ).

**Table 13: Maternal Health care services utilization among Dalit and non- Dalit women**

Type of Service	Dalit	Non Dalit	Total	P-Value
<b>ANC Check up</b>	n = 151 (45.5%)	n = 203 (54.5%)	n = 354 (100%)	
Yes	146 (96.7%)	186 (91.6%)	332 (93.8%)	*P=0.039
No	5 (3.3%)	17 (8.4%)	22 (6.2%)	
<b>Frequency of ANC Check Up</b>	n = 146 (44%)	n = 176 (56%)	n = 332 (100%)	
1 - 3 times	35 (24%)	38 (20.4%)	73 (22%)	P=0.439
4 + time	111 (76%)	148 (79.6%)	259 (78%)	
<b>Delivery</b>	n = 150 (42.9%)	n = 200 (57.1%)	n = 350 (100%)	
HF Delivery	93 (62%)	136 (68%)	229 (65.4%)	P=0.243
Home/Outside HF Delivery	57 (38%)	64 (32%)	121 (34.6%)	
<b>PNC Check Up</b>	n = 150 (42.9%)	n = 200 (57.1%)	n = 350 (100%)	
Yes	45 (30%)	58 (29%)	103 (29.4%)	P=0.839
No	105 (70%)	142 (71%)	247 (70.6%)	

Pearson Chi-square test of significance; \*P=Fisher's Exact test of significance

## 5.2.2 ANALYSIS OF FACTORS ASSOCIATED WITH MATERNAL HEALTH CARE SERVICE UTILIZATION

### 5.2.2.1 Bi-variate Analysis of ANC Service Utilization

Table 14 shows that the disability status of women was significantly associated with utilization of ANC services ( $P < 0.001$ ) whereas women's caste did not show any association ( $P > 0.5$ ). Odds of utilizing ANC services by women with disability was lower compared to women without disability (OR 0.17, 95% CI 0.07 – 0.42).

This study also found a decrease in the proportion of women who attended ANC with increasing age ( $P < 0.001$ ). The younger age group women were more likely using services compared to higher age group. The odds ratio for 15 – 24 years and 25 – 34 years women had much higher (OR 9.66, 95% CI 2.91 – 32.12 and OR 7.01, 95% CI 2.55 – 19.29 respectively) than those of 35 – 49 age groups.

Women's educational status, place of residence, occupation and autonomy had no association with ANC utilization ( $P > 0.05$ ). However, there was a higher chance of women attending ANC visits in their first pregnancy than those having multiple pregnancies ( $P < 0.05$ ). The odds of at least one



ANC utilization for single parity women had higher than those of multiple parity women (OR 3.66, 95% CI 1.40 – 9.48). Women with little or no knowledge or awareness of pregnancy danger sign were less likely to attend ANC visits than those who were aware about it (OR 0.22, 95% CI 0.07 – 0.77; P<0.05). (Table 14).

**Table 14: Association of Socio-demographic Factors with Outcome Variables by Regression**

Factors	n	%	ANC Check		OR	95% CI	P-Value
			Yes (%)	No (%)			
<b>Disability</b>	354						
Disabled	79	22%	66 (84%)	13 (17%)	0.172	0.07 - 0.42	0.000
Non-Disabled	275	78%	266 (97%)	9 (3%)	Ref		
<b>Caste</b>	354						
Dalit	151	43%	146 (97%)	5 (3%)	2.669	0.96 - 7.40	0.059
Non-Dalit	203	57%	186 (92%)	17 (8%)	Ref		
<b>Location (Place of Residence)</b>	354						
Rural	284	82%	268 (94%)	16 (6%)	1.57	0.59 - 4.17	0.365
Urban	70	20%	64 (91%)	6 (9%)	Ref		
<b>Respondent's Age</b>	354						
15 – 24 Years	134	38%	130 (97%)	4 (3%)	9.662	2.91 - 32.12	0.000
25 – 34 Years	172	48%	165 (96%)	7 (4%)	7.008	2.55 - 19.29	0.000
35 – 49 Years	48	14%	37 (77%)	11 (23%)	Ref		
<b>Respondent's Education</b>	354						
Illiterate	116	33%	106 (91%)	10 (9%)	Ref		
Literate/Primary Education (up to 5 class)	117	33%	110 (94%)	7 (6%)	1.482	0.54 - 4.04	0.441
Secondary Education (6 class & above)	121	34%	116 (96%)	5 (4%)	2.189	0.73 - 6.61	0.165
<b>Respondent's Occupation</b>	354						
Unemployed/Farmer	298	84%	278 (93%)	20 (7%)	0.515	0.12 - 2.27	0.380
Employed (Service/Small Business)	56	16%	54 (96%)	2 (4%)	Ref		
<b>Age at Marriage</b>	352						
5 – 18 Years	236	67%	222 (94%)	14 (6%)	1.018	0.40 - 2.60	0.970
19 – 40 Years	116	33%	108 (94%)	7 (6%)	Ref		
<b>Parity</b>	354						
Primipara	198	56%	192 (97%)	6 (3%)	3.657	1.40 - 9.58	0.008
Multipara	156	44%	140 (90%)	16 (10%)	Ref		

Factors	n	%	ANC Check		OR	95% CI	P-Value
			Yes (%)	No (%)			
<b>Knowledge &amp; Awareness on Pregnancy Danger Sign</b>	354						
No Knowledge at All	71	20%	63 (89%)	8 (11%)	0.223	0.07 - 0.77	0.018
Little Knowledge (Low level of Awareness)	138	39%	128 (93%)	10 (7%)	0.363	0.11 - 1.19	0.094
Enough Knowledge (High level of Awareness)	145	41%	141 (97%)	4 (3%)	Ref		
<b>Women Empowerment (Autonomy) Index</b>	354						
Low	77	22%	70 (91%)	7 (9%)	0.455	0.11 - 1.83	0.268
Medium	208	59%	196 (94%)	12 (6%)	0.742	0.20 - 2.71	0.652
High	69	20%	66 (96%)	3 (4%)	Ref		

Family related factors such as husband's level of education, source of family income and household wealth were also found influential for ANC service utilization ( $P < 0.05$ ). Women whose husband's level of education was class six and above had five times higher odds than those with illiterate or non-educated husbands (OR 4.92, 95% CI 1.63 – 14.81). The study also showed that women with unemployed husbands were less likely to attend ANC services compared to the women with employed husbands (OR 0.40, 95% CI 0.16 – 0.98). Similarly, women whose family income was solely based on farming were less likely to receive ANC than women whose household income was of mixed source (OR 0.21, 95% CI 0.08 – 0.57) (Table 15).

**Table 15: Association of Family related and Other factors with Outcome (Dependent) variables**

Factors	n	%	ANC Check		OR	95% CI	P-Value
			Yes (%)	No (%)			
<b>Husband's Education</b>	352						
Illiterate	59	17%	51 (86%)	8 (14%)	Ref		
iterate/Primary Education (up to 5 class)	99	28%	92 (93%)	7 (7%)	2.062	0.71 - 6.01	0.185
Secondary Education (6 class & above)	194	55%	188 (97%)	6 (3%)	4.915	1.63 - 14.81	0.005
<b>Husband's Occupation</b>	352						
Unemployed/Farmer	127	36%	115 (91%)	12 (9%)	0.399	0.16 - 0.98	0.044
Employed (Service/Small Business)	225	64%	216 (96%)	9 (4%)	Ref		
<b>Main source of Family Income</b>	354						
Farming & Daily wages	97	27%	84 (87%)	13 (13%)	0.211	0.08 - 0.57	0.002
Employment (Service, small business)	67	19%	64 (96%)	3 (5%)	0.696	0.17 - 2.86	0.615
Others (Mixed source of income)	190	54%	184 (97%)	6 (3%)	Ref		

### 5.2.2.2 *Bi-variate Analysis of Recommended ANC Four Plus visits*

Table 16 illustrates that there is no significant relationship between an individual's disability and caste and the full-recommended number of antenatal care visits. ( $P>0.5$ ).

None of the demographic factors showed a significant association with four or more ANC visits; however, some education and empowerment factors (respondent's education, occupation and empowerment) and a family related factor (husband's education) showed some relationship with 4 or more ANC visits ( $P<0.05$ ). Compared to illiterate women, there was higher odds of using full-recommended ANC visits with the increase in level of women's education (OR 3.61, 95% CI 1.84 – 7.08 for secondary or above education; OR 2.27, 95% CI 1.22 – 4.23 for literate or primary level education). It was also evident that women with lower level of empowerment/autonomy had lower odds of using the full services [Low vs. high empowerment (OR 0.23, 95% CI 0.09 – 0.57) and medium vs high (0.44, 95% CI 0.19 – 1.02)]. Unemployed women were less likely to use the recommended four plus ANC visits than those who are engaged in regular services or business ( $P<0.05$ ). The study also found that there was no association between knowledge/awareness and utilization of full recommended ANC services ( $P>0.05$ ). (Table 16).

None of the family related factors (husband's occupation, source of family income and household wealth), with the exception of the husband's level of education ( $P<0.05$ ), were found to be influential for four plus ANC visits ( $P>0.05$ ). Odds of full ANC visits for those women with educated husbands was more than double compared to the women with non-educated husbands. (Table 16).

**Table 16: Association of Socio-demographic Factors with Outcome Variables by Regression**

Factors	ANC Check						
	n	%	<4 visit (%)	4+ visit (%)	OR	95% CI	P-Value
<b>Disability</b>	332						
Disabled	66	20%	19 (29%)	47 9(71%)	0.630	0.34 - 1.16	0.138
Non-Disabled	266	80%	54 (20%)	212 (80%)	Ref		
<b>Caste</b>	332						
Dalit	146	44%	35 (24%)	111 (76%)	0.814	0.48 - 1.37	0.440
Non-Dalit	186	56%	38 (20%)	148 (80%)	Ref		
<b>Location (Place of Residence)</b>	332	100					
Rural	268	81%	64 (24%)	204 (76%)	0.522	0.24 - 1.11	0.093
Urban	64	19%	9 (14%)	55 (86%)	Ref		
<b>Respondent's Age</b>	332						
15 – 24 Years	130	39%	22 (17%)	108 (83%)	2.077	0.90 - 4.82	0.088
25 – 34 Years	165	50%	40 (24%)	125(76%)	1.322	0.60 - 2.91	0.488
35 – 49 Years	37	11%	11 (30%)	26 (70%)	Ref		
<b>Respondent's Education</b>	332						
Illiterate	106	32%	37 (35%)	69 (65%)	Ref		
Literate/Primary Education (up to 5 class)	110	33%	21 (19%)	89 (81%)	2.273	1.22 - 4.23	0.010
Secondary Education (6 class & above)	116	35%	15 (13%)	101 (87%)	3.611	1.84 - 7.08	0.000
<b>Respondent's Occupation</b>	332						
Unemployed/Farmer	278	84%	68 (24%)	210 (76%)	0.315	0.12 - 0.82	0.018
Employed (Service/Small Business)	54	16%	5 (9%)	49 (91%)	Ref		
<b>Age at Marriage</b>	331						
5 – 18 Years	222	67%	55 (25%)	167 (75%)	0.561	0.31 - 1.02	0.059
19 – 40 Years	109	33%	17 (16%)	92 (84%)	Ref		
<b>Parity</b>	332						
Primipara	192	58%	35 (18%)	157 (82%)	1.671	0.99 - 2.82	0.054
Multipara	140	42%	38 (27%)	102 (73%)	Ref		
<b>Knowledge &amp; Awareness on Pregnancy Danger Sign</b>	332						
No Knowledge at All	63	19%	16 (25%)	47 (75%)	Ref.		
Little Knowledge (Low level of Awareness)	128	39%	31 (24%)	97 (76%)	1.065	0.53 – 2.14	0.859
Enough Knowledge (High level of Awareness)	141	42%	26 (18%)	115 (82%)	1.506	0.74 – 3.06	0.258
<b>Women Empowerment Index</b>	332						
Low	70	21%	24 (34%)	46 (66%)	0.227	0.09 - 0.57	0.002
Medium	196	59%	42 (21%)	154 (79%)	0.435	0.19 - 1.02	0.056
High	66	20%	7 (11%)	59 (89%)	Ref		

Factors	ANC Check						
	n	%	<4 visit (%)	4+ visit (%)	OR	95% CI	P-Value
<b>Husband's Education</b>	331						
Illiterate	51	15%	19 (37%)	32 (63%)	Ref		
Literate/Primary Education (up to 5 class)	92	28%	21 (23%)	71 (77%)	2.007	0.95 - 4.24	0.068
Secondary Education (6 class & above)	188	57%	32 (17%)	156 (83%)	2.895	1.46 - 5.73	0.002
<b>Husband's Occupation</b>	331						
Unemployed/Farmer	115	35%	27 (23%)	88 (77%)	0.858	0.50 - 1.48	0.579
Employed (Service/Small Business)	216	65%	45 (21%)	171 (79%)	Ref		
<b>Main source of Family Income</b>	332						
Farming & Daily wages	84	25%	18 (21%)	66 (79%)	1.222	0.66 - 2.27	0.525
Service/Employment	64	19%	9 (14%)	55 (86%)	2.037	0.93 - 4.44	0.074
Others (Mixed source of income)	184	56%	46 (25%)	138 (75%)	Ref		
<b>Household Wealth Index</b>	332						
Low (<40% in ranking)	67	20%	21 (31%)	46 (69%)	0.615	0.29 - 1.31	0.208
Middle (40 – 60% in ranking)	192	58%	36 (19%)	156 (81%)	1.216	0.63 - 2.36	0.562
High (>60% in ranking)	73	22%	16 (22%)	57 (78%)	Ref		

\*3 Disabled not Delivered; 1 non-Disabled miscarriage

### 5.2.2.3 Bi-variate Analysis of Delivery service use

A number of variables observed showed significant associations with health facility delivery on simple logistic regression (Table 17). The respondent's disability, age, education, age at marriage, number of pregnancies, husband's education, source of family income, household wealth and ANC check-up were observed as highly significant ( $P < 0.001$ ); whereas respondent's caste, their level of empowerment (Autonomy) and husband's occupation did not show any association with place of delivery ( $P > 0.05$ ).

The odds of health facility delivery for disabled women was 50% lower compared to non-disabled (OR 0.50, 95% CI 0.30 – 0.84). Similarly, odds of HF delivery for rural women was lower compared to urban women (OR 0.49, 95% CI 0.27 – 0.91). Women who got married at less than 19 years of age (OR 0.38, 95% CI 0.23 – 0.64) and having the low level of empowerment (OR 0.59, 95% CI 0.29 – 1.21) had lower odds of HF delivery compared to their counterparts. The same pattern of lower odds were found in those with lower wealth groups women (OR for the lowest group 0.17, 95% CI 0.08 – 0.36 and OR for middle wealth group 0.47, 95% CI 0.34 – 1.13) compared to higher wealth groups (Table 17).

Education was observed to be the strongest factor influencing whether delivery was at a health facility (HF) or at home, followed by pregnancy at a younger age, ANC check-up and parity. Women with secondary level or above education had much higher odds than those who were

illiterate or had no education (OR 14.63, 95% CI 6.94 – 30.83). Similarly, the odds ratio of HF delivery for the younger age group women between 15 – 24 years was 4.78, 95% CI 2.36 – 9.68; for the women who got their ANC visits was 4.51, 95% CI 2.60 – 7.82 and for primipara was 4.40, 95% CI 2.75 – 7.06. Women’s knowledge and awareness on pregnancy danger signs and family income source are also found to be strong predictors for giving birth at health facility (OR 2.05, 95% CI 1.12 – 3.75 for adequate knowledge and awareness and OR 3.68, 95% CI 1.77 – 7.67 for having services or employment as family income) (Table 17).

**Table 17: Association of Socio-demographic Factors with Outcome Variables by Regression**

Factors			Delivery		OR	95% CI	P-Value
	n	%	HF (%)	Home (%)			
<b>Disability</b>	350						
Disabled	76	22%	40 (53%)	36 (47%)	0.500	0.30 - 0.84	0.009
Non-Disabled	274	78%	189 (69%)	85 (31%)	Ref		
<b>Caste</b>	350						
Dalit	150	43%	93 (62%)	57 (38%)	0.768	0.49 - 1.20	0.243
Non-Dalit	200	57%	136 (68%)	64 (32%)	Ref		
<b>Location (Place of Residence)</b>	350*	100					
Rural	280	80%	175 (63%)	105 (36%)	0.494	0.27 - 0.91	0.023
Urban	70	20%	54 (77%)	16 (23%)	Ref		
<b>Respondent's Age</b>	350						
15 – 24 Years	132	38%	104 (79%)	28 (21%)	4.776	2.36 - 9.68	0.000
25 – 34 Years	170	48%	104 (61%)	66 (39%)	2.026	1.10 - 3.87	0.033
35 – 49 Years	48	14%	21 (44%)	27 (56%)	Ref		
<b>Respondent's Education</b>	350						
Illiterate	116	33%	49 (42%)	67 (58%)	Ref		
Literate/Primary Education (up to 5 class)	117	33%	73 (62%)	44 (38%)	2.269	1.34 - 3.84	0.002
Secondary Education (6 class & above)	117	34%	107 (91%)	10 (9%)	14.631	6.94 - 30.83	0.000
<b>Respondent's Occupation</b>	350						
Unemployed/Farmer	296	85%	184 (62%)	112 (38%)	Ref		
Employed (Service/Small Business)	54	15%	45 (83%)	9 (17%)	3.043	1.43 - 6.46	0.004
<b>Age at Marriage</b>	349						
5 – 18 Years	235	67%	138 (59%)	97 (41%)	0.379	0.23 - 0.64	0.000
19 – 40 Years	114	33%	90 (79%)	24 (21%)	Ref		
<b>Parity</b>	350						
Primipara	194	55%	155 (80%)	39 (20%)	4.404	2.75 - 7.06	0.000
Multipara	156	45%	74 (47%)	82 (53%)	Ref		

Factors	Delivery						
	n	%	HF (%)	Home (%)	OR	95% CI	P-Value
<b>Knowledge &amp; Awareness on Pregnancy Danger Sign</b>							
	350						
No Knowledge at All	70	20%	41 (59%)	29 (41%)	Ref		
Little Knowledge (Low Awareness Level)	136	39%	81 (60%)	55 (40%)	1.042	0.58 - 1.87	0.891
Enough Knowledge (High Awareness))	144	41%	107 (74%)	37 (26%)	2.045	1.12 - 3.75	0.020
<b>Women Empowerment Index</b>							
	350						
Low	75	21%	47 (63%)	28 (37%)	0.592	0.29 - 1.21	0.150
Medium	206	59%	131 (64%)	75 (36%)	0.616	0.34 - 1.13	0.119
High	69	20%	51 (74%)	18 (26%)	Ref		
<b>Husband's Education</b>							
	349						
Illiterate	58	17%	22 (38%)	36 (62%)	Ref		
Literate/Primary Education (up to 5 class)	99	28%	56 (57%)	43 (43%)	2.131	1.10 - 4.14	0.025
Secondary Education (6 class & above)	192	55%	150 (78%)	42 (22%)	5.844	3.11 - 10.99	0.000
<b>Husband's Occupation</b>							
	349						
Unemployed/Farmer	125	36%	77 (62%)	48 (38%)	Ref		
Employed (Service/Small Business)	224	64%	151 (67%)	73 (33%)	1.289	0.82 - 2.04	0.275
<b>Main source of Family Income</b>							
	350						
Farming & Daily wages	95	27%	59 (62%)	36 (38%)	1.078	0.65 - 1.79	0.771
Service/Employment/small business)	66	19%	56 (85%)	10 (15%)	3.684	1.77 - 7.67	0.000
Others (Mixed source of income)	189	54%	114 (60%)	75 (40%)	Ref		
<b>Household Wealth Index</b>							
	350						
Low (<40% in ranking)	80	23%	35 (44%)	45 (56%)	0.171	0.08 - 0.36	0.000
Middle (40 – 60% in ranking)	198	57%	135 (68%)	63 (32%)	0.472	0.24 - 0.92	0.028
High (>60% in ranking)	72	21%	59 (82%)	13 (18%)	Ref		
<b>ANC Check-up</b>							
	330						
< 4 visits	71	22%	29 (41%)	42 (59%)	Ref		
4+ visits	259	78%	196 (76%)	63 (24%)	4.506	2.60 - 7.82	0.000

\*3 Disabled not Delivered; 1 non-Disabled miscarriage

#### 5.2.2.4 Bi-variate Analysis of PNC service use

Table 18 shows associations between PNC service utilization and the same selected variables as the analysis above, using simple regression. Socio-demographic factors such as respondent's disability, education, age, age at marriage, parity and occupation were significant at  $P < 0.05$ . The odds ratio of utilizing PNC service for both age groups 15 - 24 and 25 - 34 years was more than double (OR 2.25, 95% CI 0.97 – 5.24 and 2.33, 95% CI 1.02 - 5.31 respectively), compared to the 35 – 49 year olds. The odds of using PNC services for non-disabled women were reported as 2.13, 95% CI 1.13 – 4.01; and for women with primary education 1.54, 95% CI 0.86 – 2.77 and secondary or above 1.87, 95% CI 1.05 – 3.33. Women who married below 19 years of age were reported as approximately 40% less likely to receive PNC compared to those married at 19 years old or above

(OR 0.60, 95% CI 0.37 – 0.97). Inversely, those women having their first child had nearly the double odds using PNC than those having two or more pregnancies (OR 1.87, 95% CI 1.16 – 3.01).

These results shows husband’s level of education, ANC visits and HF delivery are strongly associated with PNC utilization ( $P < 0.001$ ). The bivariate analysis, reflecting previous **findings from 5.2.2.1** noted above, also showed that higher the education level of the husband, the more likely the women was to receive PNC service. The odds for those women whose husband’s education levels were primary and secondary or above were 2.85, 95% CI 1.21 – 6.73 and 3.13, 95% CI 1.40 – 6.99 respectively. Similarly, the odds of using PNC service for the women having ANC visits and HF delivery were reported as higher compared to those not receiving their ANC (OR 3.86, 95% CI 1.83 – 8.12) and HF delivery services (OR 3.68, 95% CI 2.06 – 6.56) (Table 18).

Economic, awareness and empowerment related factors such as husband’s occupation, source of family income, household wealth, knowledge/awareness and empowerment showed no relation with PNC service utilization ( $P > 0.05$ ). Moreover, respondent’s place of residence and caste also did not show significant relation for PNC service utilization ( $P > 0.05$ ). However, women attending ANC visits and HF delivery had significantly higher chances of receiving PNC services ( $P < 0.001$ ) (Table 18).

**Table 18: Association of Socio-demographic Factors with Outcome Variables by Regression**

Factors	n	%	PNC Check		OR	95% CI	P-Value
			Yes (%)	No (%)			
Disability	350						
Disabled	76	22%	14 (18%)	62 (82%)	Ref		
Non-Disabled	274	78%	89 (33%)	185 (67%)	2.131	1.13 - 4.01	0.019
Caste	350						
Dalit	150	43%	45 (30%)	105 (70%)	Ref		
Non-Dalit	200	57%	58 (29%)	142 (71%)	1.049	0.66 - 1.67	0.839
Location (Place of Residence)	350	100					
Rural	280	80%	89 (32%)	191 (68%)	1.86	0.99 - 3.53	0.056
Urban	70	20%	14 (20%)	56 (80%)	Ref		



Factors	n	%	PNC Check		OR	95% CI	P-Value
			Yes (%)	No (%)			
<b>Respondent's Age</b>	350						
15 – 24 Years	132	38%	41 (31%)	91 (69%)	2.253	0.97 - 5.24	0.059
25 – 34 Years	170	48%	54 (32%)	116 (68%)	2.328	1.02 - 5.31	0.045
35 – 49 Years	48	14%	8 (17%)	40 (83%)	Ref		
<b>Respondent's Education</b>	350						
Illiterate	116	33%	26 (22%)	90 (78%)	Ref		
Literate/Primary Education (up to 5 class)	117	33%	36 (31%)	81 (69%)	1.538	0.86 - 2.77	0.150
Secondary Education (6 class & above)	117	34%	41 (35%)	76 (65%)	1.867	1.05 - 3.33	0.034
<b>Respondent's Occupation</b>	350						
Unemployed/Farmer	296	85%	80 (27%)	216 (73%)	0.499	0.28 - 0.91	0.023
Employed (Service/Small Business)	54	15%	23 (43%)	31 (57%)	Ref		
<b>Age at Marriage</b>	349						
5 – 18 Years	235	67%	61 (26%)	174 (74%)	0.601	0.37 - 0.97	0.037
19 – 40 Years	114	33%	42 (37%)	72 (63%)	Ref		
<b>Parity</b>	350						
Primipara	194	55%	68 (35%)	126 (65%)	1.866	1.16 - 3.01	0.011
Multipara	156	45%	35 (22%)	121 (78%)	Ref		
<b>Knowledge &amp; Awareness on Pregnancy Danger Sign</b>	350						
No Knowledge at All	70	20%	20 (29%)	50 (71%)	Ref		
Little Knowledge (Low level Awareness)	136	39%	35 (26%)	101 (74%)	0.866	0.45 - 1.65	0.663
Enough Knowledge (High level Awareness)	144	41%	48 (33%)	96 (67%)	1.250	0.67 - 2.33	0.483
<b>Women Empowerment (Autonomy) Index</b>	350						
Low	75	21%	21 (28%)	54 (72%)	0.729	0.36 - 1.48	0.381
Medium	206	59%	58 (28%)	148 (72%)	0.735	0.41 - 1.31	0.299
High	69	20%	24 (35%)	45 (65%)	Ref		
<b>Husband's Education</b>	349						
Illiterate	58	17%	8 (14%)	50 (86%)	Ref		
Literate/Primary Education (up to 5 class)	99	28%	31 (31%)	68 (69%)	2.849	1.21 - 6.73	0.017
Secondary Education (6 class & above)	192	55%	84 (33%)	128 (67%)	3.125	1.40 - 6.99	0.005
<b>Husband's Occupation</b>	349						
Unemployed/Farmer	125	36%	35 (28%)	90 (72%)	Ref		
Employed (Service/Small Business)	224	64%	68 (30%)	156 (70%)	1.121	0.69 - 1.82	0.644
<b>Main source of Family Income</b>	350						
Farming & Daily wages	95	27%	24 (25%)	71 (75%)	0.867	0.50 - 1.52	0.619
Service/Employment (Service, small business)	66	19%	26 (39%)	40 (61%)	1.668	0.93 - 3.00	0.088
Others (Mixed source of income)	189	54%	53 (28%)	136 (72%)	Ref		

Factors	n	%	PNC Check		OR	95% CI	P-Value
			Yes (%)	No (%)			
Household Wealth Index	350						
Low (<40% in ranking)	80	23%	18 (23%)	62 (77%)	0.546	0.27 - 1.12	0.097
Middle (40 – 60% in ranking)	198	57%	60 (30%)	138 (70%)	0.817	0.46 - 1.45	0.490
High (>60% in ranking)	72	20%	25 (35%)	47 (65%)	Ref		
ANC Check-up	330						
< 4 visits	71	22%	29 (41%)	42 (59%)	Ref		
4+ visits	259	78%	196 (76%)	63 (24%)	3.859	1.83 - 8.12	0.000
Place of Delivery	350						
Health Facility Delivery	229	65%	86 (38%)	143 (62%)	3.679	2.06 - 6.56	0.000
Home Delivery	121	35%	17 (14%)	104 (86%)	Ref		

\*3 Disabled not Delivered; 1 non-Disabled miscarriage

### 5.2.2.5 Multi-variate Analysis

Table 19 below shows odds ratios for factors associated with all four service utilization outcomes, adjusted for selected socio-demographic and household factors. Factors likely to be in causal pathway such as women’s education, occupation, knowledge/awareness, empowerment, household income and wealth are not included in the analysis. Overall, disabled respondents reported less odds in all four different outcome variables. Caste was not associated with any of the service utilization outcomes, so is not included here. Disabled respondents reported 0.17 (95% CI 0.07 – 0.42) lower odds of having had more than one ANC visit than non-disabled respondents.

Table 19 shows that disabled women had 83% lower odds of using at least one ANC compared to non-disabled women. Adjustments for women’s age, parity and husband’s occupation reduced but did not explained the association between disability and ANC utilization. Adjustment for women’s place of residence (Location) and husband’s education strengthened the association. Women’s marriage age did not change the association. Even after inclusion of all variables in the model, the relation between disability and utilization of at least one ANC service was still apparent.

In unadjusted model, there was no association between disability and full-recommended ANC visits (ANC 4+). Adjusting for any of the potential confounding variables did not show significant relationship between disability and ANC 4+ visit.

Disabled women had 50% lower odds of HF delivery compared to non-disabled women. After adjustment for women’s age and husband’s education separately, there was no association between disability and HF delivery. While adjustment for place of residence (Location) and parity reduced the association and adjustment for marriage age and husband’s occupation strengthened

the association, and the relationship was still significant. In the full model, there is not significant association between disability and HF delivery.

The confounders affected the relationship between disability and PNC in the same way as in HF delivery. However, the association is still significant in the full model.

**Table 19: Unadjusted and adjusted odds ratio (95% confidence intervals) of disability with maternal health care utilization (Please refer Annex F tables 9 – 12 for the detailed analysis by outcomes)**

Factors	ANC 1 visit		ANC 4+ visit		HF Delivery		PNC visit	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
<b>Disability Only</b>	<b>***0.17</b>	<b>0.07 - 0.42</b>	<b>0.63</b>	<b>0.34 - 1.16</b>	<b>**0.50</b>	<b>0.30 - 0.84</b>	<b>*0.47</b>	<b>0.25 - 0.88</b>
<b>Disability + Location</b>	<b>***0.14</b>	<b>0.06 - 0.36</b>	<b>0.67</b>	<b>0.36 - 1.23</b>	<b>*0.54</b>	<b>0.32 - 0.91</b>	<b>**0.43</b>	<b>0.23 - 0.81</b>
Rural	2.57	0.89 - 7.45	0.55	0.26 - 1.17	0.54	0.29 - 1.00	*2.09	1.10 - 3.99
Urban	Ref		Ref		Ref		Ref	
<b>Disability + Women's Age</b>	<b>*0.30</b>	<b>0.11 - 0.80</b>	<b>0.73</b>	<b>0.38 - 1.40</b>	<b>0.72</b>	<b>0.41 - 1.26</b>	<b>0.54</b>	<b>0.28 - 1.05</b>
15 - 24 yrs	*5.32	1.44 - 19.65	1.81	0.74 - 4.42	***4.08	1.92 - 8.08	1.71	0.70 - 4.17
25 - 34 yrs	**4.64	1.59 - 13.53	1.21	0.53 - 2.72	1.79	0.91 - 3.54	1.88	0.80 - 4.43
35 - 49 yrs	Ref		Ref		Ref		Ref	
<b>Disability + Age at Marriage</b>	<b>***0.17</b>	<b>0.07 - 0.44</b>	<b>0.58</b>	<b>0.31 - 1.10</b>	<b>**0.38</b>	<b>0.22 - 0.66</b>	<b>**0.42</b>	<b>0.22 - 0.80</b>
Below 18 yrs	0.72	0.27 - 1.93	*0.5	0.28 - 0.95	***0.32	0.18 - 0.55	*0.53	0.33 - 0.87
18 yrs and above	Ref		Ref		Ref		Ref	
<b>Disability + Parity</b>	<b>***0.20</b>	<b>0.08 - 0.49</b>	<b>0.68</b>	<b>0.36 - 1.25</b>	<b>*0.61</b>	<b>0.35 - 1.06</b>	<b>*0.52</b>	<b>0.27 - 0.98</b>
Primi	*3.01	1.12 - 8.06	1.61	0.95 - 2.72	***4.18	2.60 - 6.73	*1.74	1.07 - 2.82
Multi	Ref		Ref		Ref		Ref	
<b>Disability + Husband's Education</b>	<b>**0.23</b>	<b>0.09 - 0.58</b>	<b>0.80</b>	<b>0.42 - 1.53</b>	<b>0.64</b>	<b>0.37 - 1.12</b>	<b>0.56</b>	<b>0.29 - 1.07</b>
Illiterate	Ref		Ref		Ref		Ref	
Primary Education	1.49	0.49 - 4.54	1.94	0.91 - 4.12	1.96	1.00 - 3.84	*2.58	0.08 - 6.14
Secondary & above	*3.26	1.03 - 10.31	2.75	1.37 - 5.54	***5.28	2.77 - 10.04	*2.75	1.21 - 6.22
<b>Disability + Husband's Occupation</b>	<b>***0.16</b>	<b>0.07 - 0.40</b>	<b>0.63</b>	<b>0.34 - 1.16</b>	<b>**0.50</b>	<b>0.30 - 0.83</b>	<b>*0.47</b>	<b>0.25 - 0.88</b>
Unemployed/Farming	*0.40	0.16 - 0.99	0.87	0.50 - 1.49	0.76	0.48 - 1.20	1.13	0.69 - 1.83
Regular service/Business	Ref		Ref		Ref		Ref	
<b>Full Model</b>	<b>*0.26</b>	<b>0.08 - 0.84</b>	<b>0.79</b>	<b>0.39 - 1.60</b>	<b>0.68</b>	<b>0.35 - 1.32</b>	<b>*0.48</b>	<b>0.24 - 0.98</b>

\*P<0.05, \*\*P<0.01, \*\*\*P<0.001

Models with interaction terms that look at the effect of interactions between exposures and key predictors of service utilization such as age, education and socio-economic factors and their association in utilization for disabled and non-disabled, and Dalit and non-Dalit women were examined. Given the data, in most cases there was insufficient evidence of interaction effect between disability and women's age, education, parity, husband's education or household wealth and income source at 5% significant level. However, in a number of cases we found some evidence

of effect modification (Table 20 and 21). For the models looking at service utilization by husbands education and disability status. The higher the education of a woman's husband, the higher the odds they had of delivering at a HF. However, if the woman was disabled, the benefit of her husband having a higher education was not as strong [0.19, 0.05, 0.75]).

A similar pattern was found in the caste group by their education and their husband's education (Table 21).

**Table 20: Models with interaction terms analysing the effects of interactions between key predictors and service utilization by disability**

Predictors	ANC1			ANC4+			Delivery			PNC		
	OR	95% CI	P Value	OR	95% CI	P Value	OR	95% CI	P Value	OR	95% CI	P Value
<b>Disability + Age</b>												
Disabled	0.24	0.04 - 1.24	0.087	0.83	0.20 - 3.43	0.800	0.65	0.20 - 2.06	0.462	1.23	0.26 - 5.88	0.794
Non-disabled	Ref											
<b>Age</b>												
15 - 24 years	13.22	1.14 - 153.39	0.039	2.02	0.65 - 6.34	0.226	4.41	1.64 - 11.88	0.003	2.98	0.83 - 10.76	0.096
25 - 34 years	2.39	0.45 - 12.75	0.308	1.27	0.42 - 3.85	0.674	1.55	0.60 - 3.97	0.364	2.83	0.79 - 10.18	0.110
35 - 49 years	Ref											
<b>Disabled</b>												
15 - 24 years	0.13	0.01 - 2.33	0.166	0.61	0.08 - 4.50	0.626	0.41	0.08 - 2.15	0.290	0	0	0.999
25 - 34 years	7.14	0.47 - 108.02	0.156	0.95	0.18 - 4.89	0.947	1.69	0.42 - 6.79	0.459	0.56	0.10 - 3.31	0.524
35 - 49 years	Ref											
<b>Disability + Education</b>												
Disabled	0.34	0.09 - 1.27	0.109	0.71	0.29 - 1.76	0.462	0.63	0.27 - 1.48	0.292	0.27	0.08 - 0.99	<b>0.048</b>
Non-disabled	Ref											
<b>Education</b>												
Illiterate	Ref											
Primary Education	1.49	0.39 - 5.73	0.564	1.94	0.97 - 3.85	0.060	2.28	1.25 - 4.14	0.007	1.29	0.68 - 2.44	0.440
Secondary and above	102245..	0	0.996	4.58	1.99 - 10.53	0.000	21.06	7.76 - 57.17	0.000	1.56	0.82 - 2.95	0.176
<b>Disabled</b>												
Illiterate	Ref											
Primary Education	0.66	0.09 - 5.22	0.697	2.49	0.41 - 15.11	0.323	0.75	0.21 - 2.78	0.671	2.01	0.35 - 11.45	0.434
Secondary and above	0	0	0.996	0.425	0.10 - 1.84	0.253	0.36	0.08 - 1.76	0.208	2.42	0.48 - 12.07	0.282
<b>Disability + Parity</b>												
Disabled	0.27	0.09 - 0.78	0.015	0.67	0.29 - 1.52	0.334	0.58	0.28 - 1.17	0.126	0.44	0.17 - 1.13	0.089
Non-disabled	Ref											
<b>Parity</b>												
Primipara	5.45	1.11 - 26.75	<b>0.037</b>	1.60	0.87 - 2.91	0.129	4.03	2.35 - 6.92	<b>0.000</b>	1.65	0.97 - 2.80	0.065
Multipara	Ref											
<b>Disabled</b>												
Primipara	0.34	0.05 - 2.64	0.305	1.03	0.30 - 3.60	0.963	1.17	0.38 - 3.67	0.783	1.37	0.38 - 4.99	0.631
Multipara	Ref											

Predictors	ANC1			ANC4+			Delivery			PNC		
	OR	95% CI	P Value	OR	95% CI	P Value	OR	95% CI	P Value	OR	95% CI	P Value
<b>Disability + Husband's Education</b>												
Disabled	1.03	0.32 - 3.33	0.963	1.03	0.32 - 3.33	0.963	1.77	0.60 - 5.20	0.299	0.83	0.18 - 3.86	0.811
Non-disabled	Ref											
<b>Husband's Education</b>												
Illiterate	Ref											
Primary Education	2.14	0.86 - 5.29	0.100	2.14	0.86 - 5.29	0.100	3.01	1.29 - 7.02	<b>0.011</b>	2.74	0.95 - 7.91	0.063
Secondary and above	3.12	1.36 - 7.14	<b>0.007</b>	3.12	1.36 - 7.14	<b>0.007</b>	9.20	4.05 - 20.90	<b>0.000</b>	3.32	1.22 - 9.05	<b>0.019</b>
<b>Disabled</b>												
Illiterate	Ref											
Primary Education	0.76	0.15 - 3.99	0.750	0.76	0.15 - 3.99	0.750	0.36	0.08 - 1.52	0.164	1.02	0.16 - 6.62	0.981
Secondary and above	0.66	0.14 - 3.07	0.591	0.66	0.14 - 3.07	0.591	0.19	0.05 - 0.75	<b>0.018</b>	0.42	0.07 - 2.66	0.357
<b>Disability + Source of Family Income</b>												
Disabled	0.25	0.05 - 1.30	0.099	0.63	0.28 - 1.38	0.245	0.72	0.35 - 1.46	0.355	0.40	0.16 - 1.02	0.054
Non-disabled	Ref											
<b>Income</b>												
Farming/wages	0.26	0.06 - 1.13	0.072	1.30	0.63 - 2.72	0.480	1.31	0.72 - 2.40	0.382	0.83	0.44 - 1.57	0.570
Service/Business	1.12	0.11 - 11.02	0.921	1.77	0.76 - 4.10	0.185	5.01	2.02 - 12.43	<b>0.001</b>	1.58	0.83 - 2.98	0.162
Others (Mixed)	Ref											
<b>Disabled</b>												
Farming/wages	0.78	0.10 - 6.01	0.808	0.86	0.21 - 3.45	0.830	0.56	0.18 - 1.80	0.331	1.57	0.37 - 6.71	0.541
Service/Business	0.33	0.02 - 6.48	0.462	2.17	0.21 - 22.69	0.517	0.30	0.06 - 1.57	0.153	1.31	0.24 - 7.24	0.757
Others (Mixed source)	Ref											
<b>Disability + Wealth</b>												
Disabled	0.83	0.15 - 4.54	0.823	0.82	0.15 - 4.54	0.823	1.36	0.15 - 12.36	0.786	0.73	0.13 - 4.07	0.720
Non-disabled	Ref											
<b>Wealth Index</b>												
Low wealth group	0.80	0.32 - 1.97	0.626	0.80	0.32 - 1.97	0.626	0.26	0.11 - 0.60	<b>0.002</b>	0.70	0.31 - 1.58	0.389
Middle wealth group	1.22	0.60 - 2.50	0.584	1.22	0.60 - 2.50	0.584	0.49	0.24 - 1.01	<b>0.050</b>	0.89	0.49 - 1.63	0.700
High wealth group	Ref											
<b>Disabled</b>												
Low wealth group	0.58	0.08 - 4.36	0.600	0.58	0.08 - 4.36	0.600	0.28	0.03 - 3.10	0.301	0.64	0.08 - 5.04	0.671
Middle wealth group	1.05	0.15 - 7.33	0.958	1.05	0.15 - 7.33	0.958	0.68	0.07 - 7.01	0.743	0.68	0.10 - 4.70	0.695
High wealth group	Ref											

**Table 21: Models with interaction terms analysing the effects of interactions between key predictors and service utilization by caste**

Predictors	ANC1			ANC4+			Delivery			PNC		
	OR	95% CI	P Value	OR	95% CI	P Value	OR	95% CI	P Value	OR	95% CI	P Value
<b>Caste + Age</b>												
Dalit	3.83	0.73 - 20.18	0.114	3.11	0.67 - 14.44	0.147	1.28	0.40 - 4.09	0.683	0.32	0.07 - 1.56	0.159
Non-Dalit	Ref											
<b>Age</b>												
15 - 24 years	15.30	3.05 - 76.64	<b>0.001</b>	5.00	1.57 - 15.94	<b>0.007</b>	6.10	2.35 - 15.84	<b>0.000</b>	1.30	0.41 - 4.12	0.653
25 - 34 years	7.35	2.35 - 22.97	<b>0.001</b>	2.30	0.84 - 6.34	<b>0.106</b>	2.83	1.22 - 6.60	<b>0.016</b>	1.17	0.37 - 3.67	0.792
35 - 49 years	Ref											
<b>Dalit</b>												
15 - 24 years	0.24	0.02 - 3.19	0.278	0.15	0.02 - 0.89	<b>0.037</b>	0.58	0.14 - 2.45	0.460	2.91	0.51 - 16.53	0.228
25 - 34 years	1.07	0.07 - 16.12	0.960	0.25	0.05 - 1.38	0.112	0.44	0.12 - 1.66	0.226	3.71	0.67 - 20.47	0.132
35 - 49 years	Ref											
<b>Caste + Education</b>												
Dalit	3.57	0.72 - 17.61	0.118	1.79	0.79 - 4.05	0.161	1.01	0.48 - 2.11	0.990	1.14	0.47 - 2.76	0.769
Non-Dalit	Ref											
<b>Education</b>												
Illiterate	Ref											
Primary Education	1.43	0.44 - 4.65	0.554	3.66	1.45 - 9.23	<b>0.006</b>	2.06	0.99 - 4.28	<b>0.054</b>	1.91	0.82 - 4.46	0.135
Secondary and above	2.86	0.82 - 9.95	0.099	7.27	2.84 - 18.62	<b>0.000</b>	20.83	7.42 - 58.46	<b>0.000</b>	2.11	0.81 - 5.46	0.125
<b>Dalit</b>												
Illiterate	Ref											
Primary Education	0.84	0.08 - 8.54	0.883	0.38	0.11 - 1.37	0.140	1.21	0.42 - 3.46	0.727	0.64	0.20 - 2.10	0.463
Secondary and above	0.5	0.03 - 7.80	0.624	0.19	0.05 - 0.74	<b>0.017</b>	0.41	0.09 - 1.83	0.240	0.82	0.25 - 2.73	0.745
<b>Caste + Parity</b>												
Dalit	5.30	1.45 - 19.41	<b>0.012</b>	1.32	0.63 - 2.78	0.469	1.11	0.59 - 2.09	0.736	1.01	0.48 - 2.14	0.984
Non-Dalit	Ref											
<b>Parity</b>												
Primipara	6.35	1.99 - 20.26	<b>0.002</b>	2.36	1.14 - 4.89	<b>0.020</b>	5.14	2.72 - 9.75	<b>0.000</b>	1.71	0.89 - 3.31	0.108
Multipara	Ref											
<b>Dalit</b>												
Primipara	0.21	0.02 - 1.83	0.159	0.46	0.16 - 1.32	0.147	0.69	0.27 - 1.79	0.446	1.26	0.48 - 3.32	0.638
Multipara	Ref											

Predictors	ANC1			ANC4+			Delivery			PNC		
	OR	95% CI	P Value	OR	95% CI	P Value	OR	95% CI	P Value	OR	95% CI	P Value
<b>Caste + Husband's Education</b>												
Dalit	2.67	0.49 - 14.48	0.256	1.94	0.61 - 6.21	0.263	1.40	0.48 - 4.07	0.536	4.50	0.82 - 24.57	0.082
Non-Dalit	Ref											
<b>Husband's Education</b>												
Illiterate	Ref											
Primary Education	1.56	0.45 - 5.33	0.482	1.79	0.66 - 4.86	0.257	1.91	0.76 - 4.81	0.170	6.82	1.44 - 32.32	0.016
Secondary and above	6.44	1.70 - 24.43	<b>0.006</b>	6.93	2.64 - 18.22	<b>0.000</b>	10.05	4.17 - 24.20	<b>0.000</b>	7.89	1.79 - 34.65	0.006
<b>Dalit</b>												
Illiterate	Ref											
Primary Education	2.68	0.17 - 41.53	0.481	1.21	0.26 - 5.61	0.806	1.20	0.32 - 4.57	0.786	0.22	0.03 - 1.49	0.122
Secondary and above	0.47	0.04 - 5.21	0.535	0.15	0.04 - 0.63	<b>0.009</b>	0.30	0.08 - 1.05	0.060	0.19	0.03 - 1.19	0.076
<b>Caste + Source of Family Income</b>												
Dalit	1.68	0.30 - 9.40	0.555	1.12	0.57 - 2.20	0.733	0.65	0.36 - 1.16	0.147	0.91	0.48 - 1.72	0.774
Non-Dalit	Ref											
<b>Income</b>												
Farming/wages	0.16	0.05 - 0.52	<b>0.002</b>	1.81	0.72 - 4.56	0.210	0.73	0.37 - 1.45	0.372	0.95	0.42 - 2.13	0.891
Service/Business	0.86	0.15 - 4.88	0.865	2.67	0.95 - 7.51	0.063	3.49	1.35 - 9.03	<b>0.010</b>	1.50	0.56 - 4.07	0.424
Others (Mixed)	Ref											
<b>Dalit</b>												
Farming/wages	3.12	0.30 - 32.01	0.338	0.47	0.13 - 1.66	0.242	2.35	0.84 - 6.55	0.104	0.85	0.28 - 2.62	0.778
Service/Business	0.58	0.03 - 11.68	0.723	0.50	0.10 - 2.42	0.387	1.01	0.22 - 4.56	0.990	1.19	0.34 - 4.11	0.784
Others (Mixed source)	Ref											
<b>Caste + Wealth</b>												
Dalit	0	0	0	0.77	0.24 - 2.44	0.656	0.76	0.22 - 2.64	0.665	1.20	0.43 - 3.33	0.726
Non-Dalit	Ref											
<b>Wealth Index</b>												
Low wealth group	0	0	0	0.73	0.24 - 2.21	0.581	0.13	0.05 - 0.35	<b>0.000</b>	0.77	0.30 - 1.98	0.586
Middle wealth group	0	0	0	1.09	0.47 - 2.52	0.847	0.48	0.21 - 1.14	0.096	0.76	0.37 - 1.57	0.462
High wealth group	Ref											
<b>Dalit</b>												
Low wealth group	0	0	0	0.85	0.17 - 4.11	0.835	1.89	0.41 - 8.73	0.416	0.48	0.11 - 2.10	0.330
Middle wealth group	0	0	0	1.37	0.35 - 5.39	0.652	1.00	0.25 - 3.97	0.997	1.13	0.35 - 3.73	0.836
High wealth group	Ref											



### **5.2.3 SUMMARY OF KEY FINDINGS**

The results from this study clearly show that it is the disability status of pregnant Nepalese women, not their caste that determines the utilization of at least one antenatal care visit, health facility delivery and postnatal care visit. There were differences between disabled and non-disabled women in the uptake of the recommended four or more antenatal care visits, but this difference was not statistically significant. Adjustment of women's place of residence (location) and husband's education strengthened the association between disability and at least one ANC visits whereas women's age at marriage and husband's occupation strengthened the association between disability and utilization of both HF delivery and PNC services. Even after the adjustment of all potential confounders, the association retained between disability and at least one ANC visit, and PNC, but the association disappeared in the case of HF delivery. It also shows that higher the education of husband, the higher the utilization of HF delivery but this was not equally pertinent for disabled women.

#### **5.2.4 ACCESS**

Access to health care is an important determinant of maternal health care service utilization. The percentage of the population utilizing healthcare service among different socio-economic strata could be an indicator of access to healthcare services to that particular population.

The study followed the concept and framework of access as recommended by Penchansky, Thomas, & et. al, (1981) and Aday & Andersen (1974). Thus, accessibility in this study is defined as the relationship between policy, supply, client characteristics and also utilization of services.

The concept of access and its operationalization in health care has varied. This study examined access from both the supply aspect, as distribution and delivery system, and demand aspect, as population characteristics with generally accepted and widely used five dimensions as shown in conceptual framework (**Chapter Two, section: 2.14.1**) that included Accessibility, Availability, Affordability, Acceptability and Accommodation.

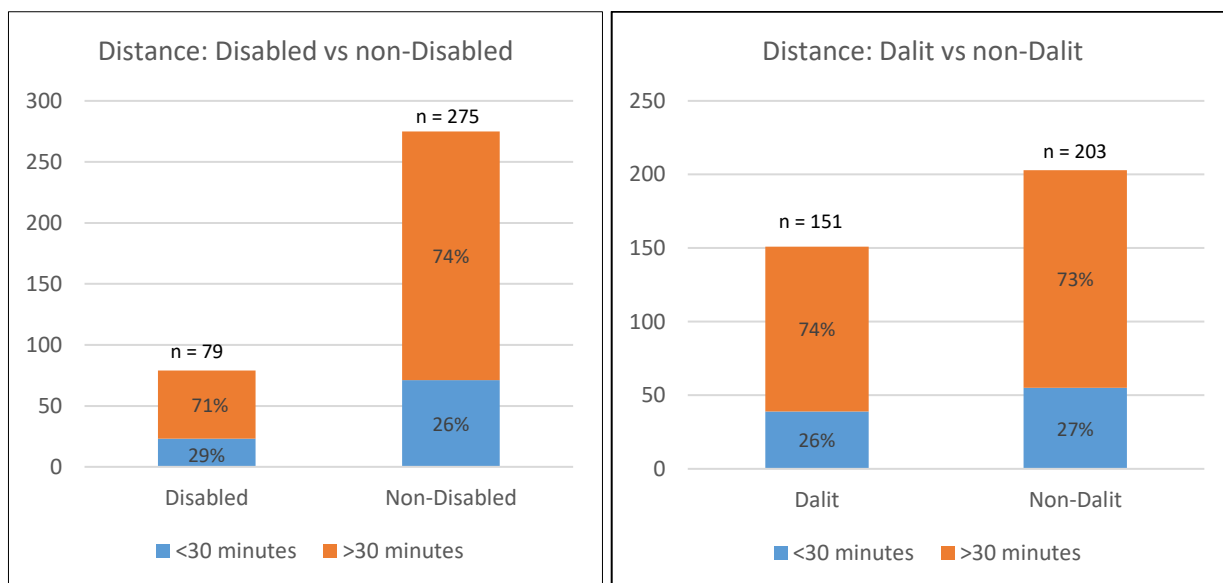
Those access dimensions were assessed using primary data collected by survey, an in-depth and semi-structured interview with service users, policy planner, implementers and community leaders. Health facilities at primary and secondary levels across Rupandehi district where research participants used services in their last pregnancy were taken as the basis for analysis.

##### ***5.2.4.1 Accessibility***

###### **Location and Distance to HF**

A slightly higher percentage of disabled women compared to non-disabled (29% vs 26%) reported that the nearest health facility from their place of residence was within 30 minutes walking distance for those with no walking disability. However, not real differences between Dalits and non-Dalit women (74% vs 73%) reported that their place of residence was far from health facilities that took them more than 30 minutes of walking to reach the nearest health facility. However, these differences did not show any statistical significance in both cases ( $P>0.05$ ). (Figure 9).

**Figure 9: Comparison by distance**



When discussing with the policy planner during his interview, he expressed a concern that there are uneven and irrational distribution and location of health facilities in this area in particular because they are often established on the basis of political interest and influence, rather than the needs and convenience of people:

*“The basis for distribution and the structure for services were based on political division. Health Post has been kept in every Village Development Committee, Primary Health Care Centres within every electoral constituency, and then district hospitals at district level have been established but without determining population of the area. Neither the population nor the caseload or prevalence was taken as a basis. It was distributed in a haphazard manner.”*

**- KII Participant # 6**  
(18<sup>th</sup> March 2015; MoHP)

A deaf participant expressed her experience while visiting the health facilities saying:

*“It was easy in the health centre once I reached there, but the health centre was far so I got leg pain while going for check-ups”.*

**- A 23 year old deaf non-Dalit service user (Participant # 16)**  
(10<sup>th</sup> February 2015; Ekla)

Another disabled participant said that the location of the health facility was not only a matter of distance for her; it was also not practical for her to go hospital for services:

*“..... because the hospital was far, my husband also had to go to work and I cannot go without him. He used to go for work leaving me at home alone. Would he go for work or take me to*

*hospital? If he would not go to work then we would have nothing to eat. We do not have any agriculture lands, and other source of income. We do labour to survive.”*

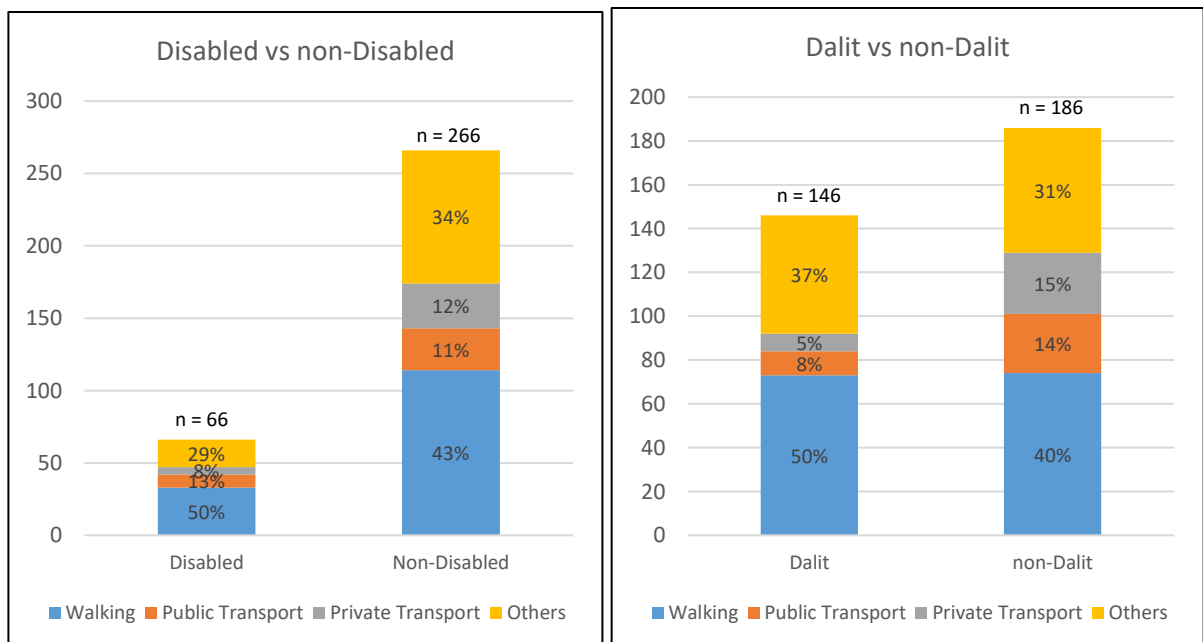
- **A 35 year old disabled Dalit woman (Participant # 1)**  
 (17<sup>th</sup> February 2015; Kerbani)

**Road and Transport**

Half of disabled and Dalit (both with and without disability) respondents reported that they walked to health facilities for their ANC check-ups – the percentage for non-disabled and non-Dalit was 43% and 40% respectively. Over one-third of non-disabled and slightly less disabled participants (29%) used a low cost means of transport such as rickshaw, bicycle or bull-cart. However, the proportion of Dalits (37%) was significantly higher than non-Dalits (31%) using such means of transport for their ANC visits (P=0.004).

Approximately one in ten women used public transport such as buses. The proportion of disabled women using public transport was slightly more than non-disabled (13% vs 11%). Contrarily, Dalits used less public means of transport than non-Dalits (8% vs 14%) while visiting health facilities for ANC. A significant proportion of women used private transport like rikshaws and bull carts. A higher percentage of non-disabled than disabled (12% vs 8%) and non-Dalit than Dalit women (15% vs 5%) used private means of transport while receiving ANC services. The differences between disabled and non-disabled was not statistically significant (P= 0.513), however, the differences between Dalits and non-Dalits was significant (P= 0.004) (Figure 10).

**Figure 10: Comparison by use of transport**



These findings can be substantiated by the qualitative interviews, during which participants reported sustained difficulties with transport services. Some respondents stated they do not have roads or transport links to health facilities, and also the health facilities lack basic requirements to actually deliver services. One disabled service user interviewed shared her challenges as:

*“No transport services are available here and it was difficult for me to walk up to the health post. So we called the sister here at home to help me and delivered at home.”*

- **A 27 year old disabled non-Dalit woman (Participant # 8)**  
(19<sup>th</sup> February 2015; Saljhundi)

Likewise, another non-disabled Dalit participant described her difficulties accessing delivery services due to unavailability of transport services, particularly at night, to go health facilities for their delivery. She further described that she had nobody to accompany her to the health facility at night. These factors forced her to deliver at home:

*“Sister had told me during the last ANC check-up to give birth at health facility but I started with labor pain at night and my husband was not at home during the delivery. There were neither vehicles available nor anyone who could take me to the health post nearby. During the first two pregnancies, I even did not know about giving birth at health post or hospital. Only in my third pregnancy, I did get the information when I went for ANC. But I could not get to a health facility for the last delivery too and I delivered at home.”*

- **A 22 year old Dalit woman (Participant # 24)**  
(17<sup>th</sup> February 2015; Bishnupura)

A high-ranking government official who is responsible for policy planning talked about the overall poor situation of basic infrastructure and facilities across the country:

*“The existing professional health workers have been giving services to the best limit possible. In some places, our HFs are not linked to motor-able road; have no water supply and electricity facilities which are the basic amenities to provide health care services to the people. We have to accept the fact that there is not even a single hospital which is disabled-friendly in our country.”*

- **KII Participant # 6**  
(18<sup>th</sup> March 2015; MoHP)

#### Travel time and Cost

Travel time and cost are key factors for seeking services. It is common practice for inhabitants in rural areas to walk to services. In some cases, they are carried to health facilities when there are no vehicles available to transport them. Due to the difficult geographical terrain and poor road infrastructures, traveling is a big challenge for people. It is often costly and time consuming to

transport patients to health facilities generally; and it is even more costly for disabled people. Some of the participants during their in-depth interviews expressed their problem as:

*“I had gone for check-ups in good time so I didn’t wait but I had to walk for half an hour to reach there.”*

- **A 35 year old disabled non-Dalit woman (Participant # 15)**  
(10<sup>th</sup> February 2015; Ekla)

*“...there wasn’t any problem to go but it is for those people who can afford vehicles when in need so that they can go to hospital. I gave birth to all my babies at home since I didn’t have money to rent a vehicle.”*

- **A 35 year old Muslim disabled woman (Participant # 15)**  
(10<sup>th</sup> February 2015; Ekla)

#### 5.2.4.2 Availability

##### Staff Adequacy and Availability

Staff insufficiency and their availability in health facilities are common issues in most of the health facilities. It has been reported that the staff situation is gradually improving. However, some gaps remain:

*“We had shortage of health workers few years back. As of now a lot improvement has occurred. Talking about Rupandehi there were 20-25% vacant posts in the past but it has reduced to 10% approximately last year. All the posts are being filled up from the Lok-Sewa (Public Service) exams. Apart from that, we also hire staffs in temporary basis. With this effort, the staff situation has been improved. At the moment we have only 3-4% posts are vacant in Rupandehi.”*

- **KII Participant # 5**  
(1<sup>st</sup> March 2015; Pokhara)

Staff shortage is often not only a matter of numbers; it is also the matter of their competency particularly their knowledge of women with disability and availability in needs. Female interviewees expressed mixed opinions and experiences of staff adequacy and competency:

*“May be my mom used to ask them time and again but there was no one around me if I wanted anything.”*

- **A 33 year old non Dalit Blind (Participant # 11)**  
(11<sup>th</sup> February 2015; Karahiya)

The service users in their in-depth interviews often reported provider's carelessness and lack of sincerity on duty. This can be illustrated by a mother-in-law who spoke about her experiences of taking her daughter-in-law in hospital for her delivery:

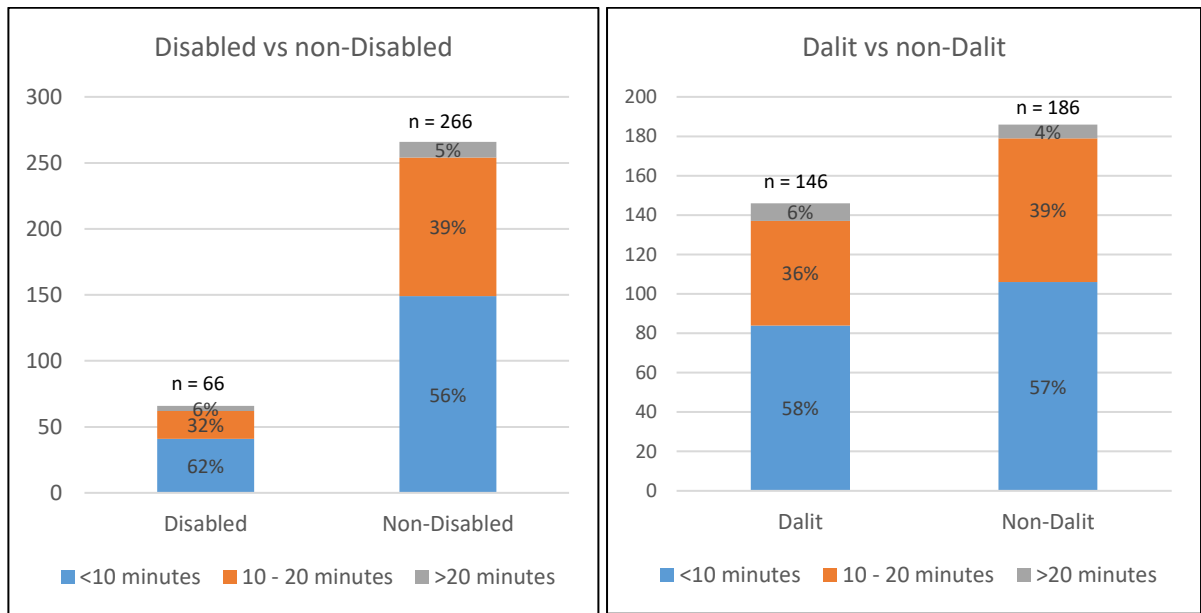
*“At the time of my first grandson, doctors and nurses were all asleep. When I saw the head of the baby coming out I rushed to call the nurses. Only after I asked them, then they came and took her to delivery room. Sometimes later, they said they could not deliver the baby there and asked me to take her to Butwal. I got furious and scolded them for not informing me in time as we were there since eight in the morning to nine in the evening. Had they informed me on time I would be able to take her, but it was too late and I being an old lady alone how would I take her to another hospital at night? Then again, they left me with her. When I saw the baby with the umbilical cord tied around its neck at 2 at night I shouted and went again to call the nurses.”*

- **Mother-in-Law of a 24 year old non Dalit woman (Participant # 37)**  
(12<sup>th</sup> February 2015; Myaulihawa)

#### Time spent by the providers

A higher proportion of disabled (62%), compared to just over half (56%) of non-disabled, and nearly the equal proportion of Dalit (58%) and non-Dalit (57%) respondents reported that the providers spent less than 10 minutes for their ANC check-ups. About one out of three disabled (32%) and two out of five non-disabled (39%), and slightly higher percentage of Dalit (36%) and non-Dalits (39%) than disabled women (32%) said that the providers gave 10 – 20 minutes per consultation for them. One out of twenty women, nearly an equal proportion in both disabled vs non-disabled and Dalit vs non-Dalits women reported that the providers gave them more than 20 minutes for their check-ups. However, there was no statistical significance found for these differences among either disabled and non-disabled ( $P=0.491$ ) or Dalits and non-Dalits groups ( $P=0.557$ ) (Figure 11).

**Figure 11: Comparison by time spent by the providers**



It was commonly reported by many women in their interview that the providers gave more time, with better services, for the known clients. One of the non-Dalit women expressed her experience of the provider taking more than half an hour while checking her pregnancy:

*“Since we knew each other previously we talked about other things too and in total it took more than half an hour for me while checking ANC.”*

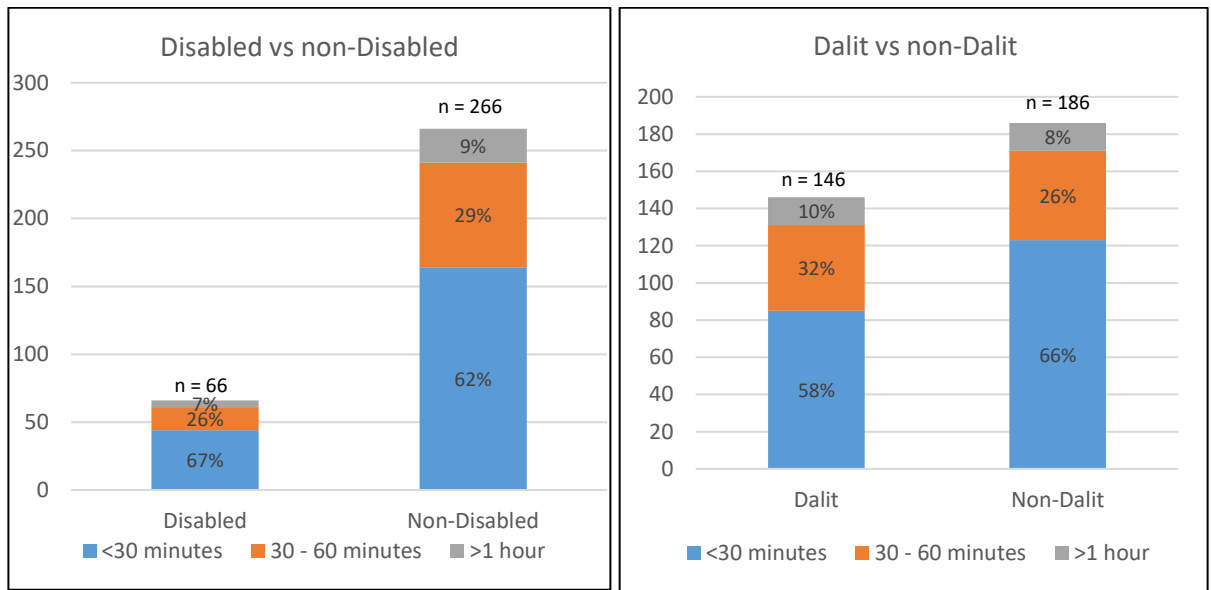
- **A 35 year old disabled non-Dalit woman (Participant # 6)**  
(19<sup>th</sup> February 2015; Saljhundi)

### Waiting Time

Two-thirds of respondents reported that their waiting time for receiving service was less than 30 minutes; over a quarter reported their waiting time as between 30 minutes and an hour; and a small proportion (9%) reported waiting more than an hour. Disabled women reported that they waited less time compared to non-disabled women. In comparison, Dalit women waited a longer time than of non-Dalit women. However, no statistical significance was found between both groups, disabled vs non-Disabled (P=0.742) and Dalit vs non-Dalits (P=0.333) (Figure 12).



**Figure 12: Comparison by waiting time**



In the interviews, participants expressed mixed views about waiting time to receive services; with some saying that they did not need to wait as the service was immediately available and others reporting that they had to wait for some time:

*“I did not really wait when I went for check-up or when I took my baby for injection; occasionally it was crowded and needed to wait some time that was not too long.”*

- **A 35 year old disabled non-Dalit woman (Participant # 6)**  
(19<sup>th</sup> February 2015; Saljhundi)

*“It was comfortable....need not to wait, received services immediately. They took me directly to delivery room.”*

- **A 23 year old non-Dalit, deaf woman (Participant # 16)**  
(10<sup>th</sup> February 2015; Ekla)

*“I had to wait.....there would be many women and I had to wait sometime for ANC check-ups.”*

- **A 27 year old disabled non-Dalit woman (Participant # 8)**  
(19<sup>th</sup> February 2015; Saljhundi)

#### Equipment, Materials and Drugs

A lack of equipment and supplies in most health facilities was a frequently reported and ongoing problem. This situation is often reported as part of a very real issue of limited or lack of resources, but one higher-level government official interviewed felt that this was perpetuated by poor management and organization of available resources:

*“It was really problematic getting a bed in the hospital. We have experienced a case while had gone to Lumbini hospital taking my aunt for her delivery. We did not get a bed for her, the sisters were busy with other cases and my aunt gave birth in a standing position and kept holding the baby. It was so hard for her. Because of not having enough beds we had trouble there.”*

- **A 25 year old Dalit woman (Participant # 19)**  
(15<sup>th</sup> February 2015; Rudrapur)

*“It was too crowded there, there were too many women for delivery at that time and the beds were not enough. So I received a bed later at 11 after waiting much time. The problem of unavailability of bed is for all. Immediately after birth I was kept on the floor with a mattress, in order to empty the bed for others.”*

- **A 21 year old Dalit woman (Participant # 27)**  
(20<sup>th</sup> February 2015; Budhanagar)

The government official stated and accepted that the shortage of medicines and supplies at health facilities is not because of a lack of resources, but rather more likely to be due to policy and systems defects that delay procurement and supply:

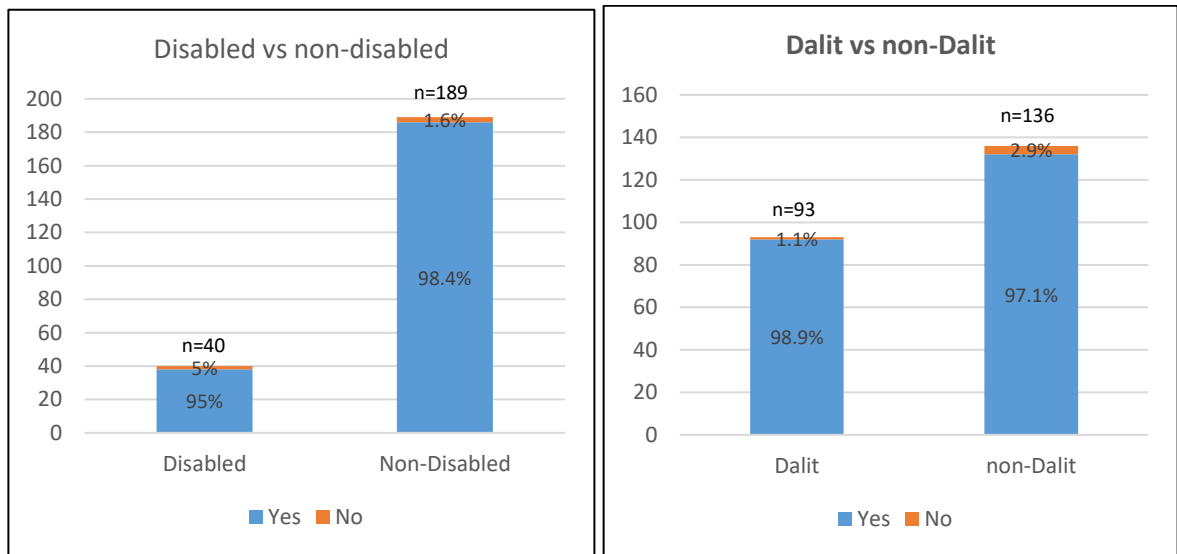
*“The question about if these medicines are in adequate quantity or not. Initially there was shortage of the medicines but the Government increased budget for it so the problem was reduced later but there is still some problem prevalent in some places. While I came here, we had shortage of 3-4 items last year but it is now managed. If the health facility does not ask for the medicine in time there might be shortage having less in stock..... Due to the delay on Tender process, there is delay on medicine procurement and supply too. We have some problem with procurement policy that causes delay in procurement and delivery of medicines.”*

- **KII Participant # 5**  
(1<sup>st</sup> March 2015; Pokhara)

#### Information Communication

Almost all survey participants (98%) reported that they were informed about travel cost and delivery incentives provided by the state (Figure 13). A few disabled women – a proportionately higher percentage (5%) than non-disabled (1.6%) and few non-Dalit women, slightly higher (2.9%) compared to Dalit women did not know about the incentives. However, the difference in both groups - disabled vs non-disabled and Dalit vs non-Dalits - were found to be statistically insignificant (P=0.180 for disabled vs non-disabled, P=0.343 for Dalit vs non-Dalit).

**Figure 13: Comparison by receiving information**



Information and communication is an important element for seeking health care services. Yet, inadequate knowledge and awareness among the service seeking population, poor information and also language factors are reported as common barriers to health care services among disabled women. Not all population groups knew the availability of certain services with equal clarity, for example one women stated:

*“..... she (the nurse) didn’t check other things and never explained; only palpated my abdomen and sent me back with some medicines. That was the same for all.”*

- **A 27 year old disabled non-Dalit woman (Participant # 8)**  
(19<sup>th</sup> February 2015; Saljhundi)

*“I couldn’t get an idea about that at this institution here. One of the sisters was confused whether I was pregnant or not. When I went to Dhakdahi PHC they told me to do a urine test to confirm my pregnancy. They did not explain things clearly to me the first time and I returned back to home. The next time I went, the doctor asked me who had checked me before. Once I told him the doctor was annoyed with his staff, asking why they didn’t check me properly.”*

- **A 30 year old disabled Dalit woman (Participant # 3)**  
(20<sup>th</sup> February 2015; Siktahan)

Many women, disabled and non-disabled and Dalits and non-Dalits, commonly reported that the health providers did not give them information clearly. Some of them missed their postnatal check-ups as the providers did not inform them about this during their ANC or delivery:

*“I did not go for check-up after delivery because I had not known that I needed to. They had given me some painkiller and liquid medicines to clean the wound and my husband used to help me with cleaning it. He also did not say that we should go for a check-up.*

- **A 25 year old non Dalit woman (Participant # 33)**  
(15<sup>th</sup> February 2015; Rudrapur)

Sometimes the challenges were not just about what the women were told, but also how they were told it, for example the mother of a deaf participant, who is an active FCHV in her community, expressed her opinion that the state should provide a Sign Language interpreter to communicate with those who are deaf:

*“Whatever is given they are giving well. But it would be much more helpful if they could provide special service to deaf and disabled people. Whoever can speak they can share their feelings but those who are unable to speak, they won’t be able to share it so I think they should provide interpreter or special service with priority for them.”*

- **Mother of a 23 year old non-Dalit deaf woman (Participant # 16)**  
(10<sup>th</sup> February 2015; Ekla)

A DPO leader and member of local health facility operation and management committee commented that neither the female community health volunteers nor the other actors in the community disseminated information to the people as envisioned by the health delivery system:

*“I do not know about the female community health volunteers (FCHVs) of other places but right now I am talking about the FCHVs of Devdaha, they have not been able to make the information accessible to the women in this area. Also the leaders and the activists have not been able to spread that information and news.”*

- **KII Participant # 1**  
(21<sup>st</sup> February 2015; Devdaha)

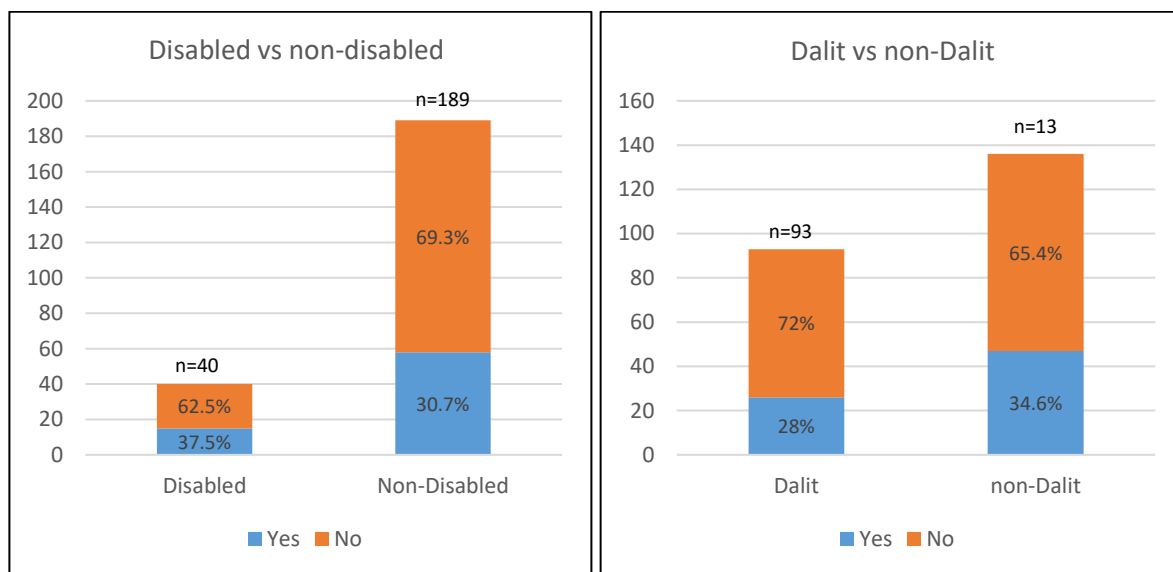
#### **5.2.4.3 Affordability**

##### **Cost for services, medicine and supplies**

Figure 14 shows that out of the total survey of participants attending health facilities for their deliveries, one third of both disabled vs non-disabled and Dalits vs non-Dalits reported that health facilities charged them for services and supplies despite the government provision of free maternal health care. A higher proportion of disabled (37.5%) than non-disabled (30.7%) and higher proportion of non-Dalits (34.6%) than Dalits (28%) reported that the health facility charged them for services and supplies during delivery. However, these differences were not found to be

statistically significant in either disabled vs non-disabled ( $P= 0.401$ ) or Dalit vs non-Dalits ( $P= 0.292$ ) groups.

**Figure 14: Comparison of service users by extra cost paid for services and supplies**



The government of Nepal has made a commitment to provide basic primary health care service free of cost to its citizens. Since the enforcement of the “Maternity Incentive Scheme” in 2005, the government has reimbursed transport costs to women who have four or more ANC check-ups, and distributed delivery incentives for those giving birth at health facilities. In 2009, under the “Aama Surakshya Karyakram” scheme (Safe Motherhood Programme), government expanded these services and declared free maternal health care services up to tertiary level. However, some respondent reported that these provisions have not reached to all groups of people equally:

*“Under Aama Surakshya Karyakram as per the access of transportation expense of Rs 1,500 for mountain region, Rs 1,000 for hill and Rs 500 for Terai are given....not to the general public but only to those who come for delivery. Government provides transportation expense to those for delivery and every services including delivery are free of cost...free of cost is universal, and service is free to all who ever come to take the service.”*

- **KII Participant # 6**  
(18<sup>th</sup> March; MoHP)

*“While talking about medicines there are 35 free medicines in Birthing Centre and 32 in other health posts/sub health posts which are used in primary care. Recently the government has decided to increase from 32 to 35 items in Health Posts and 60 in PHCCs but it has not been*

*implemented as if now but is soon to be. In addition, the vaccines, medications for TB, Leprosy, malaria, dengue and other program items are all free.”*

- **KII Participant # 5**  
(1<sup>st</sup> March 2015; Pokhara)

It is perhaps not surprising that the government vows provision of free services, but in reality free provision does not occur. Moreover, due to poor implementation of policies, the most marginalized and vulnerable are the least likely to receive these benefits. As one respondent noted:

*“It costs money. They asked me for 40 thousand in the Medical College, 20 thousand in Bhim Hospital. AMDA also asked a huge amount at the beginning. When my sister-in-law and I started crying and they considered reducing the amount and giving some time for us to get the money from our home/village. However, we paid Rs 5,101 for the operation.”*

- **A 26 year old disabled non-Dalit woman (Participant # 17)**  
(10<sup>th</sup> February 2015; Ekla)

*“It costs money to go hospital and at home it doesn’t cost any. They charge even for check-up and medicines.”*

- **A 35 year Muslim disabled woman (Participant # 15)**  
(10<sup>th</sup> February 2015; Ekla)

Many of the participants interviewed, including FCHVs, reported that it is often difficult to get free services and cash incentives. While some did report that they received free services and also the full incentives as provisioned, others did not:

*“In case of delivery in hospital and four ANC visits, there is a provision of Rs 900 but they have to spend Rs 400 to 500 for transport in each visit and how could they just for Rs 500? Women visit the hospital for the sake of getting the money even by fighting in their family but they get only Rs 500 for check-up and cannot get Rs 400. I, myself got Rs 500 in my case and was not given Rs 400. As the women like me, are not given the full amount, how could be the poor and ignorant people treated well? There is much negligence in hospital. That’s why women have lost their lives at home without visiting the hospitals.”*

- **KII Participant # 2**  
(16<sup>th</sup> February 2015; Dhakdahi)

## Income

Approximately eight out of ten of the female disabled participants reported that they were unemployed and their occupation was that of subsistence farmer. The rate was slightly higher amongst non-disabled respondents (84.7%). Moreover, one-third of disabled participants and nearly an equal proportion of non-disabled participants reported that their husbands were also unemployed or worked as seasonal farmers. However, over half of disabled (50.6%) and slightly more than half of non-disabled women (54.5%) reported a mixed income source for their family.

About nine out of ten Dalits and just over eight out of ten non-Dalits reported themselves as being unemployed or seasonal farmers. Similarly, more than one-third of Dalit respondents (37.1%) and nearly the same proportion of non-Dalits (35.3%) reported that their husbands were not employed and only had seasonal farming occupations. Over half of non-Dalit women (51.2%) and slightly more than half of Dalit women (57%), reported having a mixed source of household income. However, none of the differences in respondent's occupation, the husband's occupation or household income showed any association statistically ( $P>0.05$ ) (Table 22).

**Table 22: Occupation and Income**

	Disabled	Non-disabled	P-value	Dalit	Non-Dalit	P-value
<b>Respondent's Occupation</b>	n=79	n=275		n=151	n=203	
Unemployed/Farmer	65 (82.3%)	233 (84.7%)	$P=0.599$	132 (87.4%)	166 (81.8%)	$P=0.150$
Employed (Service/Business)	14 (17.7%)	42 (15.3%)		19 (12.6%)	37 (18.2%)	
<b>Husband's Occupation</b>	n=77	n=275		n=151	n=201	
Unemployed/Farmer	27 (35.1%)	100 (36.4%)	$P=0.834$	56 (37.1%)	71 (35.3%)	$P=0.733$
Employed (Service/Business)	50 (64.9%)	175 (63.6%)		95 (62.9%)	130 (64.7%)	
<b>Main Source of Family Income</b>	n=79	n=275		n=151	n=203	
Farming/Daily wages	28 (35.4%)	69 (25.1%)	$P=0.141$	43 (28.5%)	54 (26.6%)	$P=0.194$
Employment (Service/Small Business)	11 (13.9%)	56 (20.4%)		22 (14.6%)	45 (22.2%)	
Other Sources/Mixed	40 (50.6%)	150 (54.5%)		86 (57%)	104 (51.2%)	

Very few (6.3%) disabled women reported that they received disability allowance (which is very nominal) from the government. Around eight out of ten disabled (78.9%) and nine out of ten non-disabled (88.2%) respondents said they received the transport or delivery incentives given by the state under the Safe Delivery scheme for their last delivery. A comparatively higher proportion of

Dalits (90.2%), versus 84.1% of non-Dalit women, received this incentive. None of these differences show any significance statistically however ( $P>0.05$ ) (Table 23).

**Table 23: Allowances and Incentive**

	Disabled	Non-disabled	P-value	Dalit	Non Dalit	P-value
Receive allowances?	n=79					
Yes	5 (6.3%)					
No	74 (93.7%)					
Received Transport/delivery incentive	n=38	n=186		n=92	n=132	
Yes	30 (78.9%)	164 (88.2%)	$P=0.128$	83 (90.2%)	111 (84.1%)	$P=0.185$
No	8 (21.1%)	22 (11.8%)		9 (9.8%)	21 (15.9%)	

It has been reported that maternity care services, including drugs and supplies, are free of cost but some hospitals did charge for some items and sometimes for services as well. Due to this, respondents encountered financial problems not only paying transport costs but also paying for the cost of services and supplies. Moreover, respondents reported that the hospital deducts the charges from their incentives and therefore they receive nothing in hand:

*“They had given me Rs 500 for delivery but they deducted it all as the charge of the hospital. On top of that we had to pay Rs 50 as bed charge.”*

- **A 31 year old disabled non-Dalit woman (Participant # 12)**  
(11<sup>th</sup> February 2015; Deepnagar)

*“There was no one to help me to go to the hospital. I had the financial problem too. I did not have money even to pay for the transportation. This was the reason not to go hospital. There were not any other reasons to deliver at home.”*

- **A 31 year old disabled non-Dalit woman (Participant # 9)**  
(17<sup>th</sup> February 2015; Bishnupura)

#### 5.2.4.4 Acceptability

Many women interviewed described issues of acceptability among both provider and users. Gender, attitude and experience of the providers were reported as major concerns while seeking services. The user’s caste/ethnicity and disability were also reported as influencing factors for acceptability in receiving services. The rejection of a disabled woman by health services could be



an indicator of inexperienced providers in the facilities. With regards to gender, some participants described their experience with male service providers, for example:

*“There will of course be some difference between ladies and gents. Uncomfortable as in... they did not do or say anything bad but if it is a lady doctor we can tell our problem openly. But when a male doctor looks at us, it is not comfortable.”*

- **A 30 year old Dalit woman (Participant # 18)**  
(15<sup>th</sup> February 2015; Rudrapur)

*“.... it comes to the mind that either there will be ladies or gents to examine, whether the doctor is experienced or not. But I was lucky and all the time there was ladies to examine me.”*

- **A 25 year old Dalit woman (Participant # 19)**  
(15<sup>th</sup> February 2015; Rudrapur)

Almost all women interviewed expressed their hesitation to be examined by the male service provider. Even a service user from the same profession reported feeling uncomfortable seeing a male provider:

*“Certainly that matters. All women want to be checked by a lady doctor. Some women hesitate to go for a check-up with a male doctor/provider. I have found one of the main reasons not attending HF for ANC and delivery among village women is male providers. There was female gynaecologist and other female general doctors in my hospital so I didn’t have any hesitation to receive the service.”*

- **A 26 year old non-Dalit disabled (Auxiliary Nurse Midwife) (Participant # 7)**  
(19<sup>th</sup> February 2015; Saljhundi)

A non-Dalit women in her in-depth interview shared that the examination place was very basic with a bench type examination bed; however, her privacy was maintained during her check-ups:

*“...there was a bench/bed, they asked me to lie down on the bed and pulled the curtain and checked me privately.”*

- **A 35 year old disabled non-Dalit woman (Participant # 15)**  
(10<sup>th</sup> February 2015; Ekla)

Other women found the providers positive, nice and behaving respectfully while providing the service. Two disabled and one non-disabled non-Dalit women described their experiences as:

*“The sisters were nice. They behaved well and provided services in a lovely manner. Nurses in Bhim hospital were very happy to provide service to me.”*

- **A 23 year old deaf non-Dalit woman (Participant # 16)**  
(10<sup>th</sup> February 2015; Ekla)

*“The sisters there kept on saying to me that you have already done the regular check-ups so you can have the baby normally but in case if there is some problem, we have our ambulance ready. If we cannot do it here then we will send you to the zonal hospital immediately that is why I was completely confident with it. I was already there in Butwal but I got restless so I returned back. I was there till 5pm and when I returned I had started the labor pain.”*

- **A 26 year old disabled non-Dalit woman (Participant # 10)**  
(11<sup>th</sup> February 2015; Devdaha)

*“They asked me if I had any problem. They behaved nicely to me. While going during pregnancy, they checked the condition of baby, palpated and measured abdomen with tape and took my weight as well. After the check-up they told me that the baby is fine.”*

- **A 26 year old non-Dalit woman (Participant # 36)**  
(12<sup>th</sup> February 2015; Myaulihawa)

However, many of the women interviewed encountered poor attitudes and behaviours of the providers while seeking the services. Such attitudes were expressed as misbehaviour, rudeness and use of abusive words; scolding and even slapping:

*“I felt I was not treated well. I had to stay in line like other normal people; in addition, if I asked anything they used rude and abusive words. I do not know if that was their normal way of speaking or behaving to all or that was only to me, but I did not find them polite. I had heard that private hospitals have better management and care, so I went to AMDA.”*

- **A 33 year old blind non-Dalit woman (Participant # 11)**  
(11<sup>th</sup> February 2015: Karahiya)

*“The sister who looked after me was comparatively polite than others because those who were crying out of pain were being scolded by other sisters. I found them very rude.*

- **A 31 year old disabled non-Dalit woman (Participant # 12)**  
(11<sup>th</sup> February 2015: Karahiya)

*“The woman was not listened to, and was shouted at instead, was compelled to give birth terribly. She has promised that she will never go to the hospital again. There are many weaknesses in hospitals. If they don't behave properly to the clients, beat them; scold them, how can those women visit the hospitals.”*

- **KII Participant # 2**  
(16<sup>th</sup> February 2015; Dhakdahi)

A majority of the women interviewed who have had bad experiences opined that such negative attitudes and behaviours were mostly encountered by providers in secondary and tertiary level

public hospitals. Very few respondents reported such attitude and behaviour issues with providers in privately run or grassroots (community) health facilities:

*“There were no such natural differences. They were treating everyone equally. I used to tell them that I had a dislocated joint and had Bone TB. Therefore, I have a bit shorter leg with a slightly deviated hip and asked them if they could do the normal delivery for me and took their suggestion. They said the normal birth could be possible and the condition of the baby was also good. They also said that if there were any complications then they have an ambulance as well and they will send me immediately. They also said that I need not to pay the fare. They reassured me that they would give me all the services and facilities they have. I was totally relieved at that time.”*

- **A 26 year old disabled non-Dalit woman (Participant # 10)**  
(11<sup>th</sup> February 2015: Devdaha)

A government senior official in his interview accepted that there is a lack of creating a welcoming environment for the clients in government health facilities. He expressed his view in regards to staff attitude as:

*“..... they strictly follow the technical part. Other things like client relation, behaviour with the patients and creating suitable environment, we have found flaws in them. That some of them have formally done well and we also have received some complaints regarding the same.”*

- **KII Participant # 5**  
(1<sup>st</sup> March 2015; Pokhara)

In some cases, the respondents reported that they were not very confident with the providers since they felt the providers were very young and lacked experience and skills to assist them:

*“.....because of the twins, the sisters did not know how to deliver them. They were young girls. These days those sisters don't do anything....., they only observe ..... Will it happen just by looking to us....? Instead they ask us to put effort!”*

- **A 35 year old physical disabled Dalit woman (Participant # 1)**  
(17<sup>th</sup> February 2015: Kerbani)

*“My blood group is negative. In my previous pregnancy, they said I had to be injected within 24 hours while having my daughter and they did not have that facility. Therefore, they referred me to AMDA from the health post. I did in AMDA previously then I thought they would not be able*

to read the report here in the health post and went to AMDA again.”

- **A 28 year old disabled Dalit woman (Participant # 4)**  
(11<sup>th</sup> February 2015; Devdaha)

*“I don’t get better taking medicine from government hospitals. The problem gets aggravated once I take the medicines from those hospitals. I believe doctor Gupta, he runs a private clinic near our own place at Sankarpur, and if we go there, I get better. In hospitals, they always give me green colored cetamol (paracetamol) that makes me worse, giving me sleeplessness, burning legs and more body pain. In the private clinic, Dr Gupta gives me suitable medicine including a tonic that helps me. He also advised me to take more green vegetable and that was also helpful”*

- **A 30 year old disabled Dalit woman (Participant # 3)**  
(20<sup>th</sup> February 2015; Siktahan)

In some cases, it was also found that culture has influenced acceptance by providers and how women seek services from a health facility:

*“All the people in ‘Purdah’ (Vail) do not like going out for check-up but some do. They like to call the doctor to their home if they do not like going to the health centres for check-up.”*

- **A 35 year old Muslim disabled woman (Participant # 15)**  
(10<sup>th</sup> February 2015; Ekla)

#### 5.2.4.5 Accommodation

##### Physical infrastructures and Access

Most of the health facilities in the study area were found to be inaccessible. The physical infrastructures including external barriers such as lack of ramps and internal barriers in delivery rooms and toilets as well as inaccessible equipment were reported by many disabled women. A non-Dalit blind service user described her experience as:

*“It is not comfortable for a disabled person, even the toilet. A blind person cannot walk inside - had there been orientation it would have been easier. Infrastructure is also not easy for disabled persons, from toilet or to consultation rooms. I felt even sisters do not have the awareness. They ask us to go to certain numbered room, since we cannot see we will have to ask and go. Some people show the direction, which is difficult.”*

- **A 31 year old blind non-Dalit woman (Participant # 12)**  
(11<sup>th</sup> February 2015; Deepnagar)

A DPO leader, who was also the member of management committee in a local health facility, reported that not only the disabled women but also non-disabled women often encountered

barriers during their labour and delivery, and specifically cited wheelchair inaccessible entrances and toilets in the buildings. Furthermore, none of the health facility staff interviewed were given any orientation on how to deal with disabled persons:

*“.....if they do reach to the health facility then the staffs there ask go here and there but do not help so they won't know where she will bump. Although the government is saying that health facilities should be made disabled friendly, but they are not. When you reach there in that scenario if a woman who has to use a wheel chair after she gives birth or even before that to go to the toilet, the toilets is not disabled friendly. There are no ramps for the wheelchairs in the health facilities, the government hasn't instructed or oriented the health service providers how they should behave for a disabled people while coming for services.”*

- **KII Participant # 1**  
(21<sup>st</sup> February 2015; Devdaha)

Government policy planners accept the reality of difficulties encountered by disabled women due to inaccessible infrastructures. Surprisingly, both health providers and policy planners did not know about adjustable delivery tables and other equipment for those with disabilities. They were unaware whether it is available even in their central level maternity referral hospital:

*“The provision of adjusted equipment and beds to examine for the persons with disabilities were not there. If the woman was able to climb on the bed or if it was comfortable for her to deliver on the bed, then we put her on the delivery bed during childbirth, if it was uncomfortable for her to deliver on a delivery bed then we put her on normal bed for her delivery. The hospital does not have a facility to support complex/severe disabled cases for her delivery.”*

- **A 26 year old disabled non-Dalit woman (Health provider) (Participant # 7)**  
(19<sup>th</sup> February 2015; Saljhundi)

*“Adapted beds are not available. I do not think it is available even at Prashuti Griha (A tertiary level maternity hospital) in Kathmandu. So it is not available at districts but there is provision for delivery services in general.”*

- **KII Participant # 6**  
(18<sup>th</sup> March 2015; MoHP)

*“.....such services are not at available. We do not even have disable-friendly toilets. They have problem even to walk as we do not have corridors.”*

- **KII Participant # 6**  
(18<sup>th</sup> March 2015; MoHP)

### Internal Arrangement and Space Availability

Poor infrastructure, inadequate space and poor internal arrangements of available space are common characteristics of health facilities in Nepal. In addition to the access difficulties created by the geographic remoteness and built infrastructures, the participants reported that they encountered difficulties with poor management of available space and materials whilst in the health facilities:

*“I felt a bit uneasy in the health post; there was no place to sit and everyone was sitting on the floor. It will be cold to sit on the floor. We had to stand or sit on the cold floor. But now they have made it outside but still there is no planning and facility to sit. It is very hard for a pregnant woman to stand or sit long on the floor. The seats should be made available.”*

- **A 26 year old physical disabled non-Dalit woman (Participant # 10)**

*(11<sup>th</sup> February 2015; Devdaha)*

*“.....in terms of access, as I said those who are poor, Dalits, marginalized and geographically secluded do not have access....so how can they get services? Provision for special intervention should have been made, which however is not seen. For disabled also, nothing much has been done. We do not have disabled friendly hospitals. Even if people with disability come to take services they do not get services they should be getting because services are equal for all. There should have been additional services for them but we do not have it.”*

- **KII Participant # 6**

*(18<sup>th</sup> March 2015; MoHP)*

### Opening Times

Inconvenient and limited opening hours of health facilities were often reported by the participants in both quantitative and qualitative interviews as one of the reasons for non- utilization of services. The quantitative survey result showed that out of 22 women who did not receive ANC services at all in their last pregnancy, 18% reported that the reason was due to the health facility being closed when they tried to visit. Some other participants interviewed stated that the services at village-level health facilities were inconvenient as they had short opening times, as illustrated by an employed physical disabled woman:

*“They used to ask me to come for check-up. But I had to go on duty which made it difficult to wait for long in the mid-day.”*

- **A 26 year old physical disabled non-Dalit woman (Participant # 10)**

*(11<sup>th</sup> February 2015; Devdaha)*

### **5.2.5 SUMMARY OF KEY FINDINGS**

The results presented here demonstrate that maternal health care services are not easily and equitably accessible to all social groups, preventing full utilization of services for all women.

Irrational distribution and location of health facilities, often far from what might be seen as deprived areas and communities, with poorly linked road and transport facilities, were found to make maternal health care services inaccessible, in particular for Dalits, disabled women and the poor.

A majority of the users surveyed perceived that the health facilities are staffed adequately and easily accessible for services but this was not the case for every group. The policy implementer, a civil servant, accepted the fact that there were challenges of staff shortages, inadequate and often delayed supplies of drugs in the health facilities due to poor management, and other policy and system defects despite policies to the contrary.

The data demonstrates disparities in many aspects of providing services. For example, it was commonly seen that little time was given by the providers for disabled and Dalit women during examinations, and beds were unavailable during delivery for those who had not been seen in the doctors' private clinic. Most importantly, lack of information and communication was found to be a key barrier in accessing maternal health services. Almost all participants expressed the opinion that the providers did not give enough information or clearly explain issues or information about their pregnancy during consultations. Moreover, in the case of disabled women - particularly for those with communication difficulties - there was no provision for extra support.

The analysis also found mixed opinions by the users around what was 'acceptable'. Factors such as provider's gender, negative attitude and insensitivity toward disability, and limited exposure and experience around the care and treatment of disabled women were found to be related to negative service environments. Social and cultural factors, such as the reluctance of Muslim women to be examined by a male doctor, and little or no confidence in the providers' skills were also found to influence the degree to which the pregnant women themselves accepted services.

The study also revealed that utilisation of maternal health services involves cost, despite the policy of free maternal health care provision. However, representatives of the government themselves acknowledge that these policies are poorly implemented, and that maternal services are often not affordable for low-income groups.

It was also found that people were required to pay direct and indirect costs for services and materials. Clients were often asked to have extra tests and examinations beyond maternal care protocols for pregnancy and delivery that were not covered by the government's free maternal health care provision. In addition, expensive transport cost, opportunity costs (cost of lost work) and additional costs related to being disabled such as cost for someone to accompany them, have made the services out of reach for disabled women in poor economic situations.

It was apparent that none of the health facilities were accommodating the needs of disabled and working women, with barriers identified in physical infrastructure, materials and equipment - including opening times.

The study also noted that many issues raised here do not support by statistical analysis, however number of issues in the qualitative interviews such as provider's negative attitude; hesitation on behalf of the women to receive services by the male providers; and perceptions of staff adequacy and availability were common concerns of women across all groups. Some issues were of greater concern for specific groups however. For example, disabled and non-Dalit women reported that the distance, transportation and health facility opening time was not the major problem for vast majority of them, whereas it was one of the biggest problems for Dalit women. Similarly, information, communication and physical environment of health facilities were more of a concern for disabled women than Dalit and non-Dalit women. The issue related to cost was predominantly reported as major concern by Dalit and Disabled women.

In sum, the study found maternal health care service more inaccessible particularly for disabled and Dalit women. The following section discusses on the key findings in the preceding sections.

## **5.3 DISCUSSION**

### **5.3.1 DISCUSSION: MATERNAL HEALTH CARE SERVICE UTILIZATION**

The study found that maternal health care service utilization, ANC and health facility delivery, except PNC services in the study district was better than the national average. However, utilization was not equitable among the study groups (i.e. disabled Dalit, disabled non-Dalit, non-disabled Dalit and non-disabled non-Dalit) with lower utilization by women with disability, despite the government's effort over past decades to improve the health status of marginalized women. Nepal's second Long-term Health Policy (1997 – 2017) and Health Sector Support Program implementation plans incorporated gender equality and social inclusion strategy to mainstreaming excluded groups such as disabled and Dalits (GoN/MoHP, 2004), however the improvements in



their maternal health indicators was minimal (GoN/NPC, 2013). This study also shows that disabled women have lower utilization of all services compared to non-disabled Dalit women and non-disabled non-Dalits. It found that the disability status of pregnant Nepalese women was associated with reported utilization of at least one antenatal care visit, health-care facility delivery and post-natal care visits. Moreover, the result showed that disabled women have the lowest socio-demographic indicators. Multivariate analysis of their health care utilization and socio-economic indicators (particularly education and wealth) confirmed that these were the dominant factors affecting their utilization. It suggests that disabled women were less likely to utilize maternal health services due to their household socio-economic circumstances. However, the analysis of quantitative and qualitative data reveals the relationship between disability and socio-economic status is complex with poverty as a contributory cause and consequence of disability (Trani et al., 2011).

There are no other statistics available to compare the findings of this study to any others in Nepal since the government has limited mechanism for recording disability data, nor have previous studies on maternal health care collected disability data in their studies. However, the few qualitative studies conducted in Nepal focusing on the maternal health of disabled women indicate poor utilization of services, which contrasts with some findings from developed countries (Morrison et al., 2014; UCL/LCD, n.d.). For example, a UK study found disabled women receive more maternal health care services than their non-disabled counterparts during pregnancy (Redshaw et al., 2013). This research speculates that the reasons for this might include pre-existing familiarity with health care services on behalf of women with disabilities prior to their pregnancy; and the possibility of a more structured and intensive approach to disability pregnancy care offered by well-developed health systems in developed countries.

There was no **caste differences** identified in the utilization of maternal health care services. Dalit pregnant women utilized services less than non-Dalit in both disabled and non-disabled groups. Nonetheless, the utilization of at least one ANC visit was unexpectedly higher among Dalits in both disabled and non-disabled Dalits groups compared to their non-Dalit counterparts, while the recommended four or more ANC visits and health facility delivery were lower than non-Dalits. The quantitative data showed that women with lower level of education had less utilization of antenatal care. However, the qualitative interviews with Dalit women also revealed that health workers did not provide basic relevant information to many women about the progress and health

of their pregnancy, nor the benefits of attending for further care. Therefore, perhaps it is not surprising that few completed the recommended four ANC visits.

The lower maternal health care utilization among Dalits compared to non-Dalits in Nepal (GoN/MoHP/DoHS, 2013; GoN/MoHP/PD, 2011; Khanal et al., 2014; MoHP/NewEra/OrgMacro, 2007; Paudel & Pitakmanaket, 2010; Shah et al., 2015) and in India (Saroha et al., 2008; Saxena et al., 2013; Sharan et al., 2005) is reported consistently in the literature. Other research findings have also reported a gap between health providers and recipients of care in Nepal with poor communication and engagement of providers (Niraula, 1994). Furthermore, some researchers have noted that Nepalese women are overloaded with work in and outside their home, and many do not have enough time to visit a health facility frequently (Matsumura & Gubhaju, 2001). Dalit women on average have even longer workdays and often more physically demanding tasks, which may not leave them enough time or energy to seek services (Bhattachan et al., 2009).

The mixed nature of the findings in this research were consistent with the mixed nature of findings of a relation between caste and service utilization reported in the literature. For example, a number of studies reported social class and caste as important determinants influencing access and utilization of maternal health care (Saroha et al., 2008; Saxena et al., 2013), whereas others reported no relation (Niraula, 1994).

This study found significantly lower utilization of post-natal care among all study groups in comparison to national statistics and as consistently reported by previous researchers (Dhakal et al., 2007; Khanal et al., 2014).

An encouraging finding of this study is the effect of ANC attendance and health facility delivery on PNC utilization: it found that women who attended four or more ANC visits (as per national guidelines) were more likely to give birth at a health facility. Similarly, the possibility of attending postnatal care was higher among women who attended ANC and gave birth at a health facility. Other studies in Nepal (Khanal et al., 2014) support this premise, as well as in an entirely different context, Ethiopia (Worku et al., 2013). However, another study conducted in Nepal (Shah et al., 2015) contradicts this finding, as that did not show any effect of ANC use on health facility delivery.

As stated in the MoHP "National Medical Standard for Reproductive Health: Volume III", women who deliver at a health facility should have more access to their first PNC within 24 hours of

delivery (GoN/MoHP/FHD, 2009). However, this study suggests that not all women who delivered at health facility received their PNC check. This is supported by the qualitative findings, which revealed that many women were discharged immediately or after only few hours after delivery without postnatal checks, sometimes because of insufficient beds due to heavy pressure created by high flow of delivery clients **(Section: 5.2.4.2)**.

The qualitative findings also revealed that mothers were not counselled properly and providers were not giving any information about the PNC check-up to women when they attend ANC or health facility delivery. Women also often confused when they should come for PNC with the dates for their baby's vaccination, which is normally much later (45 days after delivery). Low levels of awareness and women not perceiving any risks after childbirth are amongst the most common reasons for not utilizing PNC services. The qualitative findings below **(Chapter Seven, section: 7.2.1.4)** also revealed that rigid cultural practices and traditional beliefs of purity, impurity and "evil eyes" (misfortune due to malicious super-natural spirits), which often prevent recently delivered mothers and new-borns to be touched by anyone or leave the house before 12 days after delivery. Similar findings are reported by another study in Nepal (Khanal et al., 2014).

### **5.3.2 DISCUSSION: FACTORS ASSOCIATED WITH MATERNAL HEALTH CARE SERVICE UTILIZATION**

The study identified a number of individual, socio-demographic and family related factors associated with maternal health care service utilization. These are woman's age and parity, education, occupation, empowerment, husband's education, source of family income and household wealth. These factors are discussed in turn below.

#### **5.3.2.1 Age and Parity**

Women's age was associated with utilization of at least one antenatal care, and parity with health facility delivery. The association was an inverse one, indicating that younger women were more likely to attend at least one ANC. Similarly, women were more likely to deliver at a health facility for their first birth. This finding corresponds to previous studies carried out in Nepal (Karkee et al., 2014; Wagle et al., 2004), India (Saroha et al., 2008), Turkey (Celik & Hotchkiss, 2000) and Tanzania (Kruk et al., 2010) where age and parity showed clear association with maternal health care service utilization. This suggests that women having a first time pregnancy may perceive more risks, as commonly reported in the qualitative interviews. Some of the fears expressed were due to lack of prior experience of childbirth (a factor that might be experienced by women anywhere);

whilst other common anxieties stemmed from a lack of reliable information that could arguably have been reduced by better information given by health workers during pregnancy.

#### ***5.3.2.2 Education***

Women's level of education was a strong predictor for utilization of maternal health care services, showing a positive association with the recommended four ANC visits and having a HF delivery. Women with higher education were found to be more likely to have regular ANC visits as recommended and health facility delivery, consistent with findings from other settings (Ahmed et al., 2010; Celik & Hotchkiss, 2000; Pandey et al., 2011; Worku et al., 2013). One reason for this could be that educated women have a greater understanding of the benefit of using services. Moreover, education may enhance women's autonomy, increasing their status in the family and helping them to access services more easily (Matsumura & Gubhaju, 2001).

#### ***5.3.2.3 Occupation***

Women's occupation appeared to be an important factor in determining maternal health service uptake. The current study identified the fact that women engaged in paid employment or involved in business were more likely to receive the full-recommended ANC and PNC services. This supports the findings of a number of recent scholars (Dhakal et al., 2007; Khanal et al., 2014; Paudel & Pitakmanaket, 2010). Women with paid occupations are more economically independent and consequently have better access to services.

#### ***5.3.2.4 Empowerment Index***

Using an index constructed with tools that assessed women's involvement in decision-making, participation in external networks and citizenship status, the study confirmed that women with higher empowerment scores were more likely to attend four or more ANC visits, a rate much higher than those with lower empowerment scores. Ahmed et al., (2010); and Pandey et al., (2011) report similar finding in their studies. Empowered women may have more access to information and resources as well as autonomy and ability to make their own decision to seek and attend services. It provides evidence of the need for women's empowerment to be placed within the broader context of public health initiatives to increase utilization of maternal health care services.

#### ***5.3.2.5 Husband's Education***

Of all the family characteristics, the multivariate analysis identified that the husband's level of education, together with the main source of family income and household wealth was significantly associated with maternal health care service utilization. Women with educated husbands were

more likely to utilize recommended ANC visits and give birth at a health facility. This finding is consistent with the results of previous studies in Nepal (Paudel & Pitakmanaket, 2010), Bangladesh (Chakraborty, Islam, Chowdhury, Bari, & Akhter, 2003) and Peru (Elo, 1992). Educated husbands may have better information and knowledge about the risks of pregnancy and service availability. In addition, educated men may seek more educated wives and educated women with an educated family may have a more supportive environment with their knowledge and exposure that may enable them to seek the services.

#### *5.3.2.6 Source of Family Income*

When the effect of family income source and household wealth was examined, the study found that women having mixed and regular sources of family income were more likely to attend at least one ANC and have a health facility delivery. Worku et al., (2013) found similar findings in Ethiopia. This indicates that regular and varied sources of income may give confidence and choices for women to pay the costs for service use.

#### *5.3.2.7 Household Wealth*

Household wealth was found to be an important factor in maternal health care utilization. After controlling other factors, the result showed that its effect was only with the health facility delivery, indicating that women from wealthier families are more likely to give birth at a health facility. This may have been due to easy availability of other maternal care services (such as antenatal and postnatal care) to all women nearby with no cost. This differs from the findings of Celik & Hotchkiss, (2000); Dhakal et al., (2007); Paudel & Pitakmanaket, (2010), whose studies concluded that household wealth was also associated with increased antenatal and post-natal care visits.

Nonetheless, the findings of this study align more closely with previous studies carried out in Nepal by Pandey et al., (2011) and Ahmed et al., (2010) that also concluded that more women from economically well off families have a skilled or health facility delivery.

Better household economic status may also result in greater women's ability and willingness to pay out of pocket expenses associated with health care utilization. Maternal health care services are free in Nepal; however, women often need to pay other costs for services, supplies and transportation. Hence, the extra costs for services and expensive transportation frequently create a barrier.

### 5.3.3 DISCUSSION: ACCESS

The findings above revealed that women with disabilities and Dalit women did not have equitable access to maternal health care services, despite the national implementation of Safe Motherhood initiatives designed to improve access for all. The study tried to understand this more by exploring the factors relating to both supply and demand for maternal health care services.

Discussion with policy makers and implementers revealed that specific needs of women with disabilities are invisible at policy and planning level; this translated into health care settings, which were unsuitable to cater to the basic needs of many women with disabilities and a workforce that was uninformed and ill prepared to provide appropriate care (**see below Chapter Seven, section: 7.2.1.7**).

Considering demand side factors (household and societal barriers) to seeking care, the study found that many women with disabilities were less empowered to make their own decisions and more reliant on the knowledge and attitude of other family members, who were often reported negative attitudes prevalent in society as a whole. They were also more reliant on the family members in seeking health care, rendering them more vulnerable to not accessing the care they needed.

Dalit women who accessed maternal health services did not report that any negative experiences were attributable to their caste. However, more detailed exploration with Dalit women revealed a persistent and prevailing self-perception of inferiority and low self-esteem, which reduced their confidence and willingness to seek services that were usually provided by health workers from higher social groups. This internal perception was independent of any behaviour, good or bad, displayed to them by health workers. This will be discussed in more detail in **Chapter Seven**.

#### *5.3.3.1 Distribution/Location of HF and availability/adequacy of services, staff, supplies and drugs*

Like many other low income country studies (e.g. Buor, 2004), this study found disproportionate distribution and availability of health care facilities, which tended to favor urban populations. The policy planners accept the presence of an uneven distribution of health services, with decisions of where to site services often based on political interest and power rather than equity and population needs (**Findings above: 5.2.4.1**). A significantly higher proportion of Dalits reported that the location of health facilities was far for them compared to non-Dalits. In fact, Dalit settlements are often separated and far from the higher caste population, while health facilities

are normally located near to well off or socially powerful groups (Bhattachan et al., 2009; Gurung, 2003).

The main factors affecting accessibility and utilization of health care services commonly reported in the literature are long distances to health facilities, poor roads and high transport costs especially in hills and rural area, long waiting and unhelpful opening times of health facilities. In addition, high rates of absenteeism of health care staff often impeded service utilization (Choulagai et al., 2013; Thomas et al., 2012). Not all of those issues were equally pertinent to this study area due to gentler local geography and comparatively better road-transport networks than in the other districts of Nepal. Due to this reason, the issue of transport and travelling time was not cited to be a major problem. However, poor and irregular transport services (often unavailable at night) hindered service utilization, particularly for disabled and Dalits women.

The study found a better distribution and availability of basic ANC services at community level in rural areas, but due to the poor quality and limited facilities, women preferred to attend private or higher-level health facilities located in urban areas. Since there is no established system or hierarchy of care, and limited services at lower level health facilities, women often attended secondary and tertiary care centers, even for normal ANC visits and delivery. The consequence of this is overcrowded secondary and tertiary services and reduced quality of care due to insufficient staff and unavailability of beds.

Location of services was not the only issue. Insufficient maternal health care staff and their unavailability in public health facilities are common problems across Nepal (GoN/MoHP/DoHS, 2014; Thomas et al., 2012). The percentage of staff shortages in health facilities are high, ranging from 11% - 23% across Nepal (about 10% of sanctioned posts in the study district were found to be unfilled) (**Findings above: 5.2.4.2**) and has been recognized as a significant challenge by policy and strategy planners; exacerbated by political instability, poor planning and ineffective policy implementation (The World Bank et al., 2006).

Despite significant staff shortages (GoN/MoHP/DoHS, 2014), the study found mixed opinions regarding staff adequacy, availability and the quality of services given to them. Participants from all groups reported that maternal health care staff were adequate in health facilities and were easily available for them. Contrarily, a significant number of women, both disabled and non-disabled, in the qualitative study reported their service providers as being incompetent, irregular attending health facility and unavailable them. This finding is consistently reported in many

previous studies in Nepal and other low income countries (Bohren et al., 2014b; Thomas et al., 2012).

A lack of equipment, drugs and supplies in most health facilities was a common problem reported - but the study found that this was not always due to resource constraints. Policy and system defects, poor management and poor organization of available resources were found to be major contributors to the problem. Participating policy planners and implementers acknowledged and accepted this as discussed above (**Section: 5.2.6.2**).

The Government of Nepal is committed to providing free maternal health care services at all levels including through the provision of travel cost reimbursement and health facility delivery incentives. However, the study found the financial cost of receiving care included transportation costs, extra service fees and cost for medicines, were unaffordable to low income women especially the disabled and Dalits women. The study found that the majority of women, who attended health facility received delivery incentives, but that travel reimbursements have not reached all women equally. Due to the imperfect health systems, the government's Safe Motherhood program may have been following "inverse equity hypothesis" which states that well-off people gets most of the initial benefit from new interventions, while needy people benefit less and at a later stage (Victora, Vaughan, Barros, Silva, & Tomasi, 2000). Similar findings related to financial inaccessibility in receiving care for low-income group women have been found in other studies conducted in Nepal as well as in other countries (Anwar, Killewo, Chowdhury, & Kanta, 2004; Ensor, 2005; Ganle, Parker, Fitzpatrick, & Otupiri, 2014; Thomas et al., 2012).

This suggests two key policy implications; a need to review of the effectiveness and equitable coverage of financial incentives provisioned under the "Safe Motherhood Program"; and the need to develop a comprehensive demand side financing strategy to reach the poor and to enable their access to services in a sustainable and effective way.

#### **5.3.3.2 Acceptability**

The study found both positive and negative feelings and experiences of service users in regards to acceptability. Many women described providers with negative attitudes in their qualitative interviews, citing disrespect, rude and abusive behavior. Mostly disabled and Dalit women experienced negative and disengaged attitudes of providers (**Findings above: 5.2.4.4**). The qualitative findings also indicated that male providers only could present a barrier for women in accessing maternal health services for all women.



Policy planners and implementers interviewed accepted that their health providers lack the skills to create a welcoming environment, particularly for disabled and poor people.

These findings are consistent with a large body of literature. For example, Duong, Binns, & Lee, (2004) and Silal, Penn-kekana, Harris, Birch, & McIntyre, (2012) found in their study in Vietnam and South Africa, that provider-client relationships had a major impact. A number of other studies have found similar findings where poor provider attitudes and behavior negatively affected women's access to maternal health care (Drainoni et al., 2006; Karkee et al., 2014; Silal et al., 2012).

### *5.3.3.3 Accommodation*

The government had committed in public policy to ensure that health buildings and infrastructure are accessible; however, this is not reflected in reality. None of the health facility buildings and structures in the study district were found to be accessible. Access and accommodation problems extended to settings across the continuum of care including the building, its internal arrangements and service delivery systems (**Findings above: 5.2.4.5**). The provision of adjusted equipment and beds to meet the needs of disabled people in the health facilities was found wholly unanticipated by policy planners and senior health ministry officials.

The study found the access issue further exacerbated by short and inconvenient health facility opening hours. Maternal health care services were often reported to be inaccessible for women with limited or no hearing. There was no provision of alternative communication systems or mechanisms to communicate with those having hearing difficulties.

Health facility buildings that are inaccessible for disabled people are a common problem in low-income countries, widely reported in the literature (Becker et al., 1997; Dhungana, 2006; Smith et al., 2004). Studies in both low and high-income countries have also consistently reported difficulties encountered by disabled people in receiving health care due to the unavailability of adjusted equipment (Nosek et al., 2001). However, the intensity of difficulties encountered by disabled people can be greater in low-income countries due to limited resources and its poor management.

The literatures reports the problem with inconvenient health facility opening time and no alternative provision for the communication with hearing difficulties in both low-income and high-income countries (O'Hearn, 2006; Smith, 2008; Thomas et al., 2012).

Overall, the study found lower utilization of services by disabled and Dalit women in the study area despite government's effort to provide equitable maternal health care services to all. The study did not find any effect of women's caste status in utilization of services; however, disability in association with their household factors found influencing service uptake. Supply factors, such as uneven distribution and poor management of services and resources affects all women (disabled and non-disabled), while provider's inadequate knowledge and skills to address the special needs of disabled women coupled with environments such as inaccessible buildings and equipment and restricted opening time compounded the restricted nature of many services for women with disabilities.

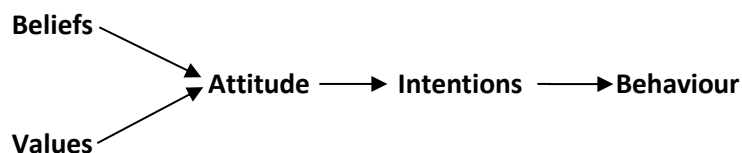
The following chapter provides additional discussion of barriers by reviewing societal and provider's attitudes towards disability.

## CHAPTER SIX: SOCIETAL AND HEALTH CARE PROVIDER'S ATTITUDE TOWARDS DISABILITY

### 6.1 CHAPTER OVERVIEW

This chapter examines societal and health care provider's attitude specifically towards persons with disabilities and disabled user's experiences of maternal health care service utilization using data and information derived from the qualitative and quantitative analysis.

Attitude is defined as the combination of beliefs and feelings held by the individual that predisposes the person to behave in a certain way. It comprises affective, cognitive and behavioural components. Fishbein & Ajzen, (1975) describes attitude in the diagram below:



This diagram shows the relationship between people's attitude, their knowledge and their behaviour. Attitudes are influenced by prejudice and individual's experience with positive or negative reinforcement. The role of direct experience is found particularly important in attitude formation (Fossey, 1993; French, 1994; Sdorow, 1990). Attitudes and behaviour are correlated; however, attitude is only one factor among several such as habits, social norms and group pressure that influence individual behaviour. It is often acknowledged that negative attitudes and behaviour come from people not having adequate knowledge. Moreover, some studies have also found demographic factors influencing on people's attitudes (Cacioppo, Petty, & Crites, 1994; Leutar & Raic, 2008).

Measuring attitude is a complex task, which is often a mixture of feelings, presumptions, underlying values and intentions. An effective measure of the people's and/or societal attitudes towards disabled people is far from simple. The literature informs us that disabled people often experienced barriers receiving health services due to provider's inappropriate attitudes and behaviours (Becker et al., 1997; Kleinitz et al., 2012; Smith et al., 2004). Measuring attitudes of health providers towards disability is important to understand their perception so that training for health professionals could be improved in order to foster positive views.

This chapter is organized into four sections. The first section presents themes generated by focus group discussions and participant in-depth interviews about societal attitudes toward disabled;

the second section presents the findings of a health care provider's attitude survey; the third section presents women's experience of service use during pregnancy and childbirth and the last section discusses and integrates the key findings from the both qualitative and quantitative interviews.

## **6.2 RESULTS**

### **6.2.1 SOCIETAL ATTITUDE AND BEHAVIOURS TOWARDS WOMEN WITH DISABILITIES (IN RELATION TO THEIR MATERNAL HEALTH NEEDS)**

This section looks at the attitudes and behaviours of people and society interviewed in Nepal towards disabled people, in particular reference to motherhood and maternal health care for disabled women. In order to understand societal attitudes towards disabled women and the prejudice faced by women with disabilities, this section describes the following themes generated by qualitative data from six focus group discussions; six key informant's interviews; and in-depth interviews of 17 disabled women. Quantitative data from surveys have been presented in support of these themes where relevant.

#### *6.2.1.1 Stigma, Stereotype and Prejudice*

The terms 'stigma' and its consequences such as prejudice, stereotyping and discrimination, are often used interchangeably in the literature. Goffman, (1963) identified stigma as a feature that discredits and makes the person experiencing it different from others. This phenomenon is often accompanied by stereotyping, rejection, loss of status and discrimination (Link & Phelan, 2001). A number of factors such as lack of knowledge, superstition, belief systems, fear and exclusion contribute to a person being stigmatized. .

Participants in qualitative components of this study indicated that women with disabilities are stigmatized and discriminated against in various forms by society including by their own family. For example, disabled participants reported they were often excluded from religious events and festivals by their community; and at the family level they are often seen as a source of family shame, as exemplified by their not being introduced to visitors.

#### *6.2.1.2 Misconception and misunderstanding of disability*

As in other societies globally, myths and misconceptions about disability such as '*disabled people as tragic figures that society should pity*' (Disabled People's International, n.d.; Munyi, 2012; Sukhramani & Verma, 2013; The World Bank, 2007), were found commonly in this study.

Participants reported that their disabilities were seen to be something they were blamed for, and they frequently encountered inappropriate behaviour by neighbours and society. Stigmatization

and stereotyping beliefs about disability often humiliated those disabled women we interviewed. Societal values have been shaped by a range of elements, including Hinduism, as well as cultural and historical beliefs. Whilst Hinduism has equality as a central belief, the portrayal of persons with disability is almost universally negative due to the myths and misconceptions (Simkhada et al., 2012; The World Bank, 2007; Waldman, Perlman, Chaudhry, 2010).

A Dalit disabled woman with a physical impairment expressed her frustrations about how the community treats her due to their misconceptions about disability:

*“if somebody is going abroad and meets a disabled person, they say – it is bad luck, I saw the face of a disabled..... We are blamed if they are unsuccessful in work; this is the kind of discrimination we are facing. If we participate in any ceremonies and weddings, they say, ‘Why did she come here? Everybody will see her and some bad things may happen’.”*

- **A 30 year old physically disabled Dalit woman (Participant # 3)**  
(20<sup>th</sup> February 2015; Siktahan)

Another blind participant gave the following example of how they are often seen as inadequate by society and treated with scorn:

*“There was an incident during my first baby. It was during “Teej festival” (Festival of women) when I had gone to a fair. My baby was three and half months old. A woman there said that it was **pathetic** to see a blind person having children. I did not recognize the woman but I got very angry. Why did I have to be a character of sympathy when everything was normal? Had the baby been in pain or had it been crying such comment would be meaningful. I returned home without going around.”*

- **A 28 year old blind non-Dalit woman (Participant # 13)**  
(11<sup>th</sup> February 2015; Devdaha)

### **6.2.1.3 Doubts about sexuality and ability to conceive and care**

Participants in their interview reported and re-iterated that folk beliefs about their sexual desire and reproductive capability persisted, and that their sexual well-being was often neglected. In Nepali culture, women do not openly talk about sex and sexuality; however, as a ‘female-only’ team facilitated discussions about these topics, women being interviewed became more open. The participants in FGDs and in-depth interviews stated directly and sometimes indirectly (due to cultural and social mores) - that their family members and their neighbours spoke negatively about their sexual desire and ability to conceive. Many of the FGD participants agreed that disabled people have the same desires as non-disabled people. However, one of the educated,

physically disabled participants in her in-depth interview opined that her grandmother-in-law was suspicious about her sexual appetite and her ability to conceive:

*“We had a grandmother here but it’s been about 2 years since she expired; she used to keep on asking if I would have the baby so I guess she might have had that feeling. After 6 months of her being expired I became pregnant.”*

- **A 26 year old physically disabled non-Dalit woman (Participant # 10)**  
(11<sup>th</sup> February 2015; Devdaha)

Another physically disabled participant in her interview expressed the opinion that her neighbours often talked about her ability to conceive:

*“...they used to say as I myself was disabled, how would I conceive a child, how would I stand, they did not say other negative things.”*

- **A 35 year old physically disabled Dalit woman (Participant # 1)**  
(17<sup>th</sup> February 2015; Kerbani)

In contrast, almost all FGD participants (none of the FGD participants had a disability) expressed the view that women with disabilities can be pregnant and give birth, but that they would not be capable\_(have no ability) to care for and rear the baby:

*“They have to care for the baby, how do they care if they are disabled?”*

- **Respondent # 2 (FGD/Dalit Women)**  
(17<sup>th</sup> February 2015; Patkauli)

A non-Dalit woman in the FGD shared her experience:

*“One of the disabled gave birth and after having the baby she was not able even to lift the baby and we used to lift the baby for her and helped for breast feeding.*

- **Respondent # 3 (FGD/non-Dalit Women)**  
(19<sup>th</sup> February 2015; Saljhundi)

Several other participants in the same FGD supported them and one of them further stated the negative view referring to her community:

*“Generally the people in the community say when they are disabled and cannot do things on their own, why should they give birth to their children?”*

- **Respondent # 8 (FGD/non-Dalit Women)**  
- (19<sup>th</sup> February 2015; Saljhundi)

Interestingly, one of the female community health volunteers in the focus group discussion

expressed a different view, as the meaning of giving birth to a baby for a mother is to be satisfied with all senses. She suggested that if the mother cannot see the baby or hear the cry of the baby and cannot play with them, then what would be the meaning to be a mother:

*“If they are blind then it will be difficult. If they give birth, there will be a problem. Who will take care of the child? If they cannot hear the baby’s cry then what is the meaning of giving birth? It will be really difficult...”*

- **Respondent # 1 (FGD/Female Community Health Volunteers)**  
(17<sup>th</sup> February 2015; Rudrapur)

One of the blind participants in her interview described the mixed assumptions and doubts of her neighbours on her ability to care for and rear the baby. She expressed her disappointment that even after demonstrating the ability doing all household chores, the family and the neighbours doubted her:

*“I did hear such comments and doubt on how I would take care of a baby when I myself could not see. But they had seen me doing all the household chores. So people had mixed opinion; some said I would take proper care whereas the other said I would not.”*

- **A 35 year old blind non-Dalit woman (Participant # 6)**  
- (19<sup>th</sup> February 2015; Saljhundi)

Also in other sectors such as employment, disabled people are viewed as incapable. A blind teacher stated that her disabled friend was not accepted as a teacher even after passing the examinations for the job:

*“It is my experience that in every field/sector people feel that we are incapable and can’t help. Even if we pass the job interview, people doubt our ability to teach for example. People often make comments so as to how a blind person can teach?”*

- **A 28 year old blind non-Dalit woman (Participant # 13)**  
(11<sup>th</sup> February 2015; Devdaha)

#### 6.2.1.4 *Passing on a disability*

Another widely and strongly believed misconception is that a **disability will usually be passed on to the baby**. This was found to be one of the main reasons for negative attitudes among non-disabled people towards disabled people’s marriage and pregnancy. Disabled people’s marriage was often made complicated with such misconceptions. Some of the participants in the focus group discussions stated that the baby and subsequent generations would inherit any disability present in the mother. Others in the same discussion disagreed. Few participants demonstrated

any knowledge and awareness of the differences in origin of many disabilities, or that some disabilities were congenital whereas many were not. As one of the FGD participants expressed:

*“They should not give birth. The baby might also have a disability due to the disabled mother, so it is risky”*

- **Respondent # 1 (FGD/Dalit Women)**  
(17<sup>th</sup> February 2015; Patkauli)

Another participant in a separate FGD supported the above view with:

*“As I read in the book, it is said that it could go up to seven generations; it could be in one or other in the family or generation.”*

- **Respondent # 2 (FGD/Non-Dalit Women)**  
(19<sup>th</sup> February 2015; Saljhundi)

One blind participant expressed her frustration that people often discouraged her from becoming pregnant in her in-depth interview:

*“They said disability is often hereditary, since both of us were blind everyone thought our life would be complicated with a baby. They said we should not have planned for a baby and most suggested it would have been better if we had used family planning devices. I used to say to my neighbours that not all disability is hereditary; some could be and some not; whatever happens we will see.... “*

- **A 33 year old blind non-Dalit woman (Participant # 11)**  
(11<sup>th</sup> February 2015; Karahiya)

Having a family member with a disability is not only an individual issue, but a concern of the whole family. The study participants reported that society stigmatizes other non-disabled members in the family as well, and that this often complicates their marriages and relations; with one blind participant stating:

*“There are many such things. When there is a blind person at home, everything gets connected to him/her. For example, I am a blind in my home, so when my elder brother was getting married, the issue of looking after me was raised by many. Also people tend to think the baby to be born in the house will also be blind, people think it is heredity. So there are such issues. People often looked at the eyes of my brother’s children; so it is obvious that they would talk about our baby “.*

- **A 28 year old blind non- Dalit woman (Participant # 13)**  
(11<sup>th</sup> February 2015; Devdaha)



Similarly, another physically disabled woman stated her disappointment during her pregnancy with the discouragement by her neighbours:

*“Neighbours and other people made me more disappointing saying you will have a disabled child but my mother and sister-in-law counselled me and all the time said do not think like this.”*

- **A 35 year old physically disabled Dalit woman (Participant # 2)**  
(17<sup>th</sup> February 2015; Parroha)

Contrarily one of the physically disabled participants said that her neighbours did not expect her baby would inherit her disability. Instead, they often talked about her husband’s disability would be transferred to their baby. Her husband had epilepsy:

*“Nobody suspected my disability would be transferred to my child but they talked that how she will care for that many children as a disabled woman. Also my husband had epilepsy and all suspected that the baby may have the same.”*

- **A 35 year old physically disabled Muslim woman (Participant # 15)**  
(10<sup>th</sup> February 2015; Ekla)

Societal and cultural beliefs exert a strong influence upon individuals, creating doubts and fears even if the individual is educated. For example, a well-educated, physically disabled participant who did not initially believe her disability would be transferred to her baby, later developed doubts on hearing from her neighbours that the baby may inherit her disability:

*“I had a fear that my baby would have the same disabilities as me when I heard things from the society. Because of the belief that we have in society I had doubts in my mind.”*

- **A 26 year old physically disabled non-Dalit woman (Participant # 10)**  
(11<sup>th</sup> February 2015; Devdaha)

Some non-Dalit women participants in one FGD argued that all babies born from disabled parents do not acquire disability:

*“It is not that the babies of the disabled parents would also be disabled. It’s not like that sir....It is said that it would go genetically....this and that....but it is not seen in everyone. Some disabled ones have very clever and smart children.....let alone the deaf!”*

- **Respondent # 1 (FGD/non-Dalit Women)**  
(19<sup>th</sup> February 2015; Saljhundi)

Another participant in the same discussion added:

*“... they may have normal children. There are examples that the deaf has very clever children. Both the mother and father are deaf but their children are talent. In some cases there could be hereditary.”*

- **Respondent # 2 (FGD/non-Dalit Women)**  
(19<sup>th</sup> February 2015; Saljhundi)

#### **6.2.1.5 Marriage**

Some participants in the focus group discussions conducted among non-disabled women expressed their view that disabled people should be paired off with other disabled people. Interestingly, the majority of the disabled participants interviewed were married to a disabled male partner. In addition, most of them had chosen their partner and had decided themselves whom to marry, as opposed to having an arranged marriage, which is in contrast to the social norms in the study area. These participants reported that their families had not considered their own marriage at all; therefore, they had sought a partner of their own. The study participants reported that marriage of a disabled person is a most complex issue. Marriage between disabled and non-disabled people was often not easy. The factors contributing to this were reported to include benevolent protection from parents who fear that another family would not treat their daughter properly; fear from the paternal family that the woman would not be “good enough” for their son and would prompt malicious gossip; fear about conception, childcare and domestic responsibilities.

A few of the study participants were disabled women who had married a non-disabled man. They reported that their partners had married them expecting to acquire their parent’s property as part of the ‘dowry’, which was an incentive for the marriage. However, they reported that these arrangements had not often succeeded, with further dispute between the families, and subsequent breakdown of the relationship in many cases. One of the disabled participants, whose parents had bequeathed their property to her, had gotten married to a non-disabled man described her experience:

*“My husband had been asking for this property to convert on his name but I didn’t agree. Then he started torturing me. I could not live together with him and I got separated. It has been around 2 to 3 years now since we separated.”*

- **A 31 year old physically disabled non-Dalit woman (Participant # 9)**  
(17<sup>th</sup> February 2015; Bishnupura)

One of the key informants, a disabled male who lead a disability group from a well-off family encountered social and family pressures against his getting married. Nevertheless, he successfully married a (non-disabled) girl; however, their families did not accept their marriage. He described his situation:

*“I am from wealthy family and I became disabled when I was 10 years. My relatives insisted me to have marriage but no one parent would be willing to accept me to get married with their daughter. As I am educated person, I worked in Land Reformation Department in Taksar, Gulmi as being Khardar. I worked as being a teacher too. Within two years, I was close with a SLC (School Leaving Certificate) passed girl and we prepared for marriage. She was also the girl from wealthy family. Her two elder brothers were not married and she was the eldest among her three sisters. We decided to elope on the day of Dashain festival assuming that other people would be busy in Dashain celebration and no one would care for us and our families will also have no time to search for us.”*

- **KII participant # 1**  
(21<sup>st</sup> February 2015; Devdaha)

Another FGD participant reiterated the opinion that disabled women should be married to disabled men and vice versa. Sometimes it is successful and sometimes it is tragic. She explained this with a story about a couple who both had intellectual disabilities:

*“A disabled person should be married to a person like him/her. I have seen similar case near my home. Sadly, they could not take care of their daughter. She did not like anyone touching her baby, but the mother dropped the baby in the fire while giving her oil massage near to fire. The baby died of burns. What to say in such case - should they have baby or not? She had a beautiful daughter but she could not take care of her child”.*

- **Respondent # 4 (FGD/Female Community Health Volunteers)**  
(17<sup>th</sup> February 2015; Rudrapur)

#### **6.2.1.6 Disabled women’s pregnancy and childbirth as an additional burden to the family and society**

The study found that families and neighbours took a disabled woman’s pregnancy and childbirth as an additional burden for them - participants in one focus group discussion expressed their views, stating:

*“If the family is educated they will do by any means, but for a poor or weak family that might be difficult for them to care for the baby.”*

- **Respondent # 3 (FGD/Dalit Women)**  
(17<sup>th</sup> February 2015; Rudrapur)

Another participant in a separate discussion noted:

*“It would be difficult if a disabled woman with mobility problem gives birth. Others may help for 1 – 2 days but who will care their baby all the time? – Nobody will care for always. In such cases, it is better not to give birth. If the woman cannot take care of the baby, it would be difficult to those for giving birth as well. They will also have difficulty to care and rear the child. If she is blind or only the mobility disabled, she should give birth even for her own future support. It would be better to give birth as per the individual’s physical ability.”*

- **Respondent # 1 (FGD/Non-Dalit women)**  
(19<sup>th</sup> February 2015; Saljhundi)

The second respondent in the same discussion added:

*“It would be as per situation. Some love them and care more. But if they have given birth even with their severe type of disability then the family or neighbours may perhaps look negatively and may disgust.”*

- **Respondent # 2 (FGD/Non-Dalit women)**  
(19<sup>th</sup> February 2015; Saljhundi)

It was found that disabled women faced enormous pressure from society’s negative attitudes about their pregnancy and childbirth. On many occasions, they stated that they themselves felt guilty and a burden, and faced discouragement in all aspects of life, such as attending school and finding employment. Many disabled respondents reported that their family, particularly their mother-in-law, were not very helpful for them and during their pregnancy. However, after the baby was born the study found that mothers reported that most of the mother-in-law’s welcomed and enjoyed their new grand-children:

*“Relatives and society views us as burden to them and they think they have to look after us throughout their life. This opinion is prevalent in every person of the society. They think a blind person is incapable of doing every kind of things. May be some blind people do not get married because they do not want to. But people think they did not get married because of their*

*blindness, nobody understands that even blind people have choices in life. Such things make us feel really bad.”*

- **A 28 year old blind non-Dalit woman (Participant # 13)**  
(11<sup>th</sup> February 2015; Devdaha)

Another physically disabled Dalit participant stated that she often came across negative behaviour from her neighbours. She would not be invited to neighbour's functions, as they considered her disability a burden to others. Others saying:

*“.....why to invite disabled people to the ceremony, instead of getting help from them we have to care for them...they cannot do anything....they come, sit and only talk .....they are not helpful....”*

- **A 30 year old physically disabled Dalit woman (Participant # 3)**  
(20<sup>th</sup> February 2015; Siktahan)

The same participant described the fact that she faced much more trouble from her family members than the neighbours during her pregnancy and childbirth. She reported that her mother-in-law was totally unhelpful and negative towards her pregnancy and her husband took her to her own parental house for the delivery:

*“Other family members said, ‘We should feed her and take care of her child too, let her stay there.’ My mother in law said, ‘if I had given birth to you, I would care for you’, so I stayed 5 - 6 months with my mother. Nobody came from my husband's family to bring me back from my maternal home. When my baby started to crawl, my husband came to bring me back, without the permission of his mother. My mother said, ‘I will not send my daughter if you cannot take care of her. I will care for her whatever I can’.”*

- **A 30 year old physically disabled Dalit woman (Participant # 3)**  
(20<sup>th</sup> February 2015; Siktahan)

Furthermore, it was often the mother-in-law's who were reported to have a powerful influence over the attitude of their sons. As the woman above continues:

*“I felt bad...I had given birth to a child that had added more trouble...I was tolerating the rudeness and bad behaviour while I was alone....but after having the baby I had the additional responsibility to care for the baby. Nobody would marry me as well....I had pain and became restless by thinking all this. Somebody had talked to my husband so he came to take me back with him.”*

- **A 30 year old physically disabled Dalit woman (Participant # 3)**  
(20<sup>th</sup> February 2015; Siktahan)

### 6.2.1.7 *Lack of understanding about disability, disabled people's needs and rights (Insufficient knowledge about disability)*

Nearly all the FGD participants were found to have little knowledge or understanding about disability. Many of the participants in all the FGDs (including the FCHVs) reported that they had little experience with disabled people. Two participants reported that their family member or relatives have a disability and few others reported their neighbours have disabled members in their families. None of the FGD participants had a disability and only one participant agreed with disabled people's right to have children.

When asked about adult relationships and intimacy, several disabled respondents in their in-depth interviews reported that their parents did not understand their emotional and sexual needs and never talked to them about marriage.

However, many of them agreed that emotions and desires about sexuality and pregnancy for disabled women are similar as for non-disabled women. Two of the FGD participants expressed their thoughts:

*"....of course they want to have a baby. Every woman wants to have baby. People think that after having baby, it will grow up and support. He will earn and feed the family later."*

- **Respondent # 3 (FGD/Dalit Women)**  
(17<sup>th</sup> February 2015; Patkauli)

*"I think that the desire for sexuality is the same for disabled and non-disabled but there are differences in problems and difficulties."*

- **Respondent # 7 (FGD/non-Dalit Women)**  
(19<sup>th</sup> February 2015; Saljhundi)

### 6.2.1.8 *Discrimination, Rejection and Exclusion*

#### 6.2.1.8.1 **Discrimination**

Some of the non-disabled FGD participants and many of the disabled participants in their in-depth interviews reported that disabled women are discriminated against in every sphere of life. Some disabled participants reported that FCHVs do not visit them, while non-disabled women are visited and counselled during their pregnancy. A few participants reported that whilst initially invited to attend women's group meetings, they subsequently felt ignored and their opinion disrespected and they left the group. They further stated that the discrimination is not only outside their home but it also exists within their home. One of the disabled participants described the discrimination she faced from her own family members during her pregnancy and childbirth:

*"There was so much....I am afraid to talk with anyone about those times, and the*

*discriminations and troubles that I faced. I have to reassure myself and I like to take satisfaction because of my children. Both of us, me and my sister-in-law, delivered at home. Nobody helped me but the entire family cared throughout the 24 hours while my sister-in-law gave birth. I was at my maternal home when I gave birth to my son and had good food, but with my daughter, they gave me cheap food.”*

- **A 30 year old physically disabled Dalit woman (Participant # 3)**  
(20<sup>th</sup> February 2015; Siktahan)

Another physically disabled Dalit woman reported that she was discriminated at work by the neighbours due to her disability. She stated that her mother also frequently abused and discriminated against her - both before her marriage and continues to do so as she lives close by:

*“I had one elder sister, she is dead now. There are two younger sisters, they love me but mother hates me. They are far away so mother loves them, I am disabled and she do not love me! My leg became weak and my mother used to verbally abuse me; she said that it would be better if I had died. My brother-in-law had seen all this behaviour and he helped me to get married.....We do not have our own land. We constructed our house in their (parents) land. She asked us to leave. She always used to say bad words and quarrelled with me. We did not even get to eat the cooked food sometimes. I used to shed tears daily.”*

- **A 35 year old physically disabled Dalit woman (Participant # 1)**  
(17<sup>th</sup> February 2015; Kerbani)

A focus group discussion participant described the discrimination and exploitation from the family to a deaf person:

*“I have a niece who cannot speak well, she got married but people at her home didn’t care her. They thought the deaf people should be given leftover food, as she cannot speak for herself. Such is the perspective of people”.*

- **Respondent # 2 (FGD/Female Community Health Volunteers)**  
(17<sup>th</sup> February 2015; Rudrapur)

Interestingly, one disabled respondent reported that she never encountered such discrimination from her family or neighbours:

*“No, I did not hear such a thing from the family nor from the neighbours. I didn’t face any discrimination either.”*

- **A 26 year old physically disabled non-Dalit woman (Participant # 7)**  
(19<sup>th</sup> February 2015; Saljhundi)

This illustrates that whilst many disabled women have poor experiences of attitudes towards them this is not universal. Factors of caste and education are not fully predictive of which women have a positive and negative experience, reflecting a more complex contributory phenomena.

#### 6.2.1.8.2 Rejection of Reproductive Choice

As noted above, the study found that the relatives and families in the study population commonly do not accept disabled people's right to marriage, pregnancy and childbirth. The reasons reported were family prestige, over protection by parents, lack of understanding about disability and disabled people's needs, and misconceptions created by stereotyping and prejudice.

A physically disabled Dalit woman stated that her husband was blamed for getting married to her and excluded for several years by his parents and relatives because he had married her. She expressed her disappointment:

*"They did not talk to me and my husband for a year. They had scolded so much saying he would have searched a non-disabled woman, why did he marry me....., they said I cannot plant paddy, cannot do other works, why he married with such a woman? They did not speak for a year with him too. Later they said him that 'it was your fate, you did not follow what I said but married such (a person)'. But earlier they used to scorn us saying he would not have child by marrying a disabled women."*

- **A 35 year old physically disabled Dalit woman (Participant # 1)**  
(17<sup>th</sup> February 2015; Kerbani)

Another blind participant had the similar story. She chose her blind partner herself and their marriage was initially rejected by the husband's family until it was clear the child had not inherited their blindness:

*"During the first child, the problem was that we had not been accepted from our home/ family as we got married ourselves. Moreover, people thought that our babies would also be blind. Only when they realized that the baby could see, then only was I taken home along with the baby. They bought a separate home in Bhairahawa and kept us there. But now it's different, we have very good relation with other family members (home). Earlier it was very difficult."*

- **A 28 year old blind non- Dalit woman (Participant # 13)**  
(11<sup>th</sup> February 2015; Devdaha)



### 6.2.1.8.3 Exclusion

In qualitative and quantitative interviews, disabled women were asked about their involvement in major family decisions and attendance at neighbour’s functions in order to understand their inclusion in the family as well as outside the family. Among 79 respondents, a quarter reported that they were never included in family decisions. A similar proportion (26.6%) said they were invited sometimes to functions and events, although one out of seven (15.2%) said they were never invited by the neighbours in their functions (Table 24).

**Table 24: Disabled women involved in family decision making**

	n (%)	Never	Sometimes	Always
<b>Invited in Family Decision</b>	79 (100%)	19 (24.1%)	21 (26.6%)	39 (49.4%)
<b>Invited to Neighbour’s Functions</b>	79 (100%)	12 (15.2%)	29 (36.7%)	38 (48.1%)

Participant were also asked about their involvement in community level women’s groups, with the survey revealing that the majority (62%) of disabled respondents reported that they were not involved in these groups.

Some disabled participants reported that they, if there were or had been involved in such groups, sometimes were discriminated against, disdained or considered inferior by other group members. This made them feel excluded and humiliated, prompting many of them to leave the group. One participant reported that the group doubted her ability to pay or make monthly savings contributions without income and did not invite her to become a member.

She stated:

*“What should I say why, they don’t call when the neighbours go there that is why I don’t feel like going there and I will not go there...They might have the thought ‘how will I get money to be in the group’”.*

- **A 31 year old physically disabled non-Dalit woman (Participant # 9)**  
*(17<sup>th</sup> February 2015: Bishnupura)*

It was also apparent that many communities excluded disabled people from participating in ceremonies and rituals, considering their presence bad luck. One of the participants reported:

*“Some people say it is unfortunate if they see us; some do not like us to be present in ceremonies and rituals considering us as a symbol of bad luck. If I go somewhere and anyone*

*comments negatively, I do not go again. I have heard somebody saying “she came herself in spite of sending other family members.”*

- **A 30 year old physically disabled Dalit woman (Participant # 3)**  
(20<sup>th</sup> February 2015; Siktahan)

#### **6.2.1.9 Powerlessness: Fear, Violence, Abuse and exploitation**

The study found that people in the society think of disabled women as weak and having no power. Their ability and strengths were often undermined. Such an environment created feelings of weakness and fear in the mind of disabled women, as one of the study participants noted:

*“Sometimes I had such feeling. I felt myself as weak, not able to do anything. Even when people said something good I felt they were saying it to humiliate.”*

- **A 31 year old disabled non-Dalit woman (Participant # 9)**  
(17<sup>th</sup> February 2015; Bishnupura)

Another participant shared the same view:

*“When they were afraid I was a bit afraid as well, they made me afraid; they used to talk about my weakness. Listening to that I also developed some doubt myself and had some harassment and felt an inferiority complex.”*

- **A 26 year old physically disabled non-Dalit woman (Participant # 10)**  
(11<sup>th</sup> February 2015; Devdaha)

A disabled Dalit woman participant expressed her dissatisfaction at being stigmatized and mistreated due to her disability:

*“Being disabled is more painful....If I did not have a disability nobody would speak bad or painful words to me...I would not seek support or help from anybody....society would not consider me a symbol of bad luck and I would not be excluded.”*

She further added:

*“...whenever I listened something bad I get hurt, some people were talking in signs, some were gossiping, somebody laughed at me and some said – we should not talk/do like this. That humiliated me.”*

- **A 30 year old physically disabled Dalit woman (Participant # 3)**  
(20<sup>th</sup> February 2015; Siktahan)

The survey conducted among 354 women in this study showed that more than two out of five women, both disabled and non-disabled, in nearly equal proportion, had encountered physical

assault. This proportion found over half for Dalits and more than one-third for non-Dalit women. However, significantly higher proportion of disabled than non-disabled (12.7% vs 2.5%) with P-value=0.001 and slightly more proportion of non-Dalits than Dalits (5.9% vs 3.3%) with P-value=0.004) reported that they encountered physical assault regularly (Table 25).

**Table 25: Distribution of participants by physical assault and torture**

Physical assault/Torture	Disabled (n=79)	Non-disabled (n=275)	P - Value	Dalits (n=79)	Non-Dalits (n=275)	P - Value
Never	46 (58.2%)	159 (57.8%)	0.001	75 (49.7%)	130 (64%)	0.004
Sometimes	23 (29.1%)	109 (39.6%)		71 (47%)	61 (30%)	
Regularly	10 (12.7%)	7 (2.5%)		5 (3.3%)	12 (5.9%)	

A slightly higher proportion of disabled than non-disabled (7.6% vs 6.2%) (P-value=0.156) and Dalit than non-Dalit women (7.3% vs 5.9%) (P-value=0.346) reported that they faced sexual harassment or abuse (defined as verbal or physical conduct of a sexual nature) (Table 26).

**Table 26: Distribution of participants by sexual harassment and abuse**

Sexual Harassment/Abuse	Disabled (n=79)	Non-disabled (n=275)	P - Value	Dalits (n=79)	Non-Dalits (n=275)	P - Value
Yes	6 (7.6%)	17 (6.2%)	0.156	11 (7.3%)	12 (5.9%)	0.606
No	72 (91.1%)	258 (93.8%)		140 (92.7%)	190 (93.6%)	
No Response	1 (1.3%)	0 -		0 -	1 (0.5%)	

Some of the respondents in their interviews reported that their husband or other family members abused them. One of the participants reported that her mother frequently abused her verbally and physically due to her disability. She was, the women stated:

*“.....helped by my brother-in-law, he was known all about me and my trouble, how I was suffering being scolded and beaten. I could do work and was also doing, but she (mother) used to beat me saying that I was seating idly and eating doing nothing.”*

- **A 35 year old physically disabled Dalit woman (Participant # 1)**  
(17<sup>th</sup> February 2015; Kerbani)

Another participant stated that her husband, asking her to transfer property to his name, mistreated her verbally and physically:

*“After marriage when they were asking my property and I denied giving them, then they started torturing and misbehaving”.*

She further added:

*“He used to drink and beat me that’s why..... I am disabled and he wanted to take my property. He did not help at all while constructing this house. Our house was collapsed and I recently constructed this one”.*

- **A 31 year old physically disabled non-Dalit woman (Participant # 9)**  
*(17<sup>th</sup> February 2015; Bishnupura)*

#### **6.2.1.10 Identity**

Negative attitudes were also expressed in relation to identity. In response to the survey conducted as part of this study among 79 disabled participants asking the question “How do other people call you?”, over a quarter (26.3%) respondents reported that they are called solely by their disability, not their name. The disabled women reported that on many occasions as a child they were not given a name at all. In the eyes of others, their identity was their disability.

Many participants also reported that they are often humiliated and dominated, named and called by their disability, if not using bad language that spoils their individual identity. One of the study participants described her feelings when this occurs:

*“Sometimes the quarrel happens and they behave rudely to me calling with my disability. They call me as lame. I feel hurt when they call me lame. Everybody gets hurt when you call out lame even to the by-passers.”*

- **A 35 year old physically disabled Dalit woman (Participant # 1)**  
*(17<sup>th</sup> February 2015; Kerbani)*

#### **6.2.1.11 Encouragement, Sympathy, Love and Support**

Despite the negative social environment, many participants, both in focus group discussions and individual interviews, reported that their families and neighbours were supportive and positive toward disabled people. Some disabled participants reported that their neighbours were kind, sympathetic and supportive during their pregnancy and encouraged them to go for services. Some also reported that FCHVs visited them at home during their pregnancy.

As one of the FGD participants stated:

*“All people will not have the similar thoughts; some views in a negative sense and disgust; some say that she needs help for herself and how she rears the baby and some others show their sympathy”.*

- **Respondent # 1 (FGD/Non-Dalit women)**  
(19<sup>th</sup> February 2015; Saljhundi)

Some disabled participants reported that their family members were positive and helpful about their marriage and pregnancy. A visually disabled woman stated that her mother-in-law and other family members regularly reassured her, saying that her blind husband would be able to create a happy life for them:

*“Even my mother-in-law used to say that my husband would keep me happy no matter what, so she often told me not to worry. Even my great-mother in law was supportive and so were other family members.”*

- **A 31 year old visually disabled non-Dalit woman (Participant # 12)**  
(11<sup>th</sup> February 2015; Deepnagar)

Another disabled participant stated that her sister and mother cared for and counselled her keeping her with them during her pregnancy and childbirth, while she was discriminated against by her mother-in-law during her pregnancy:

*“Yes, sometimes I used to regret it...I also said this to my mother...she tried to convince me that many people (who have disability) do not get married, but you are lucky so you got married....who could have known that your new family members would not care for you after marriage. Sometimes I thought to commit suicide by taking poison even after conceiving.”*

- **A 30 year old physically disabled Dalit woman (Participant # 3)**  
(20<sup>th</sup> February 2015; Siktahan)

Attitudes of benevolent prejudice were also reported regularly in the qualitative research data collection. Some participants reported that their neighbours were generous to them showing their concerns about their disability and pregnancy. As one disabled Dalit woman stated:

*“They used to show sympathy on me saying that how would I work with such a big belly and one leg, how would I walk, how would I cook and wash the dishes, care for the children, how I would send them to school.....!”*

- **A 35 year old physically disabled Dalit woman (Participant # 1)**  
(17<sup>th</sup> February 2015; Kerbani)

A Muslim disabled woman reported a more supportive family and social environment about her pregnancy and childbirth:

*“All family members behaved me well, brought foods according to their earnings and gave it me to eat. Nobody had bad feelings towards me and I did not find anyone discriminating or behaving differently than before...My relatives as well as neighbours were happy while they knew I got pregnant again; some distributed the sweets as well.”*

- **A 35 year old physically disabled Muslim woman (Participant # 15)**  
(10<sup>th</sup> February 2015; Ekla)

### **6.2.2 SUMMARY OF KEY FINDINGS**

The culture and social attitudes towards disabled people are often unfavourable, with misconceptions about disability in general, stereotyping and a prejudiced social environment all contributing.

In relation to the nature of attitudes and social behaviours towards disabled people, several key issues have emerged from this research. Most important of these is that despite people’s openly prejudiced views, some degree of “benevolent prejudice” towards pregnant disabled women was not uncommon.

Amongst the other key factors that arose were issues around disabled people’s marriage, their ability to conceive, give birth and safely raise a baby. These were found to be the major concerns of others in their communities, causing some women with disability to think negatively about their own pregnancy and motherhood. Moreover, many disabled and non-disabled respondents reported anxieties and fears that their impairment would be transmitted to their babies and reported disabled women’s pregnancy and childbirth as an additional burden for the family and society.

The study found little exposure to, and insufficient knowledge about disability among non-disabled participants, leading to blanket assertions, which result in discrimination, rejection and exclusion of disabled people by society and their families. The results clearly showed that disabled women encountered violence, abuse and discrimination inside and outside their home. Many disabled women reported that they faced violence from their family members, particularly from their mother-in-law’s and husbands. Some also encountered discrimination from their mothers and other family members. The study demonstrated that disabled women live under various forms of oppression, which includes being denied opportunities and rejection. Moreover, the results

show that disabled people are often not valued in Nepalese society and sometimes have no individual identity or name beyond that of their disability.

In conclusion, the results showed that negative societal attitudes towards disabled women, their pregnancy and childbirth are common. These results are important as the health and pregnancy outcomes for a pregnant woman and her baby can be affected by the health care and advice she receives. The evidence suggests that women's utilization of health services during pregnancy is influenced by their experiences of health care and health provider's attitude and behaviours towards them (Bohren et al., 2014a; Mason et al., 2015). It may therefore be assumed that negative societal attitudes towards disabled women, their pregnancy and childbirth have an impact on the outcomes of these. The following sections discuss the provider's attitude and the user's experience on service utilization.

### **6.2.3 PROVIDER'S ATTITUDE AND BEHAVIOURS TOWARDS PERSON WITH DISABILITIES**

The attitudes and behaviour of health care providers obviously have a significant influence on many aspects of care; for example, the negative attitudes of providers may affect the use of services for a disabled user. To examine this, this section presents results from a survey measuring the attitudes toward disabled person (ATDP), along with in-depth interview results obtained from Key Informant interviews and the disabled women who used the services. The first part describes the characteristics of survey respondents and the second part presents the main results.

#### *6.2.3.1 Characteristics of survey participants*

Table 27 shows selected characteristics of health care providers who responded to the ATDP survey. A total 396 providers participated in this survey, and the findings have been collated into three groups based on their role and likely contact with pregnant disabled women. Of these, more than half (54.3%) were female community health volunteers (n=215) who are the first contact to provide maternal health service in Nepal's health delivery system. Approximately 24% (n=94) were auxiliary nurse midwives (ANMs) and nurses who provide the majority of professional maternal care in health services. The remaining 22% (n=87) were other health workers (AHW, HA, doctors) who provide more general medical care, including maternal care. The male: female ratio of the participants was 1:4. The majority (77.3%) of the providers were from rural health facilities (n=306), which consist of health posts, sub-health posts and birthing centres; whereas 22.7% (n=90) participants were from urban health clinics and hospitals. By age, the largest number of providers (85.6%) were between 25 – 54 years (n=339), with a small portion (6.1%) below 25 (n=24), and 8.3% (n=33) above 54. The age of respondents ranged between 18 – 60 years and the mean age 40. Less than 1 out of 10 providers were Dalits. This is summarised in the table below:



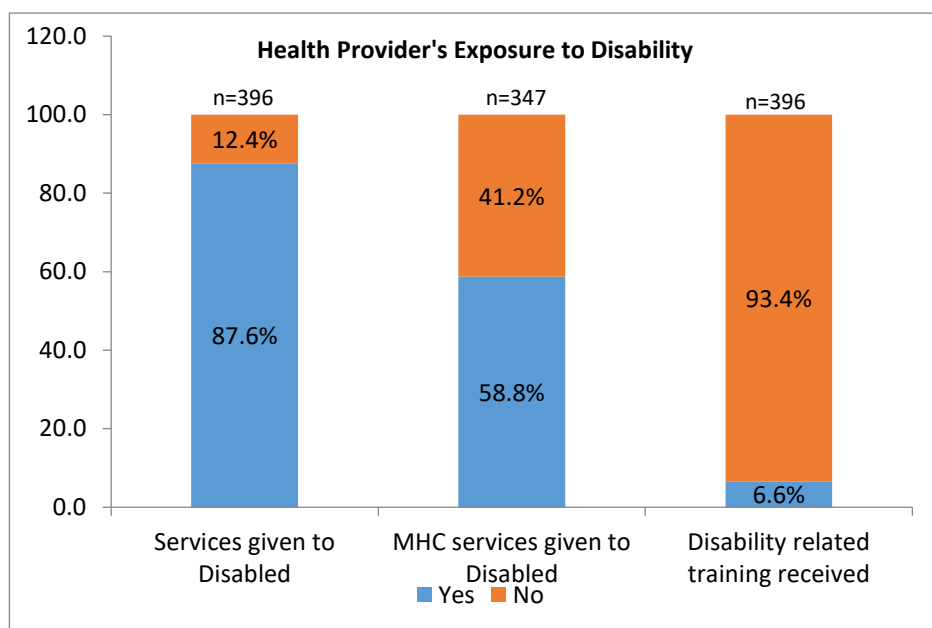
**Table 27: Distribution of respondents by selected background characteristics**

<b>Background Characteristics</b>	<b>Numbers</b>	<b>%</b>
<b>Respondent's Location</b>	<b>396</b>	<b>100</b>
Rural	306	77.3
Urban	90	22.7
<b>Respondent's Age</b>	<b>396</b>	<b>100</b>
18 – 24 Years	24	6.1
25 – 34 Years	89	22.5
35 – 44 Years	135	34.1
45 – 54 Years	115	29.0
55 – 60 Years	33	8.3
<b>Respondent's Gender</b>	<b>396</b>	<b>100</b>
Male	73	18.4
Female	323	81.6
<b>Caste Group</b>	<b>396</b>	<b>100</b>
Dalit	35	8.8
Non Dalit	361	91.2
<b>Provider's Type</b>	<b>396</b>	<b>100</b>
Dr/HA/AHW	87	22.0
Nurse/ANM	94	23.8
FCHVs	215	54.3
<b>No of Respondent by Health Facility Type</b>	<b>396</b>	<b>100</b>
Hospital	45	11.4
PHCC	48	12.1
HP	27	6.8
SHP	231	58.3
UHC	45	11.4
FCHV: Female Community Health Volunteer, ANM: Auxiliary Nurse Midwife, HA: Health Assistant, AHW: Auxiliary Health Worker; PHCC: Primary Health Care Centre, HP: Health Post; SHP: Sub-Health Post; UHC: Urban Health Clinic		

### 6.2.3.2 Contact or Exposure of Participants to People with Disabilities

Survey participants were asked about their exposure/contact to people with disabilities and any training related to disability received before or during their service period. The majority of health care providers (87.6%) were found to have been exposed to people with disabilities through provision of services; and 57.8% have given maternal health care services to women with disabilities. Interestingly, only 6.6% health care providers have received some sort of disability-related training (Figure 15).

**Figure 15: Health provider's exposure to disability**



### 6.2.3.3 Attitude Survey Results

The overall ATDP mean score obtained by the respondents was 78.52 (SD=14.75) ranging from a minimum score of 38, to the highest of 127. The nurses/ANMs scored on average 85.59 (SD=13.45), followed by the general clinical health workers (Mean score=82.64, SD 15.10), who ranged from 56 to 127 and 44 to 115 respectively. The lowest score was obtained by FCHVs (mean=73.75, SD=13.40) ranging from 38 to 108 (Table 28).

**Table 28: Mean ATDP score by provider's type**

Provider's Type	n	Mean	SD	Range
All	396	78.52	14.75	38 - 127
Dr/HA/AHW	87	82.64	15.10	44 - 115
Nurse/ANM	94	85.59	13.45	56 - 127
FCHVs	215	73.75	13.40	38 - 108

### *Analysis of association between some selected factors and ATDP scores*

Mean comparison and statistical significant was assessed using ANOVA statistics to understand the association between variables. The association was considered significant with  $P < 0.05$ .

All demographic variables examined, except the provider's location ( $P > 0.05$ ) are found to be significant. The rural health care providers had lower mean ATDP score (mean=77.78; SD=14.97) than urban providers (mean=81.02; SD=13.74) (Table 29).

Mean ATDP scores were lower for older versus young health providers ( $P < 0.001$ ). Male providers scored higher ATDP scores compared to females (mean=82.97 vs 77.51) ( $P < 0.005$ ). In the caste groups, Dalit providers scored lower (mean=69.69; SD=12.55) than non-Dalits (mean=79.37; SD=14.68), giving a strong association between caste and attitude ( $P < 0.001$ ). Nurse/ANM scored higher (mean=85.59; SD=13.45) compared to Dr/HA/AHW (mean=82.64; SD=15.10) and FCHVs (mean=73.75; SD=13.40) ( $P < 0.001$ ) (Table 29).

**Table 29: Bivariate Analysis of ATDP score and demographic variables**

Factors related to attitude	n	Mean score	SD	P – Value
<b>Location</b>	396	78.52	14.75	
Rural	306	77.78	14.97	P=0.066
Urban	90	81.02	13.74	
<b>Age</b>	396	78.52	14.75	
18 – 24 Years	24	82.96	13.28	P=0.000
25 – 34 Years	89	83.74	14.74	
35 – 44 Years	135	76.76	13.84	
45 – 54 Years	115	77.72	14.78	
55 – 60 Years	33	71.15	14.77	
<b>Gender</b>	396	78.52	14.75	
Male	73	82.97	15.26	P=0.004
Female	323	77.51	14.46	
<b>Caste</b>	396	78.52	14.75	
Dalit	35	69.69	12.55	P=0.000
Non Dalit	361	79.37	14.68	
<b>Provider’s Type</b>	396	78.52	14.75	
Dr/HA/AHW	87	82.64	15.10	P=0.000
Nurse/ANM	94	85.59	13.45	
FCHVs	215	73.75	13.40	

Table 30 shows higher mean ATDP scores to those who gave maternal health care services (mean=79.49; SD=14.75), and had received some sort of disability-related training (mean=79.04; SD=12.86) than those who did not provide MHC services (mean=76.35; SD=14.78), or had not received any disability-related training (mean=78.48; SD=14.87). By contrast, the mean score was lower (mean=78.20; SD=14.83) for those who had been exposed to persons with disabilities through provision of general service or treatment, versus those who were not exposed (mean=80.78; SD=14.12). However, none of the exposure factors were significantly associated ( $P > 0.05$ ) to ATDP score.

**Table 30: Bivariate Analysis of ATDP score and exposure variables**

Exposure Variables	n	Mean	SD	P - Value
Service/Treatment given to disabled	396	78.52	14.83	
Yes	347	78.20	14.83	P=0.252
No	49	80.78	14.12	
MHC service given to disabled women	347	78.20	14.83	
Yes	204	79.49	14.75	P=0.052
No	143	76.35	14.79	
Disability related training received	396	78.52	14.75	
Yes	26	79.04	12.86	P=0.852
No	370	78.48	14.87	

#### 6.2.4 SUMMARY OF KEY FINDINGS

Overall, the attitude survey reveals that the health care providers in Rupandehi perceive people with disabilities as different from people without disabilities. Furthermore, based on the additional qualitative research and literature reviewed about the interpretation of such result it is suggested that health worker's perception of difference is indeed a negative one. The result confirmed the findings that the demographic factors such as geographical location, provider's age, gender, caste and profession type were strongly associated with their attitude score. However, exposure or contact factors did not show any significant association in determining positive attitude towards people with disabilities by service providers.

The response analysis of providers by caste revealed that Dalit providers had the lowest (most negative) score of any professional or caste sub-groups. However, it is not clear whether the distribution of Dalits providers in this survey was not equal to that in the workforce as a whole, and most Dalits in the sample were FCHVs.

The next section examines the service user's experience and their perceptions of the provider's attitude and behaviour towards them while providing maternal health care services.

## **6.2.5 DISABLED USER'S EXPERIENCE AND PERCEPTION OF HEALTH CARE PROVIDER'S ATTITUDE TOWARDS THEM**

### **6.2.5.1 Sensitivity and Care**

Mixed experiences and opinions were reported about the provider's sensitivity and care towards disabled women. Some respondents in their in-depth interview expressed a positive experience with the health providers, while others did not. Many of them reported that the providers were kind, caring and treated them respectfully in a welcoming environment. Several stated that they received counselling and advice in their ANC visits and consolation and support during childbirth by the nurses and doctors. One of the women in her interview acknowledged her positive experience with providers by saying:

*"They treated nicely and made me understand properly. They would help me lie down themselves...Sister helped me in the health post, and later in the hospital both doctor and sister helped me."*

- **A 35 year old disabled Dalit woman (Participant # 1)**  
(17<sup>th</sup> February 2015; Kerbani)

Another two participants reported a similar experience. They stated that providers were helpful and caring towards them during their ANC visits and gave them confidence in delivery:

*"I found health workers happy to see me whenever I went to hospital. They used to help me holding my hand while I entered into the hospital...they always told me "didi (sister), walk carefully" when the floor of hospital was damp and slippery."*

- **A 30 year old physically disabled Dalit woman (Participant # 3)**  
(20<sup>th</sup> February 2015; Siktahan)

*"Ummmm..... They encouraged me very well. They helped me very much. They consoled me very much and they were very helpful to me every time even I was screaming."*

- **A 26 year old physically disabled non-Dalit woman (Participant # 10)**  
(11<sup>th</sup> February 2015; Devdaha)

However, as noted above, not all the participants reported that the providers were sensitive and caring. Some said that providers were discouraging, rude and abusive. Three disabled women reported that they were not given full ANC check-ups or information when using services. They added that the nurses frequently scolded and shouted during the delivery. The providers in private hospitals were reported to be comparatively polite, sensitive and better caring than providers at higher/secondary level public hospitals.

While being asked about her perception of provider's skills and behaviour, a disabled participant stated:

*"Well sir, I did not think of who is capable or skilled. All I wanted was to be treated well and polite. I got the impression that the staffs there (at the government hospital) did not give proper care. It was 4-5 years back, I do not know if it is the same now as well."*

- **A 33 year old blind non-Dalit woman (Participant # 11)**  
(11<sup>th</sup> February 2015; Karahiya)

The vast majority of the in-depth interview participants reported that provider's did not explain things to them properly or give information about their pregnancy while attending antenatal clinics. It was evident that only a very few were advised to go for delivery in a health facility and none of them were informed about the need for post-natal check-ups. One of the participants reported her experience while attending ANC clinic:

*"She didn't check other things and never explained; only palpated my abdomen and sent me back with some medicines."*

- **A 27 year old disabled non-Dalit woman (Participant # 8)**  
(19<sup>th</sup> February 2015; Saljhundi)

A similar experience was reported by another participant during her first pregnancy check up in a primary health care centre:

*"When I went to Dhakdahi PHC they told me to do a urine test to confirm my pregnancy. They did not explain things clearly to me the first time and I returned back to home. The next time I went, the doctor asked me who had checked me before. Once I told him, the doctor was annoyed with his staff, asking why they didn't check me properly."*

- **A 30 year old disabled Dalit woman (Participant # 3)**  
(20<sup>th</sup> February 2015; Siktahan)

In addition to the problems faced by other disabled women, all of the blind service users stated that they were not guided or given proper information about where the consultation room was, and overall they found the system in the health facility was frustrating for them:

*"We never got the information. They only made me go from one room to the next. What would be their loss to provide help to their patients?"*

- **A 33 year old blind non-Dalit woman (Participant # 11)**  
(11<sup>th</sup> February 2015; Karahiya)

Poor care, rude and impolite staff - particularly in public health facilities - were a common experience reported particularly by Dalit and non-Dalit disabled women using the services:

*"I found staff in government hospital rude and not at all polite."*

- **A 31 year old disabled non-Dalit woman (Participant # 12)**  
(11<sup>th</sup> February 2015; Deepnagar)

She further claimed that others shared her bad experiences with the providers in public health facilities:

*"...it is for all because I have heard many people say about sisters in government hospital that they are very rude and treat people bad. Some of them were polite too but all of them were not like that. I might have that impression. Mostly, listening to others as well it is found that sisters in government are more rude and aggressive than in private hospitals nor do they care."*

- **A 31 year old disabled non-Dalit woman (Participant # 12)**  
(11<sup>th</sup> February 2015; Deepnagar)

#### 6.2.5.2 *Maintaining distance and avoiding communication*

Health practitioners often struggled to understand disabled peoples' needs as they are not formally trained to provide services to this group. Their attitudes were reported to be distant and uncommunicative to the disabled women. This was a hindrance in receiving services and was also embarrassing for disabled women.

Additional findings from health providers revealed that they avoided talking to disabled people because they are not sure how to communicate with them. It was common that the providers did not ask the woman directly about her problem, but rather regularly asked whomever had accompanied her; leaving the disabled women totally ignored.

Some of the interview participants complained about provider's poor interpersonal and communication skills that often kept them distant from disabled service users. For example, a blind woman expressed her frustration when seeking the services:

*"They (providers) used to say I was blind, and behaved as if I was deaf and could not hear them. So they asked my mom...When nobody spoke to me, I thought it was because my mom was there so they did not ask me anything but only to my mom. But after I returned home I started to feel bad; I felt they treated me like someone mentally retarded or deaf so they asked my mom rather than asking me".*

- **A 33 year old blind non-Dalit woman (Participant # 11)**  
(11<sup>th</sup> February 2015; Karahiya)

### 6.2.5.3 Preparedness of health workers for providing care to women with disabilities

The study found providers lacking in knowledge about caring for disabled persons and also having a poor understanding of disabled people's needs and rights. Service providers were found to be untrained in specific skills such as communication, which would enable them to give better and more targeted services for disabled people. Many disabled service users also perceived that providers had no confidence to treat them. One of the service users recalled her experience:

*"I couldn't get an idea about that at this institution here. One of the sisters was confused whether I was pregnant or not."*

- **A 30 year old disabled Dalit woman (Participant # 3)**  
(20<sup>th</sup> February 2015; Siktahan)

Another user was not confident with the provider's skills and ability to handle her delivery:

*"I was very afraid during the delivery time wondering if they could or couldn't do because I was disabled; if they would understand me or not, and if they could handle me properly or not, I was fearful of all these things.....until the final result I was afraid."*

- **A 26 year old disabled non-Dalit woman (Participant # 10)**  
(11<sup>th</sup> February 2015; Devdaha)

Many of the disabled women reported that the attitudes of providers and their understanding about disability were negative and often discouraging; denying disabled women's rights to sexual and reproductive health. Some participants reported that they faced challenges due to preconceived mind-sets and limited understanding about disability and disabled people's desire and expectations. One of the participants with low vision reported that she was surprised by the doctor's advice not to have any more children due to her disability. She wondered what different risks she would have than non-disabled women:

*"Doctor suggested me not to have more than one child when I had gone for check-up of my baby. Due to this, I aborted two pregnancies. They said this baby is healthy and not to take risk with other pregnancies."*

- **A 31 year old visually disabled non-Dalit woman (Participant # 12)**  
(11<sup>th</sup> February 2015; Deepnagar)

The participant's interview clearly suggests that the health facilities are poorly prepared and informed to give services to disabled women. Some respondents stated that they faced problems



in the government hospital because the providers were not confident to handle their delivery. One of the participants:

*"I was there for two days. I was about to deliver and asked them whether it is possible here or not; finally they said we can't deliver you here and then I had to go to AMDA (hospital)."*

- **A 35 year old disabled Dalit woman (Participant # 1)**  
(17<sup>th</sup> February 2015; Kerbani)

Many of the disabled participants said they avoided public hospitals and preferred to go to private institutions, even though it was costly. It was reported that it was not only a matter of provider's insufficient knowledge and skills to provide the services but also the rude and abusive behaviour towards them in public health facilities that encouraged them to seek services from private providers. A blind woman gave her view for the reason to attend a private hospital:

*"This is the reason why I prefer private hospital rather to government, - at least you get service and respect in private for the fee you pay."*

- **A 33 year old blind non-Dalit woman (Participant # 11)**  
(11<sup>th</sup> February 2015; Kerbani)

Another blind participant spoke about her bad experience in all health facilities, with no system in the registration to identify disabled women, and service providers lacking basic knowledge and skills:

*".....and the other thing is, the nurses do not know how to hold us while walking. For people with blindness they should not push (pat) from behind and ask us to walk as we might bang in front somewhere. So, I feel mentioning us as blind in our card would be much helpful."*

- **A 28 year old visually disabled non-Dalit woman (Participant # 13)**  
(11<sup>th</sup> February 2015; Devdaha)

## **6.2.6 SUMMARY OF KEY FINDINGS**

Women with disabilities often encountered health facility-related challenges, particularly provider's negative attitudes when they accessed maternal health care services. In the in-depth interviews, some of the participants reported that they perceived the providers as kind, respectful, caring and helpful. However, the majority of in-depth interview participants expressed the view that the providers were insensitive, uncaring and rude.

Most importantly, the in-depth interviews highlighted some provider's poor knowledge, skills and preparation for providing care to disabled women. The provider's poor understanding of disabled people's needs and rights, their lack of warmth and kindness, and poor interpersonal and communication skills with disabled women resulted in some women feeling distressed and humiliated when they used health services. However, they encountered this problem less in private health facilities than public health facilities.

## **6.3 DISCUSSION**

### **6.3.1 DISCUSSION: SOCIETAL ATTITUDE AND BEHAVIOURS TOWARDS WOMEN WITH DISABILITIES (IN RELATION TO THEIR MATERNAL HEALTH NEEDS)**

The study found negative social attitude towards disability prevailed in the study district. Findings revealed that disabled people are stigmatised and discriminated against in various forms by society and even their own families. Three different types of attitudes noted by the study participants and encountered by disabled women were exclusion and damaging attitudes. However, as a third type, some non-disabled people expressed more inclusive types of attitudes; showing willingness to engage with people with disabilities. The exclusion of people with disabilities were often expressed through patronising attitudes towards disabled people. These were often manifested as people in the community questioning the ability of disabled people to exercise their right to participate in society and more specifically, in questions about disabled people's right to make and enact key life decisions such as marriage, pregnancy and childbirth. Other damaging types of attitudes reflected discomfort that non-disabled people felt with people with disability, which led to open hostility, and deliberate and covert exclusion and discrimination. A number of factors such as inadequate knowledge about disability and disabled people's needs, misconception, myths and belief, as well as fear of contagion or uncertain about how to act (Thompson, 1982), all contributed to this negative attitude (**Findings above 6.2.1**).

These attitudes are reported widely in the literature. Consistent with this finding, the literatures also show that the negative attitudes more commonly exist among poor, illiterate and traditional

societies in least developed, resource poor countries (Rao, 2003; Goldstein, 2012; The World Bank, 2007; Thompson & Fisher, 2012). The myths and misconceptions about disability expressed by the participants in this study are also commonly found in religious and mythological beliefs in many religions including Hinduism, Buddhism and Islam etc. For example, in India and Nepal many people believe that disability is a punishment or curse from God. Moreover, disabled people are traditionally perceived as inauspicious and are often discouraged from attending religious and wedding functions (Rao, 2003; Simkhada et al., 2012; The World Bank, 2007).

In light of these broader findings, findings from this study consistently found that the most frequent and therefore most important issue in attitudes towards disability was that disabled women have significant challenges from their family and their communities and societies with regards to getting married and having children. Family shame and the misconceptions about 'passing on' their disability to their children were given as main reasons why families and communities excluded them. Unconditional acceptance of a disabled person marrying a non-disabled person was rare. Non-disabled participants in focus group discussions suggested that disabled people should not marry non-disabled people; rather it would be easier to marry someone with the same type of disability. Moreover, positive perceptions about the ability of disabled women to give birth and rear their children were minority views. However, strong variation regarding this perception found by disability type. For example, women with intellectual disabilities often presumed more risk to the child than other type of disabilities. The families may also perceive the disabled person as a burden since they assume they might be able to do less to contribute to the family income. Such negative attitudes led to discrimination within families with little or no priority given to the needs of women with disabilities including their treatment, rehabilitation or other essential care required.

The literature highlighted similar findings of the research conducted in Korea and India (Dalal, 2006; UNESCAP, 2012). Issues related to disabled women's ability to marry and doubts about their ability to give birth and rear children are consistently highlighted by number of studies conducted in countries such as India and Korea (Rao, 2003; Dalal, 2006; Lee et al., 2005; The World Bank, 2007). However, not all research is consistent on this. In contrast to the findings of this study, a Nepali study found positive women's attitudes towards disabled women's marriage and having children (Simkhada et al., 2012). Such contradiction in people's views is not surprising in a multi-cultural society like in Nepal.

Negative attitudes were found often linked to individual or societal behaviours, for example: isolation, rejection or maintaining distance from people with disability. Attitudes of aversion, fear, guilt, pity or sympathy may reflect different actions or behaviour of the individual or society. In addition to societal and cultural norms, people are influenced by standards and expectations of personal attributes; for example beauty, physical ability, wholeness, productivity and performance, socio-economic status and health status. In many low-income countries, traditional attitudes of pity and charity are prevalent (Thomas, 2001; UNESCAP, 2012).

The study also confirmed that disabled women were more prone to violence, abuse and exploitation, with women with intellectual disabilities and hearing disabilities particularly subject to domestic abuse, violence and exploitation. Both qualitative and quantitative data showed that proportionately higher percentage of disabled women facing physical and sexual abuse compared to non-disabled women (**Findings above 6.2.1.9**). Research conducted in Nepal and other countries has consistently reported powerlessness and substantial social marginalization of disabled women along with frequent victimization leading to abuse, violation and exploitation (Rao, 2003; Puri, Misra, & Hawkes, 2015; The World Bank, 2007).

It is well documented in the literature that negative societal attitudes towards people with disabilities persist worldwide, including in developed countries (Antonak, Fiedler, & Mulick, 1989; Hannon, 2007; Smith et al., 2004; The World Bank, 2007; WHO, 2011b). Evidence shows that many people hold negative and paternalistic attitudes towards disabled people. Nonetheless, many researchers have highlighted the fact that negative attitudes towards disability is changing gradually (Aiden & McCarthy, 2014). The study consistently showed some of this changing attitude with respondent's reporting as some degree of "benevolent prejudice" towards disabled people. As outlined above (**Findings 6.2.1.11**), there were numerous examples provided of human kindness. Some of those appeared to come from individual personalities and others from their own family experiences of disabilities. However, whilst the study participants perceived these as positive experiences, it could be argued that these actions were more closely linked to paternalistic caring, rather than reflecting notions of equality and mutuality. However, increased education and levels of awareness among the public, changing socio-cultural contexts, and policy changes, might also have influenced people's changing views to some degree.

### **6.3.2 DISCUSSION: PROVIDER'S ATTITUDE AND BEHAVIOURS TOWARDS PERSON WITH DISABILITIES**

The survey results highlighted the negative attitudes towards disabled women among health care providers in the study district (**Findings above: 6.2.3.3**). The mean ATDP score for the respondents in this study was found to be significantly lower (mean score 78.5) than the normative score of 113 presented by Yuker, Block, & Young, (1970). Literature reported the provider's ATDP scores consistently greater than 100.

Lack of knowledge combined with caste prejudice may have resulted in stereotyping and negative attitudes among the providers. Previous studies in different context highlight that provider's attitudes and behaviours often reflect broader societal prejudices. For example, the social structure, culture and beliefs that help form the providers views may consider poorer, minority ethnic groups, lower caste people and those with a disabled as inferior. Providers carrying the same view may like to maintain their position in the hierarchy as upper class and educated, being more superior and powerful (Goldstein, 2012).

Despite this, this research found inconsistent results in the relationship between the provider's attitude and some socio-demographic variables. There were slightly higher ATDP scores among health care providers working in urban settings; but there was no relationship observed between the place of work and provider's attitude. Compared to female providers, males had higher ATDP mean scores, indicating that males have more positive attitudes towards disabled people. Conversely, nurses and auxiliary nurse midwives (all female) had higher scores than the other two categories of professional groups; one which comprised all men (doctor, health assistant and community medicine auxiliary) and the another comprising all women (female community health volunteers). Of the total female respondents, more than 70% were community health volunteers whose exposure, education, and awareness about disability and disability rights may have been comparatively lower than that of nurses and midwives. Given the higher percentage of respondents with low levels of education and knowledge, the lower ATDP mean score for females might have been over-weighted reflecting the attitudes of female community health volunteers. This is consistent with the literatures, which reports inconsistent in regards to gender difference in ATDP scores. However, many studies conducted among medical and nursing schools found women held more positive attitudes towards people with disabilities (Au & Man, 2006; Tervo, Palmer, &

Redinius, 2004; Thompson, Emrich, & Moore, 2003). In fact, Yuker, Block, & Young, (1970) recommended the normative ATDP score to be higher for female than for male (113 vs 110).

Age and number of years practicing medicine correlated negatively with attitude scores of healthcare workers. The study found that younger healthcare providers were more positive in their attitudes toward persons with disabilities than the older providers. This finding was consistent with the findings of a study conducted in South India and Bhutan; but contradicts the findings of studies conducted in Europe and North America (Bakheit & Shanmugalingam, 1997; Dorji & Solomon, 2009; Tervo et al., 2004). More positive attitudes among younger healthcare providers perhaps indicates a generational change in how disability is viewed, with disability becoming more culturally acceptable in Asian cultures now when compared to the past.

The study also confirmed that provider's caste significantly correlated with ATDP score. Non-Dalit respondents had more favorable attitudes towards disabled people compared to their Dalit counterparts. This demonstrates that Dalits view disabled different from non-disabled and this may affect negatively on maternal health care for disabled women.

Demographic variables such as age, gender, education and place of living have, however, often been reported by different studies as insignificant in attitudes towards disabled people (Paris, 1993; Perry, 2008; Yuker, H. E., & Block, 1986). Antonak (1981) reported the most influential factors in attitudinal scores were exposure and the intensity of the contact with disabled persons. In contrast, this study did not show any correlation between ATDP score and exposure and knowledge variables. In fact, the ATDP scores for the providers who had received disability related training were higher than those who had not. This finding contradicted the study findings of Cervasio & Fatata-Hall, (2013) conducted among nurses in the United States which examined their attitude before and after disability education; and suggests that short training and exposures may not be enough to change the attitudes of Nepalese health care providers towards disabled people.

It is also worth noting that the negative attitudes among health care providers found in this study may simply reflect general negative attitudes of Nepalese society towards disabled people, particularly as the majority of health care providers have received no training or awareness interventions to alter broader social attitudes and perceptions.

### **6.3.3 DISCUSSION: DISABLED USER'S EXPERIENCE AND PERCEPTION OF HEALTH CARE PROVIDER'S ATTITUDE TOWARDS THEM**

The study revealed mixed findings in regards to user's perception of provider's attitude towards disabled women. Some of the disabled participants in their in-depth interview expressed overall positive experiences with healthcare providers, while others did not. The range of positive attitudes and behaviours displayed towards disabled women have been identified in many studies including this (**Findings above: 6.2.5.1**): they range from being open, friendly, and welcoming to respectful and caring. The most common negative attitudes informed by the literature in relation to healthcare workers were that they were disrespectful, abusive, rude, discriminatory, and neglectful (Mannava, Durrant, Fisher, Chersich, & Luchters, 2015). Goldstein, (2012) in their systematic review found a range of inter-related reasons for these attitudes, with socio-cultural, organizational and individual factors contributing to the attitudes and behaviours of healthcare workers.

Interestingly, this study also found that negative attitudes and abusive behaviour predominantly among public health care providers in higher-level health facilities, rather than the staff in private health facilities and community-based birthing centers. Amongst the possible explanations for this could be that there is less community involvement in the higher-level health care facilities in management and service delivery. Provider's negative attitude and abusive behaviours predominantly in public health facilities rather than private health facilities was consistent with the findings of Mannava et al., (2015).

A recent qualitative study (Joanna Morrison et al., 2014) conducted in Nepal among women with disability had similar findings in relation to user's perception towards health care provider's attitudes. However, their study revealed that provider's negative attitude and abusive behaviour differed according to disability type, and were experienced more by women with hearing and speech impairments.

The literatures also suggests that there is not much difference among health care provider's attitude and behaviours in either low or high-income countries. Consistent findings, for example insensitive, abusive health providers with lack of knowledge, skills and limited information about disabled people's need were also reported in studies conducted in US and UK (Becker et al., 1997; Frohmader et al., 2013; Walsh-Gallagher, Sinclair, & Conkey, 2012).

More often, in resource-poor countries, the lack of respectful care from healthcare providers may have due to their dissatisfaction with the healthcare system. The literatures suggests that negative attitudes and behaviours of healthcare workers are frequently related to their poor working conditions, which include heavy workloads, long working hours, shortage of equipment and medicines (Mannava et al., 2015). Moreover, maternal health care providers are often predominantly female, with relatively low status in health system hierarchy and with poor salaries. Many of them may have been inadequately trained and supervised at work, and have limited autonomy - yet have great responsibilities. Maternal health care providers in Nepal are not excluded from this situation and it maybe that their negative attitude and behaviours could be a reflection of their dissatisfaction with the Nepalese healthcare system.



## **CHAPTER SEVEN: INHIBITING AND ENABLING FACTORS IN ACCESS AND UTILIZATION OF MATERNAL HEALTH CARE SERVICES**

### **7.1 CHAPTER OVERVIEW**

Expanding upon previous chapters, which discussed about access to health care, socio-cultural environment and health care provider's attitudes towards women with disability, this chapter, now examines the inhibiting and enabling factors for all women including disabled and Dalit women in accessing maternal health care services. This chapter builds on findings in the preceding chapters to more distinctly identify and discuss in detail inhibiting and enabling factors that affect access and utilization of maternal health care. Qualitative interviews and focus group discussions already reviewed in the previous chapter will be supplemented by quantitative survey data and additional data from other key informants, including community leaders, activist/advocates and policy planners to provide a broader overview and context within which to understand these factors.

Results of these were organized into a number of key themes, which have been further categorized in this chapter as 'inhibiting' or 'enabling' factors. It is important to note that the dichotomy of inhibiting versus enabling factors, in fact, was often found to be less pronounced than anticipated. Interestingly, it was often found that instead of stark distinctions between those two factors, there were often unanticipated links. These themes are described in detail below, and supported by additional data as necessary to illustrate this.

This chapter is organized into three sections. The first section presents the 'inhibiting' factors while the second section examines the 'enabling' factors. Each section contains a table of identified themes and categories and a description of these themes. The chapter ends with the discussion of the findings from the two result sections.

### **7.2 RESULTS**

#### **7.2.1 INHIBITING FACTORS**

The study identified a number of factors that hinder women in general, and disabled and Dalits in particular from receiving care. Nine key themes were generated from the qualitative data analysis describing inhibiting factors. The concepts identified in the interviews and focus group discussion texts in the preceding chapter, were grouped together generating themes based on their similarities and relationships.

The table below (Table 31) shows the themes and related categories generated from the qualitative interviews of the participants.

**Table 31: Identified themes and factors inhibiting maternal health care service utilization by order of important based on findings**

Themes	Categories
<b>Attitudinal Barrier</b>	<ul style="list-style-type: none"> <li>Negative Providers</li> <li>Uncooperative family</li> <li>Negative neighbours</li> </ul>
<b>Socio-cultural Barrier</b>	<ul style="list-style-type: none"> <li>Social structure and hierarchy</li> <li>Social prestige to deliver at home</li> <li>Restricted Autonomy and freedom</li> <li>Gender</li> <li>Tradition Beliefs and practices</li> <li>Superstition</li> </ul>
<b>Policy and System Barrier</b>	<ul style="list-style-type: none"> <li>Discriminatory/Faulty policy and system</li> <li>Policy not implemented</li> <li>The charges and cost of services</li> </ul>
<b>Access Barrier</b>	<ul style="list-style-type: none"> <li>Difficult geography</li> <li>Long distance to HF</li> <li>Poor road condition and Transport system</li> <li>Inconvenient Health Facility Opening Time</li> <li>Long Waiting Time</li> <li>Inadequate beds and medicines</li> <li>Un-accommodative Physical structure</li> </ul>
<b>Barrier due to Powerlessness</b>	<ul style="list-style-type: none"> <li>Fear</li> <li>Humiliation, Shame and Shyness</li> <li>Vulnerable/Powerless</li> <li>Abuse and Harassment</li> </ul>
<b>Knowledge, Information and communication Barrier</b>	<ul style="list-style-type: none"> <li>Lack of knowledge/Awareness</li> <li>No information given</li> <li>Language problem</li> <li>Poor communication between provider and service user</li> </ul>
<b>Poor Birth Preparedness and logistical arrangement</b>	<ul style="list-style-type: none"> <li>Local understanding pregnancy and childbirth as a normal event</li> <li>No complications at previous childbirth</li> <li>Poor economic condition</li> </ul>
<b>Perceived Quality of Care Barrier</b>	<ul style="list-style-type: none"> <li>Poor and incomplete service</li> <li>Not confident of provider's skills</li> <li>Insensitive staff</li> <li>Inadequate/little time given by the provider</li> <li>Privacy not maintained</li> <li>Unreliable HF services</li> <li>Poor sanitation and cleanliness</li> </ul>
<b>Barrier due to Restrictions and Limitations</b>	<ul style="list-style-type: none"> <li>Restrictions imposed by HF</li> <li>Isolated from family and lonely feeling</li> <li>Restricted freedom</li> </ul>

The barrier themes are discussed below based on order of importance according to thesis findings.

### 7.2.1.1 Attitudinal Barriers

As has already described above individual interviews with women with disabilities and the focus group discussions with groups of other women, all identified the attitudes and behaviour of various actors including health care providers, family members and neighbours as influential factors in their seeking and receiving care. Most importantly of these, the underlying prejudice and beliefs of healthcare providers, neighbours and family members toward disabled women appear to create subtle and overt barriers to the use of maternal health care services by them.

#### Health care providers

Data analysis of the attitude survey conducted among health care providers (n=396) indicated more negative attitudes toward disabled women than the global average (**Please refer Chapter Six above**).

Participants in the qualitative interviews supported these findings, with disabled and non-disabled Dalits and non-Dalit women all reporting that they had experienced negative attitudes of providers –reporting a number of providers were rude, impolite, abusive and discriminatory. However, some disabled participants felt that they were more discriminated than others - often ignored, discouraged and discriminated against by the providers while seeking services.

A participant expressed her experience and perceptions of provider's attitude towards them while seeking the service as:

*“I worked as a volunteer in a government hospital right after my training; there I saw such discrimination and misbehavior to some clients. Some of the staffs behave like this ....not all.”*

She further added:

*“It is much in government hospitals. I also worked in government hospital before as a volunteer. I have listened and seen such behaviors sometimes while taking the clients there. It was not done by all, but some of them showed such behaviors. It is less in the private hospitals but can be found more in the government hospitals.*

- **A 26 year old disabled non-Dalit woman (Participant # 7)**  
*(19<sup>th</sup> February 2015; Saljhundi)*

It was reported that the providers in the higher-level public hospital were more abusive, discriminatory and held more negative attitudes compared to community based lower level birthing centres and health posts. Providers in private hospitals were reported to be comparatively positive and kind to all groups:

*“I found it different than AMDA. May be because it is government and AMDA is private. I then understood why people go to private facilities, I found much difference there, and it was very different. I went there after labour pain started but the bed was not available. Also nurses there are very rude, they do not respect patients.”*

- **A 31 year old disabled non-Dalit woman (Participant # 12)**  
(11<sup>th</sup> February 2015; Deepnagar)

This was true not only of providers in health facilities, but also of community level volunteer health providers; for example, Female Community Health Volunteers (FCHV) are often reported as discriminatory. The participants in their interviews and group discussions stated that FCHVs in some communities discriminate, making home visits on the basis of social status, caste hierarchy and power. Two participants, one a Dalit and the other a disabled Dalit stated that FCHVs in their village never visited them or gave information during their pregnancy:

*“May be we are poor that’s why. They might visit landlords and wealthy families. Poorer families will be neglected and left behind always...”*

- **A 26 year old Dalit woman (Participant # 21)**  
(20<sup>th</sup> February 2015; Butwal)

*“They do not come to my home but we talk when they pass from here, we recognize each other.”*

- **A 30 year old disabled Dalit woman (Participant # 3)**  
(20<sup>th</sup> February 2015; Siktahan)

Community leaders and women’s advocates reported that the government’s targeted program on maternal health care has not reached Dalits and poor marginalized community even though they are the key targets yet due to the negative attitudes of providers and society. One community leader expressed her view:

*“If we see from the depth, the cases of the Dalit and the disabled are quite different. They (Dalits) are economically weak, don’t have access to the information, the programs such as Gaunghar (Outreach) Clinic, Ghardailo (Door to door) program launched by the government have not reached up to them because of the mind set of untouchable, the discrimination as in many of the places hasn’t been eliminated yet.”*

- **KII Participant # 3**  
(16<sup>th</sup> February 2015; Bhairahawa)

### Family attitudes

As noted already in **Chapter 6**, across all social groups in Nepal, female elders - especially mother-in-law's of pregnant women - hold greatest influence over, or make decisions for, their daughter-in-law about seeking services during pregnancy and childbirth. Participants in the focus group discussions often reported that elderly women held ideas that are more old-fashioned and had limited exposure to the outside world, so often held negative and discriminatory attitudes towards their daughters-in-law in general. This in turn prevented them from seeking maternal health care services. However, this attitude is found to be particularly discriminatory in the case of women with a disability.

Disabled women are reported to be more discriminated against than non-disabled women in an extended family:

*“Both of us, me and my sister-in-law, delivered at home. Nobody helped me but the entire family cared throughout the 24 hours while my sister-in-law gave birth. Mother-in-law called a doctor (health worker) here for her - she did not call anyone for me. We did not call FCHV and she also did not come herself.”*

- **A 30 year old disabled Dalit woman (Participant # 3)**  
(20<sup>th</sup> February 2015; Siktahan)

Family co-operation and the role of the husband have also been found crucial in facilitating or preventing a woman from seeking services during her pregnancy. Survey data showed that 15.7% (n=121) of women who delivered at home reported that their family did not allow them to go to a health facility. Regression analysis on this data further indicated that women with husbands who were literate or educated had better opportunities for seeking services (OR for >4 ANC 2.01 with P-value=0.068, OR for HF delivery 2.13 with P-value=0.025 and OR for PNC 2.90 with P-value=0.017).

This was further substantiated by information from the qualitative interviews, with some participants, both disabled and non-disabled, reported that they encountered barriers due to uncooperative family members and husbands who were not supportive. For examples, a disabled woman spoke about her frustration that her family was not caring, and prevented her from seeking services:

*“It’s not that I did not know but you know how the mother-in-law and sister-in-law’s are. They said they all got their babies at home so why should I go to the hospital and did not let me go.*

*I felt like it was OK even if I die here, when they did not let me go to the hospital.”*

- **A 35 year old disabled Dalit woman (Participant # 2)**  
(17<sup>th</sup> February 2015; Parroha)

Some other participants in their interview expressed their disappointment that their husbands were not caring and did not encourage them to seek the services during their pregnancy:

*“My husband is usually not like that, meaning he is not that caring and trustworthy. He drinks and does not care much that is why he did not do much for me.*

- **A 31 year old disabled non-Dalit woman (Participant # 9)**  
(17<sup>th</sup> February 2015; Bishnupura)

#### **Attitudes of Neighbour**

As the individual and focus group already presented in **Chapter 6**, shows negative attitudes of neighbours were influential in determining the extent to which women sought pregnancy care. Additional interviews and discussions with community leaders and advocates also reflected these findings. It was reported the neighbours exerted a powerful pressure on the family; and listening to the neighbour’s past experience of pregnancy and delivery at home had a negative effect on the decisions of mother-in-law’s with regards to allowing their daughters-in-law to attend health facilities. One of the female community leaders told the interviewer that:

*“Other women in the community who have already given birth to children say that they gave birth to their baby while walking, so they wonder why others -especially their daughter in law - need a check-up. This creates an environment of mental torture within the house. Such problems exist not only in Dalit families but also in the non-Dalits and even economically well-off families.”*

- **KII Participant # 4**  
(16<sup>th</sup> February 2015; Bhairahawa)

#### **7.2.1.2 Socio-cultural Barriers**

As noted in the preceding chapter, social structures, women’s status and roles both within the home and family and outside have been found strongly influential in maternal health care service utilization (Matsumura & Gubhaju, 2001), with social norms, value systems, beliefs; and cultural and traditional practices being further complicating factors for women in seeking and receiving care. The role of women in Nepalese society is considered as subordinate and in general, there is a male head of family who makes the major family decisions. However, the mother-in-law also plays a major role in day-to-day household decisions and particularly dictates in matters of seeking

health care. In a nuclear family arrangement where the couple is living independently from their parents, the wife may have a better opportunity to make her own decisions or influence her husband to seek services. However, in joint and extended families, the mother-in-law decides whether or not to seek service:

*“It is in all communities, Madhesi, Dalits.... However, it is more rigid in Madhesi. Madhesi women must ask their in-laws or husband for everything, they cannot do anything on their own decision... they hardly go outside of their home...mostly they ask to their mother-in-law’s.”*

- **Respondent 1, FGD # 5 (FCHV)**  
(16<sup>th</sup> February 2015; Siddharthanagar)

Many interview participants stated that they had intended to give birth at a health facility but their in-laws did not permit this:

*“I wanted to go to health post but they (mother-in-law and husband) did not take me. They said it can be delivered at home so I did not go.*

- **A 26 year old non-Dalit woman (Participant # 34)**  
(21<sup>st</sup> February 2015; Motipur)

Women in some social and ethnic groups, Madhesi and Muslims in particular, were found to have far less freedom than others, and in matters that extended beyond decisions about seeking health care into other aspects of daily life including going out of the home, for example going to market. Madhesi women reported being particularly suppressed, which was sometimes linked to family prestige or honour being damaged if a newly married woman goes out of the home alone. Other prejudices remained strong, as an elderly Dalit woman in a focus group discussion expressed:

*“I have a newly married daughter-in-law and I have decided not to let her go out for a year. The newly married daughter-in-law’s can’t go for outside work.”*

- **Respondent 2, FGD # 1 (Dalit Women)**  
(17<sup>th</sup> February 2015; Patkauli)

Another focus group participant stated the prime decision maker in the household is the father-in-law. She stated:

*“Daughters in law are not allowed to go anywhere without the permission of their father-in-law. We should not go out without asking the family head”.*

- **Respondent 1, FGD # 5 (FCHV)**  
(16<sup>th</sup> February 2015; Siddharthanagar)

### Home delivery as a measure of womanhood

The interview participants reported that giving birth without medical help is seen as an indicator of a woman's strength and weakness. As a measure of womanhood and also to protect and promote family prestige and honour, the women in some social groups preferred to give birth at home:

*"If we go to the hospital for delivery we will be considered as a weak woman and people will say that you couldn't give birth at home, and get defamed."*

- **A 38 year old Dalit woman (Participant # 23)**  
(17<sup>th</sup> February 2015; Bishnupura)

### Unmarried pregnancy and lack of privacy in health facilities as a barrier to seeking care

Another area rarely addressed but which produced interesting findings in this study was that of unmarried woman who were pregnant. Focus group participants commented that whilst it occurs, unmarried pregnancy and childbirth in Nepali society and culture is rare and unacceptable. The participants felt that pregnant unmarried women feared seeking care due to unwanted disclosure of their pregnancy and childbirth, which could lead to serious social and psychological consequences for the women as well as the family. The focus group participants further commented that none of the health facilities has a system to register such clients confidentially and assure their privacy. Furthermore, they reported that failure of health facilities and providers to maintain confidentiality is one of the greatest barriers to seek care:

*"Firstly, they might not know that they are pregnant, or even if they know they do not tell. People will raise question upon how a women without husband got pregnant. In addition, she might be scared to share. Secondly, even when her pregnancy starts to be seen through her bulky abdomen, it becomes difficult for us to say. Her family might give opposite reaction. Thirdly, if they go to the hospital they are asked to tell their husband's name. So these might be some of the reasons...This is for all, even for those without disability. It is attached to prestige of one's family so they neither go for check-up nor for delivery."*

- **Respondent 1, Focus Group Discussion # 6 (FCHV)**  
(17<sup>th</sup> February 2015; Rudrapur)

Another participant supported it and added:

*"Of course it becomes odd when one asks the reason and nitty-gritty without any confidentiality in the hospital. After all how can one give answer in a public place like hospital to such questions?"*

- **Respondent 2, Focus Group Discussion # 6 (FCHV)**  
(17<sup>th</sup> February 2015; Rudrapur)



### Gender factors of health provider and child

The gender of the health care provider and the child was found to be significant in seeking and acceptance of maternal care services. Almost all in-depth interview participants and some of the focus group participants reported that they feel uncomfortable seeking services from a male provider. Similarly, it was also reported that the baby's gender often influenced women to seek services.

A disabled participant expressed the same experience and their hesitation about being examined and delivered by a male health care provider:

*"May be because of our tradition and culture I also felt it would have been easier if it was nurse rather than doctor (male) so that I could ask things I want without any reluctance."*

- **A 33 year old disabled non-Dalit woman (Participant # 11)**  
(11<sup>th</sup> February 2015; Karahiya)

Other participants described that it was not only embarrassing to be checked and delivered by a male provider, but also they could not be open and frank with them and sometimes they felt scared.

*"It is true that I feel shy to have check-up and to give birth with male doctors. There are no other reasons.....I was scared if there would be male doctor. It was also one of the reasons."*

- **A 30 year old Dalit woman (Participant # 20)**  
(12<sup>th</sup> February 2015; Myaulihawa)

Moreover, in Muslim cultures more restrictions are present in relation to contact with non-family males and therefore when seeking health care from male providers. Women from conservative Muslim families were often not able to seek health care outside their home, with the presence of male providers being the main reason for them not to attend. One Muslim participant stated:

*"Our culture is different, they give birth at home. Even if they get long labour pain, they wait for 2 to 3 days at home. They permit only if the problem is severe... The only thing that people talk about is that there would be male and female health workers in hospital but at home, we can call only female to help in delivery. Some people think like this and so they prefer home delivery."*

- **A 35 years old physically disabled non-Dalit (Muslim) woman (Participant # 15)**  
(10<sup>th</sup> February 2015; Ekla)

The participants reported that Madhesi women are not allowed to go alone to seek services even if the health facility is near. An escort is mandatory especially when seeking health services. This restriction was found not only among Muslim women, but also among women from other culture and religions including Hindu. One of the participants stated that:

*“...it is not possible. If my husband is unable to accompany, we can go with mother in law and father in law or other members in the family but never with others.”*

- **A 35 year old disabled non-Dalit woman (Participant # 15)**  
(10<sup>th</sup> February 2015; Ekla)

Focus group participants noted that care seeking and service use could also be influenced by the sex of the foetus or the new-born. It was reported that many women do not seek care if it is known that the sex of the foetus is female. Not to attend postnatal care and the immunization clinic in the case of girl child was reported as common. The Female Community Health Volunteers in their focus group discussion stated:

*“In our Madhesi Community, we need a boy. Although they give birth to more than five girls, they want to have a boy.....There are lots of cases like that.... They go for immunization if she has a baby boy and they don't if she has a baby girl.”*

- **Respondent 1, FGD # 5 (FCHV)**  
(16<sup>th</sup> February 2015; Siddharthanagar)

Local customs and rituals, traditions, practices and beliefs, are strongly linked with care seeking. Across all religion, caste and ethnic groups, different but common rituals and traditional practices were often reported as creating barriers. The common belief system of purity and impurity considers women to be impure immediately after giving birth and their seclusion were found as a barrier for women to seek postnatal care. This practice is reported among all caste and ethnic group women including Muslims. Untouchability as an issue was not reported as strongly among Muslim women as it was reported within Hindu families. One Muslim woman explained:

*“If there are other persons in the family to work, we keep ourselves secluded for 45 days. Those who do not have anyone to work at home start working after 8 days once they give the name to the baby on 7th or 14th day. For 45 days, we do not go to Masjid and read Namaz (the holy book) as well. It is accepted to be touched and examined by health personnel in the case of sickness or regular check-ups....that would not be a problem.”*

- **A 35 year old disabled non-Dalit woman (Participant # 15)**  
(10<sup>th</sup> February 2015; Ekla)

Another Dalit woman stated:

*“They (the nurses) told me to visit in 3rd day but my father said how is it possible. Then I thought after having “Nwaran” (baby’s name giving ceremony) I will also be able to walk in 15 days. There was also vaccination day on 30th of the month.”*

- **A 25 year old Dalit woman (Participant # 19)**  
(15<sup>th</sup> February 2015; Rudrapur)

Local customs about giving birth in the same spot as the previous generation, for example where the mother-in-law delivered her baby, was reported by some participants as an important tradition but of course, becomes a barrier to accessing care elsewhere:

*“I delivered my 4 babies in my old house in Lalpur. During my 5th delivery my sister-in-law was somewhat scared as I shifted to my new home here, so she thought may be this land is not that good for delivery, and she wanted to take me to her home. But I did not go to her home for delivery. There is no other reason.”*

- **A 38 year old Dalit woman (Participant # 23)**  
(17<sup>th</sup> February 2015: Bishnupura)

**Belief in the value and utilization of traditional healers and birth attendants**

Traditional birth attendants and healers found to be important health providers in the villages.

Many women from different cultures and social groups reported they are well trusted and called to assist at delivery. Due to their easy availability, cheap service and community acceptability they are often consulted as a first provider, although in some communities the inter-caste acceptability of traditional birth attendants and allocation of their roles at delivery is complex. For example, “untouchable” caste group women are used to cut the cord in some culture while in others they are not allowed to touch the baby and mother. However, some interview participants expressed that local traditional healers and birth attendants created barriers to them in seeking facility services:

*“I was ready to go to hospital for the last time too, but she (Traditional Birth Attendant) said that it can be delivered at home so I did not go. She said it can be delivered at home after massaging...”*

- **A 26 year old non-Dalit woman (Participant # 34)**  
(21<sup>st</sup> February 2015; Motipur)

The study found a strong influence of traditional birth attendants for home delivery. They gave confidence to women and families for home deliveries and they were also helpful practically, supporting them even after giving birth:

*“Sister-in-law asked if I should be taken to Butwal but the “Sudeni” (Traditional birth attendant) said it can be done here and there was no need to go. They did it here saying we did not have enough money to pay hospital.....I used to feel as if I would die. However, I had to deliver anyhow. I would feel secure in my heart. Sometimes, I had also the feeling that it would be better if I had gone to the health post, but again I would feel secure once the “Sudeni” were there.”*

- **A 35 year old disabled Dalit woman (Participant # 2)**  
(17<sup>th</sup> February 2015; Parroha)

*“I delivered at home by my own wish. My sister-in-law is a traditional birth attendant in this area and she did everything to support me during delivery. I do not have any other reason. I took injection, I checked my pregnancy and also took my children for injections.....that was not a problem...there was no problem for me so I gave birth at home.”*

- **A 30 year old Dalit woman (Participant # 20)**  
(12<sup>th</sup> February 2015; Myaulihawa)

#### Folk Beliefs and Superstitions

Women reported not attending ANC, particularly in the first trimester, and PNC immediately after birth, due to the fear of witchcraft, ghosts or evil spirits. It was believed that for a woman the early period of pregnancy, and for a new-born the postnatal period, are the time they are most vulnerable to witchcraft, ghosts or spirits.

Similarly, some women reported being cautious about good days or bad days to go out with their baby:

*“I do not know but they (mother-in-law and other family members) do not let the woman be alone just after giving birth. If we walk alone then something might possess us - this is what they say and they do not let us be alone.”*

- **A 35 year old disabled Dalit woman (Participant # 2)**  
(17<sup>th</sup> February 2015; Parroha)

*“After delivery the evil and spirit may trouble and we call “DhamiJhankri” (Traditional Healers) to know this. If ‘DhamiJhankri’ say this is by “evil and spirit” then they treat for it and if it is not*

*related to “evil and spirit” then they say it can’t be treated by them and advise us to go to hospital...The God/Goddess also does not tolerate it and some may have trouble with “evil and spirits” too, especially to the baby. They would have “Moch” (like Malnutrition).*

- **A 27 year old disabled non-Dalit woman (Participant # 8)**  
*(19<sup>th</sup> February 2015; Saljhundi)*

### **7.2.1.3 Policy and system barriers**

Policy flaws, discriminatory and weak health systems, poor implementation of existing policies and the invisibility of disability in policy arenas were reported as major issues and barriers to women receiving care.

During the interview with the policy implementer and planners, it was found that care protocols are not developed or followed at all levels. For example, many women reported that they have not received the complete care package while attending ANC clinics in health facilities. For example, no urine albumin and haemoglobin tests are done (which is mandatory for ANC) in lower level health facilities during their routine ANC check-ups. Similarly, many women reported that they were asked to have unnecessary video x-rays (ultrasound scans) from health providers private clinics and that added additional cost to them. The lack of guidance or standards developed for local providers and planners, particularly for disability care, was another important contributory factor to poor quality of care highlighted by the participants. The policy planner stated:

*“We do not have a protocol. For those who come for antenatal, we check their blood pressure, we take their history, give them iron tablets, TT injection... and we say it is enough. Should we not see albumin, sugar albumin? Is that not a minimum thing? But we do not see those. Also... again while checking by a trained person, it is not stated what the level of that should be? .....so without testing haemoglobin level we randomly give iron tablets. So, protocols of services and comprehensive services have not developed yet.”*

- **KII Participant # 6**  
*(18<sup>th</sup> March 2015; MoHP)*

The interview participants commented that none of the health policy, plans and strategies adequately cover the issues of disability. Some very basic provisions, such as accessible infrastructure, are found in the policy for new construction; however, there is no plan for retrofitting of existing infrastructures nor interventions, monitoring or reporting mechanisms in the system related to accessibility. In regards to this, the policy planner interviewed above stated:

*“There is no targeted intervention. There could have been provision of providing more facilities if Dalits, disadvantaged or poor vulnerable come to take the service, provisions for some special facilities may be. But services are equal for all- when services are equal only those who are aware and who are well-off have the reach of such services.”*

- **KII Participant # 6**  
- (18<sup>th</sup> March 2015; MoHP)

Despite maternal care services being free of cost for all in Nepal, many women reported that the costs of care and transportation were the main barriers for them. The provision of transportation cost reimbursement along with other incentives, such as health facility delivery are also provisioned in the government health policy to encourage women to access services. However, such policy provisions and interventions appear to be rooted in principles of equality rather than equity, and it was reported to be not very helpful for disabled women and for those living in remote areas.

In addition, some health facilities charge extra for providing services or tests that are arguably not necessary or within care guideline. The policy planners interviewed as part of this study also acknowledged this flaw in the policy; as well as poor regulation and monitoring:

*“There is a decrease in access to facilities...for people with disability. As I said earlier, we cannot expect equity by putting everyone in the same basket. There should be separate baskets. Due to this in terms of access.....As I said, those who are poor, Dalits, marginalized and geographically secluded do not have access.....so how can they get services? Provision for special intervention should have been made, however this is not seen. In terms of differently-abled also, nothing much has been done. We do not have disability friendly hospitals. Even if people with a disability come to take services, they do not get the services they should be getting because the services are equal for all. There should have been additional services for people with a disability but we do not have it.”*

- **KII Participant # 6**  
(18<sup>th</sup> March 2015; MoHP)

A disabled woman expressed her disappointment when faced with extra services and cost in the hospital, and with no discount for disabled women:

*“Doctor asked me to do a video x-ray for which I asked them if they had some facilities regarding it for the disabled. They made me wait saying they had to ask the director. I waited for hours but nobody came up with the decision. So, I paid Rs 350 and did my video x-ray. This is*

*the reason why I prefer private hospital rather to government, - at least you get service and respect in private for the fee you pay.”*

- **A 33 year disabled non Dalit woman (Participant # 11)**  
(11<sup>th</sup> February 2015; Karahiya)

Importantly, policy planners and community leaders highlighted the fact that disability issues are not covered adequately in health worker’s training curricula and there is also no induction, orientation or skill training for health care providers in disability. Thus the service given and quality are determined by the individual practitioners rather than through policy or training:

*“The government should have consideration to give training to the health service providers on how to behave and how to provide health services to our disabled pregnant sisters which I haven’t heard and seen till now.”*

- **KII Participant # 1**  
(21<sup>st</sup> February 2015; Devdaha)

#### **7.2.1.4 Access Barriers**

In the preceding chapter, physical access to health facilities and easy availability of services are influential factors affecting utilization of maternal health services were reported in survey, interviews and focus group discussions. Community leaders and advocates also noted that difficult geographical conditions, poor roads and transport systems, and long distance to health facilities were barriers to seeking care by participants. In addition, participants also spoke about inaccessible infrastructures and health facility buildings; unpredictable and poor availability of services, inadequate materials and supplies; and inappropriate equipment; all of which have made services out of reach for many, particularly for disabled women. This is substantiated by the result of the logistic regression analysis (**Chapter 5, section: 5.2.2.3**) showed that rural women are less likely to access the health facility delivery compared to urban women (OR 0.49, CI 0.27 - 0.91; P-value=0.023).

One of the interviews reported that the geographical remoteness and lack of available services nearby prevented her from having a hospital delivery in her first pregnancy:

*“There was no hospital nearby in the hill (village) at that time. The only people who used to go to hospital were those who had problems for 3-4 days. Otherwise everyone delivered at home.”*

- **A 35 year old non-Dalit woman (Participant # 31)**  
(20<sup>th</sup> February 2015; Butwal)

Another woman stated a similar problem:

*“Everything was good except the health post was rather far, health post was too far; I started labor pain and delivered at home.”*

- **A 35 year old Dalit woman (Participant # 22)**  
(10<sup>th</sup> February 2015; Ekla)

Moreover, one woman stated that there was no birthing facility at her area while she gave birth:

*“I delivered all in the home because there was no facility previously. I used to have 6 days of labor pain, I used to walk, and on the 7th day, I delivered. Nowadays, even when there is a little labor pain they take to health post for delivery.”*

- **A 38 year old Dalit woman (Participant # 23)**  
(17<sup>th</sup> February 2015; Bishnipura)

In the qualitative interviews, participants and community leaders from all groups (disabled, Dalits and non-Dalits) reported women encountered difficulties when seeking services due to the limited availability of transport options, and poor proximity and access to the facility. Dalit participants particularly complained that the distance to the health facility and unavailability of transport were major problems for them. In the absence of reliable public transport services during the day and no services available at night, they often decided to deliver at home.

Furthermore, several interviewees and focus group participants reported that their local health facilities do not offer 24-hour services and the opening times were not convenient. The hospitals and some local birthing centres offer delivery services for 24 hour; however due to staff shortages and other logistical problems (particularly in local health facilities), the other services were available in the daytime only. Antenatal and postnatal services are available during certain hours on specific days, which limit the opportunity for working women for those living far from health facilities to use the services. Long waiting times in crowded clinics, and no arrangement for sitting in the waiting place was also reported as being very difficult, particularly for disabled women.

Participants expressed the range of difficulties:

*“That day government hospital was not open so..... that is why; it is closed on Monday, only opens on Sunday and Wednesday.”*

- **A 21 year old Dalit woman (Participant # 27)**  
(20<sup>th</sup> February 2015; Buddhanagar)



*“I think that it was a Saturday. We had gone there in the hospital but it was closed and I had to do the x-ray due to urgency.”*

- **A 35 year old non-Dalit woman (Participant # 31)**  
(20<sup>th</sup> February 2015; Butwal)

As noted earlier, lack of available beds, inadequate supplies and no medicines in the health facilities are common problems reported by both advocates, community leaders and participants in their interviews and focus group discussions. Due to the scarcity of beds, some women reported giving birth in a standing position and others said they shared their bed with other women in labour whilst giving birth. It was also reported that delivery beds were readily made available for women who had attended the private clinics of hospital staff and doctors. This reported institutional abuse and unethical malpractice often discouraged women who could not afford private services:

*“During delivery there were many women so it was a problem. There were not enough beds so I had to wait for some time. Only when I was severe I did get the bed. There were many like me who had been waiting for a bed even after the labour pain started. It was not easy to get a bed. I thought I would die when they said there was no empty bed. I did feel disappointed when I did not get bed.”*

- **A 25 year old non-Dalit woman (Participant # 33)**  
(15<sup>th</sup> February 2015; Rudrapur)

*“If we have been to their clinic (before), then they arrange bed for us but if we haven't gone to their clinic then they don't care at all...”*

- **Respondent # 7 (FGD/Non-Dalit women )**  
(19<sup>th</sup> February 2015; Saljhundi)

*“They also used to keep two persons in a bed. While keeping double she felt difficult and I felt uncomfortable as well. Another one was kept on my daughter-in-law's bed at the time of delivery and after sometime another bed was available and I kept her to another bed.”*

- **A 21 year old Dalit woman (Participant # 27)**  
(20<sup>th</sup> February 2015; Buddhanagar)

*“They do not give the medicine there. If they give, they do not give the complete medicine. Sometimes they give one or two items and then ask us to buy the rest from outside. They do not give even the free medicines for fever that the government has supplied. I therefore do not go in general.”*

- **Respondent 3, FGD # 1 (Non Dalit Women)**  
(19<sup>th</sup> February 2015; Saljhundi)

*“They said I had to be injected within 24 hours while having my daughter and they did not have that facility/medicine. So they referred me to AMDA from the health post.”*

- **A 28 year old disabled Dalit woman (Participant # 4)**  
(11<sup>th</sup> February 2015; Devdaha)

In addition to the above difficulties, disabled participants reported additional physical barriers once they reached a health facility. Many health facilities did not have ramps for wheel chair users, toilets were inaccessible, and the internal layout of many health facilities were challenging for disabled women. Moreover, none of the health facilities (even the medical college hospitals) keep beds and equipment suitable or designed for disabled women. Some disabled participants reported that they had to deliver on the floor of the delivery room due to the difficulties of being on standard delivery bed:

*“If the woman was able to climb on the bed or if it was comfortable for her to deliver on the bed, then we put her on the delivery bed during childbirth, if it was uncomfortable for her to deliver on a delivery bed then we put her on normal bed for her delivery.”*

- **A 26 year old disabled non-Dalit woman (Participant # 10)**  
(19<sup>th</sup> February 2015; Saljhundi)

*“No there was nothing like that.... There were steel ladders there. I used the steps and easily climbed on the bed. The bed was not suitable and also it was very difficult for me during the delivery.”*

- **A 26 year old disabled non-Dalit woman (Participant # 10)**  
(11<sup>th</sup> February 2015; Devdaha)

Some disabled participants reported that they did not receive care services even if they attended health facilities, because they lacked the most basic amenities necessary and in some cases, the providers did not want to take the risk of giving services to disabled women, perceiving disability to be a complex issue. One of the disabled interviewees said:

*“I had gone again but it was already the time of delivery and after the check-up they told me it cannot be delivered here in this centre and asked me to go to hospital immediately.”*

- **A 26 year old disabled non-Dalit woman (Participant # 17)**  
(10<sup>th</sup> February 2015; Ekla)

#### **7.2.1.5 Barriers due to powerlessness**

The patriarchal nature of Nepali society considers women inferior to males in the family and society. Moreover, caste hierarchy and stigma places Dalits and disabled women at the bottom in the social structure and with no power to make decisions. Low social regard and their own perception of themselves as being inferior to higher caste and non-disabled people, contribute to low self-esteem, and feelings of weakness among people with disability and Dalits despite legislation to the contrary. From the evidence here, many of these women were found to be vulnerable, weak and prone to abuse. It was reported that fear, shame and humiliation created by physical as well as mental factors often prevented them from seeking services. This is substantiated by the quantitative data analysis above in **Chapter Five**, which suggested that women having a lower empowerment index were less likely to seek maternal health care services (OR 0.23 with P-value=0.002 for >4 ANC).

A female leader in her interview described that seeking and receiving health services are all power games. She further stated that those having power always seek care and have easy access to services- and those with no power do not receive:

*“.....Personal as well as power relations sir; it depends upon whether they know someone in that place and if they have access to power. If a person from an economically or socially backward community who is wearing old clothes, such people are sent back. We hear many such incidences. They say they do not have medicine, not even Cetamol and send back the sick person empty handed.”*

- **KII Participant # 4**  
(16<sup>th</sup> February 2015; Bhairahawa)

Some disabled and Dalit participants shared their problems about not being confident to attend health facilities, and their feelings of humiliation and an inferiority complex when seeking services:

*“I could not share about my problem confidently when I used to go for check-up. I was afraid if I would lose my way or if I would not reach the hospital. I was afraid what if I did not recognize the doctor.”*

- **A 31 year old disabled non-Dalit woman (Participant # 12)**  
(11<sup>th</sup> February 2015; Deepnagar)

*“I knew that pregnancy should be checked but due to the shyness I hesitated to go for ANC. Later, everybody said I should go then I started to go for regular check-ups.”*

- **A 35 year old disabled non-Dalit woman (Participant # 6)**  
(19<sup>th</sup> February 2015; Saljhundi)

A number of women expressed that the reason for not going to the health facility was their own fear, shyness and sense of humiliation. They were also afraid of being given an injection, cutting (episiotomy) or operation during childbirth, and also of previous people’s death in the hospital:

*“A wrong impression that one has to undergo surgery after visiting a hospital is one of the main reasons. Also people think that even if surgery is not necessary, hospitals usually recommend surgery as a source of income due to which people from the community are reluctant to visit hospitals during pregnancy.”*

- **KII Participant # 4**  
(16<sup>th</sup> February 2015; Bhairahawa)

Many of the interview participants, particularly Dalits and disabled expressed the fear that they did not have any idea how they would be helped in the hospital during their labour. Most of them had the misconception that they will have surgery if they go to hospital.

*“I had some fear too. But it was also that since the first child was born at home, I thought even this child would be born at home. Money was not the reason rather it was fear; I was too young in age also so...”*

- **A 26 year old Dalit woman (Participant # 26)**  
(20<sup>th</sup> February 2015; Butwal)

*“I was shy and was not willing to go. Earlier I did not know anything, I was so afraid, shy and other people scolded me... some fear creates inside in the mind to go hospital for delivery since the people die there. Everyone has that thought inside them but no one speaks out.”*

- **A 35 year old non-Dalit woman (Participant # 31)**  
(20<sup>th</sup> February 2015; Butwal)

Another reported reason for not seeking services, particularly post-natal care, was that they were physically too weak to go. Two of the participants commented:

*“They (pregnant women) go...but not all. Most of them go for pregnancy check-ups but do not go for delivery. Again very few go for PNC within three days, with the reason that they will be weak at that time and it will be difficult to go. They do not go even if they have a problem. If it*

*gets worse and becomes complicated then they rush to Bhairahawa but they do not go to the local Health Facility.”*

- **Mother (FCHV) of a 23 year old deaf non-Dalit woman (Participant # 16)**  
(10<sup>th</sup> February 2015; Ekla)

*“I was weak. Also my in-laws and other family members did not support me so I could not even tell them.”*

- **A 30 year old Dalit woman (Participant # 18)**  
(15<sup>th</sup> February 2015; Rudrapur)

The participants, both in focus groups and interviews reported that the poor and lower caste group women consistently encountered physical and emotional abuse when seeking health care. A Dalit leader told the interviewer that she observed such behaviour (verbal and physical assaults) on many occasions in the hospitals while taking the women for delivery:

*“In Lumbini zonal hospital, medical college there they beat the patients. Then how can they get the services? I have faced it with myself. That was the situation when I took my daughter-in-law and what (can you think) about the others.”*

- **KII Participant # 2**  
(16<sup>th</sup> February 2015; Dhakdahi)

#### **7.2.1.6 Knowledge, information and communication barriers**

Women’s knowledge and awareness, information, language and communication have been found to be crucial factors in the seeking and receiving of services. Logistic regression analysis of survey data (**Chapter 5 above**) indicated that the chance of illiterate women seeking services was less likely than literate and educated women (OR for literate or having primary education was reported 2.27 for >4 ANC and HF delivery with P-value=0.010 and 0.002 respectively and 1.54 for PNC with P-value=0.150). Similarly, the individual’s knowledge and awareness index showed lower odds in seeking services for women with lower levels of awareness, compared to women with high levels of awareness.

In qualitative data analysis, awareness levels were noted to be low among many study participants. Many women, mostly disabled and Dalit, reported that they did not know about check-ups in pregnancy. Nobody had talked to them about this and they did not seek health care:

*“I did not know while I was pregnant for the first and second time. I came to know it during my last pregnancy but I never went for check-up... There was no such practice to go for check-up*

*while I was pregnant for the first time. Nobody told me about that. I stayed 10 years in my parental house. In the last time, I got an injection and the female health volunteer who sometimes used to come to the village gave me some medicines too, but she did not tell me about the antenatal check-up. My father told me to go for an injection. I was so weak; I did not have blood in my body.”*

- **A 34 year disabled Dalit woman (Participant # 5)**  
(15<sup>th</sup> February 2015; Jogada)

Many of the study participants reported the absence of FCHVs in their communities; discriminatory attitudes where they are present; poor information giving and counselling in the health facilities; and not having other means of receiving information as being major barriers for them in seeking services. One of the disabled non-Dalit participants explained:

*“I did not know how many times to do a check-up. There were no female health volunteers nearby when I was pregnant, so other non-disabled pregnant women also did not get services from female health volunteers. They come here for polio vaccination and they don’t do any discrimination when giving polio drops to the babies”.*

- **A 26 year disabled non-Dalit woman (Participant # 17)**  
(10<sup>th</sup> February 2015; Ekla)

Most of the participants stated that they were not informed or called for post-natal care, even if they had ANC check-ups and had given birth in a health facility.

Some participants said:

*“No, I did not go. I delivered at home so I did not know that I should go to hospital even after delivery. Nobody told me in the health facility too at the time of ANC. They suggested for delivery at health institution but did not talk about check-up after delivery.”*

- **A 22 year old Dalit woman (Participant # 24)**  
(17<sup>th</sup> February 2015; Bishnupura)

*“Very shortly they gave a few bits of information, but women do need more advice at times which was not given.”*

- **A 29 year old non-Dalit woman (Participant # 32)**  
(20<sup>th</sup> February 2015; Shankarnagar)

Some of the participants in the interviews and focus group discussions reported that language and communication were barriers for certain women including deaf women or women. It was also reported that providers often behaved badly towards women in the health facility due to their language and communication problems:

*“...the only difference is that Madhesi people can’t communicate well to hill people. They talk in their own language, so health professionals from the hills do not understand what they are telling. They don’t even try to understand them asking the problem.”*

- **Respondent 1, FGD # 1 (Dalit Women)**  
(17<sup>th</sup> February 2015; Patkauli)

Another participant observed this behaviour when she attended a health facility and described the language and communication problem between providers and users:

*“Madhesi are not well behaved, they get over emotional. Although there are many modern ways, they are very rigid with their traditions. The problem is with their language as Madhesi’s language is not understood which might also be the reason for staff in health post or hospital getting angry.”*

- **A 24 year old non-Dalit woman (Participant # 37)**  
(12<sup>th</sup> February 2015; Myaulihawa)

#### **7.2.1.7 Poor birth preparedness and logistical arrangements**

Poor birth preparedness and logistical arrangements found to be other key barriers for all groups of women. Some study participants reported that they had intended to give birth at a health facility but the labour began at home and were unable to get to a facility. In most cases, labour began at night and they did not have any means of transport to get to a health facility. Moreover, financial constraints, unclear or poor understanding about their delivery date, heavy workloads for the women and other family members, and a lack of someone at home to take care of other children or to accompany her to the health facility were all common problems found in the study.

One disabled participant noted that she did not have time to go for check-ups due to her busy schedule:

*“You know that we live in villages and we seldom get time from our busy schedule. It is good to go on time before I get sick but due to lack of time I couldn’t go for routine check-up so I went only when I felt weak”*

- **A 35 year disabled non-Dalit woman (Participant # 15)**  
(10<sup>th</sup> February 2015; Ekla)

An interview participant described difficulties arranging vehicle transport at night that compelled her to end up delivering at home:

*“It was night so we did not know where to go. During both times, it was the same. During my elder son's birth I had pain all night and he was born early in the morning, the same happened with the younger one. ....That is also the thing; also I was scared to go alone as there was no one to accompany me.”*

- **A 26 year old Dalit woman (Participant # 26)**  
(20<sup>th</sup> February 2015; Butwal)

Similarly, FCHVs reported the same problem during the focus group discussion:

*“The labour starts at night and there would not be enough time to take to hospital. They deliver at home while preparing to go.”*

- **Respondent 2, FGD # 5 (FCHV)**  
(16<sup>th</sup> February 2015; Siddharthanagar)

#### **7.2.1.8 Barriers relating to perceptions of quality of care**

Women's perception on care quality was an important determinant for seeking services.

Incomplete or poor service, women's lack of confidence in the provider's skills, not enough time given by the providers, unreliable services and an unwelcoming environment in health facilities were all reported as factors that often made women hesitate when seeking care. Across all groups, women commented on these common barriers; however disabled and Dalit women in particular consistently reported their hesitation to seek care due to impolite or inappropriate behaviour of health professionals and their perception of the poor quality of care provided in the health facilities. They told a range of stories about their experiences:

*“I was checked in a sitting position keeping me on a chair. They did not keep me on bed, they examined me in a standing and a sitting position. They asked me to lie down on the bed if I had a problem or pain, but I did not have any problem so they examined me in that position.”*

- **A 30 year old disabled Dalit woman (Participant # 3)**  
(20<sup>th</sup> February 2015; Siktahan)

*“I heard from others that in government hospital they do not give much care. I have a daughter-in-law whom I took to a government hospital after two months of my delivery. When I took her at that time nurses said not to shout or chatter, stay quiet and they did not give good care. I felt so uncomfortable that I myself started advising her on behalf of them. Sisters there*



*did not look after and care well.”*

- **A 21 year old Dalit woman (Participant # 27)**  
(20<sup>th</sup> February 2015; Buddhanagar)

The participants were not confident in the abilities of the health providers. They considered them inexperienced, lacking training and necessary skills:

*“I was not confident on the nurses, only when I saw doctor I was relieved. Even during the check-up, it is different - the one done by the nurse and the doctor. I found it different.”*

- **A 31 year old disabled non-Dalit woman (Participant # 12)**  
(11<sup>th</sup> February 2015; Deepnagar)

Interview participants reported that it is not only a matter of staff competency but also the reliability of services in the health facilities. A number of women stated that they did not have trust and confidence in the services provided in some health facilities – and that on many occasions they wasted their time attending those health facilities. For example, one women explained why she made the decision she did about her own daughters care:

*“I did not want to take her to the local health facility in Lankapur (Lumbini Primary Health Centre) because all the nurses there were young and beginners, and I did not have confidence on them. I had listened a lot about their services from others.... taking the cases they keep waiting for 24 hours, 10 hours, 8 hours and finally refer to Bhairahawa. I did not like to waste time and keep my daughter in a risky situation. So I thought better to take her straight to Bhairahawa.”*

- **Mother of a 23-year's old deaf non-Dalit woman (Participant # 16)**  
(10<sup>th</sup> February 2015; Ekla)

Insensitive staff and their rude behaviours often discouraged women from attending health facilities to receive services. In addition, some participants spoke about being given poor information, no guidance and support in the health facility, uncaring and insensitive providers, and staff being unaware of how to deal appropriately with disabled women. One disabled woman reported her experience:

*“They asked me to sit; I told them I cannot see having low vision. But they did not ask me other details. I felt even sisters do not have the awareness. They ask us to go to certain numbered room, since we cannot see we will have to ask and go. Some people show the direction, which is difficult.”*

- **A 31 year old disabled non Dalit woman (Participant # 12)**  
(11<sup>th</sup> February 2015; Deepnagar)

Another disabled participant described her similar experience:

*“I wanted to ask them few things about their rude behaviours when I had stayed in line. Their rudeness may be due to heavy workload; they have to see many patients and also may be I couldn’t clearly ask my confusions. With all these reasons I went to another hospital.”*

- **A 33 year old disabled non-Dalit woman (Participant # 11)**  
(11<sup>th</sup> February 2015; Karahiya)

One of the FCHVs in focus group discussion described staff and provider’s behaviour in the health facilities:

*“When we send people there, the lady sitting there in reception gets irritated, that’s why we don’t feel like sending (clients).”*

- **Respondent # 1 (FGD/Non-Dalit women)**  
(19<sup>th</sup> February 2015; Saljhundi)

*“Doctors don’t tell us anything and the local women complain to us that they (doctors and other service providers) do not listen to them. They give immediate service respectfully to the educated people but won’t care (neglect) for uneducated people.”*

- **Respondent # 1 (FGD/FCHV)**  
(16<sup>th</sup> February 2015; Siddharthanagar)

Moreover, interview participants commented on a range of other challenges particularly in government hospitals, including the failure of health facilities to maintain the confidentiality of clients; poor sanitation, unclean wards and dirty environments, all of which often made women hesitate when seeking services:

*“Some places were dirty. But the room where I was shifted immediately after operation was clean and nice.”*

- **A 22 year old Dalit woman (Participant # 25)**  
(20<sup>th</sup> February 2015; Shankarnagar)

Some participants reported that they attended both public and private health facilities receiving services during their pregnancy and perceived that the private health facilities where they received services were clean while the government health facilities were reported as unclean wards and with poor sanitation:

*“The hospital I stayed was very clean. They used to clean 2-3 times a day. But government hospital is not like this. Toilet would also be very dirty. Lumbini Hospital is so dirty that postnatal women will be prone to infections.”*

- **A 29 year’s non-Dalit woman (Participant # 32)**  
(20<sup>th</sup> February 2015; Shankarnagar)

#### **7.2.1.9 Barriers due to restrictions and rules imposed by health providers during care and within health facilities**

Some study participants reported restrictions imposed by health facilities and health providers such as prescribing birth positions and isolation from family. Similarly, loneliness, and a lack of emotional support at health facilities were common experiences for all groups and often prevented women from seeking care. This is again substantiated by the quantitative data, and logistic regression analysis of the survey data on these findings (**Chapter Five, section 5.2.2**) suggested disabled women were then less likely to seek care than non-disabled (OR 0.50 with P-value=0.009 for HF delivery and OR 0.47 with P-value=0.019 for PNC).

Due to these restrictions and limitations, rural women in general and disabled women in particular prefer to deliver at home. One disabled woman described her problems giving birth in a restricted environment:

*“The women in the villages say that there would be restrictions in the hospital; we are not allowed to give birth in our own comfortable position, we have to obey what they say in the hospital, freedom is restricted. We feel comfortable to give birth in our own house in a free environment.”*

- **A 26 year disabled non-Dalit woman (Participant # 7)**  
(19<sup>th</sup> February 2015; Saljhundi)

*“I thought it would be comfortable at home and I did not like to go hospital. I think it is good to give birth at my own home. If it is at home there would be other people around to take care but in hospital I would be alone; there are younger nurses and they don’t care for the patients and I do not trust them much. The senior sisters (nurses) did care before when I had taken my son while he had illness. I had known a sister in the government hospital at that time and she helped us very much. She still inquiries about me and my family. She is now retired. If there are health workers that know you then they do care, otherwise they don’t...”*

- **A 30 year Dalit woman (Participant # 20)**  
(12<sup>th</sup> February 2015; Myaulihawa)

### **7.2.2 SUMMARY OF KEY FINDINGS**

The study identified a number of barriers for women, particularly for disabled and Dalit women, in accessing maternal health care services during their pregnancy and childbirth. There was a series of barriers identified ranging from mainly personal ones to socio-cultural, physical and related to policy and systems.

Discrimination, mistreatment, abuse and neglect, reflecting negative attitudes of service providers generated dissatisfaction, distrust and avoidance of accessing services among many women. The study found reports of such behaviour at all levels of health facility and experienced across all groups of women - however the providers at higher-level facilities were found to be more negative and abusive to women regarded as poor and powerless. Negative family attitudes were found to be a particular factor in adversely affecting disabled women in receiving care.

Access barriers relating to the physical location of services and the proximity to a health facility as well as lack of transport were reported by all women as reasons for not seeking care; however, disabled women also reported that unsuitable beds, and difficulties getting into buildings and around them internally, often made services inaccessible for them to use. Moreover, the scarcity of material and beds in the health facilities (as well as sometimes corrupt, inequitable methods of bed allocation), long waiting times, and expensive travel and transport costs were common problems for all groups of women.

Socio-cultural factors present deeply rooted complex barriers for all groups of women, but disabled, Dalit, and Madhesi women are more oppressed due to social hierarchy, restricted personal freedoms and discriminatory societal attitudes towards them. These groups of women in particular have little personal power or self-determination, and this can exacerbate their feelings of fear and humiliation. Traditional beliefs and customs influence decisions for delivery options and also seeking post-natal care. Illiteracy, lack of knowledge and information, and communication problems between users and providers add more complexity among those groups.

The study found that the poor quality of care received, untrained and inexperienced providers, unreliable services, and unwelcoming and unsuitable health facility environments, were critical barriers, particularly for disabled and Dalit women. In addition, rigid health worker attitudes and practices when insisting on birth positions and a lack of warmth and emotional support were all discouraging factors for women with regards to attending health facilities for delivery.

The practical implementation of government policy and systems such as free maternal care services, often fail to effectively mitigate supply-side barriers, due to weak leadership and poor implementation strategies.

In sum, the analysis of quantitative and qualitative data found numerous barriers that all women faced in seeking and receiving care; however, it evidenced that disabled and Dalit women encountered additional barriers as outlined above.

### 7.2.3 ENABLING FACTORS

In addition to the range of factors inhibiting women’s access to maternal health care, the interview and focus group discussions identified a number of enabling factors in seeking care. Ten key themes, listed here in order of importance based on findings, were generated from the qualitative data analysis describing enabling factors. Following the same process described in preceding section, the themes were generated identifying concepts in the interviews and focus group discussion texts, and then these concepts were grouped together into categories based on their similarities and relationship generating the themes. They are shown in the table below (Table 32).

**Table 32: Themes describing enabling factors for maternal health care service utilization in order of importance based on findings**

Themes	Subthemes/Categories
Helpful Provider	<p><b>Positive attitude</b></p> <ul style="list-style-type: none"> <li>• Provider with Positive Attitude</li> <li>• Non discriminatory</li> <li>• Welcoming and respectful</li> </ul> <p><b>Supportive behaviour</b></p> <ul style="list-style-type: none"> <li>• Polite and nice providers</li> <li>• Caring (extra care given)</li> <li>• Inspiring and encouraging provider</li> </ul>
Supportive government policy	<p><b>Free Maternal Health Care service</b></p> <ul style="list-style-type: none"> <li>• Aama Surakshya Karyakram (Safe motherhood program)</li> </ul> <p><b>Government Incentive</b></p> <ul style="list-style-type: none"> <li>• Provision of Cash/Travel incentives</li> <li>• Material incentives (i.e. mosquito nets)</li> </ul>
Supportive family and community environment	<p><b>Cooperative and Encouraging Family members/Husband (Supportive family)</b></p> <ul style="list-style-type: none"> <li>• Husband’s role and influence on and support to go for health check-up/delivery</li> <li>• Mother-in-law asked her to go for check-up/took her to HF</li> <li>• In-law’s role, support and influence on accessing health facility (e.g. Father in law arranging transport to health facility)</li> </ul> <p><b>Supportive Neighbours and friends</b></p> <ul style="list-style-type: none"> <li>• Neighbours shared their experience and gave confidence</li> <li>• Neighbours encouragement regarding check-ups</li> <li>• Encouraging friends</li> </ul>
Easy Access to Services	<p><b>Personal Link to provider (health care facility)</b></p> <ul style="list-style-type: none"> <li>• Familiarity with the provider</li> <li>• Provider known/relative</li> </ul> <p><b>Facilities and service efficiency</b></p> <ul style="list-style-type: none"> <li>• Availability of facilities, beds and materials</li> <li>• Quick services (No waiting)</li> <li>• Proximity, distance</li> </ul>
Awareness and self-consciousness	<p><b>Education/Awareness</b></p> <ul style="list-style-type: none"> <li>• Already aware about pregnancy check-ups Motivated/inspired by NGO awareness raising program</li> </ul> <p><b>Information</b></p> <ul style="list-style-type: none"> <li>• Information and encouragement by FCHVs</li> <li>• Information about government. incentives</li> <li>• Informed/called by providers (during ANC)</li> <li>• Information sharing and motivation by neighbours and friends.</li> </ul>

Themes	Subthemes/Categories
<b>Perceived risk and fear (fear of potential harm)</b>	<p><b>Individual impairment/limitation</b></p> <ul style="list-style-type: none"> <li>• Fear about disability (often their disability was the reason to seek service)</li> </ul> <p><b>Myths and beliefs</b></p> <ul style="list-style-type: none"> <li>• Fear about 'passing on' their disability to their baby</li> </ul> <p><b>Self-consciousness and feeling of threats</b></p> <ul style="list-style-type: none"> <li>• Severity of sickness during/after pregnancy determining factor in decision to attend HF</li> <li>• Fear of complications during delivery (e.g. – health facility seen as safer for the mother and baby)</li> <li>• Overdue delivery date</li> </ul> <p><b>Previous experience (of complications)</b></p> <ul style="list-style-type: none"> <li>• Previous caesarean delivery</li> <li>• Previous complications in pregnancy/delivery</li> </ul> <p><b>Curiosity and fear of pregnancy outcome (delivery)</b></p> <ul style="list-style-type: none"> <li>• Fear of trouble/complications</li> <li>• Fear of stillbirth</li> <li>• Afraid to deliver at home</li> </ul>
<b>Resource availability</b>	<p><b>Access to Family resources</b></p> <ul style="list-style-type: none"> <li>• Access to family resources (e.g. family pay for services)</li> </ul> <p><b>Access to Community resources</b></p> <ul style="list-style-type: none"> <li>• Financial loans available from cooperatives</li> </ul>
<b>Autonomy</b>	<p><b>Sufficiently informed and supported by others</b></p> <ul style="list-style-type: none"> <li>• Level of FCHVs information and advice given regarding HF</li> <li>• Informed by the provider's during ANC visits</li> </ul> <p><b>Individual's decision making power/Authority</b></p> <ul style="list-style-type: none"> <li>• Independent decision after consultation to go for health facility check-up</li> <li>• Her own decision without consultation (but asked to go)</li> </ul>
<b>Service satisfaction//Effect of previous experience</b>	<p><b>Perceived better quality of care</b></p> <ul style="list-style-type: none"> <li>• Friendly providers</li> <li>• Affordable</li> <li>• User's perception on better quality of care</li> <li>• Full ANC check-up as per protocol</li> <li>• Neat and Clean HF environment</li> </ul> <p><b>Trust and confidence</b></p> <ul style="list-style-type: none"> <li>• Trust and confidence in HF/provider's - skill</li> <li>• Regularity/Predictability/Availability (of services &amp; staff)</li> <li>• Good previous experience</li> <li>• Privacy maintained /separate room</li> </ul> <p><b>Cultural Acceptability</b></p> <ul style="list-style-type: none"> <li>• Female provider</li> </ul>
<b>Desire of modernity/ Demand of the changed society/ context</b>	<p><b>Seeking Comfortability</b></p> <ul style="list-style-type: none"> <li>• Safety and comfort</li> <li>• Availability of facilities</li> <li>• Use of facilities</li> </ul> <p><b>Social prestige/social pressure</b></p>

Below each of these are discussed in turn.

### 7.2.3.1 *Helpful Provider*

The study found the health care provider's role to be crucial in influencing women to seek care: they reported that providers with positive, non-discriminatory, polite and caring attitudes were

more likely to encourage women to repeat their attendance at a health facilities to seek further services, as illustrated by the following examples:

*“Nobody showed discriminatory behaviour towards me. Doctors were very cooperative and they took extra care saying both of us were blind. They suggested us not to have third child. They also said educated people like us should not give birth to too many children and also they took proper care during my stay there.”*

- **A 28 year old disabled non-Dalit woman (Participant # 13)**  
(11<sup>th</sup> February 2015; Devdaha)

*“They did not show any differences. I informed my mother. I am a deaf so I repeatedly went for check-up, X-ray and they told to come immediately to the health centre if I had any problem. They checked my blood pressure, weight, and abdomen. My mother is a health worker so I did this all as she suggested.”*

- **A 23 year old disabled non-Dalit woman (Participant # 16)**  
(10<sup>th</sup> February 2015; Ekla)

Others said they had received counselling and that providers had given them clear information about their pregnancy condition. One of the participants stated her satisfaction as below:

*“That was the reason why I was going to the health centre and people tried to convince me positively....In the hospital they assured me that everything is fine, your child will not have disability. They said not to worry and do not cry.”*

- **A 30 year old disabled Dalit woman (Participant # 3)**  
(20<sup>th</sup> February 2015; Siktahan)

Some disabled participants reported that providers gave them extra care and support once they were informed them about their disability:

*“Once I had taken Kunti with me, so during that time they knew I had the problem of low vision and they took extra care of me.”*

- **A 31 year old disabled non-Dalit woman (Participant # 12)**  
(11<sup>th</sup> February 2015; Deepnagar)

Another participant reported:

*“They called me first from the queue. There were many other people waiting. They treated me nicely.”*

- **A 26 year old disabled non-Dalit woman (Participant # 17)**  
(10<sup>th</sup> February 2015; Ekla)



Such positive responses were not only reported by women with disabilities; one non-disabled non-Dalit participant also expressed similar views about the provider, and how they had treated her very nicely and persuaded her to have a health facility delivery:

*“When I had gone for the pregnancy check-up, the nurses advised me for a hospital delivery. They said that it would be easier in the hospital since there are more facilities, there won’t be any risk for both mother and baby. We also realized that if any complication appears nobody can help at home but it would be safe in the hospital... Their behaviour towards me was very good. They talked very well and they did not have any pride in them. They explained things clearly whatever I asked, they did not get irritated or angry to explain.”*

- **A 23 year old non-Dalit woman (Participant # 29)**  
(20<sup>th</sup> February 2015; Butwal)

#### 7.2.3.2 Supportive government policy

Respondents in both the individual interviews and focus groups reported that the government’s free maternal health care provision and incentive scheme was a motivating factor for women to seek care. This is a positive sign; however, despite those incentives, not all pregnant women seek care for a variety of reasons such as poor quality of care, rigid traditional beliefs and cultural practices. One of the focus group discussion participants commented:

*“They do come these days. They get clothes and also money. Despite of this not everyone comes to take services.”*

- **Respondent 3, Focus Group Discussion # 6 (FCHV)**  
(17<sup>th</sup> February 2015; Rudrapur)

Another participant in the same focus group discussion added,

*“It has attracted many. On top mosquito net has been much more effective. Even mother-in-law’s are seen to encourage their pregnant daughter-in-law’s to visit hospitals these days saying that it is easier at hospital. They are ready to pay than to clean the clothes and dirt at home.”*

- **Respondent 1, Focus Group Discussion # 6 (FCHV)**  
(17<sup>th</sup> February 2015; Rudrapur)

Women themselves often decide where they want to seek care within the health care system. If there is multiple choices available, attending higher-level health facility and bypassing the local facility is common in Nepal. However, due to government incentives, such as travel

reimbursement and mosquito nets more easily available at lower level health facilities many women do decide to attend these lower levels facilities:

*“...they did not ask anything nor did I spend. I walked to health post while going for pregnancy check-up and did not spend any money.”*

- **A 35 year old Dalit woman (Participant # 22)**  
(10<sup>th</sup> February 2015; Ekla)

*“I got Rs 500 after the delivery. I was supposed to get a mosquito net as well but I did not claim that because my husband did not want it.”*

- **A 25 years old Dalit woman (Participant # 19)**  
(15<sup>th</sup> February 2015; Rudrapur)

Another non-Dalit participant reported that her reasons for attending the local health facility were free check-ups and receiving iron tablets. She expressed,

*“...because when the iron tablets given from Butwal finished, I visited health post. During that time, I also had my check-up done there. When I went there, a female community health volunteer informed me about the provision of mosquito repellent net distribution to pregnant women.”*

- **A 29 year old non-Dalit woman (Participant # 32)**  
(20<sup>th</sup> February 2015; Shankarnagar)

The focus group participants felt that the awareness level of community people regarding the importance of seeking maternal care has improved. They reported that people are informed about the government provision and incentive schemes. Moreover, the participants commented that Dalits in fact have advantages over the other groups in claiming those incentives.

*“Dalits are more aware on these issues now. They claim for money when they have their check-up done for the fourth time. We help them prepare papers; also we have provided them with mosquito nets. They get money for delivery as well as for doing check-up for four times. Female Health Volunteers coordinate to take that money.”*

- **Respondent 1, Focus Group Discussion # 6 (FCHV)**  
(17<sup>th</sup> February 2015; Rudrapur)

### **7.2.3.3 Supportive family and community environment**

Participants identified a supportive environment that included cooperation, support and encouragement from family, neighbours and friends as a key facilitator in their seeking care during

pregnancy. Some of the women reported that their in-laws and husbands encouraged them to seek services, as well as supported them logistically to go to the health facility (e.g. money, transportation). In most cases, it was the husband, who influenced the mother's choices: making the decision about his wife's pregnancy check-up and whether or not she had hospital delivery.

For example, one participant reported that:

*"Everyone in the family and the neighbours said I should go for the check-ups but it was my first time so I did not know about it. While I was pregnant my husband had to go to his job so he asked his mother to take me to hospital and I went with her."*

- **A 23 year old non-Dalit woman (Participant # 29)**  
(20<sup>th</sup> February 2015; Butwal)

While another said:

*"Everyone in the family encouraged me. Father-in-law, mother-in-law also encouraged me and I also had the information that I should have gone for check-ups."*

- **A 25 year old Dalit woman (Participant # 19)**  
(15<sup>th</sup> February 2015; Rudrapur)

Another participant said that her family encouraged her to attend a higher-level health facility from the beginning of her pregnancy, as there was no birthing facility at local health post:

*"It was not because of poor service in health post but ultimately it was necessary to go to hospital for delivery so I went there for my check up as well, with advice from the family."*

- **A 21 year old Dalit woman (Participant # 28)**  
(20<sup>th</sup> February 2015; Shankarnagar)

Other participants acknowledged the support of their family members including husband during their pregnancy and childbirth:

*"My husband used to tell me that all go for the check-up and you also should go. He inspired me to go for check-up."*

- **A 35 year old disabled non-Dalit woman (Participant # 15)**  
(10<sup>th</sup> February 2015; Ekla)

*"Firstly I did not go. My husband was also at home while it was 3 months. Later he also encouraged me to visit health institutions after 3 months and often took me for check-up...At*

*that time I did not have much pain (betha). After having dinner I did not know much; at around 1-2 am in the morning father (father-in-law) called the vehicle and took me to the hospital.”*

- **A 25 year old Dalit woman (Participant # 19)**  
*(15<sup>th</sup> February 2015; Rudrapur)*

Many women in the interviews and focus groups described how their friends, relatives and neighbours shared their experience and gave them confidence to attend health facilities. For example, several disabled women who were encouraged by their neighbours, friends and relatives to go to the health facility:

*“Our neighbours knew about it (her pregnancy) later from the Health post, and then they used to suggest me to keep on going to the health post for the check-up. They used to say that we should go for check-up normally after three months of being pregnant. After I went there then only I clearly knew that I need to go for check-up regularly. They had given me suggestions and I had read about it as well. My mother also used to say those things.”*

- **A 26 year old disabled non-Dalit woman (Participant # 10)**  
*(11<sup>th</sup> February 2015; Devdaha)*

*“Friends and relatives had come to me....some of them had already given births and shared the information who had checked their pregnancy and suggested me to go for check-up. They said that if the baby is not in the right position they will give medicine and treatment, keeping the baby in the right position in the health post.”*

- **A 26 year old disabled non-Dalit woman (Participant # 17)**  
*(10<sup>th</sup> February 2015; Ekla)*

#### **7.2.3.4 Easy Access to services**

Many women interviewed stated that the proximity of health facilities, availability of services and materials, and provision of quick and efficient services influenced their decision about seeking care. Moreover, some women commented that familiarity with the health provider made them more comfortable about attending the health facility. One of the participants said that the availability and range of services and facilities motivated her to attend a higher-level health facility. However, she also attended local health posts as well, since the community health volunteer informed her about the provision of mosquito net distribution to those attending their ANC:

*“It was as what we decided in our family. Video x-ray, urine test and all check-up services are available there. When I went for a consultation for the first time, they asked me to come again so I continued to go there. When I had slight abdominal pain, I used to take advice from phone as well. I also used to take advice of female community health volunteer if I got some problem and she also suggested me to visit health post so I used to go.”*

- **A 29 year old non-Dalit woman (Participant # 32)**  
(20<sup>th</sup> February 2015; Shankarnagar)

Some participants stated that private hospitals are better choices for those with money because of the quick service and the availability of providers:

*“The service is faster, it is clean, but in the government hospital the service may not be available in the same time, Drs. may not be accessible..... So, the private is preferred by those who have money.”*

- **A 26 year old disabled non-Dalit woman (Participant # 7)**  
(19<sup>th</sup> February 2015; Saljhundi)

Personal links and familiarity with health facility staff and providers was reported as a strong facilitator in women attending maternal care services:

*“I was not scared when I went for delivery. I had been familiar with everyone there. Even when I used to meet doctors on the way, they used to talk, so I was not scared.”*

- **A 35 year old disabled non-Dalit woman (Participant # 6)**  
(19<sup>th</sup> February 2015; Saljhundi)

*“The ANM working there knows me. They behaved well, just like you are talking with me at the moment. The ANM provided me services with love. She is very nice.”*

- **A 35 year old disabled non-Dalit woman (Participant # 15)**  
(10<sup>th</sup> February 2015; Ekla)

#### **7.2.3.5 Awareness and self-consciousness**

The study found that women’s education and awareness levels had a positive influence on their seeking and receiving care (with those with more education and awareness more likely to seek care). This has been demonstrated through the logistic regression of findings in the survey data (**Chapter 5, section: 5.2.2**), which showed that the probability of women attending ANC check-ups, delivery and PNC increased with their level of education. Similarly, women with higher scores on the knowledge and awareness index were more likely to seek care. This can be further

substantiated by findings from the qualitative interview and focus group data. Two participants, who were educated to the college level and had good exposure to information, media and health promotion, described their ideas:

*“We were aware that we should go for check-up but I was shy. When neighbours especially Nirmala madam who already had children told us we should go, we decided to go for check-up.”*

- **A 35 year old disabled (Blind) non-Dalit woman (Participant # 6)**  
(19<sup>th</sup> February 2015; Saljhundi)

*“No, that’s not because of others. I know at which time I have to go for check-up. I care about the health of myself and also to know the condition of the child inside me, so I went for a check-up. It is not because somebody told me.”*

- **A 25 year old Dalit woman (Participant # 19)**  
(15<sup>th</sup> February 2015; Rudrapur)

Focus group respondents also expressed views that similarly, educated family members were generally more supportive and encouraged the pregnant woman to attend pregnancy checkups and health facility delivery. They also reported that NGOs also conducted education and awareness raising programs; and that schoolchildren were often helpful influencers in the family, educating mothers-in-laws and other family members about the need to encourage women to seek care during pregnancy. One of the focus group discussion participants claimed:

*“In the villages now people are educated; mother-in-laws and father-in-laws are also given education by their children and are convinced about it, so it is not like that.”*

- **Respondent 1, FGD # 2 (Dalit women)**  
(17<sup>th</sup> February 2015; Rudrapur)

In order for communities to be informed and aware, information and communication were reported as necessary. Female community health volunteers, health workers, neighbours and the media were reported as the main sources of information:

*“The Female health volunteer informed me and I visited health post alone both times. I also visited nearby outreach clinic once.”*

- **A 35 year old disabled non-Dalit woman (Participant # 15)**  
(10<sup>th</sup> February 2015; Ekla)

*“We received medicines from health post.....female health volunteers provided information, gave vaccination and inoculation in the communities.”*

- **A 35 year old Dalit woman (Participant # 22)**  
(10<sup>th</sup> February 2015; Ekla)

Other participants reported that health workers informed them about delivery incentives and dates for their next visit. They reported that health workers informed them about danger signs during pregnancy and encouraged them to seek care:

*“I had gone directly myself and later at the time of delivery the health post said the baby seems small and they asked me to go to Butwal Lumbini hospital.”*

- **A 30 year old Dalit woman (Participant # 18)**  
(15<sup>th</sup> February 2015; Rudrapur)

*“Health post people told me that I would get Rs.500 if I give birth there. They kept me alert saying that if I had bleeding or fits/unconsciousness during pregnancy then that is a sign of danger.”*

- **A 25 year old Dalit woman (Participant # 19)**  
(15<sup>th</sup> February 2015; Rudrapur)

One educated disabled participant stated that she was encouraged by her mother to seek services; however, she herself was aware about it from reading books and getting information from the media:

*“I told you before, my mom used to ask me to go to hospital for check-up. Also I had heard many times through media too, something through reading. So I went regularly.”*

- **A 33 year old disabled non-Dalit woman (Participant # 11)**  
(11<sup>th</sup> February 2015; Karahiya)

Another participant stated that she was well informed by her previous experience:

*“I was informed earlier by other people but I already had experience of previous two pregnancies so I went by myself. My husband did not need to tell me anything in this matter. I went 4 times to the health post myself and once I visited the village clinic as well.”*

- **A 35 year old Dalit woman (Participant # 22)**  
(10<sup>th</sup> February 2015; Ekla)

#### **7.2.3.6 Perceived risk and Fear of potential harm**

Perceived risk for themselves and for their baby and fear of delivery complications was identified as one of the major factors for women choosing to seek care during pregnancy and childbirth.

Previous experience of complications; fear of adverse pregnancy outcomes; an individual's limitations due to their impairment; as well as sometimes myths and beliefs about disability being transferred from mother to child, were all reported as being driving forces for women to seek care. Women across all groups reported that greater self-awareness and the desire to reduce risks and complications were the reasons that they sought care, as can be seen in the following example:

*"I care about the health of myself and also to know the condition of the child inside me, so I went for a check-up. It is not because somebody told me. As I have had all those information and also seen other mothers having problems, I had full realization that it is the critical stage and I should be careful. I was also aware of that if something goes wrong to the mother then this would affect the child and vice-versa. Therefore I wanted to be in a good condition and to have the delivery without problem to both mother and baby so I was encouraged to go health facility."*

- **A 25 year old Dalit woman (Participant # 19)**  
(15<sup>th</sup> February 2015; Rudrapur)

Some participants reported that their reason to seek care was for early detection of any pregnancy problems to give birth safely, minimize risks during pregnancy and give birth comfortably as the example below demonstrate:

*"When I had gone for the pregnancy check-up, the nurses advised me for a hospital delivery. They said that it would be easier in the hospital since there are more facilities, there will not be any risk for both mother and baby. We also realized that if any complication appears nobody can help at home but it would be safe in the hospital. I was thin and my family was afraid for my delivery; that's why."*

- **A 23 year old non-Dalit woman (Participant # 29)**  
(20<sup>th</sup> February 2015; Butwal)

Other participants reported that their reason to seek services was due to problems and sickness particularly when they felt their life was in danger:

*"I felt that there could be a danger to myself and my baby if I do not go to hospital. I had the safe feeling going there. "*

- **A 26 year old disabled non-Dalit woman (Participant # 7)**  
(19<sup>th</sup> February 2015; Saljhundi)



Fear of the baby lying in an abnormal position led another woman to have regular check-ups and a health facility delivery:

*“I went from time to time. Because they had said, my baby was in reverse position, which had scared me. Due to which I went for video x-ray to check the position. I even went to many medical clinics. Even after coming here I went to Butwal hospital as I did not know anyone in the health post.”*

- **A 28 year old disabled non-Dalit woman (Participant # 13)**  
(11<sup>th</sup> February 2015; Devdaha)

Another participant was afraid due to complications in her previous pregnancy, for which she had a caesarian delivery, and this made her seek services and a health facility delivery this time:

*“My previous baby was very small and had to be kept in ICU. Since I had already faced that problem, I went to Butwal for the check-ups during my second pregnancy... My first child had been delivered by operation so I was more cautious during the second time. Video x-ray and all tests were normal but still I had caesarean in the second time too.”*

- **A 29 year old non-Dalit woman (Participant # 32)**  
(20<sup>th</sup> February 2015; Shankarnagar)

In addition to the common reasons for all women seeking care outlined above, disabled women also reported a range of other factors in them seeking care, in particular anxiety about their ability to give birth because of their impairment:

*“If I did not have any disability I would not have gone to hospital and spent this much money”.*

- **A 26 year old disabled non-Dalit woman (Participant # 17)**  
(10<sup>th</sup> February 2015; Ekla)

Another disabled woman was so afraid that she was not going to be able to give birth that it forced her to seek care.

*“I had the fear but the other problem was that I had very small hip and because of that I was fearful with the thought that it will be hard for me to have the normal delivery. “*

- **A 26 year old disabled non-Dalit woman (Participant # 10)**  
(11<sup>th</sup> February 2015; Devdaha)

Difficulties related to delivery for disabled women as well as concerns about disability being transferred to the baby was also another reason reported by some disabled women to seek care. As one disabled participant stated:

*“I thought, since I had complications in my body it would be better to visit the doctor. I have had fear that my baby would be disabled like me, and I would have complications while giving birth because of my disability.”*

- **A 28 year old disabled Dalit woman (Participant # 4)**  
(11<sup>th</sup> February 2015; Devdaha)

#### 7.2.3.7 Resource availability

Easy access to family and community resources were reported as key enabling factors in care seeking. Participants commented in some interviews and focus groups that women who have access to family resources to pay the cost for travel and services or whose husband or family members paid her costs were more likely to seek care during pregnancy and delivery. They described some communities in the study district have created funds - for example through women’s groups, cooperatives and community emergency funds - to support women with their cost during pregnancy and delivery. It was reported that women in these communities who have had access to such resources more often seek care.

Participants in a focus group discussion conducted with non-Dalit women claimed that all women in their community seek services these days due to the easy access to resources, provided through several options:

*“Everybody go to hospital these days. There are lots of organizations who support and give advice, even the hospital gives money. Moreover, there are cooperatives that support 15 – 20,000 rupees for this so nobody give birth at home and generally go to hospital. Community, forestry committee helps and also the ward gives support for this.”*

- **Focus Group Discussion # 3 (Non-Dalit women)**  
(19<sup>th</sup> February 2015; Saljhundi)

A Dalit woman described that her cost was paid or shared by her husband and family members while seeking care:

*“I did not find any shortcomings. I paid the cost myself since I am separated from family. My husband was not at home and mother-in-law had also given me some”*

- **A 25 year old Dalit woman (Participant # 19)**  
(15<sup>th</sup> February 2015; Rudrapur)

Similarly, another disabled woman who received antenatal service as well as delivery care described:

*“He (husband) helped me by paying for my food, clothes, medicine..... My husband brings clothes for me; I don’t need to buy it here”.*

- **A 23 year old disabled non-Dalit woman (Participant # 16)**  
(10<sup>th</sup> February 2015; Ekla)

#### **7.2.3.8 Autonomy**

Some women living in a nuclear family, particularly disabled women who had full control in decision-making reported seeking services more than those whose autonomy was curtailed. For example, there were a number of disabled women in the sample, who lived with their husbands, but separately from their husband’s wider family, reported that they decided by themselves about whether to go to the health facility for ANC:

*“The Female health volunteer informed me and I visited health post alone both times. I also visited nearby outreach clinic once.”*

- **A 35 year old disabled non-Dalit woman (Participant # 15)**  
(10<sup>th</sup> February 2015; Ekla)

Conversely, an educated Dalit woman living in a joint/extended family told how she was conscious about the need for check-ups during pregnancy, but was not in a position to decide herself independently about going to a health facility:

*“After the permission of family members, I had gone. It was known to me but I went after mother and father-in-law told me to go.”*

- **A 21 year old Dalit woman (Participant # 28)**  
(20<sup>th</sup> February 2015; Shankarnagar)

However, while a lack of information and confidence were often reported as crucial factors for autonomous decision-making, particularly by disabled women. Most of those who reported positively had received the information and encouragement from neighbours and friends and decided themselves to seek care:

*“I went there with my own decision. Some sisters used to tell that I should go there and Kamala sister also told so to go that’s why I went there.”*

- **A 35 year old disabled Dalit woman (Participant # 2)**  
(17<sup>th</sup> February 2015; Parroha)

### 7.2.3.9 Service satisfaction/effect of previous experience

Women's perception of quality of care and satisfaction with service on previous visits was identified as being a strong predictor in their decision to make subsequent visits to a health facility. The participants mentioned that the provision of better care with complete check-ups, convenient, readily accessible and affordable services, and the cleanliness of the health facility were factors that were important for them. Some participants stated that receiving complete ANC check-ups, having enough time with health workers, and having their privacy maintained in a friendly environment, all encouraged them to seek care. A disabled participant commented on her service experience:

*"A lady checked me. She checked my blood pressure, weight, my abdomen and gave me tablets and injection. They gave me three injections. She told me to eat good food and have light work only at home. They also advised me to have less work and more rest because of my weakness but it wasn't possible for me as I was the single adult of my house and I have to do all the work."*

- **A 35 year old disabled non-Dalit woman (Participant # 15)**  
(10<sup>th</sup> February 2015; Ekla)

Quality and good service were also the concern of other family members when deciding to seek care and choosing a health facility with previous experience of service being a deciding factor for attendance:

*"..... Family said we have to do video x-ray... they said the service there is good so we decided to go there initially, and then continued to go."*

- **A 29 year old non-Dalit woman (Participant # 32)**  
(20<sup>th</sup> February 2015; Shankarnagar)

A Dalit woman commented that her provider examined her, whilst maintaining her privacy and giving enough time:

*"She examined me in a separate room maintaining my privacy. There was curtain too. It took about 30 minutes have the whole examination."*

- **A 35 year old Dalit woman (Participant # 22)**  
(10<sup>th</sup> February 2015; Ekla)

One of the disabled participants stated her experience:

*“It was comfortable....need not to wait, received services immediately; the beds and surrounding was also clean.”*

- **A 23 year old disabled non-Dalit woman (Participant # 6)**  
(10<sup>th</sup> February 2015; Ekla)

A range of factors including free treatment, trust and confidence in the provider’s skills and reliable services in the health facility were all also reported as facilitating the women to seek care.

A disabled woman stated that health providers gave her confidence:

*“If I had pain in lower abdomen.... They had asked me to come for delivery. They had assured that they would do their best it in the health post itself, otherwise they would send to the Mission Hospital if became complicated. Mission Hospital is also free.”*

- **A 35 year old disabled non-Dalit woman (Participant # 6)**  
(10<sup>th</sup> February 2015; Saljhundi)

So while the motivating factor for attending private health facilities were reported as efficient and the quality of services, the attraction of government health facilities was primarily the free service:

*“The services are the same but in the private it will be available immediately. They have better quality of services too. In the private hospital, they have more staff where as in government hospitals there will be more patients but they always face the problem of staff shortage. Therefore, few staff cannot provide good services for many people. Most of the delivery cases go to the government hospital due to the free service. People say it is the same doctor giving the service in both private and government hospital. Some go to private seeking more facility and quick service.”*

- **A 26 year old disabled non-Dalit woman (Participant # 7)**  
(19<sup>th</sup> February 2015; Saljhundi)

#### **7.2.3.10 Desire of Modernity/Demand of the changed society/ context**

Participants also mentioned that due to the changed social context, women view attending health care facilities, and having a health facility delivery as indicators of modernity. However, some focus group participants also commented that women these days are more intolerant of pain and aspired to having a comfortable delivery by attending a health facility:

*“It’s because of the present context rather than the fear. People are well aware and are educated these days that is the reason as well.”*

- **A 23 year old non-Dalit woman (Participant # 29)**  
(20<sup>th</sup> February 2015; Butwal)

*“Nowadays people say that it is good to go to hospital because, if the baby is delivered at home we need to call the Sudeni (Traditional Birth Attendant), and also someone should take the placenta away for disposal. But if taken to the hospital, everything will be done there and we can return home with a baby... nobody would like to deliver at home. If it is delivered at hospital they cut the cord and dispose of the placenta themselves and also give bath to the baby.”*

- **Respondent 1, FGD # 5 (FCHV)**  
(16<sup>th</sup> February 2015; Siddharthanagar)

Two other interview participants described their reasons for attending the health facilities:

*“The complications are also more these days and this generation can’t bear the pain. If anything wrong happens that would be regrettable so we think it will be better if we take them to hospital at an early stage.”*

- **Respondent 2, FGD # 1 (Dalit Women)**  
(17<sup>th</sup> February 2015; Patkauli)

*“...because it would not be safe for delivery at home. The cleanliness and other facilities would also not be possible at home and it is easier in hospital.”*

- **A 35 year old non-Dalit woman (Participant # 30)**  
(20<sup>th</sup> February 2015; Butwal)

However, some women attended health facilities for delivery because they had nobody at home to assist them or care for them at the time of their delivery:

*“There were nobody at home to help and take care except for us three; I, my little girl and her father. That’s why we thought it would be better and more comfortable at hospital than at home, so we went to the hospital.”*

- **A 21 year old Dalit woman (Participant # 27)**  
(20<sup>th</sup> February 2015; Buddhanagar)

#### **7.2.4 SUMMARY OF KEY FINDINGS**

The main enabling factors identified from the study participants were individual, socio-structural, financial, policy and service related.

Providers with positive attitudes and supportive behaviour were reported as being crucial enabling factors in women seeking care. Similarly, the study found supportive government policy, for example free maternal health care services, incentives for health facility delivery, and previous service-user satisfaction also persuaded many women to seek and receive services.

Important supporting factors were having cooperative and encouraging families and neighbours; easily accessible financial resources, and being able to make their own care seeking decisions – with women living with their husbands but independent from the extended family more likely to seek care.

Perceived risks and fears of potential harm and adverse outcomes for the mother and baby were common reasons to seek care across all groups of women; however, disabled women were more fearful of these risks due to their impairment and additional care needs. The level of information, education and awareness of services of the woman herself and her family members was another identified enabling factor for seeking care. Across all groups, women who were more informed and educated were found to seek services.

Finally, the changed social context and expectations of modernity with regards to healthcare facilities was also identified by participants as one of the reasons to seek care.

In conclusion, support, encouragement and confidence building by neighbours, friends and families found to be the most important enabling factors for disabled women to seek care.

Based on these key findings, the following section discuss about inhibiting and enabling factors for women, particularly to disabled and Dalit in seeking and receiving care.

## **7.3 DISCUSSION**

### **7.3.1 DISCUSSION: INHIBITING FACTORS**

#### *7.3.1.1 Attitudinal Barrier*

Disabled and non-disabled service users from both Dalit and non-Dalit groups reported that their hesitation in seeking services was linked to their experiences that the providers lacked sympathy, and they often perceived they were neglected, disrespected and humiliated. Poor and powerless women in particular reported such experiences. For example, disabled and Dalits often faced such behaviors by their providers during pregnancy check-ups, as well as during labor (**Findings above: 7.2.1.1**).

This finding is consistent with previous studies in Nepal that reported that the attitudes of family members and society created barrier for women with disabilities in seeking care (Hees, Cornielje, Wagle, & Veldman, 2015; Joanna Morrison et al., 2014). This barrier was mainly due to the stigmatizing behaviour of families and communities, as well as poor awareness of health care

needs of women with disabilities. Moreover, due to the lower value of disabled women in the family, their health needs may not be seen as a priority for the family.

Health care provider's attitudes and behavior were found to have a substantial influence on women's perceptions of quality of care, which in turn affected her decisions to seek care. A healthcare provider with a friendly, kind and reassuring manner can help women to reduce the fear during labor; whilst conversely, uncaring or aggressive behaviour exacerbate fears and may inhibit women from seeking care. These findings relate to provider's negative attitude and its impact on quality of care – all of which have been widely documented in the literature from different parts of the world - including Nepal. This is not unique in Nepal. Women's experience of abuse, rudeness, disrespect, uncaring attitude of the providers were reported consistently in the studies in India (Hulton et al., 2007), Guatemala (Berry, 2008), Dominican Republic (Foster et al., 2010) and Cambodia (Ith, Dawson, & Homer, 2013).

#### *7.3.1.2 Socio-Cultural Barriers*

##### **Social Hierarchy/Position**

The findings revealed the complex interplay of socio-cultural factors, which often challenged women's ability and willingness to access and use services despite their free provision. The imbalance in power relation between men and women, for example between husbands and wives, or daughters and mother-in-law at the household level affects women's decision-making autonomy and often delays or prevents women receiving care (Thaddeus & Maine, 1994). These findings have been reported in previous studies in Nepal (Pandey et al., 2011) and elsewhere (Basu, 1992; Bloom, Wypij, & Gupta, 2001; Sharan et al., 2005).

Dalits and disabled rank at the bottom of social hierarchy and they are often perceived to be discriminated, isolated and powerless. Interestingly, many Dalits and disabled participants did not perceive they were discriminated against or that there were barriers to receiving health services from society or providers because of their status - rather they frequently encountered barriers due to powerlessness resulting humiliation, shame and fear to receive the services (Dhungana, 2006). Saroha, Altarac, & Sibley (2008) reported similar finding from India, where Dalit women prefer to seek the services from traditional birth attendants to avoid humiliation and discrimination from upper caste providers in health facilities.



Morrison et al. (2014), and Acharya, Bell, Simkhada, Teijlingen, & Regmi, (2010) highlighted barriers to receiving health care services in Nepal were often related to women's low status at home and the dominance of other family members.

#### Culture and Belief

Utilization or lack of utilization was also linked to culture and belief. For example, in some sub-cultures within the study population, women who give birth without help were viewed as strong and considered socially prestigious (**Finding above: 7.2.1.4**). Across all social groups and cultures, premarital or extramarital pregnancy is socially unacceptable and would bring shame and public ridicule if disclosed making always difficult for those women to seek services. It was common practice across the entire study group to keep the mother and baby inside the home for 4 to 12 days after delivery, as the mother and baby were considered impure until they have undergone the baby's name-giving ritual. Such beliefs directly and indirectly limit women's access and utilization of maternal health care services.

Another such factor is the sex of the healthcare provider – all participants reported hesitation about being examined or delivered by a male provider, and Muslim women in particular who could afford the cost preferred to deliver at home in the presence of a female health workers (although many Muslim families are amongst the poorest and most disadvantaged). Moreover, in some of the study population, women strongly desired intergenerational continuity, giving birth at home preferably at the same place/spot where their mother-in-law had given birth, believing it to be the place for them to give birth, as it is believed that the family God may bless her and her baby if she gives birth at home. Due to this reason, families become more cautious about holiness during delivery and prefer a home delivery.

Khanal, Adhikari, Karkee, & Gavidia, (2014); Lama & Krishna, (2014); Onta et al., (2014); Simkhada, Teijlingen, Porter, Simkhada, & Al, (2006) reported from their studies that cultural and traditional practices created barriers to Nepalese women receiving care. Moreover, traditional beliefs such as possession from ghost and evil spirits during and after delivery were prevalent and created barriers for women in receiving services. A number of previous studies in Nepal and other contexts have identified similar cultural beliefs and practices as key reasons why women do not seek services. In India and Africa, Griffiths & Stephenson, (2001) and Stephenson, Baschieri, Clements, Hennink, & Madise, (2006) found the consistent findings that giving birth without help carried high prestige for women in the local community.

### *7.3.1.3 Policy and System Barrier*

The study revealed several factors related to policy, and the ways in which the health system inhibits women's ability to access and use maternal health care services, despite the government's free maternal care service provision. Unequal distribution of health facilities and health care providers were found to be an important barrier that prohibited women's full access and utilization of services. Even with the availability of services, it is not guaranteed that all women would be able to utilize the services. In recent years, the GoN has initiated health system reform; however, to date, none of the revised policies and plans adequately cover the issue of maternal health care needs for disabled women. Poor implementation of plan and policies, weak monitoring and accountability at all levels are the main reasons for poor quality services.

Moreover, with regards to staff there is currently no training on disability for health providers, nor are there plans for such training in the future, despite GoN commitments to the CRPD. The study found that none of the health policies and plans contained any plans for targeted interventions to ensure women with disabilities are included into mainstream services, nor does the health sector monitor the utilization of services by disabled women or produce disaggregated data.

Numerous studies in Nepal and elsewhere have highlighted similar findings around inadequate policies and systems to address the maternal health needs of poor and marginalized women with disabilities. Dhital, Dhital, & Aro, (2015) and Paudel, Upreti, Acharya, Tandukar, & Harvey, (2015) consistently found a gap between clients and providers with poor accountability with the current health system. They also found that poor implementation of policy provisions to improve the quality of health service and its effectiveness. Morrison et al., (2014) also highlighted the need for disaggregated data to be gathered through the health monitoring system to identify if disabled women are benefitting equally from services.

In sum, the negative experiences in the health-care system creates a sense of distrust of health providers; as well as fear and uncertainty of the type of care they will receive, which pose further obstacles to client-provider interactions leading to avoidance of seeking care. Furthermore, the inaccessible physical environment and complex socio-cultural values and systems inhibit disabled and Dalit women's access and utilization of maternal health care services.

The next section discuss about enabling factors for women in general, and disabled and Dalits women in specific in seeking and use of maternal health care services.

#### *7.3.1.4 Physical (Access) Barrier*

Consistent with the findings in other studies (Ahumuza, Matovu, Ddamulira, & Muhanguzi, 2014; Drainoni et al., 2006; Hees et al., 2015), disabled women's access and service utilization was constrained by lack of appropriate physical facilities. For example, ramps, adjustable beds (especially in labor rooms), and wheelchair accessible and disabled accessible sanitation services in health facilities were all lacking. However, in contrast to the findings of other studies in Nepal (Dhakal et al., 2007; Niraula, 1994; Onta et al., 2014; Wagle et al., 2004), Ghana (Ganle, Otupiri, Parker, & Fitzpatrick, 2015) and Uganda (Ahumuza et al., 2014) distance, road and transport were not reported as a major barrier in this study. The distance and the geographical access to health facilities in this study area were relatively short and unlikely to be an important barrier to utilization of services.

#### *7.3.1.5 Knowledge, Information and communication Barrier*

Quantitative data in preceding chapter showed that individuals with a lower score on the knowledge and awareness index had lower odds in seeking services compared to those with higher levels of awareness. Poor knowledge and levels of awareness of services (particularly among disabled and Dalit women) often prevented them from receiving services, as they did not have adequate information about services and their availability. The study also found disabled and Dalit women were more isolated and excluded from mainstream information and communication media. Female community health volunteers often discriminated against these women, for example, by not visiting or giving health information to disabled and Dalit women.

Poor interpersonal relationships between service seekers and providers (Niraula, 1994) created communication barriers that prevented providers giving women the information they need; this was particularly so for deaf women, for whom no other means of communication had been put in place. The study corroborates the finding of discrimination by community health volunteers in giving information to Dalits, previously observed in India (Shah, Mandar, et al., 2006). A study in Nepal by Hees et al., (2015) found disabled persons hesitating to communicate with health providers. Providers are often found to be uncomfortable with people with disabilities and struggle to communicate with deaf people (Kritzinger, 2011; Becker et al., 1997).

#### *7.3.1.6 Logistical Barriers*

The study identified a range of logistical issues that created barriers for women to seek care: these ranged from a lack of advance planning for delivery, including prior financial arrangements, having a person to accompany the mother, and someone to look after her other children at home. For

many poor families (particularly disabled and Dalit woman) making plans and arranging these basic requirements for delivery or check-ups was inherently difficult. Moreover, the study noted that family support and willingness was crucial for making these plans and arrangements – and families were not always supportive, particularly in the case of disabled women, due to pre-existing negative family attitudes towards their disability.

This finding is supported by past studies in Nepal and other countries. Onta et al., (2014) reported that poor logistical planning and arrangements, both at home and the health facility, hindered women for utilization of health facility delivery. Studies in Tanzania and Nicaragua revealed that the largest obstacle to receiving skilled and emergency obstetric care was the failure to arrange transportation and logistics in advance (Lubbock & Stephenson, 2008; Magoma, Requejo, Campbell, Cousens, & Filippi, 2010).

The study also found women facing difficulties in receiving services due to absent staff and the limited opening hours of the health facility. Moreover, health care providers gave priority to their own private practice with fewer hours in their designated government health facilities. The literature suggests that many low income countries, including Nepal, have been facing similar challenges in managing health care professionals (Adhikari, 2015; Ali, Bhatti, & Kuroiwa, 2008; Riaz, Zaidi, & Khowaja, 2015). This is linked to the issue of policy below.

#### *7.3.1.7 Barriers relating to perceptions of quality of care*

User's perception on quality of care is an important determinant for women in seeking and utilization of maternal health care services. The qualitative interviews revealed that poor and unreliable services, inexperienced providers with no competency to provide care - particularly to disabled women, or deal with complications exacerbated by the negative attitudes of staff often created barriers to the women in accessing and utilizing services. Moreover, poor sanitation and dirty wards and HF environment made women reluctant to attend health facilities. Most importantly, it was found that the care guidelines were not followed while providing services, which often prevented women receiving complete services.

This finding corroborates with a previous study in Nepal (Joanna Morrison et al., 2014) that concluded poor quality of care prevented women from giving birth at a health facility. However, their study identified no differences in the quality of care provided for disabled and non-disabled women.

## 7.3.2 DISCUSSION: ENABLING FACTORS

### 7.3.2.1 Supportive government Policy

Nepal's health system predominantly follows the traditional model of service delivery in which people are passive recipients. Evidences from other studies have shown improvements in health service delivery through increased community involvement in decision-making and delivery processes (Rifkin, 2014). Despite some past efforts by the Nepalese government to involve the community in health care, the system fails to provide an acceptable level of quality health care services. However, the study indicated some positive impact on patient-client relationship and increasing acceptability of services in the lower level health facilities. For example, provider-client relationship were found to be better at lower level birthing centers, where those centers were established in the best interest of community and they are actively involved in the governance and management. This finding is consistent with the emerging global emphasis on the principle of people's participation in health care with the idea that people should be able to reflect their own interest while making decision and engage in service delivery and of course, is a right based (Rifkin, 2014; WHO, 2002).

The initiatives range from free maternal health care, as promoted by the health policy of Nepal; as well as demand-side financing schemes; supporting women with delivery incentives, and transport cost for ANC visits. Although there are many shortcoming in the effective implementation of policy, and debates on the benefits to the poorer section of the population, it has been advocated as an effective means to change health-seeking behaviour of women, and increase utilization of maternal health care services (Powell-Jackson, Neupane, Tiwari, Morrison, & Costello, 2005; Witter, Khadka, Nath, & Tiwari, 2011).

Free maternity care and financial incentive programmes have been gaining popularity in recent years in many low-income countries (Powell-Jackson & Hanson, 2012). All participants in this study also reported that *Aama Surakshya Karyakram* (Safe Motherhood Program), with its delivery incentives and transport cost reimbursements was helpful in accessing maternal health care services. Other studies in Nepal support these findings as well as other countries (Jehan, Sidney, Smith, & Costa, 2012; Powell-Jackson & Hanson, 2012; Witter et al., 2011) show provision of free delivery and financial incentives were effective in not only encouraging women to seek care and increasing utilization but also having a positive impact on promoting equitable access to services.

### *7.3.2.2 Supportive Family environment and Easy Access to services*

Across all groups of women, in particular disabled women, they reported that a positive attitude by their families and particularly support from husbands and mothers-in-law were crucial in decision-making about, and use of, services. In the case of disabled women, many parents and families did not accept their marriage and pregnancy due to shame and stigma; but those who were accepted reported that having family support increased their ability to access and receive care at health facilities.

Many of the women reported that having a personal link (e.g. a family member) or becoming familiar with health care providers and /or staff at the health facilities (including private clinics) prior to delivery enabled them to get priority beds and services while attending health facilities for delivery.

The literature consistently and widely reports that cooperative family members and accessible physical infrastructure have a positive impact on maternal health care for a woman. For example, Hotchkiss, (2001) in Nepal, Sharan, Ahmed, & Strobino, (2005) in India and Pebley, Goldman, & Rodríguez, (1996) in Guatemala, found improved access to health care services had positive impact on utilization of maternal health care services.

### *7.3.2.3 Perceived risk and fear*

The literatures extensively reports awareness and risk perception of pregnancy and delivery as one of the important determining factors for women in seeking care. However, this study found the perceived risk of pregnancy and delivery much higher among disabled women than among non-disabled women. Interestingly, the study found that their own negative perception towards their disability and the myths and traditional beliefs rather than their impairment created fear of their pregnancy and childbirth that led them to seek care. All disabled participants in the study - including blind women or with those with only a mild physical disability, whether educated or illiterate, reported that they had doubts and worries about their ability to give birth, as well as anxieties about having a disabled baby.

These findings indicate that information and counselling are important for disabled women before or during their pregnancy to build their confidence and reduce unnecessary worries created by their own misconceptions.

#### *7.3.2.4 Autonomy and Resource availability*

The study found that women with more autonomy, better education and resource access were more likely to utilize services than those of with restricted freedom, illiteracy, lower levels of education and employment, or women with limited resource access (**Findings above: 5.2.3**). Numerous past studies conducted in Nepal and other contexts support these findings. For example, Matsumura, Bina, & Al, (2001) and Pandey et al., (2011) found that woman's education and empowerment were important factors in increasing utilization of maternal health care. In contrast, the study of Matsumura et al., (2001) showed a negative association between employment and use of maternal health services. Mistry, Galal, & Lu, (2009) found consistent findings with greater autonomy of women increasing the likelihood of receiving all three (antenatal, postnatal and delivery) services in India. Rutaremwa, Wandera, Jhamba, Akiror, & Kiconco, (2015) found that women's higher education were significantly associated in utilization of health care packages in Uganda. However, the findings of the study conducted by Bloom, Wypij, & Gupta, (2001) did not support the notion that decision-making autonomy was a determinant factor in receiving care.

The finding suggests that the individual characteristics of women and their ability to influence health care access are an important in seeking and utilization of maternal health care services. This indicates that a maternal health care strategy to address supply factor barriers alone may not be effective in increasing utilization and maternal health outcome of women. A focus on enhancing women's autonomy and their ability to access resources may also be needed in order to bring about changes in their health care seeking behaviour, increase maternal health care utilization and (hopefully) improve maternal health outcomes.

#### *7.3.2.5 Previous experience and service satisfaction*

The study found health care provider's positive attitude and availability of acceptable quality of care at health facility as important facilitators for women in utilization of maternal health care services. Despite many women's perception of provider's negative attitude and unhelpful behaviour, some women reported that their providers were non –discriminatory, kind, helpful and caring to them, encouraging them to seek the services. Moreover, they perceived the quality of service offered to them was good. Participants who attended private health facilities reported that provider's behaviour as well as the services offered to them was of good quality. It may be due to better working environment for health care providers with more supervision and availability of

materials and supplies in private health facilities, which is not the case in government health facilities.

The study also found that women were willing to travel long distances to receive better quality of care. Their emphasis was on quality of care rather than the cost and time. Consistent with this finding, Acharya & Cleland, (2000) found the strong effect of quality of services on utilization of maternal health care in Nepal. Similarly, Maine, (1994) debated that women's assessment of their own experiences of service, or those who they know, largely plays a decisive role in seeking care. Becker et al., (1997) found similar findings in a study conducted among American disabled women. However, a study conducted by Pandey, Lama, & Lee, (2011) in Nepal did not show any association between quality of care and utilization of health services.

#### *7.3.2.6 Desire of modernity*

The study found that seeking and utilization of maternal health care services was determined by the women's desire for modernity and maintaining superior status in their society, rather than their perceived health needs. These findings contrast with the findings from some other sub-groups, Dalits and indigenous in the study area, who felt socially respected giving birth at home. The study also noted that the women who viewed modernity and social status as prime factors to attend health care services were of better socio-economic status, while the other groups having low status in the social hierarchy and poor. The women from better off families may have had more exposure to media, and may have a better awareness of what is happening elsewhere in the world, which might be the motivating factor for them to be changed from traditional societal norms to modern practices. For example, younger more educated women reported their aspiration to have a comfortable life using modern – and hopefully available - services and facilities. Gebrehiwot, Goicolea, Edin, & Sebastian, (2012) and Moyer et al., (2014) found similar notion of findings in their studies in Ghana and Ethiopia respectively.



## CHAPTER EIGHT: CONCLUSION AND RECOMMENDATION

### 8.1 CHAPTER OVERVIEW

This chapter draws conclusions from the key findings of the results presented in preceding chapters and the analysis of literature, as they relate to the research questions posed in the study. It also reflects on the overall research process, highlighting issues emerging from the study, and their implications as well as areas for future research. The chapter concludes with recommendations for changes in policy and practice.

The objective of the study was to compare maternal health care access and utilization among disabled and non-disabled, Dalit and non-Dalit women in Rupandehi district of Nepal. It also sought to understand societal and health care provider's attitudes towards disabled and Dalit women, and identify inhibiting and enabling factors for their access and utilization of maternal health care services, with particular attention to seeing if the presence of two vulnerable attributes (disability, caste) – would be compounded, leaving women who were both disabled and Dalit most marginalised.

There is a striking vacuum in the literature relating to this subject, both globally and in the context of Nepal, leaving important questions regarding disabled and Dalit women's maternal health care unanswered. This study was designed with its key question being "what, if any, are the differences in the access to, and utilization of, maternal health care services among Dalit and non-Dalit women, with and without disabilities in Nepal? If so, what are these differences and what causes the disparities?"

This study employed a mixed methods approach and attempted to seek answers to eight key research questions stated in **Chapter Two, section 2.13**.

Findings in the preceding chapters are pulled together in this conclusion to answer the above questions.

Overall, the findings show that the situation is more complex/nuanced than initially anticipated. Some of the findings confirm and explain evidence from previous studies in Nepal, while other findings add new knowledge and understanding to the field.

The chapter is organized in four sections. The first section presents the reiterate the key findings of the thesis with reference to each chapter, then conclusion of the study in light of the research questions. The third section reflects on the overall research approach and strengths of the study.

The last section provides recommendations and overarching conclusions for the study as a whole. It should be noted that some findings address more than one objective or question and where this is the case, it will be noted.

## **8.2 KEY FINDINGS OF THE THESIS BY CHAPTER**

Conclusions based on the findings from this thesis will be presented below in two sections. The following section presents findings by *chapter*. The next section (8.3) presents the findings by *objectives* based on key findings identified by chapter. Conclusions will be drawn in each of the two following sections and then merged and used as the basis upon which Recommendations section and the Overall Conclusions section are built.

The objectives of this study were:

1. To compare and determine maternal health care service access and utilization patterns among disabled and non-disabled, Dalit and non-Dalit women in the Rupandehi district.
2. To understand the attitude and behaviours of society and maternal health care providers towards disability.
3. To identify inhibiting and enabling factors for disabled and Dalit women with regards to access and utilization of maternal health care service.

The initial chapters (1-4) provide background and methodology for the study. Presentation of findings begin in Chapter 5, which addresses objective one and the related questions to be reviewed in section 8.3 below, while Chapter 6 and 7 address objectives two and three respectively.

### **8.2.1 Key findings of Chapter 5**

- Disability status of pregnant Nepalese women was the determining factor for the utilization of at least one ANC visit, HF delivery and PNC visit. Women with disabilities were less likely to receive these services compared to women without disabilities. However, women's caste did not show any effects in service utilization.
- Women's age and parity were associated with utilization of at least one ANC service, HF delivery or PNC services, whereas women's education and knowledge about pregnancy danger signs were associated with utilization of full recommended ANC services and HF delivery. Younger women and single parity women tended more to take services compared to older women with multiple pregnancies. The likelihood of educated and knowledgeable women

being more aware of pregnancy danger signs was correlated with the utilization of full ANC services and delivered at HF more than for women with no education and little awareness of the risk of pregnancy. Similarly, urban women and those from higher wealth families had more chances to give birth at HF compared to their rural and lower wealth counterparts.

Interestingly, women's autonomy and empowerment was associated only with the utilization of full recommended ANC service – empowered women had more likelihood of taking full ANC services than women with low levels of empowerment. Socio-economic status and household factors such as women's occupation, family income and husband's education were also important predictors in the utilization of services. Women with regular employment were more likely to utilize full ANC services, HF delivery and PNC services, whereas women with educated husbands had more likelihood to utilize full services. In addition, age at marriage was influential in HF delivery and PNC service use – women married at an earlier age were less likely to deliver at HF and use PNC services. However, women utilizing full ANC services had more opportunity for HF delivery and PNC while those giving birth at HF were more likely to use PNC services.

- Maternal healthcare services were not easily and equitably accessible to all social groups, preventing their full utilization by women, particularly by women with disabilities.

### **8.2.2 Key findings of Chapter 6**

- Cultural and social attitudes towards disability were found to be unfavourable towards disability. Misconceptions about disability, negative stereotyping and a prejudiced social environment contributed to negative attitudes among the general population, as well as among health care workers.
- Issues around disabled women's marriage, their ability to conceive, give birth and safely raise a baby were the main concerns of non-disabled people in the communities causing even some women with disability to think negatively about their own pregnancy and motherhood.
- The study revealed that the healthcare providers in the study district perceive people with disabilities as different from people without disabilities. This suggests that healthcare workers perception towards disability is a negative one. The negative perceptions among health care providers differed according to provider's job type. Nurses and ANMs were found to be more positive towards disability compared to other professional subgroups such as doctors/HA/AHW and FCHVs.

- Healthcare provider's age, gender, caste, type of profession and their contacts to disability were influential in shaping the attitude of these healthcare providers towards disability and persons with disabilities.
- Women with disabilities often encountered health facility related challenges, particularly provider's negative attitudes, when they accessed maternal healthcare services. However, this finding was not universal with some of the study's disabled participants reporting that healthcare providers they saw were as kind, respectful, caring and helpful.

### **8.2.3 Key findings of Chapter 7**

- The analysis of quantitative and qualitative data found a series of inhibiting factors faced by all women seeking and receiving care; however, it was found that disabled and Dalit women encountered additional barriers.
- The barriers encountered by women with disability and Dalits ranged from personal to socio-cultural, physical and more broadly, related to policy and systems.
- Negative attitude of healthcare providers generated dissatisfaction, distrust and avoidance of accessing services among many women. This behaviour was reported at all level of health facilities and experiences across all groups of women, however, the providers at higher-level health facilities were found to be more negative and abusive towards women who were regarded as poor and powerless. As women with disabilities and Dalit women fell into these categories, they were at particular risk for receiving poor and disrespectful care.
- Negative family attitudes were found to be a particularly strong factor in adversely affecting disabled women in receiving care.
- Barriers to access relating to the physical location of services and the proximity to a health facility, as well as lack of transport were reported by all women as reasons for not seeking care; however, disabled women also reported inaccessible physical facilities such as buildings, equipment, and opening times made services all the more inaccessible for them.
- Socio-cultural factors present deeply rooted, complex barriers for all groups of women, but disabled and Dalit women are particularly prevented from accessing and utilizing services due to social hierarchy, restricted personal freedoms and discriminatory societal attitudes towards them. Traditional beliefs and customs influence decisions for delivery options and also seeking

post-natal care. Illiteracy, lack of knowledge and information, and communication problems between users and providers add more complexity among those groups.

- The study found that the poor quality of care received, untrained and inexperienced providers, unreliable services, and unwelcoming and unsuitable health facility environments, were critical barriers, particularly for disabled and Dalit women.
- The practical implementation of government policy and systems such as free maternal care services, often fail to effectively mitigate supply-side barriers, due to weak leadership and poor implementation strategies.
- The study also identified a number of factors enabling women to access and utilize maternal healthcare services. Providers with positive attitudes and supportive behaviours were crucial enabling factors, particularly for women with disabilities. The study found supportive government policy, for example free maternal health care services, incentives for health facility delivery, and previous service-user satisfaction helped persuade Dalit and poor women to seek and receive services.
- The changed social context and expectations of modernity with regards to healthcare facilities was also identified by participants as one of the reasons to seek care. This was particularly evident in the generational differences observed in the research results.

## **8.3 CONCLUSION BASED ON FINDINGS GROUPED BY OBJECTIVES**

### **8.3.1 Conclusion for Objective One**

Status of maternal health care service utilization among disabled, Dalits and non-Dalit women (Research Question i)

- A. As anticipated, women with more education, higher incomes and higher status were most likely to receive the full four ANC services. This means that non-disabled, non-Dalit women were more likely to use the full range of services. However, another important finding was that disabled women had consistently lower utilization rates of all maternal health care services than non-disabled women did, whether they were Dalit or non-Dalit, which indicates that disability a more powerful factor than caste in influencing the service utilization. Within this group interestingly, disabled Dalit women were more likely to access at least one antenatal care and postnatal care service than disabled non-Dalit women. This may reflect a broader trend, as non-disabled Dalit women were more likely to access at least one antenatal care than non-disabled non-Dalit women. Cultural and family factors seem to have a more

negative influence on disabled non-Dalit women's initiation of services than on that of Dalit women with or without a disability. Existing traditional strategies that focus strongly on Dalit women may need to be re-examined as regards programme interventions with increased focus on non-Dalit women to address or mitigate persistently negative group assumptions within the non-Dalit community about who existing care is available to or for.

Interestingly however, having once accessed services, fewer Dalit women return for further care, suggesting that greater attention is also required in programmes and service development to ensure the quality and experience of the care provided.

- B. There are differences between disabled and non-disabled women in their utilization of maternal health care services, but no differences between the general population of Dalit and non-Dalit women in relation to the services they access by their own choosing.

However, understanding the overall utilization of maternal health services by these groups is complex as there are several types of maternal health care. Some types of health care require pregnant women to access that care proactively by their own actions, whereas other types are brought directly to women by health workers – and the factors that affect each type of care seem to be different.

Notably, the evidence gathered by this study suggests that caste is not a significant factor in determining which women actively seek health care during their pregnancy. Where initiation of health-care-seeking lies with the woman (for example antenatal care), Dalit women were as likely as non-Dalit women to seek antenatal care from health facilities. However, the study findings suggest that the same was not true when the initiation of health care relies on health workers to proactively seek out women to provide care and advice to. This finding is particularly strong in relation to care provided by Female Community Health Volunteers (the least qualified level of health worker). Many Dalit women reported in their qualitative interviews that FCHVs did not visit their homes during pregnancy as they are supposed to do, even though they visit women from other caste groups.

Social deprivation and service inequalities for Dalits are well documented in the literature. Moreover, Dalit issues are highly politicized in Nepal, with Dalits arguing that they are discriminated against and denied access to public resources including services such as education and health. However, in terms of health service access and utilization, this does not seem wholly valid in the case of maternal child health services in Rupandehi. There would

need to be a separate study for wider populations covering multiple districts to better understand the complex and differing presentation of this discrimination countrywide, such as the difference between self-initiated care seeking behaviour and outreach efforts by health care workers identified as a factor here.

- C. The utilization of the PNC service in the study district was much lower among all groups in comparison to the national average. As found in both qualitative and quantitative findings reported here, the main reason for this was poor information given to the women by the health workers and volunteers during their earlier ANC and home visits. Many women were simply not informed by health workers about postnatal care, nor the reasons for its importance. In addition, strong traditional beliefs and customs among the women, family members and their communities, that did not include or advocate for PNC as a norm, were influential in women's decisions to seek care. Improved information systems about post-natal care, from health providers to pregnant women and their families, needs to be strengthened and embedded within the routine practice of maternal health workers. Complementary actions to educate and challenge social norms and community attitudes in relation to postnatal care also require investment to create an environment more supportive of women seeking appropriate care after delivery.

#### **Factors associated with service utilization (Research Question i)**

- A. A range of socio-demographic, economic and individual factors, such as women's age, parity, education, occupation, empowerment, husband's education, source of family income and household wealth were found to be associated with the utilization of maternal health care services. For example, as might be anticipated, educated, empowered women and women having better incomes were more likely to have had all three services, i.e. ANC, health facility delivery and PNC than those with no education, lower-levels of empowerment and low-income. Therefore, increasing women's access to maternal care services is reliant on interventions beyond health, such as improvement of women's education, social status, decision-making power and access to resources.

#### **Interplay between disability and caste (Research Question viii)**

- A. Among the four groups studied, disabled Dalit, disabled non-Dalit, non-disabled Dalit and non-disabled non-Dalit, this study focused on disabled Dalit women with one of the working hypotheses at the outset that disability would decrease access due to disabled women's lower caste status – that a woman who combined both attributes would be doubly

discriminated against. There are various literature that state women with multiple vulnerabilities may face extreme discrimination in terms of access to basic human rights and opportunities and resources putting them in the most marginalized group (Mehrotra, 2013). Interestingly however, data gathered here does not seem to confirm this. Instead, disability seems to overshadow caste. Disabled women, both Dalit and non-Dalit had a harder time than non-disabled peers. The study did not find any link between disability and caste having a compounding effect on access and utilization of maternal health care services. This study consistently found that disability was a much more significant barrier than caste for disabled women – both Dalit and non-Dalit. Further studies are needed to confirm this.

#### Access to maternal health care services (Research Question ii)

- A. Maternal health care services are not easily and equitably accessible to all social groups, preventing disabled and Dalit woman from full utilization of services. Disparities persisted in access and utilization among different groups despite some affirmative actions taken by the government in health care policy and development initiatives to mainstream participation of marginalized population such as Dalits. The study found the health care system too frequently characterised by limited and unequal distribution of resources, poor quality of services, distrust and unfriendly health care providers, culturally insensitive and unaccommodated health facilities with opening time and built environments making maternal health care services inaccessible particularly to disabled and Dalits women. These factors appear to account for why disabled and Dalit women have lower utilization of maternal health care services than non-disabled and non-Dalits. Despite these disparities, Nepal has made good progress in reducing maternal mortality, reaching MDG 5 and with continuing which will allow it to move towards the new Goals identified in the SDGs. However, equity of access and use of maternal health care services continues to be an essential component of government policy and planning to reduce maternal mortality. Focus continues to be on having vulnerable groups increase their utilization of services thus ensuring improved health. To make such service accessible to all, services will have to be organized and delivered in a way that is rationally distributed, technically appropriate, socially sensitive, culturally acceptable and accessible to all women including disabled and Dalits.
- B. The specific health care needs of disabled women are current invisible at data and at policy level. This translates into unsuitable health care settings and ill-prepared health care providers. For example, the integrated Health Management Information System (HMIS)



introduced under Department of Health Services, Ministry of Health (DoHS/MoHP), monitors the services delivered through health facilities in Nepal. The existing system collects disaggregated data on caste and ethnicity that includes Dalits; however, it does not collect disability data. The government has missed an opportunity to routinely collect disability information through both specific and mainstream government data collection systems. There are now good tools, such that the Washington Group Short Set of Questions ([www.washingtongroup-disability.com](http://www.washingtongroup-disability.com)) that would allow good data to be easily and quickly collected as part of Nepal's already developed data collection schemes. That would be a good place to start.

- C. Findings from this study, such as the very limited knowledge and experience of health providers on disability, strongly suggests that sensitization and practical skills training for health care workers to better support and work with people with a disability should be integrated into core pre-qualification curricula for all types and level of health worker.

### **8.3.2 Conclusion for Objective Two**

#### **Attitude towards disability (Research Questions iii, iv and v)**

- A. Qualitative and quantitative findings from this study reflected many points already raised in the established literature both from Nepal and cross-culturally, that finds that stigma and prejudice towards disability results in less social inclusion and reduced or restricted access to resources. The common but most important issue identified in this study was that the disabled women have significant challenges from family and society in every sphere of their life, including accessing health care services. This is due to inadequate public knowledge and misconception about disability, stereotyping and a prejudiced societal environment creating negative attitude towards disabled people. In order to mitigate misconception about disability, there is a need to have improved public information and advocacy campaigns.
- B. Negative attitudes are prevalent towards disabled women, their pregnancy and maternal health needs among both the lay population and health providers of the study district. Interestingly, these attitudes are not universal and nor do they always translate into negative experiences by disabled service users although negative experiences are common. Inadequate public and professional knowledge about disability and disabled people's needs contributed to these negative attitudes.

- C. As noted above, it can be concluded that lack of consistent training for professionals means that their knowledge and attitudes towards disability often are no difference than general public knowledge. It is therefore important that specific training for health care professionals is urgently needed to ensure they are aware of how to appropriately address and work with people with disability in their professional capacities.

### **8.3.3 Conclusion for Objective Three**

#### **Inhibiting factors in access and utilization of services (Research Questions iv, v and vi)**

- A. Inhibiting and enabling factors in access and utilization of maternal health care services are multi-dimensional. All women in the study district encounter demand and supply-side barriers in seeking and receiving care – such as poor quality of care, lack of communication, and logistical barriers. However, disabled women encounter additional barriers, such as those relating to the attitudes of providers and society, policies and systems. There is a need therefore to improve disabled women’s access through a range of actions simultaneously at both supply and demand side. For instance, all buildings where maternal health services are provided should be made accessible for all, with adaptations such as ramps, adjustable beds and wheelchairs accessible sanitary facilities. The demand side interventions such as provision of communication information by participatory women’s groups or other community based education efforts have proved effective in increasing access and utilization of maternal health care services in low-income countries including Nepal (Manandhar, Osrin, Shrestha, Mesko, 2004; Morrison et al., 2014).
- B. As attitudinal barriers of health workers were recognised as a significant inhibiting factor for all women using services, positive changes in health provider’s attitudes and behaviours may create more supportive health facility environments. Therefore, actions such as training and sensitization sessions are required to raise awareness and motivation of health providers to deliver professional, ethical and well-informed care. Literature suggest that provider’s negative attitude and behaviours in resource poor countries often links to their poor working conditions such as heavy workloads, shortage of equipment and materials, and poor pay scale (Mannava et al., 2015). Increased support and resources for health care providers who are delivering services to women with disabilities should be explored as one way to improve delivery of services for this vulnerable population. This could be an area for future research.
- C. As consistently documented in the literature, this study found that the existing social structure and imbalanced power relation between groups, such as Dalits versus high caste groups,

disabled versus non-disabled and female versus male restricted those subordinate group's autonomy and rights, leading them to be excluded, powerless and more vulnerable. To accelerate the dismantling of damaging social hierarchies and traditions that exacerbate disparities, there should be supportive actions to advance disability movements in civil society, and to link these with the better-developed feminist and Dalit representative groups. Currently, there is little contact between disabled people's organizations and other advocacy groups such as Dalit and feminist groups. Collaborative work and the joint action with these established advocacy groups may exert synergistic effects to bring positive social changes.

#### **Enabling factors in access and utilization (Research Questions v and vii)**

- A. Consistently in this study, it was found that women with disability reported higher levels of fear and perceived risks associated with pregnancy and delivery, for both the mother and her baby, than women without a disability. This was primarily attributed to fears about delivery complications linked to the mother's disability; and also to worries that the mother's disability would be inherited by the baby.

Better assessment of pregnant women with disabilities, including access to clear reliable information and genetic counselling (where appropriate) about the nature and type of disability, may go some way to improve delivery preparedness. Having health providers give better information to disabled mothers would also help to reduce unnecessary concerns about when and how disability is inherited— and enable better preparation in situations where that a child may be at risk of an inherited condition.

- B. An interesting and important finding was that there is a common and positive perception held by women in all groups that using health services is a modern and desirable thing to do, and that this marks women who use such services as progressive and having higher status. Such a finding provides a point of departure upon which health care providers and advocacy groups can build to increase PNC.

## **8.4 METHODOLOGICAL ISSUES, REFLECTION OF OVERALL RESEARCH FINDINGS, FIELD EXPERIENCE AND LIMITATIONS**

### **8.4.1 Issues related to literature review**

The literature review began with a search of scientific publications and credible reports from the database using a range of search engines and different search terms. The initial search of

published literature using a combined search for disability, caste and maternal health care topics produced limited results in the published literature. Peer reviewed literature around these topics was particularly scarce. As noted in the **Chapter Two**, an expanded search strategy, which took into account the broader grey literature base, when adopted, proved to be more successful. For example: several important government reports, literature and websites that report on activities of community organization and institutions were not indexed in frequently used research databases but proved helpful in locating information and policy discussions. However, the lack of a large body of literature both internationally and for Nepal in particular, underscores how limited the existing literature on this subject currently is.

#### **8.4.2 Issues related to Methodology**

Conducting research into a sensitive issue relating to a hidden population and with narrow recruitment criteria was particularly challenging, both methodologically and practically.

The study faced a number of challenges in design and field implementation. The sample design for the survey was complicated, as there were four groups with unknown populations of two groups (disabled Dalits and disabled non-Dalits). Moreover, the unequal distribution of research populations and reference populations in the study district further complicated how the sample size was determined. The study used a census method recruiting disabled women, whereas non-disabled Dalits and non-disabled non-Dalits women were recruited using multi-stage random sampling method. However, as noted above (**Chapter Three, section 3.2.3**), the sample was disproportionate and small in some groups such as disabled Dalits and disabled non-Dalits. It was therefore challenging to compare the results between these groups due to inadequate statistical power for some findings. This limitation, as noted in the previous chapters has been mitigated by supplementation of qualitative data, however, if addressing a similarly 'hard to reach' population in a future study, the survey research methodology would need careful consideration in order to attain representative samples within manageable budgets and resources.

One more limitation to note is that the qualitative nature of the study limits the generalization of these qualitative findings beyond the study setting – however, the qualitative findings not only were of interest in this study, but it is hoped, combined with the quantitative findings will help generate questions for future studies.

It is also recognized that the data was collected based on women's recall of pregnancies over the preceding 5-year period. This is a long period of time and it is possible that some women were not

able to accurately recall all pregnancies, particularly if they had had multiple miscarriages during that time period. Interviewers tried to get the most accurate recall possible, but there is a possibility that some women may not have recalled all relevant information.

Another limitation is that many women interviewed had used more than one health facility for the same pregnancy. Several women reported attending both local clinics and higher-level facilities during the course of their pregnancy and it was not always possible to determine which facility they were discussing when recounting their experiences. Interviewers tried whenever possible to clarify this, but it is possible in several cases that women were reporting on the overall experience without distinguishing between which facilities they used or used the most. In these cases, the response may reflect their cumulative experience and not be specific to a particular health facility.

Finally, as a methodological issue, this researcher notes some divergent findings between the quantitative and qualitative method, which are discussed in the preceding results chapters as well. These divergent findings are assumed to be due to the different strengths and weaknesses of the two different methodologies used in the study. In such cases, both sets of findings are discussed in-depth, presented, and compared. Such divergent or conflicting findings are taken as normal in a mixed methods study. However, such mixed methods studies are important approaches to investigating complex human phenomena, such as that which has been focus of this study. It is therefore not necessarily the case that one approach is right and the other wrong; instead, qualitative and quantitative data collection efforts capture different aspects of women's access to maternal health care issues. Discrepancies between the quantitative and qualitative findings reported here however are interesting and raise challenging issues that can be considered in future research (Slonim-Nevo & Nevo, 2009; Wagner et al., 2008).

#### **8.4.3 Issues related to field implementation**

Identifying disabled women and locating them during field visits was a problem since a number of disabled women, in particular, those living in the urban area, do not have a fixed address.

An additional issue is that only audio recording and field notes were used in the qualitative interviews. While a significant amount of data was collected, the audio recordings and field notes could not capture the body language and expressions of the participant, which would have been of great value in the interpretation of the qualitative findings. Use of audio-visual recorder in the study context was not possible due to practical and cultural reasons.

Another limitation was that there were communication problems with deaf participants. Lack of a sign language interpreter proved to be a roadblock in several interviews. While relatives who signed were used to interpret conversations when present, issues of privacy, modesty and politeness may have limited the responses given to fieldworkers by deaf women. Several additional deaf women were contacted but their lack of sign language or any other means of communication, made interviews impossible. Similarly, interviews with persons with intellectual disabilities often proved challenging – both in terms of ensuring that they understood the questions asked and in terms of the reliability of the information given.

In few cases, creating interview environments that maintained privacy were not possible for cultural, social and practical reasons. For example, in the Terai-Madheshi culture, the woman of childbearing years is not allowed to speak separately with outsiders, instead the mother-in-law speaks on behalf of her daughter-in-law.

Additionally, this researcher felt that often the format of formal interviews and focus group discussions although common vehicles for research, sometimes might not elicit true or accurate answers. In communities where these types of interactions (formal interviews/focus groups) are rare, and where being asked for an opinion may in itself be unusual for some women, then the established research apparatus may be a barrier in itself. This is compounded where new technologies, such as voice recorders, may be unfamiliar and therefore unsettling. For example, some of the participants hesitated to speak openly in the formal setting when their voices were being recorded. Informal meetings over a period of time and in a natural setting may be more appropriate and effective in getting closer to reality (Miller & Dingwell, 1997; Scott & Lyman, 1981).

Lastly, an experience reported by all interviewers was that the disabled participants were very enthusiastic and motivated to speak, and reflected positively about this in later stakeholder meetings. It was clear that the disabled women included in this study are often socially isolated and do not get many opportunities to interact with outsiders or speak about their experiences or opinions. Meeting us several times and having long conversations with people interested in them (via the interviews) may have given them relief, increased their self-esteem and help foster new ideas about how to mitigate their oppressed situation.

## **8.5 STRENGTH OF THE STUDY**

In the opinion of this researcher, the strength of this research is the use of mixed methods to offer methodological and data triangulation. The study was able to capture multiple perspectives from different sources, service users, health care providers, policy planners and community, providing rich primary data; facilitated by an experienced Nepali speaking researcher with long-standing experience in the maternal health and disability sector. As noted in the literature review section, the ability to undertake a mixed methods study around disability and caste, particularly one using such a large data set, is rare in the global literature.

Due to the exploratory nature of the research, the design and the methods, the study facilitated an in-depth understanding of disabled and Dalit women's lived experience in relation to their maternal health care utilization with a high degree of access and authenticity. Thus, it is hoped that study findings reported here may have wider applicability.

## **8.6 POLICY IMPLICATION AND RECOMMENDATION**

The findings and conclusions of the study have policy implications and therefore this section includes recommendations of relevance to policy makers, advocates, professionals and service users. Additionally, this study also raised a number of research issues that warrant further exploration.

The ideas presented below are by no means exhaustive, but intended to simulate thinking on how these study's findings might contribute to improve better health care for disabled and Dalits individuals in Nepal.

Some of the recommendations are specific on disability and some are more general and relevant for general health care improvement in Nepal.

### **8.6.1 Policy Implication**

**Health policies, service implementation and management should be based on human rights principles:**

This study finds that maternal health care services are not distributed and accessible equitably to all social groups. This is at odds with the Government of Nepal's position that recognizes health care as a fundamental right of every citizen and commits to provide basic health care services to all. It reflects a well-documented weakness in the current system.

The current health policy and system needs to be revised in alignment with a universally accepted human rights-based approach to health to provide strategies and solutions to address and rectify

inequalities, discriminatory practices and unjust power relations. Specifically Nepalese policy and country health systems must be compliant with its international commitments. Current policies and health service frameworks need to be modified to reflect Nepal's ratification of a number of UN policies and agreements related to disabled women's health including UNCRPD 2008 that Nepal signed in 2010. UNCRPD Article 25 states disabled women's health rights must be provided in the same range, quality and standard free or affordable care provisions provided for non-disabled women. This is not reflected in the existing health policy and practice where disabled women are not mentioned.

**Improvement and effective implementation of policy for fair distribution of services and resources:**

Distribution of services and resources need to be reviewed and re-allocated periodically to address population shifts between rural-urban areas. The study revealed unequal distribution of services and resources in health care. The urban concentration of health facilities, the shortage of trained human resources for health services delivery and the unequal distribution of available resources were apparent challenges in the delivery of health services in rural areas. All of this is of particular concern to women with disabilities because health care providers with knowledge of disability tend to be drawn to urban areas because of greater career options. Centres where there is a concentration of people with expertise on disability also tend to be urban based, including at universities, larger medical centres and tertiary care hospitals.

This shortage of medical personal is compounded by the fact that despite the large number of health personal trained in country, a significant group of these trained resources migrate to other countries in search of better opportunities. As an established literature has already pointed out, commercialization of health services and production of health resources without proper policy and plan, ineffective policy implementation, and poor management of human resources from their training to mobilization, has become a challenge to delivery of health services equitably to all groups of people in Nepal. It is noted here that this 'brain drain' is of particular concern to people with disabilities. Improvement and effective implementation of the policy with clear human resource plan, their training and mobilization, particularly for those with training on how to provide health care for people with disabilities, needs to be made.

**Equity approach better address special needs of disabled rather than equality:**

The study identified the fact that the "Aama Surakshya Karyakram" (Safe Motherhood Program) implemented by the Government of Nepal which is based on the equality approach, may not



address the additional needs of disabled women. For example, the equal amount of travel cost reimbursement by this program to disabled and non-disabled do not address the disabled women's additional needs for transportation. In order to improve disabled women's access to maternal health care services, the existing cash transfer policy needs to be changed to an equity approach that may help address additional needs of disabled women, such as the need for more transportation cost to improve maternal health care utilization for women who have a mobility or vision impairment.

### **8.6.2 Recommendations**

#### **Accountability in implementing policy:**

Further political commitment is needed to create and maintain accountable governance and effective implementation of policy that would lead to effective change at the ground level. Policies and plans formulated in favour of persons with disabilities, for example, **universal design** and construction of accessible health facility buildings. The Government of Nepal included the policies for accessible health facilities noted in the UNCRPD. Strong public voices and advocacy lead by the disabled people's organization can generate a constant pressure on government, which may help to turn those policies and commitments into action.

#### **Improve training to health care providers to include specific focus on disability care:**

Existing training courses and curricula designed for health care providers do not contain disability related information or concerns. None of the health care providers in the study district were found to be trained on caring for or working with disabled people. Provision of comprehensive training to maternal health care providers and sensitization training to all other health facility staff may help to improve maternal health care access for women with disabilities. In addition, disability related questions should be included in the qualifying tests for health care providers including doctors, nurses and primary care providers at all levels.

#### **Active involvement of community in health care management and decision-making:**

Community participation is recognized as an effective model in improving service delivery, particularly in low-resourced countries. However, due to the poor engagement with limited role of community members in the existing health system, health governance and quality of care remain questionable in the study area. Involving communities through more roles and responsibilities in local health care management and decision-making may increase community ownership, leading to better service provision. Disabled individuals should be part of this community oversight with their interests reflected in all community health issues, not just disability-specific ones.

**Monitoring utilization of persons with disability to be incorporated in the regular system:**

Service utilization of vulnerable and hard to reach groups needs to be monitored and assessed regularly to produce evidence and disaggregated data. The study found women with disabilities are not visible at any level in the current health monitoring system. National and lower level decision-making is undertaken in the absence of any information or intelligence about the prevalence and associated challenges of women with disabilities. This must be addressed.

**Improvement of out-reach health services:**

Community-based health services should be strengthened within revised strategies as an effective model to equitably deliver basic health services such as ANC, PNC for mothers and immunization to new-borns. More attention needs to be given for the effective mobilization of FCHVs in communicating with poor and marginalized women at the household level, particularly disabled and Dalit women. Clear service specifications, appropriate training to provide health workers with the skills to deliver the specification, and more rigorous monitoring needs to be in place to ensure that services are timely, predictable, of sufficient quality, and reach all women equitably.

**Culturally sensitive and locally acceptable PNC services to be delivered at doorstep:**

Post-natal care services should be delivered through home visiting to mitigate the requirement of local tradition and customs that confine women to the home for up to two weeks after delivery and negatively influence the utilization of maternal health care services.

**Make greater use of technology and existing aids to mitigate communication gaps:**

Women with disabilities when receiving services (particularly those with hearing disabilities) reported communication gaps and challenges but there was little evidence that alternative forms of communication and information provision were being utilized or even considered by health providers. For example, for hearing impaired women this would be ameliorated through the provision and use of simple information aides and better use of existing technology that is readily available, such as cell phones which can transmit visual displays. Cell phones that would allow a deaf a sign language user to bring an interpreter into the examining room remotely, is a new and evolving area that warrants attention. Moving forward, designated health workers should also have instruction on how to work with disabled women, with instruction in areas such as basic sign language, in order to be a resource for the service. When disabled women can access the same information that is given or available to the public, a fundamental step will have been achieved towards equity in health care.

**Mainstreaming of disability awareness within the general population:**

There is an imperative to change negative attitudes towards people with disabilities and the mainstreaming of disability awareness in the general population. Challenging stereotypes and inaccurate assumptions about disability and people with disability through mass media, art, visual representations and advertisements could be possible actions. INGOs and NGOs already work with in-country DPOs to address many topics in this area, but such work could expand with the greater focus on disability and health in general, and disability and maternal child health in particular.

**Emphasis on girl's education and women's empowerment:**

The study shows that women's education and empowerment have a strong influence on the access to and utilization of maternal health care services. Therefore, greater emphasis and resources given to educating women and increasing their status in family decision-making would contribute positively towards improved access and use of health services. In addition, empowering disabled girls and women at the individual and group level in general and specifically around maternal health concerns, would be an important contribution to bringing changes in their self-perception and sense of agency of empowerment and their access to assets and capabilities and voices (Bennett, 2005).

**Strengthen the Disability Coordination Committee within the structure of the Ministry of Women, Children and Social Welfare:**

The role and responsibilities of the existing "Disabled Service National Coordination Committee", discussed in **Chapter Four, section 4.4** should be widened and strengthened with inter-agency/ministerial policy coordination, to include advocacy for the mainstreaming of disability across the policy landscape ('disability in all policies') and the monitoring and holding to account of government actions to consider disability in all policy development.

**Strengthen representation at central and local level:**

The current provision of policy planning and access to resources as well as monitoring of delivery of services to persons with disabilities under the "Disabled Service National Coordination Committee" through the Ministry of Women, Children and Social Welfare an important start, but more can be done. Practically there needs to be additional technical knowledge, greater capacity to coordinate and monitor health care services to disabled women at local and national level. Ideally, a ministerial level position created at Ministry of Health with a dedicated portfolio for disability would be an important step forward in representing the interests of people with disabilities at the heart of government.

At the local level, there should be a representative from the disabled population on Health Facility Management Committees and also on important multi-sector thematic groups such as the Reproductive Health Coordination Committees.

### **8.6.3 Avenues for Future Research**

The current extremely limited body of statistics and studies on disability-related issues in low-income countries, especially in the issues of disabled women and their health needs, clearly indicates that further research is needed. Key research questions that this study was unable to answer given limitations in time and resources, discussed in the preceding chapters in greater depth, include (but are not limited to):

#### **Exploration and disaggregation of disabled women's health needs and utilization of maternal health services according to the type of disability:**

This study could not cover all types of disability. It studies women with four types of disability (physical, intellectual, visual, hearing) and the inferences drawn from this study reflect these four types of disabled women only. The problems and needs will differ according to the women's type of disability. Therefore, further research should target the experience, use of services and needs of women with multiple disabilities and other health conditions.

#### **More research on client-provider relationships and the effect on service utilization and care:**

The study noted poor client-provider relationships and engagement, which often has a negative impact on the quality of care and negative perceptions of service users. There are a number of questions that are unanswered in the Nepalese-disability context that warrant further exploration but the key issue on which further research should be pursued is: how does the client-provider engagement affect disabled and Dalits in access and utilization of maternal health care services; and what factors contribute to this?

#### **The causes and consequences of provider's negative attitude in maternal health care delivery:**

This research revealed that health care providers in the study district had comparatively negative attitudes and behaviours towards people with disability. The results also indicated that women using higher-level health facilities compared to those using community level health facilities more commonly encountered negative attitudes and abusive behaviours. Existing literature provides some insights and evidence to help explain this, but this is an under-researched subject in Nepal. This needs to be further explored in order to assess and improve the effectiveness of current services and interventions designed to address attitudinal barriers.

**Studies on health inequalities generated at intersection of differing forms of discrimination including disability, caste/ethnicity (and the sub-divisions), gender and poverty:**

Disabled women face intersectional discrimination in various forms on the grounds of gender, caste, poverty. The interaction of these factors with disability and its effect on creating disparities are poorly studied. Similarly, the forms of discrimination and disparities and the experiences of disabled women differs according to their caste and ethnic origins, religions, income level and the type of disability. Separate studies need to be conducted on each dimension to analyze the complexities, and identify correlations and relationships on each aspect in terms of their impact on health inequalities.

**The need for more studies to be conducted using emancipatory approaches:**

Disability is an emerging field of study and the use of conventional studies in these populations are sometimes criticized for being focused on problems, and conducted for the interest and benefits of academics and funders rather than study the population. However, more emancipatory types of research are increasingly preferred in disability research, and such research must focus on solutions and empowering disabled participants.

**8.7 OVERALL CONCLUSION**

In sum, the access and utilization of maternal health care services are not equitable among social groups with low utilization by disabled and Dalit women. Unless these vulnerable groups benefit, it is not possible to achieve the goals and targets of the new SDGs. More fundamentally, they will not reach global Human Rights objectives. Addressing disparities and increasing utilization of services in order to improve maternal health outcomes of these groups, needs to be promoted through increased knowledge, action and the empowerment of women together with improved accountability and health system mechanisms at both local and national levels. It is hoped that the findings of this thesis will contribute towards these goals.

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## APPENDICES

### APPENDIX A: PhD SCHEDULE

KEY ACTIVITIES	FIRST YEAR		SECOND YEAR		THIRD YEAR		FOURTH YEAR	
	MAY 13 - APR 14		MAY 14 - APR 15		MAY 15 - APR 16		MAY 2016 - MAR 2017	
	MAY-OCT	NOV-APR	MAY-OCT	NOV-APR	MAY-OCT	NOV-APR	MAY-DEC	JAN-MAR
<b>Familiarization</b>								
Introduction and System entry								
Basic skills development								
Background reading								
Conceptualization on research issue								
<b>Exploration</b>								
Literature review								
Finalization of study questions and objectives								
<b>Research Design</b>								
Proposal development								
Proposal presentation and approval								
Data collection tools development								
Ethical approval								
<b>Research Execution</b>								
Recruitment of research team								
Training to research team								
Piloting research tools								
Field data collection								
Data coding, cleaning, transcribe & computer entry								
Data analysis								
<b>Thesis Writing</b>								
Thesis chapter writing								
First draft Thesis development								
Thesis finalization and submission								
<b>Dissemination</b>								

**APPENDIX B: DATA COLLECTION TOOLS (QUESTIONNAIRE & CHECK LISTS FOR INTERVIEWS)**

**SURVEY INTERVIEW QUESTIONNAIRE FOR WOMEN AGE 15 – 49 YEARS**

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Objective of the study: To understand whether there is any difference in the access to, and utilization of, maternal health care services among Dalit and non-Dalit women, with and without disabilities in Nepal? If there are differences, what are these and what causes the disparity?

Namaste! My name is \_\_\_\_\_ and I am collecting data for a study/research with the above stated objective. This research is a part of safe motherhood project implemented by Namuna and Kidasha in Rupandehi. I would like to know your views and experience during the pregnancy and childbirth. The interview may take 30 – 45 minutes and I will ask you some questions related to your pregnancy, maternal health care services utilization and your experience on the behaviour of your family, neighbours and service providers while getting services. I would be very grateful if you could spend some time talking with me. I will not write down your name, and everything you tell me will be kept strictly confidential. Your participation is voluntary and you can choose not to answer any individual question or all of the questions. However, I hope that you will participate in this interview since your experience and views are very important for this research.

Do I have your permission to continue?

Yes:  Respondent agrees to be interviewed then start interview.

No:  Respondent do not agree to be interviewed then terminate interview.

Signature of Participant/Guardian.....

(Guardian's signature to be sought in the case of under 18 age participant)

Signature of Interviewer: .....

Date: .....

Interview start time: ..... End time: .....

A	SOCIO-DEMOGRAPHIC INFORMATION	CODE	SKIP PATTERN
1	ID # and name of the respondent	..... <input type="text"/> <input type="text"/> <input type="text"/>	
2	Name of VDC/Municipality and code	..... <input type="text"/> <input type="text"/>	
3	Ward number	..... <input type="text"/> <input type="text"/>	
4	Village/Tole	.....	
5	Age of respondent	..... <input type="text"/> <input type="text"/>	
6	What is your caste and ethnicity group?	Dalit (Terai) .....1 Dalit (Hill) .....2 Bramhin/Chhetri (Terai) .....3 Bramhin/Chhetri (Hill) .....4 Janjati (Terai) .....5 Janjati (Hill) .....6 Others (Specify) _____ 96	
7	What is your religion?	Hindu .....1 Buddhist.....2 Islam (Muslim) .....3 Isai (Christian).....4 Other (Specify) _____ 96	
8	Can you read and write?	Yes.....1 No .....2	<div style="border: 1px solid black; padding: 2px; display: inline-block;">GT 10</div>
9	What is the highest grade you completed?	NFE.....1 Primary (1-5)..... 2 Secondary (6-10/SLC).....3 Higher secondary (+2).....4 Higher education/university .....5	
10	What is your occupation?	Housewife/unemployed.....1 Farmer .....2 Wage Laborer (Cash).....3 Wage Laborer (Kind).....4 Small Trade/Business.....5 Service/Employment.....6 Other (Specify) _____ 96	
11	What is your current marital status?	Unmarried.....1 Married .....2 Widowed .....3 Divorced/Separated.....4 Other (Specify) _____ 96	



12	Who decided for your marriage?	Self .....1 Parents .....2 Other family members .....3 Others (specify) _____ 96	
13	What was your age at marriage?	Year <input type="text"/> <input type="text"/> Month <input type="text"/> <input type="text"/>	
<b>B</b>	<b>FAMILY BACKGROUND</b>		
14	What is your family type?	Nuclear .....1 Joint .....2	
15	Who is the household head in your family?	Respondent self .....1 Husband .....2 Father-in-law .....3 Mother-in-law .....4 Other (Specify) _____ 96	
16	What is the highest education level of your husband?	Illiterate .....1 Literate (home/NFE) .....2 Primary (1-5)..... 3 Secondary (6-10/SLC).....4 Higher secondary (+2).....5 Higher education/university .....6	
17	What is the main occupation of your husband?	Unemployed.....1 Farmer .....2 Wage Labourer.....3 Small Trade/Business.....4 Service/Employment.....5 Self-employed.....6 Other (Specify) _____ 96	
18	What is the main income source of your family?	Farming (Agriculture/Livestock).....1 Wages & labour.....2 Small Trade/Business.....3 Service/Employment.....4 House Rent.....5 Other (Specify) _____ 96	

19	Do your family own the land?	Not at all.....1 10 Dhur & less.....2 10 -14 Dhur & less.....3 15 - 19 Dhur & less.....4 1 – 3 Kattha.....5 4 – 5 Kattha.....6 6 – 10 Kattha.....7 11 – 20 Kattha.....8 1 - 2 Biggha.....9 3 - 5 Biggha.....10 11 Biggha or more.....11	
20	Do your family own the house?	Yes .....1 No.....2	<div style="border: 1px solid black; padding: 2px; display: inline-block;">GT 22</div>
21	What is the roofing material of your house?	Grass/straw .....1 Tin/Jasta .....2 Tile/khapada .....3 Cement & Concrete..... 4 Plastic/tents .....5 Others (specify) _____96	
22	Do your family keep the animals?	Yes .....1 No .....2	<div style="border: 1px solid black; padding: 2px; display: inline-block;">GT 24</div>
23	Do your family keep following animals?  (Multiple response)	Buffalo..... <input type="checkbox"/> Cow/bulls ..... <input type="checkbox"/> Horses/Mule..... <input type="checkbox"/> Goats/Sheep's..... <input type="checkbox"/> Chicken/Ducks..... <input type="checkbox"/> Pigs..... <input type="checkbox"/> Others (specify) _____ <input type="checkbox"/>	
24	Do your household have following household items?  (Multiple response)	Electricity.....1 Motorbike.....2 Riksa .....3 Bull/buff cart .....4 Bicycle .....5 Mob phone .....6 TV .....7 Radio .....8 Fan .....9 Computer ..... 10 Refrigerator.....11	

25	Do you have your own toilet at your house or in your compound?	Yes.....1 No.....2	
26	Where do you get water?	Piped Water(Public).....1 Piped Water (Pvt.).....2 Tube Well (Public/Neighbour).....3 Tube Well(Own).....4 Well (Public).....5 Well (Pvt.).....6 Other (Specify) _____ 96	
<b>C</b>	<b>DISABILITY RELATED</b>		
27	Do you have any disability?	Yes .....1 No .....2	GT sec 37
28	If Yes, What type of disability do you have?	Visual.....1 Hearing .....2 Mental.....3 Physical .....4 Multiple.....5	
29	When did you get your disability?	By birth .....888 After birth at the age of <input type="text"/>	
30	How do you rate the severity of your disability?	Mild.....1 Moderate.....2 Severe.....3 Very severe.....4	
31	Do you have disability ID card issued by Government?	Yes.....1 No.....2	GT sec 33
32	If Yes, What type or which colour card do you have?	Red.....2 Yellow .....3 Blue .....4 Green .....5 Old card.....6	
33	If not received ID card, what is the reason?	Do not know about ID card.....1 No body accompanied to go.....2 No money to pay travel & photo.....3 Went several times, couldn't get.....4 Others (specify).....5	
34	Do you receive any type of allowance?	Yes.....1 No .....2	GT 37

35	What type of allowance are you receiving?	Disability.....1 Widow ..... 2 Old age .....3 Others (specify) _____ 96	
36	If yes, Which organization has been providing this allowance?	VDC (Govt.).....1 NGO .....2 Others (specify) _____ 96	
<b>D PREGNANCY AND CHILD BIRTH</b>			
37	How many pregnancies you have had?	Total pregnancies..... <input type="text"/>	
38	How old is your youngest child now?	Born in <input type="text"/> Year <input type="text"/> Month	
39	Are you aware of any problems that are potentially dangerous to the mother during pregnancy?	Yes .....1 No .....2	→ <input type="text" value="GT 41"/>
40	What are the danger signs to the mothers during pregnancy, childbirth and after delivery?  (Multiple response)	Vaginal bleeding/haemorrhage.....1 Feel weak/faint/anaemic.....2 Fits/convulsions/seizures.....3 Swollen hands/face..... 4 Blurred vision.....5 Severe headache.....6 High blood pressure.....7 Prolonged or obstructed labor.....8 Hand/Foot/cord prolapsed.....9 Premature membrane/water bag rupture.....10 Retained Placenta.....11 Severe abdominal pain.....12 Fowl smelling vaginal discharge.....13 Fever.....14 Baby at transverse position.....15 Other (Specify) _____ 96	
41	Did you visit HF/Clinic for antenatal check-up for your (last) pregnancy?	Yes.....1 No.....2	→ <input type="text" value="SK 58"/>
42	If yes, Where did you go to receive ANC of your last pregnancy?	Gov. Hospital .....1 PHCC.....2 HP/SHP.....3 Private Hospital/Nursing home.....4 Private clinic .....5 ORC.....6 Others (specify) _____ 96	

43	Did you receive ANC services easily?	Yes.....1 No.....2	
44	How many times did you receive check up in the last pregnancy?	One.....1 Two.....2 Three.....3 Four.....4 Five or more.....5	
45	Who decided to go to HF for the ANC check-up?	Self .....1 Husband .....2 Mother-in-law .....3 Other family member .....4 FCHV .....5 Others (specify) _____ 96	
46	How did you reach to HF to check up your last ANC?	Walking .....1 Bull cart .....2 Bicycle .....3 Motorbike .....4 Public Transport (Bus, Tempo).....5 Pvt. Van, Taxi.....6 Ambulance.....7 Others (specify) _____ 96	
47	How long did you wait to get the ANC service?	Less than 30 mins. ....1 30 mins - one hour .....2 More than one hour .....3	
48	Did the health provider check the following at least once during ANC visit?  (Weight, Blood Pressure, Abdomen / Fundal height, Foetal Heart Sound)  (Multiple response)	Weight.....1 Blood Pressure.....2 Abdomen/Fundal height.....3 Foetal Heart Sound.....4 None of the above was checked.....5	
49	What information did health provider gave you during ANC visit?  (Multiple response)	About pregnancy danger sign.....1 Status of foetus/baby.....2 Nutrition.....3 Delivery or birth preparedness.....4 Medicines/Iron supplementation.....5 About next visit.....6 Others (specify) _____ 96	

50	How much time did the service provider spend with you to counselling and check up your ANC?	< 10 mins.....1 10 – 20 mins.....2 >20 mins.....3	
51	During your last pregnancy, were you given an injection (TT) in the arm to prevent the baby getting from tetanus?	Yes .....1 No.....2	
52	During your last pregnancy, did you take iron tablet?	Yes .....1 No .....2	Skip 54
53	If not taken iron/folic tablets, What is main reason for not taking the iron/folic acid tablets?	Nobody advised.....1 Not available at HF or didn't give.....2 No money to buy.....3 Didn't like it .....4 Didn't know .....5 Other (specify) _____ 96	
54	Did you pay the money in HF to buy iron tablets?	Yes .....1 No.....2	
55	In your last pregnancy, did you take any drug for intestinal worms (Albendazole)?	Yes .....1 No.....2	Skip 57
56	If not, What is main reason for not taking the Albendazole tablet?	Nobody advised.....1 Not available at HF or didn't give.....2 No money to buy.....3 Didn't like it .....4 Didn't know .....5 Other (specify) _____ 96	
57	Did you pay the money in HF to buy Albendazole?	Yes .....1 No.....2	
58	Why did not you get your ANC check-up in your last pregnancy?  (Multiple response)	Expensive/Inability to bear cost.....1 HF is not open .....2 Too far/no transport .....3 No trust to HF/Providers.....4 No quality service .....5 No female service provider .....6 Provider rude .....7 Husband/family didn't allow .....8 No facility for disabled .....9 Shame/Humiliation..... 10 Nobody found to accompany.....11 Others (specify) _____ 96	

59	How far is the HF from your place of residence?  (Write minutes in the box and all boxes must be filled up)	Walking..... <input type="text"/> Bicycle, Bull cart..... <input type="text"/> Motorized Vehicle..... <input type="text"/>	
<b>E</b>	<b>DELIVERY AND PNC RELATED</b>		
60	Where did you give birth to your last baby?	Gov. Hospital.....1 PHCC.....2 Birthing Centre (S/HP).....3 Private Hospital .....4 Private clinic .....5 Home .....6 On the way to delivery site.....7 Others (specify) _____ 96	} <b>GT 70</b>
61	Did you receive Delivery/PNC services easily?	Yes.....1 No.....2	
62	Who assisted you for your last delivery?  (Multiple response)	Dr.....2 Nurse (Staff Nurse/ANM).....3 HA/AHW .....4 Others (specify) _____ 96	
63	Was there Nurse or Dr. around for the whole/full time during your delivery?	Yes .....1 No.....2	
64	Did the HF charge the money for services and supplies for your delivery?	Yes .....1 No.....2	→ <b>SK 66</b>
65	If yes, what it was charged for?  (Multiple response)	Charged for services .....1 Charged only for supplies .....2 Charged only for Medicines.....3 Others (specify) _____96	
66	Do you know about travel cost reimbursement to the mother by the Govt. for HF delivery?	Yes .....1 No.....2	→ <b>SK 68</b>
67	Did you receive cash reimbursement for transportation from HF after delivery?	Yes .....1 No.....2	
68	How did you reach to HF to deliver your baby?	Walking .....1 Bicycle .....2 Motorbike .....3 Bull cart .....4 Public Transport (Bus, Tempo..).....5 Ambulance, Taxi, Van.....6 Others (specify) _____ 96	} <b>GT 71</b>

69	<p>Who assisted you at home for your last delivery?</p> <p>(To be asked only for Home Delivery)</p>	<p>None.....1</p> <p>HA/AHW.....2</p> <p>MCHW .....3</p> <p>FCHV .....4</p> <p>Traditional Birth Attendant.....5</p> <p>Family Members/Neighbors.....6</p> <p>Nurse (Staff Nurse/ANM).....7</p> <p>Dr.....8</p> <p>Others (specify) _____ 96</p>	
70	<p>Why did not you go to the HF to deliver your baby?</p> <p>(To be asked only for Home Delivery)</p>	<p>Expensive/Inability to bear cost.....1</p> <p>HF is not open .....2</p> <p>Too far/no transport .....3</p> <p>No trust to HF .....4</p> <p>No quality service .....5</p> <p>No female service provider .....6</p> <p>Provider rude .....7</p> <p>Home delivery is okay .....8</p> <p>Child born before reaching HF.....9</p> <p>Husband/family didn't allow .....10</p> <p>No facility for disabled .....11</p> <p>No body found to accompany.....12</p> <p>Shame ..... 13</p> <p>Culture/tradition not supportive.....14</p> <p>Others (specify) _____ 96</p>	
71	<p>Did you visit HF for PNC and neonate check-up? (Both mother and baby)</p>	<p>Yes .....1</p> <p>No .....2</p>	<p>GT 73</p>
72	<p>Why did not you visit the HF for PNC check-up?</p> <p>(Multiple response)</p>	<p>Nobody told/Didn't know.....1</p> <p>Both mother and neonates good.....2</p> <p>Expensive/Inability to bear cost.....3</p> <p>HF is not open .....4</p> <p>HF too far/no transport.....5</p> <p>No trust to HF .....6</p> <p>No quality service .....7</p> <p>Provider rude .....8</p> <p>No facility for disabled .....9</p> <p>Not supported by family.....10</p> <p>No body found to accompany.....11</p> <p>Culture/Tradition.....12</p> <p>Others (specify) _____ 96</p>	



73	Did anyone of those visit you at your home during or after pregnancy?	Yes .....1 No .....2	→ GT 75
74	If yes, Who visited you at your home during or after pregnancy?  (Multiple response)	FCHVs.....1 Govt. Health Worker.....2 NGO Health worker.....3 Relatives.....4	
75	How did you know/get health information?  (Such as about pregnancy, childbirth and health facility)	Looking posters, reading books.....1 Family members.....2 Friends & neighbours.....3 Health Workers.....4 FCHVs.....5 Radio/TV.....6 Others (specify) _____ 96	
76	Who paid for your cost related to pregnancy and delivery including travel and transport?	Self .....1 Husband .....2 Other family members .....3 Others (specify) _____ 96	
<b>F</b>	<b>EMPOWERMENT RELATED</b>		
77	Do you own any fixed asset or property such as land, house and valuables either alone or jointly with someone in the family?	Own alone.....1 Jointly.....2 Don't own .....3	→ GT 79
78	What sort of asset or property do you own (such as land, house, valuables or cash)	Cash in Bank.....1 Land.....2 Cash in Joint bank account.....3 Joint bank balance and land.....4	
79	Who decides for purchasing the household foodstuffs and other necessary assets in your family?	Household head .....1 Husband .....2 Herself .....3 Other family members.....4 Jointly including herself.....5	
80	Who purchases for the household foodstuffs and other necessary assets?	Household head .....1 Husband .....2 Herself .....3 Other family members .....4 Jointly including herself.....5	
81	Do you spend money on your own?	Yes .....1 No .....2	

82	Are you asked or invited in the discussion of major family decision such as: marriage, purchasing fixed assets, organizing rituals and cultural events?	Never.....1 Sometimes.....2 Always.....3		
83	Are you invited or do you participate in neighbour's marriage, rituals, religious ceremonies/events etc.?	Never.....1 Sometimes.....2 Always.....3		
84	Where are you allowed to go alone to the stated places and or purposes?  (Could be multiple answers)	Within own compound & neighbour's house.....1 Farming/cattle grazing/firewood.....2 HF for treatment.....3 Market.....4 Participate in the meeting .....5 Parent's House.....6 No restriction.....7 Others (specify) _____ 96		
85	In last 12 months, have you been away from your home for one or more nights?	Yes .....1 No .....2		
86	Do you belong (in the past or now) to any group?	Yes .....1 No .....2	→ <table border="1"><tr><td>GT 88</td></tr></table>	GT 88
GT 88				
87	If yes, in which group you belong with?  (Could be multiple answers)	Aama samuha .....1 Bachat samuha .....2 Mahila samuha .....3 Others (specify) _____ 96		
88	Are you in the executive committee of any group? Or represent any social organization or party in your ward/VDC or any community?	Yes .....1 No .....2	→ <table border="1"><tr><td>GT 90</td></tr></table>	GT 90
GT 90				
89	If you belong/represent; which groups or ward/VDC or social or political party do you represent in which capacity?	Executive member of group.....1 Ward women representative.....2 Women socialactivist.....3 Health/other institution' representative.....4 Social or political activist.....5 Others (specify) _____ 96		
90	Does your neighbour or community ask you to lead community events or call you to solve or mediate some conflicts in your villages?	Yes .....1 No .....2		

91	Do you have citizenship card?	Yes .....1 No .....2	
92	Have you ever participated in voting/election?	Yes .....1 No .....2	
93	Does anyone in your family, neighbour or others humiliate, abuse, torchers or hit you?  (This could be verbally in-front of others or physically)	Never.....1 Sometimes.....2 Frequently or regularly.....3	
94	Have you ever faced sexual harassment or rape in your life?  (Speaks you sexual language, touches you with bad intention and in private parts, try to have or force for sex, sex without your consent or giving you fears)	Yes.....1 No.....2	
<b>Ask Q No 95 only to women with disabilities</b>			
95	How other people call you?  <i>(By your name or by your disability or by the relation of other family members)</i>	By your name.....1 By your disability.....2 By relation.....3 Others (specify) _____ 96	

**Thank You!!**

**IN-DEPTH INTERVIEW QUESTIONNAIRE GUIDELINES FOR DALIT WOMEN WITH DISABILITY**

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**A INTRODUCTORY INFORMATION**

1. Name/ID code of respondent.....
2. Address: VDC/Municipality..... 3. Ward No.
4. Village/Tole.....
5. Age of respondent  Years
6. Which caste and Ethnic Groups you belongs to?
- |                 |                           |                            |                              |                      |
|-----------------|---------------------------|----------------------------|------------------------------|----------------------|
|                 | <input type="text"/> Hill | <input type="text"/> Terai |                              |                      |
| Bramhin/Chhetri | <input type="text"/>      | <input type="text"/>       | Newar                        | <input type="text"/> |
| Dalit           | <input type="text"/>      | <input type="text"/>       | Muslim                       | <input type="text"/> |
| Janajati        | <input type="text"/>      | <input type="text"/>       | Others (Please specify)..... |                      |
- 

**B PREGNANCY EXPERIENCE**

- 1. Please tell me about your last pregnancy. Was it intended pregnancy? How was your feeling at your pregnancy?**

***Probe:***

*Did you feel happy/proud being pregnant or feel guilty? How was your experience with your family (husband, mother-in-law, other members and parents) while you became pregnant? How the family members behaved with you?*

*How did your mother and mother-in-law treat you while they knew about your pregnancy? Were they happy or felt bad on your pregnancy?*

*Were they supportive? Who supported you and who discouraged or did not cooperate while you were pregnant? What was the reason to support or not to support you?*

- 2. How was your experience with your neighbours and society? Did you face any difficulty with them?**

***Probe:***

*How your neighbours treated you while they knew about your pregnancy? Who supported you? and who discouraged you?*

*Was their behaviour during your pregnancy different than other time? If you were treated differently, what was that? Can you explain with an example?*

*Why do they treat you differently in your opinion?*

**3. How upper caste people treat you and your disability? (This question to ask only for Dalit)**

**Probe:**

*Are there any specific caste groups behave you and your disability differently? Which caste groups specially differentiate you than others? Do the males or females particularly treat you differently? What are the reasons to treat you differently in your opinion?*

*What makes you feel very bad/difficulty in neighbours/society while they treat you differently?*

**4. Did you get ANC check for your last pregnancy?**

**Probe:**

*If not received any pregnancy check, why you did not? What prevented you receiving services? Where did you go for ANC service? Why did you go there? Why not to other place?*

*How do you get information? Who told you about the services? Did anybody such as health workers or volunteers visit you?*

**5. Tell me about your experiences while receiving ANC services?**

**Probe:**

*Who made decision to go for pregnancy checking? If you had made the decision yourself, what encouraged you to seek the service?*

*What type of service was it? How far is the service centre or Health Facility from your place? How did you get there? Who accompanied you? How many times you received the services?*

*Is the service centre accessible for everybody including you?*

**6. Tell me more about the services you received for your last ANC check?**

**Probe:**

*Who consulted/checked you? What did they check? How did they behave you? Were you comfortable? Did they explained or counselled you properly? What did they say? What information did you get in the consultation? Did you receive any medicine or injections as well? Did you get from HF for free or they asked you to buy?*

**C LABOR AND DELIVERY EXPERIENCE**

**7. Can you describe me your experience during labor and childbirth?**

**Probe:**

*Where did you give birth to your baby in the last pregnancy? Did you face any complication at the time of labour and childbirth? Who helped you? If it was home delivery, why you did not go to HF? If the delivery was at HF*

*Who decided for you to go HF? What was the reason to deliver at HF? How did you reach there?*

*Who accompanied you to the service centre? Why did you go there – why not to other places? How far and how long it took you to reach?*

## **8. Were HF staff available while you reach there?**

### **Probe:**

*Who was there? Did they check you immediately? How was their behaviour? How was the service? Were you comfortable (Privacy maintained, respectful behaviour, listened to you, emotional support or they shouted and behaved rudely?)*

*Were the bed and other materials available? Was the medicine and supplies given from the HF or you were asked to buy from outside?*

## **D PNC EXPERIENCE**

## **9. Did you and your baby was checked after delivery?**

### **Probe:**

*If you were not checked, why didn't you get that service? If you were checked, when were you checked? Who told you for check-up? Where did you go to check up? Who checked you? Can you tell me what did they check you and your baby at the time of PNC visit?*

## **E PERCEPTION ON SERVICES**

## **10. How did you find the service?**

### **Probe:**

*Was the service accessible to all including you? How were the building, examination space, bed and equipment? Was it suitable for you? How did you communicate? Did they listen to you carefully? Were the beds, equipment/materials, drugs and supplies enough and available for you? Was there enough space, clean and good environment in HF for all services?*

*How long did you wait to get examined? Was it normal/reasonable for everybody or is it too long for you?*

*Who gave the service in the facility? Were the health workers, nurses and Drs available for you? Do you think they were trained and skilful? How was the service provider's behaviour for you? How did you find the service? Did they give you enough time and explained you properly?*

*Were you comfortable while receiving the service? Was privacy maintained? Did they all, the carers, technical and non-technical persons treat you respectfully? If the provider's behaved you rude or strange, was it like this to everybody?*

## **11. What is your belief about the services?**

### **Probe:**

*Do you think the Dr/Nurse examine you carefully? Are they trained, experienced and skilled enough?*

*Do you think the HF has all necessary service facilities including medicines availability? Did you get all necessary supplies and medicines as you expected or you were asked to buy outside?*

*What is your expectation from Health Facility, Health staff and government for the care and treatment for you?*

*What makes you comfortable or motivated to receive the services during pregnancy?*

**12. How did you manage the expenses of your treatment and care?**

**Probe:**

*Was the service free? How expensive was the cost for services including travel and other expenses?*

*How your cost was covered? Who paid your bills?*

*Do you know about the government's cash reimbursement scheme for maternal health care services? Did you receive any incentives?*

**F CULTURE AND TRADITION**

**13. Is there anything that you felt you should or should not do while you were pregnant?**

**Probe:**

*Are there any specific beliefs, tradition and culture practices in your family and society about pregnancy? What should do and what should not do?*

**14. Closing Question: Do you have anything to ask us?**

**Thank you for your cooperation**

**KEY INFORMANTS INTERVIEW (KII) TOPIC GUIDE FOR POLICY  
PLANNER AND IMPLEMENTATOR**

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Objective of the study: To understand whether there is any difference in the access to, and utilization of, maternal health care services among Dalit and non-Dalit women, with and without disabilities in Nepal? If there are differences, what are these and what causes the disparity?

Namaste! My name is Hridaya Raj Devkota and I am studying at University College London (UCL), UK and working with Kidasha. I am conducting a study/research on Maternal Health Care service access to women with disability and would like to know about government policies, guidelines and health service delivery system. The interview may take 1 – 1:30 hrs and we would like to ask you a few questions related maternal health service provisions and access to marginalized and vulnerable groups of people such as Dalits and people with disabilities. We would be very grateful if you could spend some time talking with us. We will not write down your name, and everything you tell us will be kept strictly confidential. Your participation is voluntary and you can choose not to answer any question or all of the questions. You can also withdraw your participation at any time and there will be no penalty for this. However, we hope that you will participate in this interview since your experience and views are very important for this research.

We will also like to seek your kind permission to record the interview on tape so that we will not have to write every word down on the paper. The tape would be kept strictly confidential and would be deleted or destroyed immediately after transcription.

Do we have your permission to continue?

Yes:  Respondent agrees to be interviewed. Then start interview.

No:  Respondent do not agree to be interviewed. Then terminate interview.

Signature of Participant: .....

Signature of Interviewer: .....

Date: .....

Position: ..... MoHP/DoH  District Public Health Office

Place of interview: .....

Interview start time: ..... End time: .....



## INTERVIEW CHECKLIST

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1. Does MoHP have defined standards and protocols of Maternal Health Services at all levels? If yes, are those standards/protocols applicable to and followed by all HFs?
2. What policy documents states those standards and protocols? Are HF management and staff aware of it to follow those provisions?
3. How the Gender equity and social inclusion component is incorporated to the policy and how it is practiced in the districts?
4. How is the maternal health service utilization situation of vulnerable groups such as Dalits, women with disabilities? Are the services equitable to all? If not, what efforts are made at policy level to overcome the disparities?
5. Are the Human Resources (HR) sufficiently available to provide MHC services in the districts (from S/HPs to hospital)? Are HR trained to provide the services to disabled people?
6. Does the HFs have enough equipment and supplies (Meds and materials)? What is status of supply aspect at local level HFs?
7. Are the policies states about disabled friendly facilities? Which policy states that? Is it applicable in physical infrastructure, machine and equipment?
8. In your opinion, do you think the maternal health needs of disabled women are similar to others? Are the needs of that population recognized at policy level? If yes, how and what efforts are made to address those needs?
9. Do you find any disparity in policy, provision and utilization of maternal health care services among different social groups?
10. Are the maternal health care services accessible (affordable, available, acceptable....) to Dalits and disabled women?
11. Closing Question: Do you have anything to ask me?

**Thank you for your active participation and cooperation**

## KEY INFORMANTS INTERVIEW (KII) QUESTIONNAIRE GUIDELINES FOR ACTIVIST/LEADERS

### INTERVIEW CHECKLIST

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ID code of respondent: ..... Position: .....

1. Do you think problems during pregnancy, delivery and postpartum are important to women?  
Why or why not?
2. Is the extent of problems similar to all women (upper caste/lower caste; disabled/non-disabled)?
3. What do you think the disabled women giving birth to a child? Should disabled women have pregnancy? If no, why not?
4. Are the existing services accessible to Dalits and disabled? Do you think there are disparities in service provisions between upper caste and lower caste; non-disabled and disabled?
5. In your opinion, what are the problems faced by Dalit women with disability to receive MHC services during pregnancy? What are the provisions of government to address those problems? What is done at local level and what is your role on it?
6. Where would other people in your community go for seeking MHC services? Why do they go there?
7. Who gives the services (to Dalits) in general? Dr. Nurse. Health Workers. FCHVs.....
8. What are the social norms and local culture that supports and inhibits to Dalits and women with disability to take parts in social and cultural activities.
9. Does the society behave differently to Dalit disabled women than non-Dalit and non-disabled women? If they do, what are the reasons?
10. Who particularly differentiate? Are these family members, Dalits themselves, upper caste people, Male, Female?
11. Closing Question: Do you have anything to ask me?

**Thank you for your active participation and cooperation**

## FOCUS GROUP DISCUSSION (FGD) TOPIC GUIDE FOR FCHVS

### CHECKLIST QUESTIONS

---

1. Have you found any disabled women pregnant in your villages?
2. Should disabled women have pregnancy? If no, why not?
3. Have any one of you visited Dalit disabled women at their home?
4. Are they receiving services? If not, why?
5. What is the service utilization situation of those groups? (in HF)
6. Do you have special activity or provision to facilitate disabled women for service utilization?
7. How do you communicate with people with hearing disability?
8. Who do you ask the question while the disable person comes to you for services?
9. In your opinion, who would be the appropriate person to ask or answer his/her problem?
10. What do you think about the health needs of disabled people? Is it different or similar to other people?
11. How do the people get health information? Do you have any program for education and information to disabled?
12. What are the problems/barriers you face while providing services to Dalits and disabled?
13. In your opinion, what are barriers for Dalits and disabled women to receive maternal health care services during pregnancy and delivery?
14. What are the cultural and social norms and practices they have to do or not to do during their pregnancy, delivery and after delivery?

**Probe:** Is the culture and social norms differentiate between Dalits, non-Dalits and disabled in pregnancy, delivery and maternal health care service utilization? If it does, what are they?

**Thank you for this interesting discussion and for your cooperation**

## FOCUS GROUP DISCUSSION (FGD) TOPIC GUIDE FOR COMMUNITIES (DALITS)

### CHECKLIST QUESTIONS

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1. Do you think problems during pregnancy, delivery and postpartum are important to women?  
Why or why not?
2. Is the extent of problems similar to all women (upper caste/lower caste; disabled/non-disabled)?
3. What do you think the disabled women giving birth to a child? Should disabled women have pregnancy? If no, why not?
4. Are there any differences between disabled women and non disabled women giving birth to a child?
5. What are your social norms if a Dalit women without disability and Dalit woman with disability becomes pregnant?
6. What you have heard in your community about the pregnancy of a woman with disability and giving birth to a child?
7. Are there any specific social and culture norms and values in your community that are applicable to pregnant women with disability only which are different than non-disabled pregnant women?
8. Where do pregnant women with disability receive MHC services during pregnancy and child birth? Are the services available for them? Should they go for the services? Does anyone in the community help them?
9. Where would other people in your community go for seeking MHC services? Why do they go there?
10. Have anyone of you accompanied any pregnant women to go Health Facility? How the HF staffs behave Dalits and Dalit women with disability while providing the services?
11. Who gives the services (to Dalits) in general? Dr. Nurse. Health Workers. FCHVs.....

**Thank you for this interesting discussion and for your cooperation**

**FOCUS GROUP DISCUSSION (FGD) TOPIC GUIDE FOR COMMUNITIES (NON-DALITS)  
CHECKLIST QUESTIONS**

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1. Do you think problems during pregnancy, delivery and postpartum are important to women?  
Why or why not?
2. Is the extent of problems similar to all women (upper caste/lower caste; disabled/non-disabled)?
3. What do you think the disabled women giving birth to a child? Should disabled women have pregnancy? If no, why not?
4. Are there any differences between disabled women and non-disabled women giving birth to a child?
5. What are your social norms if a Dalit women without disability and Dalit woman with disability becomes pregnant?
6. What you have heard in your community about the pregnancy of a woman with disability and giving birth to a child?
7. Are there any specific social and culture norms and values in your community that are applicable to pregnant women with disability only which are different than non-disabled pregnant women?
8. Where do pregnant women with disability receive MHC services during pregnancy and childbirth? Are the services available for them? Should they go for the services? Does anyone in the community help them?
9. Where would other people in your community go for seeking MHC services? Why do they go there?
10. Have anyone of you accompanied any pregnant women to go Health Facility? How the HF staffs behave Dalits and Dalit women with disability while providing the services?
11. Who gives the services (to Dalits) in general? Dr. Nurse, Health Workers, FCHVs.....

**Thank you for this interesting discussion and for your cooperation**

## APPENDIX C: ATDP TOOL

### Attitude toward Disabled Persons (ATDP) Survey Tool adapted from the ATDP scale Form B By Yuker, Block & Young 1970

SN	Questions	-3	-2	-1	+1	+2	+3
1	Disabled persons are usually friendly	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
2	People who are disabled should not have to pay income tax	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
3	Disabled people are no more emotional than other people	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
4	Disabled persons can have a normal social life	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
5	Most physically disabled persons have a chip on their shoulder	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
6	Disabled workers can be as successful as other workers	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
7	Very few disabled persons are ashamed of their disabilities.	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
8	Most people feel uncomfortable when they associate with disabled people	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
9	Disabled people show less enthusiasm than non-disabled people	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
10	Disabled people do not become upset any more easily than non-disabled people.	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
11	Disabled people are often less aggressive than normal people	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
12	Most disabled persons get married and have children	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
13	Most disabled persons do not worry any more than anyone else	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
14	Employers should not be allowed to fire disabled employees	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
15	Disabled people are not as happy as non-disabled ones	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
16	Severely disabled people are harder to get along with than are those with minor disabilities	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
17	Most disabled people expect special treatment	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
18	Disabled persons should not expect to lead normal lives	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much

SN	Questions	-3	-2	-1	+1	+2	+3
19	Most disabled people tend to get discouraged easily	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
20	The worst thing that could happen to a person would be for him to be very severely injured	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
21	Disabled children should not have to compete with non-disabled children	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
22	Most disabled people do not feel sorry for themselves	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
23	Most disabled people prefer to work with other disabled people	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
24	Most severely disabled persons are not as ambitious as other people	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
25	Disabled persons are not as self-confident as physically normal persons	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
26	Most disabled persons don't want more affection and praise than other people	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
27	It would be best if a disabled person would marry another disabled person	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
28	Most disabled people do not need special attention	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
29	Disabled persons want sympathy more than other people	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much
30	Most physically disabled persons have different personalities than normal persons	1. Disagree very much	2. Disagree pretty Much	3. Disagree a little	4. Agree a little	5. Agree pretty much	6. Agree very much

### Additional Questions

SN	Question	Answers and code	Skip Pattern
1	Have you provided services to disabled people? (any type, any person – child or adult)	Yes.....1 No.....2	→ <input type="text" value="GT 3"/>
2	Have you given maternal health care service to disabled pregnant women?	Yes.....1 No.....2	
3	Do you have any training on disability or treating/caring disabled person?	Yes.....1 No.....2	

Thank You!

## **APPENDIX D: UN WASHINGTON GROUP DISABILITY CRITERIA (SHORT SET)**

### **Census Questions on Disability Endorsed by the Washington Group**

**INTRODUCTORY PHASE:** The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

1. Do you have difficulty seeing, even if wearing glasses?
  - a. No - no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
  
2. Do you have difficulty hearing, even if using a hearing aid?
  - a. No- no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
  
3. Do you have difficulty walking or climbing steps?
  - a. No- no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
  
4. Do you have difficulty remembering or concentrating?
  - a. No – no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
  
5. Do you have difficulty (with self-care such as) washing all over or dressing?
  - a. No – no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
  
6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?
  - a. No – no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all



**APPENDIX E: ETHICAL APPROVAL LETTERS**



**Nepal Health Research Council**

Estd. 1991

Ref. No. : 1184

**21 April 2014**

**Mr. Hridaya Raj Devkota**  
Principal Investigator  
KIDASHA, Indrapuri Marg,  
Nagdhunga, Pokhara

Ref: **Approval of Research Proposal** entitled **Maternal health care services access to (DALIT) women with disabilities in Nepal**

**Dear Mr. Devkota,**

It is my pleasure to inform you that the above-mentioned proposal submitted on 20 February 2014 (**Reg. no.34/2014** please use this Reg. No. during further correspondence) has been approved by NHRC Ethical Review Board on 17 April 2014 (2071-1- 4).

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

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

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

As per your research proposal, the total research amount is \$ **6,647.00** and accordingly the processing fee amounts to **NRS- 9,983.00**. It is acknowledged that the above-mentioned processing fee has been received at NHRC.

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

Thanking you.

.....  
**Dr. Guna Raj Lohani**  
Executive Chief



Professor Nora Groce  
Division of Epidemiology and Public Health  
UCL

29<sup>th</sup> April 2014

Dear Professor Groce

**Notification of Ethical Approval**

**Project ID: 5260/001: Maternal Health Care Service Access to Dalit Women with Disabilities in Nepal**

I am pleased to confirm that your study has been approved by the UCL Research Ethics Committee for the duration of the project i.e. until April 2016.

Approval is subject to the following conditions:

1. You must seek Chair's approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form'.

The form identified above can be accessed by logging on to the ethics website homepage: <http://www.grad.ucl.ac.uk/ethics/> and clicking on the button marked 'Key Responsibilities of the Researcher Following Approval'.

2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. Both non-serious and serious adverse events must be reported.

**Reporting Non-Serious Adverse Events**

For non-serious adverse events you will need to inform Helen Dougal, Ethics Committee Administrator ([ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)), within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair of the Ethics Committee will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

**Reporting Serious Adverse Events**

The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.

On completion of the research you must submit a brief report (a maximum of two sides of A4) of your findings/concluding comments to the Committee, which includes in particular issues relating to the ethical implications of the research.

With best wishes for your research.

Yours sincerely



**Professor John Foreman**  
**Chair of the UCL Research Ethics Committee**

Cc:  
Hridaya Raj Devkota, Applicant  
Professor R.G.Watt

## APPENDIX F: QUANTITATIVE DATA ANALYSIS TABLES

**TABLE 1: Association of Socio-demographic Factors with Outcome (Dependent) variables using cross-tabs & Pearson's Chi-square test**

Factors	n	%	ANC Check		
			Yes (%)	No (%)	
Disability	354				$\chi^2=18.299$
Disabled	79	22	66 (84%)	13 (17%)	***p-value=0.000 (df=1)
Non-Disabled	275	78	266 (97%)	9 (3%)	
Caste	354				$\chi^2=3.808$
Dalit	151	43	146 (97%)	5 (3%)	p-value=0.051 (df=1)
Non-Dalit	203	57	186 (92%)	17 (8%)	
Location (Place of Residence)	354	100			$\chi^2= 0.831$
Rural	284	80%	268 (94%)	16 (6%)	p-value=0.362 (df=1)
Urban	70	20%	64 (91%)	6 (9%)	
Respondent's Age	354				$\chi^2= 26.729$
15 – 24 Years	134	38%	130 (97%)	4 (3%)	p-value=0.000 (df=2)
25 – 34 Years	172	48%	165 (96%)	7 (4%)	
35 – 49 Years	48	14%	37 (77%)	11 (23%)	
Respondent's Education	354				$\chi^2= 2.063$
Illiterate	116	33%	106 (91%)	10 (9%)	p-value=0.256 (df=2)
Literate/Primary Education (up to 5 class)	117	33%	110 (94%)	7 (6%)	
Secondary Education (6 class & above)	121	34%	116 (96%)	5 (4%)	
Respondent's Occupation	354				$\chi^2= 0.797$
Unemployed/Farmer	298	84%	278 (93%)	20 (7%)	*p-value=0.549 (df=1)
Employed (Service/Small Business)	56	16%	54 (96%)	2 (4%)	
Marital Status	354				$\chi^2=7.701$
Married	348	98%	328 (93%)	20 (6%)	**p-value=0.006 (df=1)
Single(Unmarried/Widowed/Separated)	6	2%	4 (67%)	2 (33%)	
Age at Marriage	^352				$\chi^2= 0.001$
5 – 18 Years	236	67%	222 (94%)	14 (6%)	p-value=0.970 (df=1)
19 – 40 Years	116	33%	109 (94%)	7 (6%)	
Parity	354				$\chi^2=7.817$
Primipara	198	56%	192 (97%)	6 (3%)	**p-value=0.005 (df=1)
Multipara	156	44%	140 (90%)	16 (10%)	
Knowledge & Awareness on Pregnancy Danger Sign	354				$\chi^2=6.334$
No Knowledge at All	71	20%	63 (89%)	8 (11%)	*p-value=0.042 (df=2)
Little Knowledge (Low level of Awareness)	138	39%	128 (93%)	10 (7%)	
Enough Knowledge (High level of Awareness)	145	41%	141 (97%)	4 (3%)	
Women Empowerment (Autonomy) Index	354				$\chi^2=1.576$
Low	77	22%	70 (91%)	7 (9%)	p-value=0.455 (df=2)
Medium	208	59%	196 (94%)	12 (6%)	
High	69	20%	66 (96%)	3 (4%)	

Significance at Pearson Chi-square test; \*p-value=Fisher Exact test

**TABLE 2: Association of Family related factors with Outcome (Dependent) variables using cross-tabs & Pearson's Chi-square test**

Factors	n	%	ANC Check		
			Yes (%)	No (%)	
<b>Husband's Education</b>	<b>^352</b>				<b><math>\chi^2=9.134</math></b>
Illiterate	59	17%	51 (86%)	8 (14%)	<i>p</i> -value=0.010
Literate/Primary Education (up to 5 class)	99	28%	92 (93%)	7 (7%)	(df=2)
Secondary Education (6 class & above)	194	55%	188 (97%)	6 (3%)	
<b>Husband's Occupation</b>	<b>^352</b>				<b><math>\chi^2=4.296</math></b>
Unemployed/Farmer	127	36%	115 (91%)	12 (9%)	<i>p</i> -value=0.038
Employed (Service/Small Business)	225	64%	216 (96%)	9 (4%)	(df=1)
<b>Main source of Family Income</b>	<b>354</b>				<b><math>\chi^2=11.990</math></b>
Farming & Daily wages	97	27%	84 (87%)	13 (13%)	<b>**<i>p</i>-value=0.002</b>
Service/Employment (Service, small business)	67	19%	64 (96%)	3 (5%)	(df=2)
Others (Mixed source of income)	190	54%	184 (97%)	6 (3%)	
<b>Household Wealth Index</b>	<b>354</b>				<b><math>\chi^2=23.549</math></b>
Low (<40% in ranking)	81	23%	67 (83%)	14 (17%)	<b>***<i>p</i>-value=0.000</b>
Middle (40 – 60% in ranking)	200	57%	192 (96%)	8 (4%)	(df=2)
High (>60% in ranking)	73	21%	73 (100%)	0 (0%)	

**TABLE 3: Association between demographic, socio-economic factors and ANC check-up**

Factors	n	%	ANC Check		
			<4 visit (%)	4+ visit (%)	
<b>Disability</b>	332				$\chi^2=2.221$
Disabled	66	20%	19 (29%)	47 (71%)	$p$ -value=0.136
Non-Disabled	266	80%	54 (20%)	212 (80%)	(df=1)
<b>Caste</b>	332				$\chi^2=0.598$
Dalit	146	44%	35 (24%)	111 (76%)	$p$ -value=0.439
Non-Dalit	186	56%	38 (20%)	148 (80%)	(df=1)
<b>Location (Place of Residence)</b>	332	100			$\chi^2=2.903$
Rural	268	81%	64 (24%)	204 (76%)	$p$ -value=0.088
Urban	64	19%	9 (14%)	55 (86%)	(df=1)
<b>Respondent's Age</b>	332				$\chi^2=3.726$
15 – 24 Years	130	39%	22 (17%)	108 (83%)	$p$ -value=0.155
25 – 34 Years	165	50%	40 (24%)	125 (76%)	(df=2)
35 – 49 Years	37	11%	11 (30%)	26 (70%)	
<b>Respondent's Education</b>	332				$\chi^2=16.396$
Illiterate	106	32%	37 (35%)	69 (65%)	$p$ -value=0.000
Literate/Primary Education (up to 5 class)	110	33%	21 (19%)	89 (81%)	(df=2)
Secondary Education (6 class & above)	116	35%	15 (13%)	101 (87%)	
<b>Respondent's Occupation</b>	332				$\chi^2=6.091$
Unemployed/Farmer	278	84%	68 (25%)	210 (75%)	$p$ -value=0.014
Employed (Service/Small Business)	54	16%	5 (9%)	49 (91%)	(df=1)
<b>Marital Status</b>	332				$\chi^2=14.365$
Married	328	99%	69 (21%)	259 (79%)	* $p$ -value=0.002
Single(Unmarried/Widowed/Separated)	4	1%	4 (100%)	0 (0%)	(df=1)
<b>Age at Marriage</b>	331				$\chi^2=3.618$
5 – 18 Years	222	67%	55 (25%)	167 (75%)	$p$ -value=0.057
19 – 40 Years	109	33%	17 (16%)	92 (84%)	(df=1)
<b>Parity</b>	332				$\chi^2=3.750$
Primipara	192	58%	35 (18%)	157 (82%)	$p$ -value=0.053
Multipara	140	42%	38 (27%)	102 (73%)	(df=1)
<b>Knowledge &amp; Awareness on Pregnancy Danger Sign</b>	332				$\chi^2=1.833$
No Knowledge at All	63	19%	16 (25%)	47 (75%)	$p$ -value=0.400
Little Knowledge (Low level of Awareness)	128	39%	31 (24%)	97 (76%)	(df=2)
Enough Knowledge (High level of Awareness)	141	42%	26 (18%)	115 (82%)	
<b>Women Empowerment (Autonomy) Index</b>	332				$\chi^2=11.192$
Low	70	21%	24 (34%)	46 (66%)	$p$ -value=0.004
Medium	196	59%	42 (21%)	154 (79%)	(df=2)
High	66	20%	7 (11%)	59 (89%)	

Significance at Pearson Chi-square test; \* $p$ -value=Fisher Exact test

**TABLE 4: Association between family related factors and ANC check-up**

Factors	n	%	ANC Check		
			<4 visit (%)	4+ visit (%)	
<b>Husband's Education</b>	<b>331</b>				$\chi^2=9.736$
Illiterate	51	15%	19 (37%)	32 (63%)	$p$ -value=0.008
Literate/Primary Education (up to 5 class)	92	28%	21 (23%)	71 (77%)	(df=2)
Secondary Education (6 class & above)	188	57%	32 (17%)	156 (83%)	
<b>Husband's Occupation</b>	<b>331</b>				$\chi^2=0.302$
Unemployed/Farmer	115	35%	27 (24%)	88 (76%)	$p$ -value=0.579
Employed (Service/Small Business)	216	65%	45 (21%)	171 (79%)	df=1
<b>Main source of Family Income</b>	<b>332</b>				$\chi^2=3.332$
Farming & Daily wages	84	25%	18 (21%)	66 (79%)	$p$ -value=0.189
Service/Employment (Service, small business)	64	19%	9 (14%)	55 (86%)	(df=2)
Others (Mixed source of income)	184	56%	46 (25%)	138 (75%)	
<b>Household Wealth Index</b>	<b>332</b>				$\chi^2=4.592$
Low (<40% in ranking)	67	20%	21 (31%)	46 (69%)	$p$ -value=0.101
Middle (40 – 60% in ranking)	192	58%	36 (19%)	156 (81%)	(df=2)
High (>60% in ranking)	73	22%	16 (22%)	57 (78%)	

\*3 Disabled not Delivered; 1 non-Disabled miscarriage

Significance at Pearson Chi-square test; \* $p$ -value=Fisher Exact test

**TABLE 5: Association between demographic, socio-economic factors and place of delivery**

Factors	n	%	Delivery		
			HF (%)	Home (%)	
Disability	350				$\chi^2=7.028$
Disabled	76	22%	40 (53%)	36 (47%)	$p$ -value=0.008
Non-Disabled	274	78%	189 (69%)	85 (31%)	(df=1)
Caste	350				$\chi^2=1.364$
Dalit	150	43%	93 (62%)	57 (38%)	$p$ -value=0.243
Non-Dalit	200	57%	136 (68%)	64 (32%)	(df=1)
Location (Place of Residence)	350*	100			$\chi^2=5.308$
Rural	280	80%	175 (63%)	105 (36%)	$p$ -value=0.021
Urban	70	20%	54 (77%)	16 (23%)	(df=1)
Respondent's Age	350				$\chi^2=21.747$
15 – 24 Years	132	38%	104 (79%)	28 (22%)	$p$ -value=0.000
25 – 34 Years	170	48%	104 (61%)	66 (39%)	(df=2)
35 – 49 Years	48	14%	21 (44%)	27 (56%)	
Respondent's Education	350				$\chi^2=63.081$
Illiterate	116	33%	49 (42%)	67 (58%)	$p$ -value=0.000
Literate/Primary Education (up to 5 class)	117	33%	73 (62%)	44 (38%)	(df=2)
Secondary Education (6 class & above)	117	34%	107 (92%)	10 (8%)	
Respondent's Occupation	350				$\chi^2=9.049$
Unemployed/Farmer	296	85%	184 (62%)	112 (38%)	$p$ -value=0.003
Employed (Service/Small Business)	54	15%	45 (83%)	9 (17%)	(df=1)
Marital Status	350				$\chi^2=1.450$
Married	345	99%	227 (66%)	118 (34%)	* $p$ -value=0.345
Single(Unmarried/Widowed/Separated)	5	1%	2 (40%)	3 (60%)	(df=1)
Age at Marriage	349				$\chi^2=13.862$
5 – 18 Years	235	67%	138 (59%)	97 (41%)	$p$ -value=0.000
19 – 40 Years	114	33%	90 (79%)	24 (21%)	(df=1)
Parity	350				$\chi^2=40.281$
Primipara	194	55%	155 (80%)	39 (20%)	$p$ -value=0.000
Multipara	156	45%	74 (47%)	82 (53%)	(df=1)
Knowledge & Awareness on Pregnancy Danger Sign	350				$\chi^2=8.543$
No Knowledge at All	70	20%	41 (59%)	29 (41%)	$p$ -value=0.014
Little Knowledge (Low level of Awareness)	136	39%	81 (60%)	55 (40%)	(df=2)
Enough Knowledge (High level of Awareness)	144	41%	107 (74%)	37 (26%)	
Women Empowerment (Autonomy) Index	350				$\chi^2=2.756$
Low	75	21%	47 (63%)	28 (37%)	$p$ -value=0.252
Medium	206	59%	131 (64%)	75 (36%)	(df=2)
High	69	20%	51 (74%)	18 (26%)	

4 Cases missed: miscarriage (1) and not delivered (3) till survey date

^1 Unmarried

Significance at Pearson Chi-square test; \* $p$ -value=Fisher Exact test



**TABLE 6: Association between family related, other factors and place of delivery**

Factors	n	%	Delivery		
			HF (%)	Home (%)	
<b>Husband's Education</b>	<b>349</b>				$\chi^2=36.458$
Illiterate	58	17%	22 (38%)	36 (62%)	$p$ -value=0.000
Literate/Primary Education (up to 5 class)	99	28%	56 (57%)	43 (43%)	(df=2)
Secondary Education (6 class & above)	192	55%	150 (78%)	42 (22%)	
<b>Husband's Occupation</b>	<b>349</b>				$\chi^2=1.196$
Unemployed/Farmer	125	36%	77 (62%)	48 (38%)	$p$ -value=0.274
Employed (Service/Small Business)	224	64%	151 (67%)	73 (33%)	df=1
<b>Main source of Family Income</b>	<b>350</b>				$\chi^2=13.651$
Farming & Daily wages	95	27%	59 (62%)	36 (38%)	$p$ -value=0.001
Service/Employment (Service, small business)	66	19%	56 (85%)	10 (15%)	(df=2)
Others (Mixed source of income)	189	54%	114 (60%)	75 (40%)	
<b>Household Wealth Index</b>	<b>350</b>				$\chi^2=25.968$
Low (<40% in ranking)	80	23%	35 (44%)	45 (56%)	$p$ -value=0.000
Middle (40 – 60% in ranking)	198	57%	135 (68%)	63 (32%)	(df=2)
High (>60% in ranking)	72	21%	59 (82%)	13 (18%)	
<b>ANC</b>	<b>330</b>				$\chi^2=31.162$
<4 visits	71	22%	29 (41%)	42 (59%)	$p$ -value=0.000
4+ visits	259	78%	196 (76%)	63 (24%)	(df=1)

\*3 Disabled not Delivered; 1 non-Disabled miscarriage

Significance at Pearson Chi-square test; \* $p$ -value=Fisher Exact test

**TABLE 7: Association between demographic, socio-economic factors and PNC check-up**

Factors	n	%	PNC Check		
			Yes (%)	No (%)	
Disability	350				$\chi^2=5.664$
Disabled	76	22%	14 (18%)	62 (82%)	$p$ -value=0.017
Non-Disabled	274	78%	89 (33%)	185 (67%)	(df=1)
Caste	350				$\chi^2=0.041$
Dalit	150	43%	45 (30%)	105 (70%)	$p$ -value=0.839
Non-Dalit	200	57%	58 (29%)	142 (71%)	(df=1)
Location (Place of Residence)	350	100			$\chi^2=3.745$
Rural	280	80%	89 (32%)	191 (68%)	$p$ -value=0.053
Urban	70	20%	14 (20%)	56 (80%)	(df=1)
Respondent's Age	350				$\chi^2=4.380$
15 – 24 Years	132	38%	41 (31%)	91 (69%)	$p$ -value=0.112
25 – 34 Years	170	48%	54 (32%)	116 (68%)	(df=2)
35 – 49 Years	48	14%	8 (17%)	40 (83%)	
Respondent's Education	350				$\chi^2=4.625$
Illiterate	116	33%	26 (22%)	90 (78%)	$p$ -value=0.099
Literate/Primary Education (up to 5 class)	117	33%	36 (31%)	81 (69%)	(df=2)
Secondary Education (6 class & above)	117	34%	41 (35%)	76 (65%)	
Respondent's Occupation	350				$\chi^2=5.328$
Unemployed/Farmer	296	85%	80 (27%)	216 (73%)	$p$ -value=0.021
Employed (Service/Small Business)	54	15%	23 (43%)	31 (57%)	(df=1)
Marital Status	350				$\chi^2=2.115$
Married	345	99%	103 (30%)	242 (70%)	* $p$ -value=0.327
Single(Unmarried/Widowed/Separated)	5	1%	0 (0%)	5 (100%)	(df=1)
Age at Marriage	349				$\chi^2=4.372$
5 – 18 Years	235	67%	61 (26%)	174 (74%)	$p$ -value=0.037
19 – 40 Years	114	33%	42 (37%)	72 (63%)	(df=1)
Parity	350				$\chi^2=6.626$
Primipara	194	55%	68 (35%)	126 (65%)	$p$ -value=0.010
Multipara	156	45%	35 (22%)	121 (78%)	(df=1)
Knowledge & Awareness on Pregnancy Danger Sign	350				$\chi^2=1.975$
No Knowledge at All	70	20%	20 (29%)	50 (71%)	$p$ -value=0.372
Little Knowledge (Low level of Awareness)	136	39%	35 (26%)	101 (74%)	(df=2)
Enough Knowledge (High level of Awareness)	144	41%	48 (33%)	96 (67%)	
Women Empowerment (Autonomy) Index	350				$\chi^2=1.187$
Low	75	21%	21 (28%)	54 (72%)	$p$ -value=0.552
Medium	206	59%	58 (28%)	148 (72%)	(df=2)
High	69	20%	24 (35%)	45 (65%)	

Significance at Pearson Chi-square test; \* $p$ -value=Fisher Exact test

**TABLE 8: Association between family related, other factors and PNC check-up**

Factors	n	%	PNC Check		
			Yes (%)	No (%)	
<b>Husband's Education</b>	<b>349</b>				$\chi^2=8.391$
Illiterate	58	17%	8 (14%)	50 (86%)	<i>p</i> -value=0.015
Literate/Primary Education (up to 5 class)	99	28%	31 (31%)	68 (69%)	(df=2)
Secondary Education (6 class & above)	192	55%	64 (33%)	128 (67%)	
<b>Husband's Occupation</b>	<b>349</b>				$\chi^2=0.214$
Unemployed/Farmer	125	36%	35 (28%)	90 (72%)	<i>p</i> -value=0.643
Employed (Service/Small Business)	224	64%	68 (30%)	156 (70%)	(df=1)
<b>Main source of Family Income</b>	<b>350</b>				$\chi^2=4.125$
Farming & Daily wages	95	27%	24 (25%)	71 (75%)	<i>p</i> -value=0.127
Service/Employment (Service, small business)	66	19%	26 (39%)	40 (61%)	(df=2)
Others (Mixed source of income)	189	54%	53 (28%)	136 (72%)	
<b>Household Wealth Index</b>	<b>350</b>				$\chi^2=2.894$
Low (<40% in ranking)	80	23%	18 (23%)	62 (77%)	<i>p</i> -value=0.235
Middle (40 – 60% in ranking)	198	57%	60 (30%)	138 (70%)	(df=2)
High (>60% in ranking)	72	20%	25 (35%)	47 (65%)	
<b>ANC</b>	<b>330</b>				$\chi^2=14.083$
<4 visits	71	22%	9 (13%)	62 (87%)	<i>p</i> -value=0.000
4+ visits	259	78%	93 (36%)	166 (64%)	(df=1)
<b>Delivery</b>	<b>350</b>				$\chi^2=21.061$
HF/Institution	229	65%	86 (38%)	143 (62%)	<i>p</i> -value=0.000
Home	121	35%	17 (14%)	104 (86%)	(df=1)

\*3 Disabled not Delivered; 1 non-Disabled miscarriage

Significance at Pearson Chi-square test; \**p*-value=Fisher Exact test

**Table 9: Unadjusted and adjusted odds ratio (95% confidence intervals) of disability with at least one ANC service utilization**

Factors	Disability only		+ Location		+ Women's Age		+ Age at marriage		+ Parity		+ Husband's Education		+ Husband's Occupation		Full Model	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
<b>Disability</b>	<b>***0.17</b>	<b>0.07 - 0.42</b>	<b>***0.14</b>	<b>0.06 - 0.36</b>	<b>*0.30</b>	<b>0.11 - 0.80</b>	<b>***0.17</b>	<b>0.07 - 0.44</b>	<b>***0.20</b>	<b>0.08 - 0.49</b>	<b>**0.23</b>	<b>0.09 - 0.58</b>	<b>***0.16</b>	<b>0.07 - 0.40</b>	<b>*0.26</b>	<b>0.08 - 0.84</b>
<b>Location</b>																
Rural			2.57	0.89 - 7.45											3.06	0.92 - 10.19
Urban			Ref													
<b>Age</b>																
15 - 24 yrs					*5.32	1.44 - 19.65									5.71	0.97 - 33.80
25 - 34 yrs					**4.64	1.59 - 13.53									*4.46	1.35 - 14.75
35 - 49 yrs					Ref											
<b>Age at Marriage</b>																
Below 18 yrs							0.72	0.27 - 1.93							0.78	0.24 - 2.55
18 yrs and above							Ref									
<b>Parity</b>																
Primi									*3.01	1.12 - 8.06					1.89	0.50 - 7.19
Multi									Ref							
<b>Husband's Education</b>																
Illiterate												Ref				
Primary Education											1.49	0.49 - 4.54			1.31	0.40 - 4.34
Secondary & above											*3.26	1.03 - 10.31			1.78	0.50 - 6.31
<b>Husband's Occupation</b>																
Unemployed/Farming													*0.40	0.16 - 0.99	*0.31	0.11 - 0.88
Regular service/Business													Ref			

\*\*\*P<0.001, \*\*P<0.01, \*P<0.05

**Table 10: Unadjusted and adjusted odds ratio (95% confidence intervals) of disability with 4+ ANC service utilization**

Factors	Disability only		+ Location		+ Women's Age		+ Age at marriage		+ Parity		+ Husband's Education		+ Husband's Occupation		Full Model	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
<b>Disability</b>	<b>0.63</b>	<b>0.34 - 1.16</b>	<b>0.67</b>	<b>0.36 - 1.23</b>	<b>0.73</b>	<b>0.38 - 1.40</b>	<b>0.58</b>	<b>0.31 - 1.10</b>	<b>0.68</b>	<b>0.36 - 1.25</b>	<b>0.80</b>	<b>0.42 - 1.53</b>	<b>0.63</b>	<b>0.34 - 1.16</b>	<b>0.79</b>	<b>0.39 - 1.60</b>
<b>Location</b>																
Rural			0.55	0.26 - 1.17											0.62	0.28 - 1.37
Urban			Ref													
<b>Age</b>																
15 - 24 yrs					1.81	0.74 - 4.42									1.45	0.51 - 4.17
25 - 34 yrs					1.21	0.53 - 2.72									1.01	0.42 - 2.43
35 - 49 yrs					Ref											
<b>Age at Marriage</b>																
Below 18 yrs							*0.51	0.28 - 0.95							0.57	0.29 - 1.12
18 yrs and above							Ref									
<b>Parity</b>																
Primi									1.61	0.95 - 2.72					1.12	0.59 - 2.15
Multi									Ref							
<b>Husband's Education</b>																
Illiterate												Ref				
Primary Education											1.94	0.91 - 4.12			1.76	0.81 - 3.81
Secondary & above											2.75	1.37 - 5.54			2.20*	1.06 - 4.56
<b>Husband's Occupation</b>																
Unemployed/Farming													0.87	0.50 - 1.49	0.83	0.47 - 1.47
Regular service/Business													Ref			

\*\*\*p<0.001, \*\*p<0.01, \*p<0.05

**Table 11: Unadjusted and adjusted odds ratio (95% confidence intervals) of disability with HF delivery service utilization**

Factors	Disability only			+ Location			+ Women's Age			+ Age at marriage			+ Parity			+ Husband's Education			+ Husband's Occupation			Full Model	
	OR	95% CI		OR	95% CI		OR	95% CI		OR	95% CI		OR	95% CI		OR	95% CI		OR	95% CI		OR	95% CI
<b>Disability</b>	<b>**0.50</b>	<b>0.30 - 0.84</b>		<b>*0.54</b>	<b>0.32 - 0.91</b>		<b>0.72</b>	<b>0.41 - 1.26</b>		<b>**0.38</b>	<b>0.22 - 0.66</b>		<b>*0.61</b>	<b>0.35 - 1.06</b>		<b>0.64</b>	<b>0.37 - 1.12</b>		<b>**0.50</b>	<b>0.30 - 0.83</b>		<b>0.68</b>	<b>0.35 - 1.32</b>
<b>Location</b>																							
Rural				0.54	0.29 - 1.00																	0.59	0.29 - 1.18
Urban				Ref																			
<b>Age</b>																							
15 - 24 yrs							***4.08	1.92 - 8.08														1.83	0.72 - 4.66
25 - 34 yrs							1.79	0.91 - 3.54														1.04	0.47 - 2.27
35 - 49 yrs							Ref																
<b>Age at Marriage</b>																							
Below 18 yrs									***0.32	0.18 - 0.55												**0.41	0.22 - 0.77
18 yrs and above									Ref														
<b>Parity</b>																							
Primi												***4.18	2.60 - 6.73									**2.40	1.34 - 4.30
Multi												Ref											
<b>Husband's Education</b>																							
Illiterate																Ref							
Primary Education																1.96	1.00 - 3.84					1.66	0.80 - 3.42
Secondary & above																***5.28	2.77 - 10.04					***3.57	1.79 - 7.15
<b>Husband's Occupation</b>																							
Unemployed/Farming																			0.76	0.48 - 1.20		0.78	0.46 - 1.31
Regular service/Business																			Ref				

\*\*\*P<0.001, \*\*P<0.01, \*P0.05

**Table 12: Unadjusted and adjusted odds ratio (95% confidence intervals) of disability with PNC service utilization**

Factors	Disability only		+ Location		+ Women's Age		+ Age at marriage		+ Parity		+ Husband's Education		+ Husband's Occupation		Full Model		
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	
<b>Disability</b>	<b>*0.47</b>	<b>0.25 - 0.88</b>	<b>**0.43</b>	<b>0.23 - 0.81</b>	<b>0.54</b>	<b>0.28 - 1.05</b>	<b>**0.42</b>	<b>0.22 - 0.80</b>	<b>*0.52</b>	<b>0.27 - 0.98</b>	<b>0.56</b>	<b>0.29 - 1.07</b>	<b>*0.47</b>	<b>0.25 - 0.88</b>	<b>*0.48</b>	<b>0.24 - 0.98</b>	
<b>Location</b>																	
Rural			*2.09	1.10 - 3.99											*2.32	1.19 - 4.54	
Urban			Ref														
<b>Age</b>																	
15 - 24 yrs					1.71	0.70 - 4.17									1.05	0.38 - 2.94	
25 - 34 yrs					1.88	0.80 - 4.43									1.19	0.47 - 2.98	
35 - 49 yrs					Ref												
<b>Age at Marriage</b>																	
Below 18 yrs							*0.53	0.33 - 0.87							0.61	0.35 - 1.06	
18 yrs and above							Ref										
<b>Parity</b>																	
Primi									*1.74	1.07 - 2.82					1.53	0.85 - 2.75	
Multi									Ref								
<b>Husband's Education</b>																	
Illiterate												Ref					
Primary Education											*2.58	0.08 - 6.14			*2.50	1.03 - 6.08	
Secondary & above											*2.75	1.21 - 6.22			2.31	0.98 - 5.41	
<b>Husband's Occupation</b>																	
Unemployed/Farming														1.13	0.69 - 1.83	1.02	0.61 - 1.71
Regular service/Business														Ref			

\*\*\*P<0.001, \*\*P<0.01, \*P<0.05

## **APPENDIX G: LIST OF INDEX VARIABLES**

### **A. Information & Knowledge Index**

<b>Related Q. No</b>	<b>Indicators/Variable</b>	<b>Coding</b>
Q39	Information & Knowledge about Danger Sign	No=0, Yes=1
Q40	<b>What are the Danger Sign during pregnancy &amp; Child Birth?</b>	
	Q40_1 Vaginal bleeding/haemorrhage	No=0, Yes=1
	Q40_2 Feel weak/faint/anaemic	No=0, Yes=1
	Q40_3 Fits/convulsions/seizures	No=0, Yes=1
	Q40_4 Swollen hands/face	No=0, Yes=1
	Q40_5 Blurred vision	No=0, Yes=1
	Q40_6 Severe headache	No=0, Yes=1
	Q40_7 High blood pressure	No=0, Yes=1
	Q40_8 Prolonged or obstructed labor	No=0, Yes=1
	Q40_9 Hand/Foot/cord prolapsed	No=0, Yes=1
	Q40_10 Premature membrane/water bag rupture	No=0, Yes=1
	Q40_11 Retained Placenta	No=0, Yes=1
	Q40_12 Severe abdominal pain	No=0, Yes=1
	Q40_13 Fowl smelling vaginal discharge	No=0, Yes=1
	Q40_14 Fever	No=0, Yes=1
	Q40_15 Baby at transverse position	No=0, Yes=1
	Q40_96 Other	No=0, Yes=1



## B. WEALTH INDEX

Related Q. No	Indicators/Variable	Coding
Q20	Own House	No=0, Yes=1
Q21	Roofing Materials	Grass/Straw/Plastic/Tents=1, Tin/Jasta/Tile/Khapata=2, Cement & Concrete=3
Q23	<b>Livestock's</b>	
	Q23_1 Buffalo	No=0, Yes=1
	Q23_2 Cow/bulls	No=0, Yes=1
	Q23_3 Horse/Mule	No=0, Yes=1
	Q23_4 Goat/Sheep	No=0, Yes=1
	Q23_5 Chicken/Duck	No=0, Yes=1
	Q23_6 Pig	No=0, Yes=1
	Q23_96 Other	No=0, Yes=1
Q24	<b>Household Facilities/Assets</b>	
	Q24_1 Electricity	No=0, Yes=1
	Q24_2 Motorbike	No=0, Yes=1
	Q24_3 Riksa	No=0, Yes=1
	Q24_4 Bull/Buff Cart	No=0, Yes=1
	Q24_5 Bicycle	No=0, Yes=1
	Q24_6 Mob Phone	No=0, Yes=1
	Q24_7 TV	No=0, Yes=1
	Q24_8 Radio	No=0, Yes=1
	Q24_9 Fan	No=0, Yes=1
	Q24_10 Computer	No=0, Yes=1
	Q24_11 Refrigerator	No=0, Yes=1
Q25	Toilet	No=0, Yes=1
Q26	Water Use	Well=1, Tube Well=2, Pipe water=3

### C. EMPOWERMENT INDEX

Related Q. No	Indicators/Variable	Coding
Q12	Decision for Marriage	Others=0, Self=1
Q15	Household Head	No=0, Yes=1
Q45	Decision for ANC	Others=0, Self=1
Q77	Own assets/wealth	No=0, Yes=1
Q79	Household purchase decision	No=0, Yes=1
Q80	Household Purchase	No=0, Yes=1
Q81	Spending Decision/Autonomy	No=0, Yes=1
Q82	Inclusion in Household Decision	No=0, Yes=1
Q83	Inclusion in Neighbour/community	No=0, Yes=1
Q84	<b>Autonomy to go out</b>	
	Q84_1 Within own compound & neighbour's house	No=0, Yes=1
	Q84_2 Farming/cattle grazing/firewood	No=0, Yes=1
	Q84_3 HF for treatment	No=0, Yes=1
	Q84_4 Market	No=0, Yes=1
	Q84_5 Participate in the meeting	No=0, Yes=1
	Q84_6 Parent's House	No=0, Yes=1
	Q84_7 No restriction	No=0, Yes=1
Q85	Autonomy to spend overnight outside home	No=0, Yes=1
Q86	Group Inclusion	No=0, Yes=1
Q88	Representation	No=0, Yes=1
Q90	Leadership	No=0, Yes=1
Q91	Citizenship	No=0, Yes=1
Q92	Voting	No=0, Yes=1
Q93	Domestic violence	No=0, Yes=1
Q94	Sexual abuse	No=0, Yes=1

## **APPENDIX H: GUIDELINES/CHECKLIST FOR SELECTION OF PAPERS FOR REVIEW**

### **Assessment checklist for research paper and the study**

<b>Theoretical/Epistemology</b>		
1. Is the approach appropriate to answer the research question?	<ul style="list-style-type: none"> <li>➤ Qualitative</li> <li>➤ Quantitative</li> <li>➤ Mixed</li> </ul>	<ul style="list-style-type: none"> <li>• Appropriate</li> <li>• Unclear</li> <li>• Inappropriate</li> </ul>
2. Is the approach Justify by the author?	<ul style="list-style-type: none"> <li>➤ Does the research methodology seek to understand the views of those researched?</li> <li>➤ Does the research methodology seek to understand WHAT and WHY?</li> </ul>	<ul style="list-style-type: none"> <li>• Justified</li> <li>• Unclear</li> <li>• Not justified</li> </ul>
3. Is the purpose of the research adequately described and justified?	<ul style="list-style-type: none"> <li>➤ Was the review of secondary data conducted and presented (Gap identified)?</li> <li>➤ Is the research linked/connected to the existing body of knowledge, policy or practice?</li> <li>➤ Is there adequate reference to the literature?</li> </ul>	<ul style="list-style-type: none"> <li>• Justified</li> <li>• Unclear</li> <li>• Not justified</li> </ul>
<b>Study Design</b>		
4. Is the context of the research adequately described?		<ul style="list-style-type: none"> <li>• Adequate</li> <li>• Unclear</li> <li>• Inadequate</li> </ul>
5. Is the research question relevant to the context		<ul style="list-style-type: none"> <li>• Relevant</li> <li>• Unclear</li> <li>• Not relevant</li> </ul>
6. Are the research aims/objectives/questions clearly defined and focused?		<ul style="list-style-type: none"> <li>• Adequately defined</li> <li>• Unclear</li> <li>• Poorly defined</li> </ul>
7. Are the methods used appropriate to the research question?	<ul style="list-style-type: none"> <li>➤ Have the best methods been chosen?</li> <li>➤ Do the methods investigate what they claim to?</li> <li>➤ Is a range of methods used for triangulation or is use of a single method justified?</li> </ul>	<ul style="list-style-type: none"> <li>• Appropriate</li> <li>• Unclear</li> <li>• Inappropriate</li> </ul>
<b>Sampling and Data Collection</b>		
8. Is the sampling strategy appropriate to the research question?	<ul style="list-style-type: none"> <li>➤ Is the target population clearly identified?</li> <li>➤ How is the sample selected - random or representative in the case of quantitative</li> <li>➤ Are the inclusion/exclusion criteria clearly defined?</li> <li>➤ Usually purposive or theoretical in the case of qualitative</li> </ul>	<ul style="list-style-type: none"> <li>• Appropriate</li> <li>• Unclear</li> <li>• Inappropriate</li> </ul>

	<ul style="list-style-type: none"> <li>➤ Is the sample sufficient to understand study context, population and phenomena?</li> <li>➤ Was the sampling pre-determined or evolved as the field progressed (Qualitative)</li> </ul>	
9. Is the choice of sampling strategy justified?	<ul style="list-style-type: none"> <li>➤ Are the reasons for this choice discussed or compared to other strategies?</li> <li>➤ Who was selected and why? (Gender, caste, ethnicity...)</li> <li>➤ How were participants selected (inclusion/exclusion criteria) and why?</li> </ul>	<ul style="list-style-type: none"> <li>• Adequately justified</li> <li>• Unclear</li> <li>• Not justified</li> </ul>
10. Are data collection procedures clearly described?	<ul style="list-style-type: none"> <li>➤ How was data collected? (Survey questionnaire, checklist, topic guide...)</li> <li>➤ Were data collection tools appropriate (valid &amp; reliable)?</li> <li>➤ Were data collection tool/s pilot tested?</li> <li>➤ Where data collection was took place and why was this location chosen? (Privacy, familiarity...)</li> <li>➤ How was the data recorded and why? (Form filled, notes audio record...)</li> </ul>	<ul style="list-style-type: none"> <li>• Clear</li> <li>• Unclear</li> </ul>
11. Are the role of researcher clearly described?	<ul style="list-style-type: none"> <li>➤ Who conducted the research and how were they selected?</li> <li>➤ Are the researcher's skills, motives, background, position in-terms of power-relation (Gender, age, ethnicity...) and perspective described and discussed?</li> </ul>	<ul style="list-style-type: none"> <li>• Clear</li> <li>• Unclear</li> </ul>
12. Are the Ethical issues addressed in data collection and adequately discussed?	<ul style="list-style-type: none"> <li>➤ How was the research explained to the participants</li> <li>➤ What consent procedures were used?</li> <li>➤ How were privacy and confidentiality assured?</li> <li>➤ Was the ethical approval taken from the concern authorities?</li> </ul>	<ul style="list-style-type: none"> <li>• Adequate</li> <li>• Unclear</li> <li>• Inadequate</li> </ul>
<b>Analysis</b>		
13. Is the data analysis procedure is explicit?	<ul style="list-style-type: none"> <li>➤ Is reference made to accepted procedures for analysis?</li> <li>➤ Is it clear how the researcher processed the raw data to arrive at the stated results?</li> <li>➤ For qualitative data, were the categories and themes identified in advance or derived from data?</li> <li>➤ Are all interview/data taken into account in the analysis?</li> </ul>	<ul style="list-style-type: none"> <li>• Explicit</li> <li>• Unclear</li> <li>• Vague</li> </ul>

	<ul style="list-style-type: none"> <li>➤ Are the responses/experience compared and contrasted across different groups/individuals and study sites?</li> </ul>	
14. Is the data analysis procedure reliable?	<ul style="list-style-type: none"> <li>➤ Who was involved in the analysis and at what stage?</li> <li>➤ Did more than one person (researcher and other stakeholders) identified code transcript in the case of qualitative analysis?</li> </ul>	<ul style="list-style-type: none"> <li>• Reliable</li> <li>• Unclear</li> <li>• Potential Bias</li> </ul>
<b>Findings, Interpretation and Validity/Reliability</b>		
15. Are the findings valid, coherent internally and trustworthy?	<ul style="list-style-type: none"> <li>➤ Are findings drawn from analysis of collected data rather than the researcher's preconceptions?</li> <li>➤ Is there adequate critical discussion for and against the researcher's arguments? For example: are negative and divergent views adequately discussed?</li> <li>➤ Are quotes used to substantiate the researcher's conclusion from the analysis? (In the case of qualitative analysis)</li> <li>➤ Is triangulation or data cross checking used? (In the case of qualitative analysis)</li> <li>➤ Have findings been validated by the respondents?</li> <li>➤ Has the researcher critically reflected on his/her own bias, role and influence?</li> <li>➤ Has the research critically reflected on the quality of the data collected and skills of the research team?</li> </ul>	<ul style="list-style-type: none"> <li>• Valid</li> <li>• Unclear</li> <li>• Invalid/Potential bias</li> </ul>
16. Are the findings relevant?	<ul style="list-style-type: none"> <li>➤ Are the findings relevant to the study aim/objectives/questions?</li> <li>➤ Do they contribute new knowledge or understanding?</li> <li>➤ How important are the findings in the local context? (Geographical, socio-economic, cultural, political)</li> </ul>	<ul style="list-style-type: none"> <li>• Relevant</li> <li>• Unclear</li> <li>• Limited relevance</li> </ul>
<b>Implication/Limitation</b>		
17. Are the implications of the study clearly defined?	<ul style="list-style-type: none"> <li>➤ Are the findings placed in local context? (Geographical, socio-economic, cultural, political)</li> <li>➤ Have findings been disseminated to key stakeholders including participants?</li> <li>➤ Are findings discussed in wider context? (In relation to other studies in the same topic)</li> <li>➤ Are recommendations made for policy and practice?</li> </ul>	<ul style="list-style-type: none"> <li>• Clear</li> <li>• Unclear</li> </ul>
18. Is there adequate discussion of the study limitations?	<ul style="list-style-type: none"> <li>➤ Are study limitations described and accounted for?</li> <li>➤ Are the weaknesses of the study design discussed?</li> </ul>	<ul style="list-style-type: none"> <li>• Adequate</li> <li>• Unclear</li> <li>• Inadequate</li> </ul>

## **APPENDIX I: LIST OF QUALITATIVE INTERVIEW PARTICIPANTS WITH CODE**

<b>IN-DEPTH INTERVIEW PARTICIPANTS</b>		
Code	Age in years	Place
<b>(1 – 5) DISABLED DALIT WOMEN</b>		
1	35	Kerbani
2	35	Parroha
3	30	Siktahan
4	28	Devdaha
5	34	Jogada
<b>(6 – 17) DISABLED NON-DALIT WOMEN</b>		
6	35	Saljhundi
7	26	Saljhundi
8	27	Saljhundi
9	31	Bishnupura
10	26	Devdaha
11	33	Karahiya
12	31	Karahiya
13	28	Shankarnagar
14	35	Motipur
15	35	Ekla
16	23	Ekla
17	26	Ekla
<b>(18 – 28) NON-DISABLED DALIT WOMEN</b>		
18	30	Rudrapur
19	25	Rudrapur
20	30	Si.Na.Pa.
21	26	Si.Na.Pa.
22	35	Ekla
23	38	Bishnupura
24	22	Bishnupura
25	22	Shankarnagar
26	26	Butwal
27	21	Butwal
28	21	Shankarnagar
<b>(29 – 37) NON-DISABLED NON-DALIT WOMEN</b>		
29	23	Butwal
30	35	Butwal
31	35	Butwal
32	29	Shankarnagar
33	25	Rudrapur
34	26	Motipur
35	23	Motipur
36	26	Si.Na.Pa.
37	24	Si.Na.Pa.
<b>KII PARTICIPANTS</b>		
Code	Type of Informants	
1	DPO Leader	
2	Dalit Leader/Activist	
3	Woman Advocate/Activist	
4	Woman Leader/Activist	
5	Policy Implementer	
6	Policy Planner	

**APPENDIX J: MAP SHOWING NEPAL IN THE GLOBE**

