# ENSURING DISABILITY INCLUSIVE HEALTHCARE IN NEPAL: A QUALITATIVE CASE STUDY IN SINDHUPALCHOK DISTRICT

# Susmita Neupane



**Centre for International Health** 

**Faculty of Medicine** 

University of Bergen, Norway 2023

# Ensuring disability inclusive healthcare in Nepal: A qualitative case study in Sindhupalchok District

# Susmita Neupane

This thesis is submitted in partial fulfilment of the requirements for the degree of Master of Philosophy in Global Health at the University of Bergen (60 ECTS credits).

Faculty of Medicine
University of Bergen, Norway

Centre for International Health

August 2023

#### **ABSTRACT**

Persons with disabilities often face barriers to accessing healthcare services. Since the ratification of the UN Convention on the Rights of Persons with Disabilities (UNCRPD), Nepal has shown its commitment to disability inclusion in healthcare with several legal and implementational initiatives. The purpose of this qualitative case study was to explore the current situation, experienced challenges, and opportunities of disability inclusive healthcare at community level in a district of Nepal and to identify the barriers to inclusive healthcare from the perspective of persons with disabilities and the health coordinators of the municipalities.

The study applies a qualitative case study design for data collection, analysis, and interpretation. In-depth interviews were conducted with 10 persons with disabilities and with 12 health coordinators in the Sindhupalchok district (one from each municipality) and data collection was supplemented by observations made in four health facilities and by the analysis of plans and policies of the municipalities.

Findings reveal that though the challenges of transportation, communication, and inaccessible health facilities persist, the healthcare systems at the local level of Sindhupalchok district are gradually adapting to the needs of persons with disabilities. Moreover, the practice of federalism in the government offers opportunities to mainstream disability in the health sector. However, according to the informants, de-prioritization of disability may potentially accompany federalism. It was observed that the formulation of numerous plans and policies at the national and local levels has provided a promising framework for ensuring disability inclusive healthcare services. Nonetheless, the achievement of this would require the federal government's support, guidance, and allocation of resources.

Keywords: disability, disability inclusive healthcare, local level health system, Nepal, challenges and opportunities, equitable healthcare, qualitative case study

#### LIST OF ABBREVIATIONS

BCC Behavioral Change Communication

CBR Community-based Rehabilitation

CDC Centers for Disease Control and Prevention

CEONC Comprehensive Emergency Obstetric and Neonatal Care

DFID Department for International Development

DoHS Department of Health Services

FCHV Female Community Health Volunteer

FY Fiscal Year

GESI Gender Equality and Social Inclusion

GoN Government of Nepal

HMIS Health Information Management System

ID Card Identity Card

IEC Information, Education and Communication

LMIC Low- and Middle-Income Countries

MoF Ministry of Finance

MoHP Ministry of Health and Population

NDHS National Demographic Health Survey

NHRC Nepal Health Research Council

NSD Norsk Senter for Forskningsdata (Norwegian Center for Research Data)

OPD Outpatient Department
PWD Persons with disabilities
PHC Primary Health Care

PHCC Primary Health Care Centre

SDG Sustainable Development Goals
SRH Sexual and Reproductive Health

UN United Nations

UNCRPD United Nations Convention on the Rights of Persons with Disabilities

UK United Kingdom

US United Stated

WHO World Health Organization

#### **ACKNOWLEDGEMENT**

I am grateful to my two supervisors: Prof. Graziella Van den Bergh and Prof. David Lackland Sam for their guidance and support throughout this research journey. Your mentorship has been instrumental in shaping me into a social researcher.

I am indebted to be supervised by Prof. Graziella. Your supervision has been a transformative experience. My perspective on persons with disabilities and their experiences has broadened and this could not have been possible without your guidance and insights.

I extremely appreciate David's support and trust in me. Thank you so much, Prof. David, for never losing trust in me. You were there from the initial stage when I was still struggling with my thesis topic. I appreciate all the encouragement you provided.

I would also extend my gratitude to the University of Bergen, especially the Faculty of Medicine, for providing me with this opportunity and for organizing the writing seminars. Learning from my peers had a profound impact on my research. I would like to thank my classmate and wonderful friend Puja Tripathi for her feedback and consistent motivation. Thank you for the support I needed to complete this research. I hope you know how much I treasure our friendship.

I am thankful to the municipalities of the Sindhupalchok District for allowing me to conduct the research there. I am equally thankful to my wonderful participants who enriched the study with their knowledge and experiences.

A special note of appreciation goes to my talented research assistant Nirajan Chaulagain on the team. You made the whole fieldwork fun and full of experiences.

Lastly, I am thankful to my family and friends who are my strongest support system. Without their encouragement, this journey would have been incomplete, and I am forever grateful for your presence in my life.

# TABLE OF CONTENTS

ABSTRACT	I
LIST OF ABBREVIATIONS	II
ACKNOWLEDGEMENT	III
CHAPTER I: INTRODUCTION	1
1.1 Background	1
1.2 Disability in Nepal	3
1.2.1 Disability in data	4
1.2.2 The healthcare system of Nepal	5
1.2.3 Legal provisions to ensure the health rights of persons with disabilities	7
1.3 Objective and research questions of the study	9
1.4 Outline of the study	10
CHAPTER II: Literature Review and Theoretical Framework	11
2.1 Literature review	11
2.1.1 The Global perspective	12
2.1.2 Disability inclusion in high-income countries	13
2.1.3 Disability inclusion in low- and middle-income countries	15
2.1.4 Disability inclusion in Nepal	17
2.1.5 Summary	19
2.2 Theoretical Framework	20
2.2.1 Critical disability theory and its origin	21
2.2.2 Elements of critical disability theory	22
CHAPTER III: METHODOLOGY	26
3.1 Research design	26
3.2 Study area	27

3.3 Recruitment of the research team	28
3.4 Study participants	29
3.5 Data collection methods, tools, and techniques	31
3.6 Data management and analysis	33
3.7 Ethical considerations	36
3.8 Positioning and reflexivity	37
CHAPTER IV: FINDINGS	39
THEME I: Access to Health Services- Lived experiences and perceptions	39
4.1.1 Transportation challenges	39
4.1.2 Health infrastructures: Accessibility and inclusivity	42
4.1.3 Communication and information dissemination	46
4.1.4 Affordability	48
THEME II: Health Service Delivery- Perspective of the healthcare sector	51
4.2.1 Prioritization of persons with disabilities	52
4.2.2 Disability targeted health programs	54
4.2.3 Capacity of the health personnel	55
THEME III: Planning disability inclusive health services: The administrative level	57
4.3.1 The lack of disability-related data	57
4.3.2 Role of the Women and Child Welfare Division	58
4.3.3 PWDs' participation in the health planning	59
4.3.4 Disability inclusiveness in municipal policies	60
4.3.5 New government: New opportunities	64
Summary	65
CHAPTER V: DISCUSSION	66
5.1 Discussing some of the assumptions prior to the study	66

5.2 M	Iain findings and their implications	67
5.2	.1 The Administrative level: Federalism and its implications	67
5.2	.2 Accessibility challenges	69
5.2	.3 Health service provisions	72
5.3 L	imitations of the study	73
5.4 Tı	rustworthiness of the study	76
СНАРТ	ER VI: CONCLUSION	79
Ch	allenges in achieving disability inclusive healthcare at the local (municipal) level	79
Op	portunities to ensure disability inclusive healthcare at the local level	80
The	e current status of disability inclusivity in healthcare at the local level	81
Rec	commendation for future research	81
TABLE	S AND FIGURES	83
REFER	ENCES	91
APPEN	DIX	97
I.	NSD notification	97
II.	Approval from NHRC	98
III.	Informed Consent (English)	101
IV.	IV. Informed Consent (Nepali)	103
V.	Questionnaire guide for the interview with persons with disabilities (English)	108
VI.	Questionnaire guide for the interview with persons with disabilities (Nepali)	110
VII.	Questionnaire guide for the interview with Health Coordinators (English)	112
VIII.	Questionnaire guide for the interview with Health Coordinators (Nepali)	114
IX.	Observation guide	116

# LIST OF TABLES

Table 1: List of the participants with disabilities and their background	30
Table 2: Health facilities observed in the Sindhupalchok District	33
Table 3: Thematic analysis table	34
Table 4: Classification of Disabilities according to the problem and difficulty in any organ or	
system of the body, defined by the Government of Nepal (2017a).	83
Table 5: Prevalence and types of disability in Nepal according to Census 2021 (GoN, 2023)	84
Table 6: Type of health institutes/ facilities and the service provided at different local levels of	
government (GoN, 2017b)	85

# LIST OF FIGURES

Figure 1: Health System and services in Nepal (Public Health Update, 2020)	6
Figure 2: Administrative Map of Sindhupalchok (Nepal in Data, 2018)	27
Figure 3: Road connecting Helambu Rural Municipality and Melamchi Municipality	40
Figure 4: Toilet observed in a health facility in Melamchi Municipality	44
Figure 5: One of the six height adjustable beds of Chautara District Hospital	45
Figure 6: The information board at the registration area of Chautara District Hospital	49
Figure 7: Settlement at Melamchi Municipality	87
Figure 8: Location of one of the health posts observed during travel	87
Figure 9: Chautara District Hospital, Chautara Sangachokgadi Municipality	87
Figure 10: Helambu Health Centre, Helambu Rural Municipality	87
Figure 11: Nawalpur Primary Hospital, Indrawati Rural Municipality	88
Figure 12: Melamchi Municipality Hospital, Melamchi Municipality	88
Figure 13: OPD/ in-patient bed in Helambu Health Centre	88
Figure 14: Waiting area of Nawalpur Primary Hospital	88
Figure 15: Disability-friendly Toilet of Nawalpur Primary Hospital	89
Figure 16: A plastic chair modified to be used as a toilet seat	89
Figure 17: OPD/ in-patient bed in Helambu Health Centre	89
Figure 18: IEC corner at Chautara District Hospital	89
Figure 19: Website of Barhabise Municipality where the local laws, policies and information	on were
published	90
Figure 20: Website of Balephi Rural Municipality where the local laws, policies and info	rmation
were published.	90

#### **CHAPTER I: INTRODUCTION**

The focus of this research is disability inclusive local level healthcare services in Sindhupalchok District, Nepal. The primary objective of this study was to explore the existing status of disability inclusive policies and practices as well as the challenges and opportunities in ensuring disability inclusive health services at the local, municipal levels of government.

To provide a comprehensive understanding, the current chapter will begin with a brief overview of disability on a global scale as well as in the specific context of Nepal. Furthermore, the chapter will delve into the health needs of persons with disabilities and present the existing national and global provisions for disability inclusive healthcare. With a particular focus on Nepal, this chapter will provide detailed information about disability status, the country's health system and initiatives undertaken to ensure equitable healthcare access for people with disabilities.

#### 1.1 Background

The United Nations Convention on Rights of Persons with Disabilities (UNCRPD) describes persons with disabilities as individuals "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, p. 27).

It is estimated that 16% of the global population has a substantial disability, and this figure is anticipated to rise as life expectancy rises and noncommunicable diseases and accidents become more prevalent (WHO, 2023). Persons with disabilities are considered one of the most vulnerable groups of the population as they experience inequalities in various aspects of their life like in access to education, healthcare, and employment due to their disability. They are also subjected to violations of dignity (violence, abuse, disrespect, etc.) and are often denied autonomy (WHO, 2011).

According to the World Health Organization (WHO), people with disabilities in general experience a poorer level of health compared to people without disabilities. Their health needs vary widely depending upon their diverse range of primary health conditions. Besides, they are at heightened risk of developing secondary conditions like depression, developing co-morbid conditions and greater vulnerability to age-related conditions like Alzheimer's disease. They also have increased

rates of health risk behaviours including alcohol consumption and drug use. Additionally, persons with disabilities face a greater risk of unintentional injury (2011).

Despite having more healthcare needs, persons with disabilities are less likely to be able to meet them (UN, 2019). Misconceptions about their health often lead to the assumption that they do not require access to health promotion and disease prevention initiatives (WHO, 2011). Health prevention interventions such as immunizations, screening, and physical activities rarely target people with disabilities, regardless of the evidence demonstrating the benefits for this population. They are also often excluded from sex education programs (WHO, 2011), limiting their access to reproductive healthcare and contributing to a lack of awareness in this area (DFID, 2000). Access to oral healthcare is also limited for persons with disabilities and there is a huge treatment gap for addressing mental health problems like schizophrenia and anxiety disorders among the population (WHO, 2011).

The differences in health outcomes between persons with disabilities and those without disabilities are not always solely explained by their underlying health conditions or impairments (WHO, 2022). Even when people with disabilities seek healthcare, they encounter numerous challenges. They are three times more likely to be refused health care, four times more likely to face unfair treatment in the health care system and 50% more likely to suffer catastrophic health expenditure (WHO, 2021). According to the UN flagship report on disability, healthcare services for people with disabilities also included inaccessible buildings and diagnostic and treatment equipment, inaccessible public transport and roads, a lack of rural health facilities and communication gaps (UN, 2019).

**Disability inclusive healthcare** identifies and overcomes the barriers and allows persons with disabilities to enjoy the same healthcare rights experienced by those without disabilities (CDC, 2020). It is a strategy for creating an enabling environment to achieve the optimum degree of health and safety in society together with designing programs to prevent, treat and rehabilitate disabilities/ impairments (Miller & Albert, 2005).

Making health services inclusive not only benefits the people with an impairment but also can assist other vulnerable groups of people like the elderly, immigrants/ refugees, persons with non-communicable diseases and frequently unreached populations such as those with low socio-economic backgrounds, who share similar barriers to inclusion in healthcare (WHO, 2022).

Additionally, considering that almost everyone is likely to experience some form of disability, either temporary or permanent, at some point in their lives, implementing disability inclusive health services becomes crucial. This approach ensures that the health system meets the needs of every individual throughout their lifespan, making universal health care attainable (Corby & Bermejo, 2022).

Disability inclusion does not have to be complex or resource demanding, it can cut unnecessary costs (Corby & Bermejo, 2022). There are examples of how just with additional 3% cost can make a school latrine accessible and inclusive for all by helping several other groups like the elderly, and pregnant women (Enfield, 2018). The economic and social returns of disability inclusive health care are also notably higher. WHO argues that there could be a return of 10 USD per every USD spent on disability inclusive prevention and care for non-communicable diseases (WHO, 2022).

#### 1.2 Disability in Nepal

Nepal Government classifies disability into ten categories according to the impairment and difficulty in any organ or system of the body which includes physical disability, vision related disability, hearing related disability, deaf-blindness, speech and voice related disability, mental or psycho-social disability, intellectual disability, disability associated with haemophilia, autism related disability and multiple disability (2017a). A description of these disabilities is provided in Table 4.

Additionally, disability is categorized based on the severity and functional capabilities (GoN, 2017a):

- a. Profound disability: who has difficulty performing their day-to-day activities even with continuous support from others.
- b. Severe disability: who needs continuous support from others to perform personal and social activities.
- c. Moderate (Mid-level) disability: who can regularly participate in their daily activities and social activities if a physical facility is available, environmental barrier is ended or education or training is provided.
- d. Mild disability: who can regularly participate in their daily and social activities in the absence of physical and environmental barriers.

#### 1.2.1 Disability in data

According to the latest census report 2021 of Nepal, the national average percentage of people with disabilities in Nepal is only 2.2% with physical disability and disabilities related to vision being the most common types of disabilities (GoN, 2023). The details of disability prevalence as per their other types such as disabilities related to hearing and speech and psycho-social disability, are available in Table 5. However, these statistics are believed to result from underreporting and are expected to be much higher given the country's history of armed conflict, the earthquake of 2015, high rates of accidents and the increasing trend of the elderly population (Eide, Neupane, & Hem, 2016).

A considerable disparity in the prevalence rates of disability is observed across different studies in Nepal. In contrast to the national census, Nepal Demographic and Health Survey (NDHS) 2022 found that 29% of the total de facto population aged 5 or older have some kind of disability (MoHP, ERA, & ICF, 2022). On the other hand, some non-government organizations are found to use disability prevalence rates as low as 0.45% to as high as 8.99% in their studies (Eide et al., 2016). The data disparities can be attributed to the use of varying definitions or indicators of disability used in the surveys. The census survey questions if anyone in the family has a disability, and their responses produce the report. The interviewees of the census survey might or might not feel reluctant to identify themselves or their family members as having a disability due to the stigma attached to disability (Paudel, Dariang, Keeling, & Mehata, 2016). Whereas the NDHS used a more comprehensive framework based on the World Health Organization's International Classification of Functioning, Disability, and Health (MoHP et al., 2022) which may have contributed to the higher prevalence rate found in the survey.

Though no specific study has been carried out among persons with disabilities that gives us the actual data at the national level, many studies by disability experts have suggested lower living standards among persons with disabilities in Nepal (BYAN, 2015). Households of people with disabilities are often poorer than households without disabilities. Persons with disabilities are also less likely to achieve higher levels of education and often struggle to find paid employment (Rohwerder, 2020).

In Nepal, persons with disabilities are frequently excluded from health services due to the physical, attitudinal, and institutional barriers that have resulted in increased inequality, prejudice, and marginalization in their health (GoN, 2019b). Also, with limited access to comprehensive health and rehabilitation services, persons with disabilities generally have more health needs than persons without disabilities (Rohwerder, 2020).

#### 1.2.2 The healthcare system of Nepal

Historically, Nepal's health system has been highly centralized with the Ministry of Health and Population (MoHP) making crucial decisions that were implemented through the pyramidal structure of the health system via Regional Health Directorates and District Health Offices (Thapa, Bam, Tiwari, Sinha, & Dahal, 2019). However, in the transition of Nepal's governance from a unitary government to a central government, seven provincial governments, and 753 local governments in 2015, more authority have been granted to the local governments for planning and managing their respective areas (Padam Prasad & Sharada Prasad, 2021). The local government units include urban municipalities, rural municipalities, metropolitan cities and sub metropolitan cities which are further divided into wards (Acharya, 2018).

The constitution has transferred the primary responsibility for delivering health services to the provincial governments, resulting in a shift towards a more decentralized structure. The Ministry of Health and Population manages the health system at the federal level, the Ministry of Social Development leads at the provincial level, and local governments at the metro/sub-metropolitan, municipality, and rural municipality levels are responsible for managing the health system and services (Padam Prasad & Sharada Prasad, 2021).

#### Health services at the local level of government

Nepal Health Infrastructure Development standards developed in 2017 classify health institutions into five levels based on a minimum set of health services. These levels includes: 1) Health Posts or Community Health Units at the community level 2) Primary Hospitals at the municipality level, 3) Secondary Hospitals and health Sciences Academy at the provincial level, 4) Tertiary Hospitals and 5) Academic or Super-specialty hospitals at a federal level (GoN, 2017b). These health facilities are organized across various tiers of government. To achieve universal health coverage, the provision of general health services usually falls upon the health posts and municipal hospitals at the local level. The detail of such organizational structure is illustrated the following.

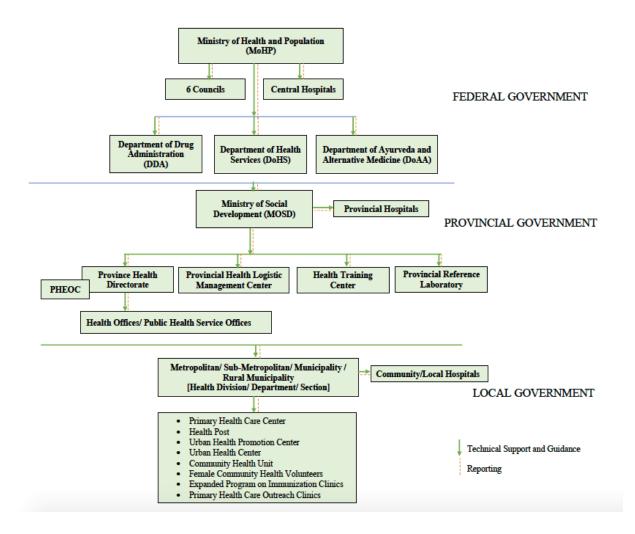


Figure 1: Health System and services in Nepal (Public Health Update, 2020)

Furthermore, the availability of health services at the local level is based on their structure. At the Ward level of rural or urban municipalities, health posts and community health units provide services such as immunization, family planning, maternal and child health services, treatment of communicable diseases, basic mental health services, primary treatment of non-communicable diseases and a few of the pathology and lab diagnostic services (GoN, 2017b).

The rural municipalities also have services provision of a primary hospital that offers common gynecological and obstetric services, outpatient department (OPD) services, comprehensive emergency obstetric and neonatal care (CEONC), basic surgery services, the primary treatment for eye/sight and dental problems and 24-hour emergency services, in addition to the basic health services (GoN, 2017b).

The wards of the metropolitan city and sub-metropolitan city offer services through their urban health promotion centers. These health facilities provide additional services related to immunization, family planning, nutrition counselling, promotion, prevention and primary treatment of non-communicable diseases, adolescent reproductive and sexual health services, psychosocial counselling, geriatric counselling, and health inspection services (GoN, 2017b). In municipalities or sub-metropolitan/metropolitan cities, primary hospitals provides health services similar to the primary hospitals of rural municipalities, along with specialized and major

# Disability inclusion in Nepal's health system: a twin-track approach

Nepal's health system acknowledges the need for disability inclusive health services and defines disability inclusive health services as "ensuring that the people with disabilities have the same rights, participation and inclusion in health services as the general population" (GoN, 2019b).

surgery services including orthopedic surgeries (see Table 7 for more information) (GoN, 2017b).

Nepal has applied a twin-track approach to achieve disability inclusion in the health sector. The first track involves ensuring that all programs and services are inclusive and accessible to persons with disabilities. This track automatically ensures that the general health services and programs are designed to meet the needs of persons with disabilities, without the need for separate or specialized services. The second track involves providing targeted disability-specific healthcare support to persons with disabilities which meets the unique needs of persons with disabilities (GoN, 2019b).

The twin-track approach has the underlying principles of non-discrimination, awareness of disability and its implication, active participation of persons with disabilities, comprehensive accessibility addressing attitudinal, structural, communication and institutional barriers, empowerment of persons with disabilities and gender equality in health services (GoN, 2019b).

## 1.2.3 Legal provisions to ensure the health rights of persons with disabilities

Nepal has made significant progress in ensuring an inclusive healthcare system through various legal provisions and policies. Though some of these legal frameworks were introduced in the 1900s, substantial changes have occurred after the ratification of UNCRPD.

Nepal ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) on 27 December 2009 and the constitution of Nepal, adopted in 2015 has established provisions

for the health rights of individuals with disabilities in line with the UNCRPD (UN, 2015). The constitution of Nepal ensures every citizen's right to seek basic health services and emergency healthcare along with their right to information about their medical treatment.<sup>1</sup>

Based on international frameworks like the UNCRPD and the Sustainable Development Goals (SDGs), 2030 and the Constitution of Nepal, several other legal initiatives and policies were introduced in the country to promote disability inclusion and remove barriers to accessing health services (UN, 2019). The National Health Policy 2019 <sup>2</sup> and the Public Health Service Act 2018 <sup>3</sup> are notable initiatives that acknowledge the difficulty of achieving equitable access to healthcare and providing priority services to vulnerable and ultra-poor individuals. These policies further emphasize on creating and enhancing a healthcare system that serves all citizens within a federal structure, founded on principles of social justice and good governance while ensuring that quality health services are accessible and utilized (MoHP, 2019).

Additionally, the Act Relating to the Rights of Persons with Disabilities 2017 <sup>4</sup> is the strongest and most widely used guiding principle in Nepal. The Act mandates that treatment for people with disabilities be provided in an environment that is accommodating to their needs (GoN, 2017a). Nepal has also implemented the Gender Equality and Social Inclusion (GESI) Strategy of the Health sector 2018 <sup>5</sup>, the National Strategy for Reaching the Unreached 2016-2030 <sup>6</sup> and the Disability Management Policy, Strategy, and 10 Years Action Plan (2015-2025) <sup>7</sup>.

Most importantly the National Guidelines for Disability Inclusive Health Services 2019 <sup>8</sup> serves as a crucial tool for the service providers and guides them in mainstreaming disability inclusion in health service delivery while operationalizing the responsibilities of healthcare providers. The guideline has introduced a progressive phased approach of the timeframe 2019-2030, focusing on capacity building, inclusive primary healthcare, disability inclusion in secondary and tertiary care

<sup>&</sup>lt;sup>1</sup> https://lawcommission.gov.np/en/wp-content/uploads/2021/01/Constitution-of-Nepal.pdf

<sup>&</sup>lt;sup>2</sup> https://publichealthupdate.com/national-health-policy-2019-nepal/

<sup>&</sup>lt;sup>3</sup> https://lawcommission.gov.np/en/wp-content/uploads/2019/07/The-Public-Health-Service-Act-2075-2018.pdf

<sup>&</sup>lt;sup>4</sup> https://lawcommission.gov.np/en/wp-content/uploads/2019/07/The-Act-Relating-to-Rights-of-Persons-with-Disabilities-2074-2017.pdf

<sup>&</sup>lt;sup>5</sup>https://nepalindata.com/media/resources/items/0/bGENDER\_EQUALITY\_AND\_SOCIAL\_INCLUSION\_STRAT\_EGY\_OF\_THE\_HEALTH\_SECTOR\_2018.pdf

<sup>6</sup> https://nepalindata.com/resource/pdf/National-Strategy-for-Reaching-the-Unreached-2016-2030/

https://www.edcd.gov.np/resource-detail/policy-strategy-and-10-years-action-plan-on-disability-management

<sup>&</sup>lt;sup>8</sup> https://www.nhssp.org.np/Resources/GESI/National Guidelines Disability Inclusive Health Services2019.pdf

also including disability-specific specialist services and scaling up actions within the health system (GoN, 2019b).

There are also other supportive initiatives of the government to increase access to health services among people with disabilities. One such is the national health insurance program <sup>9</sup> which covers the contribution fees for people with disabilities and their family members (DoHS, 2020). Moreover, a commitment to disability inclusion is evident in the country's plans. The current 15th five-year development plan (2019/20- 2023/24)<sup>10</sup> emphasizes the provision of free health services for universal access and also focuses on community-based rehabilitation programs at all levels and creating gender, elderly, and disabled-friendly health services (GoN, 2019a). The policy, program, and budget for the fiscal year 2022/23<sup>11</sup> also prioritized free treatment for persons with spinal paralysis, intellectual disability, autism, hemophilia, and profound disability. The government has stressed the establishment of rehabilitation centers with health services for persons with complete disabilities. The government also has allocated a budget to make public physical structures, infrastructures, and means of transportation disability-friendly (MoF, 2022).

#### 1.3 Objective and research questions of the study

The overall objective of the current research is to contribute to the understanding of the status of disability inclusiveness within the health system at the local (municipal) level of government in Nepal, specifically by combining the perspectives of persons with disabilities and of the health coordinators who manage the health services. The study addresses the following research questions:

- a. To what extent are the general health services at the local level of government inclusive of persons with disabilities?
- b. What are the challenges encountered in the process of making health services inclusive for persons with disabilities?
- c. What opportunities exist for the development and improvement of disability inclusive health services at the local level?

<sup>&</sup>lt;sup>9</sup> https://hib.gov.np/public/uploads/shares/health insurance 2071 policy.pdf

<sup>10</sup> https://www.npc.gov.np/images/category/15th plan English Version.pdf

<sup>11</sup> https://www.mof.gov.np/uploads/document/file/1656476715 Budget%20Translation%20031379%20cv.pdf

#### 1.4 Outline of the study

The next chapter, Chapter II, presents a literature review and theoretical framework of the study. The chapter includes research related to disability, healthcare systems and services and access and challenges encountered by persons with disabilities. Additionally, the chapter includes a presentation and discussion of the theory that I found helpful to prepare and conduct this study, whereof the critical disability theory and its elements. I will use this theory to understand the availability of disability inclusive health services from the perspective of persons with disabilities on the one hand and health coordinators, who are managers of the health services at the local level.

In Chapter III, I discuss the methodology and methods I used to carry out this study. This section has a rationale of the methods, the context of the fieldwork, and a description of data collection methods followed by ethical considerations. It also includes the conceptual framework for the study and details on how data has been analyzed.

In Chapter IV, I present the findings based on the qualitative data collected to answer the research questions. These findings are presented according to the three main themes.

Chapter V consists of a discussion where the findings are interpreted in accordance with my initial assumption, relevant studies conducted before, the critical disability theory, and the trustworthiness of the study along with the study's limitations.

The last chapter, Chapter VI concludes the study by summarizing major findings and providing a summary of the answers to the research questions.

#### **CHAPTER II: Literature Review and Theoretical Framework**

To ensure that the study is well-informed, contextually relevant and addresses pressing issues in disability inclusive healthcare, this chapter provides a comprehensive review of relevant literature and the adaptation of critical disability theory as a theoretical framework for the study.

The literature review will give a brief of available studies and their findings to highlight the existing gaps in knowledge, challenges, and opportunities in the areas of disability studies, particularly in relation to healthcare access. Whereas, employing the theoretical framework of critical disability theory, the study aims to ensure a critical perspective to analyze power dynamics, social inequalities and structural barriers affecting persons with disabilities' access to healthcare.

#### 2.1 Literature review

The majority of the studies reviewed in this chapter have explored the barriers and challenges to healthcare access among people with disabilities. Many of these studies have focused on specific types of disability and specific health issues within the context of healthcare access. Though this chapter intended to primarily review literature that are related to the challenges and opportunities in ensuring disability inclusive general or primary healthcare services, the limited availability of such research, especially within the context of Nepal, has necessitated the inclusion of studies that have focused on a specific type of disability and/or specific health services, something that in fact shows the complexity and variety of potential problems and situations persons with any type of disability need to overcome.

To conduct my literature review I employed a systematic search strategy using various sources. Initially, I performed a search on Google and Google Scholar using keywords such as disability, inclusion, disability friendly, healthcare, Nepal, mainstreaming, community healthcare, primary healthcare, local level, government, access, barriers, policies, opportunities, and challenges, disability studies, theories, and critical theory. I used the keywords both individually and in combination to ensure a comprehensive search. The searches provided a general overview of the topic and recent insights. Additionally, I explored the resources found on the webpages of global organizations such as the World Health Organization (WHO), Centers for Disease Control and Prevention (CDC), and the official websites of the Nepal Government to gather statistical and contextual information.

For a more targeted search, I used specialized databases like Oria, and databases related to social and health sciences like Taylor & Francis, PubMed, and ProQuest to get similar literature with the exact keywords. My literature review mostly includes research articles, systematic reviews and meta-analyses conducted after the year 2000.

#### 2.1.1 The Global perspective

To understand the global scenario for disability inclusiveness in healthcare and persons with disabilities' access to healthcare, I found that numerous systematic reviews were carried out, encompassing studies from both high-income and low-middle-income countries.

One such study, conducted by Dassah, Aldersey, McColl, and Davison (2018), synthesized 36 published literature that explored the factors affecting access to public healthcare (PHC) for persons with disabilities in rural areas globally. The review indicated that the limited availability of healthcare facilities and services, perceived low quality of care, geographic barriers, and affordability were the major obstacles preventing people with disabilities from accessing services. It further emphasized the need for health policies that consider all the dimensions and their interactions in addressing rural health problems. Additionally, it also emphasized the necessity of in-service training to enhance the communication skills of healthcare providers when interacting with people with disabilities.

Specifying the healthcare access to people with hearing disabilities, a literature review was carried out by Kuenburg et al. (2015) which included peer-reviewed journals from 2000 to 2015. The review found that a significant communication barrier between the healthcare providers and individuals who are deaf along with a substantial deficit in health knowledge and literacy across various deaf communities worldwide led to unmet health needs of the population with hearing disabilities globally. The literature indicated that individuals with hearing impairments generally prefer communication in sign language, either with trained sign language professionals or skilled sign language interpreters.

In addition, an article by Briggs et al. (2020) highlighted the opportunities and challenges of global health policy to arrest the global disability burden from musculoskeletal health conditions in the 21st century. According to the article, various policies, and international commitments such as the WHO Rehabilitation 2030 Agenda, the Sustainable Development Agenda and the global focus on Universal Health Coverage have the potential to improve access to healthcare and support

inclusion of persons with disabilities. The review further emphasized the need for effective implementation of such policies, continuous monitoring, and regular assessments of the broad policies into meaningful actions to achieve the objective of global inclusion of persons with disabilities.

Furthermore, the article "Global Disability: an emerging issue" (Groce, 2018) also highlighted the shift in improving assistive technology with an emphasis on universal design and international commitments as the opportunities for disability inclusion while restricted access to education and employment pertains to be the major challenges. The article further stressed that the broadly defined policies should be translated into effective implementation with regular monitoring and assessments, to make the global inclusion of persons with disabilities a success.

#### 2.1.2 Disability inclusion in high-income countries

Disability inclusion has been a prominent focus in many high-income countries and its significance has been well recognized. In the United Kingdom, Sakellariou and Rotarou (2017) observed that long waiting lists or distance, transportation problems and financial constraints were the most common self-reported factors for unmet healthcare among people with disabilities. The study compared the findings between 1284 sampled people without disabilities and 5236 people with disabilities. People with severe disabilities were found 4.5 times more likely to have unmet needs due to the cost of prescribed medicine and people with mild disability had 3.6 higher odds of facing difficulty. Additionally, women with disabilities were found 7.2 times more likely to have unmet needs due to cost, compared to men with disabilities.

In the United States (US) a qualitative study by Kroll, Jones, Kehn and Neri (2006), shed light on the barriers faced by people with physical disabilities in utilizing primary preventive services. Structural barriers such as diagnostic equipment, provider's office and insurance coverage and process barriers such as provider's knowledge and skill set, procedural accommodation, professional flexibility, and courtesy, were identified by the scholars from the five focus group discussions. Additionally, recommendations such as increasing access to facilities, equipment and procedures, improving provider disability literacy and communication, utilization of internet resources and planning for assistance needs during appointments were drawn from the study participants (Kroll et al., 2006).

Similarly, phased research in Canada explored the perceptions of primary healthcare services among people with physical disabilities through an anonymous self-report questionnaire responded to by 201 members of several disability organizations and persons with disabilities. The study revealed that 19.4% of them perceived receiving inadequate primary healthcare and 21.9% believed that there was a barrier to receiving healthcare. Though 82.1% were satisfied with the services they received, 17.4% of them reported having difficulty in obtaining services and 8% of them were refused medical treatment due to their disability (Veltman, Stewart, Tardif, & Branigan, 2001).

In the context of persons with visual disabilities, a Polish study was carried out to understand the expectations of people with visual impairment towards primary healthcare (Binder-Olibrowska, Godycki-Ćwirko, & Wrzesińska, 2022). The mixed method study was carried out among 219 persons with visual impairment, and it was observed that they have higher expectations in all dimensions of care than the general population such as in terms of equity and accessibility. The study highlighted the need for psychosocial competencies of staff, accessible clinics, adequate help to their personal needs and disability-friendly medical procedures, dignified treatment, and direct communication for quality healthcare.

Additionally, a noticeable number of studies were found carried out to draw recommendations for disability inclusive healthcare from the relevant stakeholders. One study in the US (McClintock et al., 2018) explored patient and healthcare provider recommendations to improve healthcare access and quality for people with disabilities. The focus group discussions with people with and without disabilities, and healthcare providers identified common recommendations such as promoting advocacy, increasing awareness and knowledge, improving communication, addressing assumptions, as well as modifying and creating policy. The study also emphasized the need for greater political engagement for quality health services.

Another study in the US by Bowers, Esmond, Lutz, & Jacobson (2003) found that persons with disabilities perceives that the service providers need to have three distinct but interrelated expertise: medical/technical, medical/ biographical and systems expertise for quality care. According to this expertise, service providers should have expertise in medical skills and knowledge about health and illness in the context of disabling conditions, familiarity with available technology for them, knowledge about the intersection of illness and disability in the person's life

and knowledge related to accessing, using and managing service systems. Moreover, the study suggests that expertise is developed through collaborative, reciprocal interactions between providers and patients over time (Bowers et al., 2003).

#### 2.1.3 Disability inclusion in low- and middle-income countries

This section of the literature review draws from various studies including systematic reviews and qualitative and quantitative investigations carried out in the low-income countries of mostly Asia and Africa to understand the barriers to accessing healthcare services among persons with disabilities.

A meta-synthesis of 41 qualitative studies carried out by Hashemi, Wickenden, Bright, & Kuper (2022) discusses the barriers to primary healthcare services experienced by adults with disabilities in low- and middle-income countries. The review generated three broad analytical themes: Cultural beliefs or attitudinal barriers, informational barriers, and practical or logistical barriers. The stigma and direct and indirect experiences of discrimination were found shaped by the social, cultural and community attitudes to impact the ability to perceive and seek healthcare from the demand side. Additionally, the information barriers such as lack of insight, awareness and understanding of the health issues related to impairment and experience of disability and inadequate resources such as transportation, availability of ramps, sign language interpreters, financial support, adequate health staff and medicines were found to play an important role in the utilization of primary healthcare services. The review concluded that these barriers are interrelated and impact one another in a dynamic and complex way. Thus, consideration of both the barriers faced by people with disabilities and their combined effect was recommended for full health coverage.

Likewise, a systematic review conducted by Bright and Kuper (2018) studied access to general health services for people with disabilities in low- and middle-income countries. The review included 50 studies which found that utilization of health services and healthcare expenditures were higher among people with disabilities compared to people without disabilities. The most common barriers people with disabilities found in the studies reviewed were transport difficulties, financial difficulties, and attitudes of the staff. However, the researcher also mentioned that varied ways of measuring and understanding disability across nations made it difficult to get a clear understanding of access outcomes. The review proposed developing a common measurement system for disability and healthcare access that can help have quality and comparable data.

Studies focusing on specific regions such as in the research among the 9307 individuals of four African countries: Sudan, Namibia, Malawi, and South Africa (Arne H Eide, Leslie Swartz, & Dyrstad, 2015) acknowledged the lack of transport, availability of services, scarce drugs or equipment and costs as four main barriers to healthcare access. These perceived barriers were further found to be affected by the level of urbanity, socio-economic status, and severity of activity limitations.

Furthermore, another literature review related to access was conducted by Casebolt (2020) to study the access to reproductive health services for women with disabilities in low- and middle-income countries. The review included 16 articles from eleven countries in Africa and Asia. The key barriers identified by the review were: negative attitudes of providers and society, lack of trained providers, assumptions and inadequate knowledge amongst providers, communication limitations, inaccessible facilities, lack of transportation, high costs of care and unnecessary referrals. The study identified the need for inclusive policies and training among health professionals regarding disability.

Mji et al. (2017) conducted a qualitative study using case studies from four settings to elucidate challenges experienced by people and their families with activity limitations. The authors found that access and equity to health services were influenced by several interconnected factors in a particular setting such as poverty, transportation, and education. The authors recommended the provision of a coordinated public transport system, training of health professionals in sign language and a focus on community level services such as community-based rehabilitation. At the system level, for inclusive public health services, the study found the need to clear referral pathways, development of innovative models to link private health care and a broad PHC strategy that addresses social problems (Mji et al., 2017).

Harrison et al. (2020) conducted a qualitative study in rural Malawi recruiting 12 people with disabilities. The study found three main barriers to timely and adequate health i) cost of transport, drugs, and services, ii) Insufficient healthcare resources and iii) dependence on others. Access to health services was found affected by the interconnected financial, practical, and social barriers. It was thus recommended to implement a multi-dimensional approach that facilitates integrated interventions (Harrison et al., 2020).

There were limited studies that explored the existing situation of disability inclusive or disability-friendly health facilities. Scholars from Brazil (Pinto, Köptcke, David, & Kuper, 2021) and Southern India (Nischith, Bhargava, & Akshaya, 2018) revealed inadequacies in the physical accessibilities in terms of space, accessibility features, toilets and examination tables in the health facilities whereas, the wheelchair accessibility was found comparatively higher. Another mixed method study carried out in Bangladesh (Torsha et al., 2022) revealed that the lack of disability-friendly infrastructures and communication were significant barriers in accessing public health services.

#### 2.1.4 Disability inclusion in Nepal

Research related to disability studies have only recently started getting national attention in Nepal, particularly in the sector of education. Nonetheless, a considerable number of studies have explored the barriers among persons with disabilities in healthcare access.

One noteworthy study by Van Hees et al. (2015) investigated the perceived barriers to accessing primary healthcare services by persons with disabilities in the Western region of Nepal. Based on semi-structured interviews conducted with 10 healthcare providers and 11 persons with disabilities, the study identified several environmental, financial, and personal barriers that affect access to healthcare. These included transportation barriers, family and community attitudes, lack of funds for health expenses, low self-esteem of the person with a disability, and poor public awareness of the needs of persons with disabilities. The study concluded that primary healthcare providers need to be educated about disability-related health conditions and trained to diminish barriers to accessing health services.

Moreover, research in Nepal has mainly focused on women with disabilities and their sexual and reproductive health. For instance, the mixed method study by Hridaya Raj Devkota, Murray, Kett, and Groce (2018), carried out in the Rupandehi district found that women with disabilities have lower utilization of antenatal care, health facility delivery, and postnatal care services compared to women without disabilities. Household indicators relating to education, wealth, and family circumstances were identified as the main determinants of service utilization for women with disabilities. The study also explored a range of barriers to access, including personal, sociocultural, and policy/systemic factors, with women with disabilities facing additional barriers related to physical, attitudinal, socio-cultural, and policy-related issues. The study highlighted the

negative attitudes of both society and healthcare providers towards disability, with the healthcare needs of this population being invisible at the policy level. The study pointed out the need for equity-focused policy development and adopting holistic approaches, including multi-sectoral interventions, to increase access and utilization of maternal healthcare services across the population.

Similar to the findings of the Rupandehi district (2018), another mixed-method study by Shiwakoti et al. (2021) found that factors such as illiteracy, poor socioeconomic status, and lack of information hindered the utilization of sexual and reproductive health services among women with disabilities in the Illam district. They also were found facing barriers such as lack of empowerment and family support, distant health facilities, inaccessible infrastructure, stigmatization, negative attitudes from healthcare providers, and the perception that sexual and reproductive health (SRH) services were only needed for married women. Moreover, the study revealed that the nearest health facility was not disability inclusive, with inaccessible roads being the major barrier. These findings highlight the need for awareness-raising programs, sensitization programs for healthcare providers, and disability inclusive SRH services to address these barriers and promote access to SRH services for women with disabilities.

Since external development partners are active actors in development in Nepal, many non-government organizations are working to increase people with disabilities' access to health services. There are many articles published by such organizations that highlight their activities and progress in the field. One of them relevant to this context was written by Kelli Rogers (2023). In the article "Disability inclusive healthcare has mountains to climb", Rogers bought to the attention that the lack of rehabilitation centers combined with the existing geographical, financial, and personal barriers, people with disabilities in rural areas are prohibited from getting the care required. The author also sheds light on the impact of natural disasters like floods during monsoons which is a very prominent challenge in most parts of the country.

Though an immense gap in the access and utilization of health services among people with disabilities is evident in Nepal, it cannot be attributed to the lack of inclusive policies. As also discussed in Chapter I, there are many plans, policies and guidelines developed for the inclusion of people with disabilities in the health systems of Nepal. The gap implies poor implementation of these policies.

Ramesh Baral (2018) did a "Historical Policy Review on Disability" which focused on history and policy-led aspects of disability in Nepal. Baral analyzed the policies from 1981 and found that Nepal has sufficient policies regarding people with disabilities. However, the lack of good governance, accountability and transparency contributed to the poor implementation of these policies. The scholar also observed that people with severe disability are excluded from opportunities like education and their households have lower living standards compared to those without disabilities. The study emphasized the need for research conducted in Nepal that provides evidence of the impact of inclusion of individuals with disabilities in policies and practices and from the governance perspective.

Additionally, since Nepal has a new government system, there are ongoing discussions on prioritization within healthcare. The article "Health System Strengthening: The Role of Public Health in Federal Nepal" (Sapkota et al., 2022) discussed the impact of political and administrative changes on the healthcare system in Nepal, specifically the decentralization of power and resources to the local level. It highlighted the opportunities and challenges presented by these changes, including the potential for greater local control over health services and better responsiveness to local health needs. However, the article also noted that resource constraints and inequalities in healthcare access and outcomes pose significant challenges.

#### 2.1.5 Summary

The studies conducted around the world and in Nepal show similarities in terms of barriers that people with disabilities face accessing primary healthcare. Though the intensity of these barriers may differ between high-and low-income countries, the fundamental obstacles remain similar.

The literature reviewed highlights common barriers to accessing healthcare for people with disabilities globally such as transportation difficulties, communication challenges, financial constraints, inadequate physical infrastructures, and a lack of healthcare workers trained in disability-related issues. These barriers are further compounded by factors such as disability type and severity and socio-economic status of the persons with disabilities and their households.

The findings from the literature reviews suggest that the research related to disability inclusion in healthcare has gained increasing attention since the adoption of UNCRPD in 2006. Nonetheless, finding evidence-based studies that provide an understanding of the progress in ensuring healthcare that is disability inclusive as well as studies that evaluate the impact of such services

was challenging. This could be attributed to the fact that many countries are still in the early stages of implementing their policies and guidelines for disability inclusive healthcare.

In addition, and of relevance to the specific national context, there is not enough evidence available that provides insights into how the transition to the federal government has affected disability inclusion in the healthcare system of Nepal. The current study provides an overview of how disability inclusive the local level healthcare system is and what opportunities and challenges federalism holds for the inclusion of the health needs of people with disabilities at the local level of government.

#### 2.2 Theoretical Framework

The oldest model used to understand disability was the moral and/or religious model which says that it is the punishment from God for sins committed by the person with a disability or by their parents and ancestors (Retief & Letšosa, 2018a). The medical model in the mid-1800s replaced the religious model and explained disability as a defect in the human body or a medical problem and the solution was to either cure or improve their condition to the optimum possibility and rehabilitation (Retief & Letšosa, 2018a).

There are a few other models of disability like i) the charity model which presents disability as victimhood and ii) the economic model according to which disability is a productivity challenge (Retief & Letšosa, 2018a). To some extent, all these theories present the person with a disability as a problem.

On the other hand, the social model defines disability as a socially constructed phenomenon that is a result of the interaction between an individual and an environment that fails to accommodate the individual's needs (Retief & Letšosa, 2018a). The social model argues that disability is the result of impediments within an oppressive and discriminatory society rather than impairment (Jackson, 2018).

The human rights model of disability is another concept similar to the social model of disability. Although some researchers use the terms "social model" and "human rights model" interchangeably, the human rights model emphasizes the human dignity of people with disabilities (Jackson, 2018). The right-based model acknowledges the entitlement of persons with disabilities to equal participation and opportunities in society (UNHCR, 2023).

As KC (2016) has argued, the mere use of a social or medical or human rights approach is not sufficient to provide a comprehensive understanding of the complexities in Global South countries like Nepal where people with disabilities often face challenges in meeting even their most basic survival needs. In this context, the critical disability theory emerges as a promising and appropriate theory that delves into the structural and societal aspects of disability and provides a comprehensive understanding of the real-life experiences of persons with disabilities in these regions. Additionally, Kuper et al. (2021) have advocated for the use of a participatory approach in disability studies in low- and middle-income countries (LMIC) like Nepal should incorporate the voice of persons with disabilities, as proposed by critical disability theory.

Many disability related studies in Nepal were carried out from a human rights perspective and the framework of the social model of disability. Using in addition, critical disability theory, this research aims to contribute to the promotion of disability inclusiveness and the enhancement of healthcare services in Nepal, by shedding light on the underlying power dynamics and ideologies.

#### 2.2.1 Critical disability theory and its origin

The critical disability theory draws on the foundation of critical theory, introduced by Max Horkheimer in 1937 from the Frankfurt School's Institute for Social Research. As an opposition to the traditional theories (Hall & Zalta, 2019; Hosking, 2008) that are based on a positivist approach and strictly divide inquiry and normative evaluation, critical disability theory aims to uncover the hidden beliefs and values that hinder individuals from having a full understanding of the world and critique these assumptions that lead to a distorted perception of reality, known as "false consciousness" (Nickerson, 2022). The ultimate goal of critical disability theory is to create a more democratic and equitable society for all people (Hosking, 2008).

Critical disability theory argues that the issues of people with disabilities are a result of an unequal society (Oliver, 1998) and incorporates elements of critical social theory, disability rights activism, and disability studies to analyze the systemic oppression of people with disabilities (Arstein-Kerslake & Black, 2020). The theory aims to provide a fresh perspective on disability that incorporates the experiences and needs of people with disabilities and recognizes their full citizenship and entitlement to equal rights and opportunities (Devlin & Pothier, 2006, pp. 1-2).

#### 2.2.2 Elements of critical disability theory

In a paper presented at the 4th Biennial Disability Studies Conference at Lancaster University, Hosking (2008) discusses the critical disability theory based on the seven elements which are:

#### a. The social model of disability

The critical disability theory adopts the social model of disability, which posits that the disadvantages faced by people with disabilities are not due to their impairments but rather to a social environment that fails to accommodate their needs and reinforces societal expectations of "normalcy" (Faeth, 2021; Hosking, 2008).

The social model shifts the responsibility and accountability to the society which is the first step towards inclusion (Devlin & Pothier, 2006). One example of the social model's perspective is the issue with public transportation. The problem here is not that some people can't walk, but rather that the busses are not equipped to accommodate wheelchairs. The solution to this problem lies in social and financial investments, not only in surgical procedures, assistive technology, or rehabilitation (Oliver, 1998).

Hosking argues that policymakers must address both the biomedical and social aspects of disability through prevention, treatment, and rehabilitation, as well as changing the social environment for those who face marginalization despite medical interventions (Hosking, 2008). Critical disability theory acknowledges the tension that arises between the medical model's goal to eliminate impairments and the social model's aim to value individuals with disabilities as equal members of society. The theory investigates this tension by examining concepts such as independence and interdependence, the social construction of disability and non-disability, normalcy, personal dignity, and the intersection of disability with other socially constructed categories such as class, gender, race, ethnicity, and sexual orientation (Hosking, 2008).

#### b. Multidimensionality

With the element "multidimensionality, Hosking refers to the multiple facets of disability that need to be addressed and understood (Hosking, 2008). People with disabilities are found in all social structures and classifications and cannot be classified into one single category (Sztobryn-Giercuszkiewicz, 2017).

Critical disability theory views disability as a complex phenomenon shaped by a variety of interrelated factors, including social, cultural, political, and economic systems (Hosking,

2008). It, therefore, conceptualizes the experiences of people with disabilities through a holistic lens that takes into account multiple dimensions of oppression and disadvantage (Hosking, 2008).

This multidimensional approach to understanding disability allows the theory firstly to avoid the exclusion and conformity issues that are prevalent in public policies that oversimply disability, and secondly, to emphasize the diversity and variability of people with disabilities (Hosking, 2008; Sztobryn-Giercuszkiewicz, 2017).

#### c. Valuing diversity

The critical disability theory is heavily influenced by Critical Race Theory, which postulates that disability should be given equal visibility as race, class, and gender to be considered a public issue (Rocco, 2005). The theory critiques the application of liberal values and principles to people with disabilities as liberalism is based on the principle of political and legal equality, and it treats everyone the same despite their differences in race, ethnicity, gender, or sexual orientation. This approach suppresses diversity and requires claimants to resemble the comparator. With disability, such an approach is not always effective, as it fails to acknowledge and accommodate the unique needs and challenges faced by people with disabilities (Hosking, 2008).

Critical disability theory advocates for the integration of diversity within the framework of equality, to better address the unique challenges faced by individuals with disabilities and pursue solutions to achieve their full participation (Devlin & Pothier, 2006; Hosking, 2008).

#### d. An approach based on rights

Critical disability theory challenges traditional ideas and beliefs about disability that often lead to oppression and restrict the basic human rights of people with disabilities (Devlin & Pothier, 2006). The theory acknowledges the existence of a tension between the social welfare and rights-based approaches to disability policy but does not reject the concept of liberal rights. Instead, the theory exposes the limitations of liberal rights theory in adequately addressing the diverse needs and interests of people with disabilities (Hosking, 2008).

The right-based approach to disability has no doubt reduced the civic inequalities among people with and without disabilities (Devlin & Pothier, 2006). However, the Convention on the Rights of Persons with Disabilities (CRPD) which is an example of a right-based approach

been criticized for framing disability in a way that can risk inclusive marginalization (Grue, 2019). Grue further stresses that although CRPD imposes various obligations on both individuals and systems, it does not fully address the need for a comprehensive framework that seeks to capture the complexity and diversity of experiences for understanding disability, which is essential for achieving such systemic change (Grue, 2019).

#### e. Voices of disability

Critical disability theory emphasizes the need to address the imbalance of power between individuals with and without disabilities, and to work towards giving those with disabilities more control and agency in their own lives (Devlin & Pothier, 2006). The theory comes from the real-life experiences of people with disabilities, instead of being solely developed by experts in an isolated academic setting. It is a bottom-up approach, taking into account the perspectives of those affected (Devlin & Pothier, 2006).

Critical disability theory argues that only by listening to and valuing the stories of people with disabilities society can gain a deeper understanding of their experiences (Hosking, 2008). The theory aims to give voice to marginalized groups and challenge dominant societal perspectives (Hosking, 2008).

### f. Language

Critical disability theory advocates for a language that recognizes and respects the diversity of people and challenges the language that perpetuates negative attitudes and reinforces harmful stereotypes (Hosking, 2008).

Hosking has emphasized how language, or the choice of words can influence the concept of disability. For instance, it is argued that the term "disable" was initiated to deficit inability or impotence. Similarly, a disabled person or handicapped implies that the entire person is disabled because of an impairment and the least problematic term "person with disability" with the concept of "person first" has been suggested (Devlin & Pothier, 2006).

#### g. Transformative politics

Critical disability theory believes that disability is equally an issue of social values, institutional priorities and political will (Devlin & Pothier, 2006). The theory challenges and transforms prevailing attitudes and beliefs about disability and creates more inclusive and equitable social structures for people with disability (Hosking, 2008).

The traditional policies are mostly based on liberalism which sees disability as a misfortune and deals with disability either by charity or via welfare mechanisms. On the contrary, critical disability theory, by foregrounding the experiences and perspectives of people with disabilities and critically analyzing the media representation and language used to describe disability, provides a foundation for developing policies and practices that are more responsive to the needs and interests of people with disabilities and promotes greater democratic control over institutions and social processes related to disability (Hosking, 2008).

### CHAPTER III: METHODOLOGY

The purpose of this chapter is to explain the research activities I employed in this study to answer the research questions in identifying the perspectives of persons with disability and local government level leaders and professionals on the current status, challenges and opportunities of ensuring disability inclusive healthcare at the local level of the Sindhupalchok district. I will elaborate on the study design, study area, recruitment of the research team, participants selection, data collection tools and techniques, data analysis, ethical considerations and finally my positioning and reflexivity as a researcher.

## 3.1 Research design

The study follows a qualitative case study research design due to its suitability in answering social problems and understanding them from the participant's perspective, allowing researchers to explore complex issues in real-life settings (Creswell, 2014b). The approach is well-suited for the present study as it allows an in-depth exploration of the complex issues surrounding disability inclusive healthcare.

Employing a case study research design allows an in-depth exploration of the local context, socioeconomic factors, policies, and healthcare systems of the Sindhupalchok district, which are essential for comprehending the challenges and opportunities in ensuring disability inclusive healthcare at the local levels of government. Moreover, the case study design enables gathering firsthand experiences, perspectives and insights from the key stakeholders involved in disability inclusive healthcare. This approach provides a rich and holistic understanding of the research topic.

One key feature of the case study design is the use of multiple data sources (Yin, 2009, pp. 47-49). Employing the inclusion of multiple data collection methods such as interviews with the health coordinators and persons with disabilities, document review and health facility observations, enabled the capturing of a wide range of perspectives and insights that helped in providing a more robust understanding of the research topic.

Overall, the case study approach is employed in the research as it allows a thorough exploration of the status, challenges and opportunities surrounding disability inclusiveness in the healthcare system at the local level of Sindhupalchok district. By facilitating contextual understanding,

incorporating multiple data sources and enabling a holistic examination, the study design enhances the depth and breadth of the study findings.

## 3.2 Study area

The study has been conducted in the Sindhupalchok district of Nepal. Sindhupalchok is one of the seventy-seven districts of Nepal and lies in Bagmati Province. The district spans both the Mid-Hills and High-Hills/Mountain regions. It ranges from a low point of 747m in Sangachok to a high peak of 7085m above sea level (Langpoghyang). This variation in elevation creates a diverse land topography and geography, including river valleys and mountain peaks, and diverse ecological zones and land features (RAP3, 2018).

The district is divided into three urban municipalities (Chautara Sangachokgadhi Municipality, Melamchi Municipality and Barhabise Municipality) and nine rural municipalities which are: 1) Helambu Rural Municipality, 2) Panchpokhari Thangpaldhap Rural Municipality, 3) Jugal Rural Municipality, 4) Bhotekoshi Rural Municipality, 5) Balephi Rural Municipality, 6) Indrawati Rural Municipality, 7) Tripurasundari Rural Municipality, 8) Sunkoshi Rural Municipality and 9) Lisankhupakhar Rural Municipality. These 12 municipalities represent the 12 local levels of government within the district. As such, "local levels" and "municipalities" are used interchangeably throughout the study.

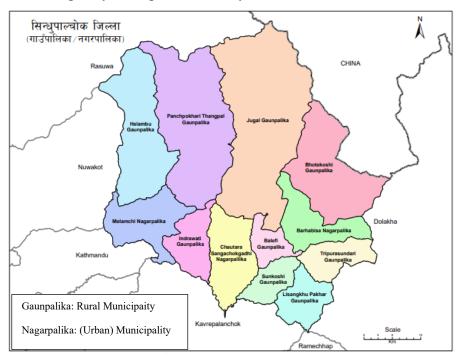


Figure 2: Administrative Map of Sindhupalchok (Nepal in Data, 2018)

The district has an area of 2542 square kilometers and a population of 262,624. The district's literacy rate is 68% which is lower than the national average of 76.2%. The majority of the population (74.4%) is engaged in agriculture for their living (GoN, 2023). Though people entirely depend upon agriculture for their survival, production is very low since most parts of the district are covered with hills. Thus, the district has a low socioeconomic status (Sindhupalchok, 2023).

According to the Census report of 2021, 3.1% of the total population of Sindhupalchok are living with disabilities. Physical disabilities, low vision, poor hearing and speech impairments are the most common types of disabilities reported in the district (GoN, 2023).

Choosing Sindhupalchok as a study area was driven by two key factors. Firstly, the district was severely affected by the devastating earthquake of 2015 which resulted in a significant number of injuries and a high level of disabilities among the injured (Bimali, Adhikari, Baidya, & Shakya, 2018). This disaster received huge international attention, and several national and international non-governmental organizations (i/NGOs) supported the government in the reconstruction and rehabilitation of the district. Since disability inclusive development was being practiced by these types of organizations, it was reasonable to assume that their project activities would have resulted in more disability inclusive practices in all sectors of development including healthcare.

Secondly, I needed to conduct research in an area which provides access to data collection. Since I had previously stayed and worked in the district, I had good connections to most municipalities of the Sindhupalchok district. Therefore, the preexisting familiarity and network facilitated contact and data collection from the selected sites.

### 3.3 Recruitment of the research team

The research team consisted of myself and the recruitment of one research assistant. I recruited a research assistant utilizing my personal connections within my professional network. A close friend of mine who used to work in an NGO based in Sindhupalchok suggested me a potential candidate who met my requirements. Receiving this recommendation, I reached out to the candidate and discussed their suitability for the role. The research assistant had to be a resident of Sindhupalchok and speak Nepali, English and Tamang which is an ethnic language commonly spoken in Sindhupalchok. The research assistant was required to have a high school degree and some experience working with people with disabilities in Sindhupalchok. Knowing sign language

was an advantage. I oriented the research assistant on the research project, its objectives, and the data collection process.

# 3.4 Study participants

Two groups of participants were recruited and interviewed. Firstly, the health coordinators of all twelve municipalities of the Sindhupalchok district were interviewed as they hold key positions in the local government and are responsible for any health-related activities in the respective municipalities. There were no specific inclusion or exclusion criteria for the enrollment of the Health Coordinators and all 12 of the health coordinators from the municipalities in the Sindhupalchok district were included in the study.

In the absence of the health coordinators in the Indrawati and Lisankhupakhar Rural Municipalities, their representatives were assigned by the municipality for the interview. For convenience, the two representatives will also be referred to as the health coordinators throughout the study.

The second group consisted of ten individuals with disabilities from different socio-economic groups and with various severities of disability. Persons with physical disabilities, blindness or low vision, hearing disabilities and speech impairments were recruited by convenience and snowball sampling. A non-government organization named Sappros Nepal, working in the district for the livelihood improvement of persons with disabilities recommended the first 2 informants and those informants further recommended someone they knew.

Only those with physical impairments, hearing and/or speech impairments and with blindness/ low vision were included. Focusing on these specific disabilities, the study aimed to understand the healthcare provision for those persons with the most reported disabilities in the district. Persons with mental and behavioral disabilities were excluded from this study as they may require different considerations and it could be challenging to accommodate their specific needs and communication requirements within the research design and data collection methods.

## Socio-economic background of the participants

### Health coordinators

Two out of the 12 health coordinators had studied or were studying bachelor's in public health whereas, the remaining 10 health coordinators came from a technical health background like

Health Assistants or Auxiliary Health Workers. Except for the health coordinators of Tripurasundari and Jugal Rural Municipality, all the other health coordinators were permanent residents of the Sindhupalchok district.

# Participants with disabilities

Ten participants with varied disabilities, living in different parts of the Sindhupalchok district were interviewed. The table below provides information regarding each participant with pseudonyms to protect their identity. It also displays their education, occupation, relationship status and the type of impairment they had.

Table 1: List of the participants with disabilities and their background

S. N.	Pseudo nym	Age	Sex	Municipality	Education	Occupation	Relationship status	Type of impairment
1	Ram	41	Male	Chautara	Master's degree	Teacher/ Musician	Married, father of one	Blindness
2	Sita	38	Female	Indrawati	Secondary school	Tailor	Married, Mother of one	Impaired Mobility
3	Hari	48	Male	Melamchi	Secondary school	Helps with Farming	Single, no children	Blindness
4	Krishna	35	Male	Chautara	Master's degree	IT officer	Married, father of one	Impaired Mobility
5	Bishnu	52	Male	Helambu	Literate	Animal husbandry	Married, no children	Partial Blindness
6	Shiva	57	Male	Barhabise	Master's degree	Teacher	Widower, father of 3 children	Hearing and Speech impairment
7	Narayan	58	Male	Bhotekoshi	Literate	Helps with Animal husbandry	Single, live in a joint family	Spinal cord injury
8	Rita	37	Female	Jugal	Secondary school	Helps in her family's shop	Single, no children	Impaired Mobility
9	Kumari	56	Female	Sunkoshi	Literate	Helps at home	Single	Impaired Mobility
10	Nabin	28	Male	Tripurasundari	Literate	Agriculture	Single	Hearing and Speech impairment

## 3.5 Data collection methods, tools, and techniques

The data collection period was from December 2022 to April 2023. Information was collected from three different sources: face-to-face in-depth interviews, document review and observation of the health facilities. However, the primary source of information was the in-depth interviews with the municipal health coordinators and with persons with disabilities.

## <u>In-depth Interviews</u>

The in-depth interviews were conducted with the help of an interview guide. All the interviews were carried out in the Nepali language and then translated and transcribed in the English language. There were times when few participants preferred responding in a mix of Tamang and Nepali languages. Two participants with hearing and speech disabilities were interviewed solely by the research assistant using sign language.

For the setting of the interview, participants were able to choose their preferred location. The interviews with the health coordinators were mostly held at their office while most participants with disabilities preferred to have interviews in the periphery of their households. Each interview lasted 30-45 minutes for both groups.

A semi-structured question guide was developed for participants with disabilities, organized into the sections: a) basic socio-economic details, b) transportation to the nearest health facility c) experience within the health facility d) receiving health-related information and communication e) health service provision, f) behavior of health professionals, g) health expenses and h) participation in health service planning (see Appendix V for details). The question guide was modified as per the disability type of the participants.

A similar interview guideline for the health coordinators was used which was divided into six sections namely: a) basic information b) disability and data in the municipality, c) availability of accessible and disability-friendly health facilities, d) disability inclusion in health service provision e) relevant training, f) involvement of persons with disabilities in program planning and g) challenges and opportunities in making health services disability inclusive (see Appendix VII for details).

To ensure the reliability and validity of the interview guide, I did a pilot test of the interview with four participants – two from each group. The participants shared similar characteristics to the study

population but were from different geographical locations. The pretest followed similar ethical considerations as planned for the study. The participants of the pilot test were informed about the objectives and handling of their data.

Apart from the interview guidelines, I considered other factors like the comfort level of the participants while responding, time taken and their overall experience. The interview guide was modified based on the findings and feedback received from the pilot testing and during consecutive interviews.

## Documents review

Each municipality's published documents, i.e., plans, policies and strategies related to health and Gender and Social Inclusion (GESI) which were studied. Most of these documents were published on their respective websites and a few of them were provided separately by the health coordinators.

## Health Facilities observation

An observation checklist was prepared to assess the inclusiveness of health facilities. Mostly, the physical infrastructures like buildings and toilets, roads, equipment, and information dissemination were focused on by the checklist. The health facilities were selected purposively to ensure geographical diversity and the representation of the different levels of services they provide. Four distinct types of government health facilities located in four different municipalities were observed based on the established observation checklist (see Appendix IX for details).

Following is a table that describes the type, location and specific details of the health facilities observed:

Table 2: Health facilities observed in the Sindhupalchok District

S.N.	Type of health	Location	Remarks
	facility		
1.	Municipal	Melamchi	Is also a referral hospital for Helambu and Indrawati
	Hospital (PHCC)	Municipality	Rural Municipalities, additional constructions were
			ongoing
2.	District Hospital	Chautara	Is now referred to as one of the provincial hospitals,
		Sangachokgadi	provides emergency care, primary and secondary health
		Municipality	services
3.	Basic Health	Helambu Rural	Due to the low population density and difficult
	Centre	Municipality	topography, the health center was established to provide
			the most basic health services.
4.	Municipal	Indrawati	The newly constructed municipal hospital is built to
	Primary Hospital	Rural	provide secondary healthcare as well but for now, due
		Municipality	to the lack of human resources, provides limited
			services.

## 3.6 Data management and analysis

After translating and transcribing the interviews in the English language, I uploaded them into the qualitative data analysis software, NVivo 12. I then used thematic network analysis as discussed by Jennifer Attride-Stirling (2001) to help organize and interpret the data.

First, to familiarize myself with the data, I collected the data together with the research assistant. This helped me get firsthand experience of understanding the perspectives of participants and their real-life situations. I listened to the recordings twice and took notes to highlight the parts I found interesting. I was also actively involved in the translation and transcription of the interviews. I read and re-read the texts and was able to find better meanings and ideas from them. Since I had field notes taken during the interviews, I compared the transcripts with audio recordings and the field notes for accuracy.

Then I approached coding with an inductive mindset. Most of the time, I coded a whole sentence or a large chunk within a paragraph depending on the context. Going through each sentence, I

coded every time I identified something relevant to my research objectives. For instance, "I always have one of my family members to help me walk to the health post" was coded as "need of accompanier to travel."

Using NVivo for data coding made it much easier and more time efficient, the text associated with the codes was marked. After coding the transcripts of 4-5 interviews for both groups of participants, very few new codes were developed. I applied the code I had already used if relevant and kept generating new codes for new or different information. I also modified the codes to incorporate new material. From the entire set of data, I generated 56 codes that were ready to be clustered into basic themes.

At this stage, I identified similarities and overlaps between the codes. With the help of NVivo, I reviewed, recoded, and merged the codes. Using this network, I clustered them into 21 basic themes and further grouped these into 12 organizing themes. The twelve organizing themes were then presented as three global themes: i) Access to health services: Lived experiences and perceptions, ii) Health service delivery: Perspective of the healthcare sector and iii) Planning disability -inclusive health services: The administrative level, as shown in the following table:

Table 3: Thematic analysis table

<b>Global Theme</b>	Organizing theme	Example of basic theme
Access to health	a. Transport challenges	Geography and road conditions
services: Lived		Natural disasters and its impact on transportation
experiences		Availability of transportation services
and		Need of an accompanier to travel
perceptions	b. Health Infrastructures:	Type of buildings and availability of elevators/lifts
	Accessibility and	Registration counter
	Inclusivity	Wheelchair accessibility
		Furniture and examination equipment
		Disability friendly toilets
		Parking and waiting areas
	c. Communication and	Need for an accompanier to communicate
	information	Availability of sign language interpreter
	dissemination	Use of Braille
		Source of information

	d. Affordability	Cost of care and disability allowance
		Health insurance
		Financial support from the municipality
		CBR to improve the economic status
Health service	a. Prioritization of people	Practice of prioritization of people with disabilities
delivery:	with disabilities	Practice of home visits
Perspective of	b. Disability targeted	Disability prevention, identification, and management
healthcare sector	health programs	Availability of physiotherapy
		Provision of targeted health camps
	c. Capacity of the Health	Educational background and experiences of the Health
	Personnels	Coordinators
		Provision of disability related trainings and
		orientations for the service providers
_	d. Health workers' attitudes	Use of respectful language
	and support	Assistance, and support to patients with disabilities
Planning	a. The lack of disability-	The practice of recording and reporting service
disability	related data	utilization data
inclusive health		Need and availability of disability related service data
services: The	b. Role of Women and	Women and Child Welfare Division as a key
administrative	Child Welfare Division	stakeholder
level		Distribution of disability ID card
		Advocacy for the welfare of persons with disabilities
		Organizing health camps for disability identification
	c. PWDs' participation in	Involvement, availability, representation of persons
	the health planning	with disabilities in planning process
		Challenges in participation
	d. Disability	Formulation, availability and alignment of municipal
	inclusiveness in	plans and policies with the federal laws
	municipal policies	Challenges in the implementation of the plans and
	1 1	policies
	3.7	T 1' ' CC 1 1'
	e. New government: new	Implications of federalism

### 3.7 Ethical considerations

The study obtained exemption from the ethical clearance both in Norway and Nepal. The study was notified to the Norwegian Centre for Research Data- Norsk Senter for Forskningsdata (NSD) (see Appendix I) and the National Health Research Council (NHRC) (see Appendix II) approved the study to be conducted in Nepal.

## Methodological amendments

The original research plan was set to explore the status, challenges and opportunities in community-based health programs implemented by non-governmental organizations (NGOs). The data collection would have included in-depth interviews with the program leaders of those NGOs and the municipal health coordinators. However, during the execution, it became apparent that very few NGOs were left in the district that implemented the health projects. Upon careful analysis and under the guidance of my supervisors, the study's focus was changed towards health services provided at the local level. To provide a more nuanced perspective on the health services of the Sindhupalchok district, it was decided to include persons with disabilities as study participants along with the municipal health coordinators.

The initial proposal was already approved by NSD and NHRC. Thus, both institutions were informed and requisite documentation reflecting the amendments was submitted. Getting NHRC's approval encountered some delays due to issues on their website and the unavailability of the reviewers. Nonetheless, as the study had previously been approved, I was advised to continue the data collection, while waiting for written confirmation of the amended research plan that I eventually received in August 2023 (see Appendix II).

Notwithstanding, throughout, the study was conducted following the guidelines required to ensure privacy, data security, secure storage of the information, and appropriately share the personal experiences of the study's participants.

## **Informed Consent**

The research team met the Mayor or the Chairperson of each municipality of Sindhupalchok. After explaining the project and the participant recruitment process, the municipality approved the data collection in their respective municipalities and health divisions.

The study participants were informed about the study and asked for their consent for participation. Moreover, the information letter and the consent form (see Appendix III for details) were sent to them beforehand for the interviewees. This gave them enough time to read, understand and make an informed decision to participate in the interview. Their right to refuse participation or withdraw at any time was highly respected.

The participants' consent for audio recording and taking notes in the interview were also taken into consideration.

# Data storage, access, and dissemination

As a primary researcher, I was responsible for the protection of participants' data. Only I as a researcher and my supervisors had access to the raw data.

All the collected data such as consent forms, interview transcripts, and field notes were kept safely in a locked cabinet. Identifiable information was removed from the audio recordings to protect the privacy of the participants. The confidentiality and anonymity of the respondents were prioritized at every level of the study.

However, for the first group of participants i.e., the health coordinators, though their names have not been used, they could be identified by their location. This was conveyed to the participants before they provided their consent for the interview. Since most of the information collected from the health coordinators was related to service provision and depicted the health system-related scenarios, they agreed to be interviewed and permitted to use their quotes or information that may help identify them. No personal information about this group of participants was analyzed. And any personal opinions they expressed were anonymized. Moreover, they were further asked if they wanted to see the transcript and analysis such as the use of their quotations before the submission, and five of them wanted to see the quotes that were used. Their decision was followed, and they had no objection to their quotes being used in the study.

## 3.8 Positioning and reflexivity

It is important to acknowledge the influence of a researcher on the research process and outcomes in qualitative research. In the research process, I bring my beliefs, values and experiences that could induce biases in the collection and interpretation of the data (Creswell, 2014b).

My extensive involvement in the Sindhupalchok district, working full-time for nearly 2 years in the past, provided me with firsthand exposure to the local context. My familiarity with the district allowed me to establish rapport and facilitate open discussion during data collection but it also might have posed biases in their responses. For instance, during my interviews with the health coordinators, my previous collaboration with them facilitated a comfortable environment and encouraged them to share their candid insights.

Additionally, my personal connection with the district through my grandparents shaped my understanding of the socio-cultural and healthcare landscape of the district and my close relationship with a family member who has a physical disability has likely shaped my perceptions regarding disability inclusive healthcare. This background enabled me to pose relevant questions that reflected the experiences of persons with disabilities.

Though my previous background and experiences generally positively influenced the data collection, it could also have influenced the participants to align their responses with my prior opinions or experiences.

To mitigate potential biases during the study, I reflected about these throughout the study. I evaluated my decisions and actions during data collection, when transcribing the data and during its interpretation, recognizing the potential for unintentionally steering conversations in a certain direction. With this mindfulness, I strived to maintain reflexivity about how my personal perspectives influenced the data.

#### **CHAPTER IV: FINDINGS**

This chapter presents my findings from the data I collected in Sindhupalchok district through indepth interviews conducted with the 12 health coordinators representing each of the 12 municipalities of the district and the 10 health service users with varying disabilities. These findings are further supported by on-site observations of the four health facilities, field observation during the data collection and the analysis of the legal documents of the municipalities.

An analysis of the data resulted in the identification of three main themes: i) Access to health services: Lived experiences and perceptions, ii) Health service delivery: Perspective from the healthcare sector and iii) Health service planning: The administrative level. The findings are organized and structured under these themes as a framework for discussing the various aspects of health accessibility, service delivery and planning. Under each theme, specific sub-themes are discussed as:

# THEME I: Access to Health Services- Lived experiences and perceptions

The first theme "access to health services" implies the ability of individuals to receive health services whenever needed. The major influencing factors for access to health services found were transportation, physical infrastructures, communication and information dissemination and affordability.

The findings on accessibility to health services are primarily based on the experiences of people with disabilities, while also incorporating the perspectives of the health coordinators to either support or contradict the experiences of the informants with disabilities.

### 4.1.1 Transportation challenges

The transportation related challenges mostly affected people with mobility related disabilities followed by people with blindness and low vision. Participants with mild and moderate disabilities and those with disabilities related to speech or hearing were less affected by the transportation challenges when the health facilities were nearby.

## Geography and the road conditions

Almost every part of the Sindhupalchok district is mountainous terrain. This presented a significant challenge for the construction and maintenance of the roads. Additionally, the district is prone to frequent natural disasters such as landslides and floods, which most of the time results in the destruction of the roads. During my travel from one municipality to the next, most of the roads were not in good condition. For instance, the roads to Helambu Rural



Figure 3: Road connecting Helambu Rural Municipality and Melamchi Municipality

Municipality which was flooded in 2021 were still covered with large rocks and debris, rendering travel extremely difficult (see Figure 3 for reference).

Having recognized the struggles faced by the public with the bad or no roads connected to their places, local government bodies have prioritized road development in every year's fiscal plan. The narrow pathways leading to the health facilities have been replaced by a wider road that can be accessed through two- and four-wheelers.

However, the roads constructed one year usually are washed away with the following year's flood or landslides, requiring repetitive construction efforts. From my observations in the field, only the district hospital at Chautara Sangachokgadi Municipality, the municipality level hospitals located at Melamchi Municipality and Indrawati Municipality had proper road accessibility. The other health posts were most often connected with either graveled roads or roads that were in the early stages of construction. I visited the district and the health facilities in the winter months which had no rain, but the evidence of recent road maintenance following the monsoon was visible.

## Availability of ambulances and transport services

In addition to the poor road conditions, the Sindhupalchok district faces another significant challenge of limited public vehicles. In most rural areas, only one or two public buses operate per day. The public busses have one seat allocated for persons with disabilities but it is not easily accessible. In cases where people with disabilities must travel to a municipality hospital or a

higher-level health facility which is far away or when the person is severely ill, the transportation challenge exacerbates. Informants reported either hiring an ambulance or any other vehicle if the household with a disability did not have a private vehicle.

Helambu Rural Municipality, which is a cold hilly region of the district and has low population density, has made significant progress in improving the health of its population. Realizing the geographical difficulties people face in this region, according to the Health Coordinator, the municipality provides a 24-hour free ambulance service. Other municipalities also reported to have begun such services, but many require a recommendation from the ward offices, which can be a lengthy process.

# Need of an accompanier

There was at least one health facility in every ward of every municipality, and these were usually within walking distance of a maximum of half an hour. Despite this, persons with disabilities often faced difficulties in accessing health services due to transportation limitations. They often required someone to assist them to travel to the health facilities. Especially, people with mobility impairments found it difficult. Narayan who lives in a joint family explained:

"I always wait for my friends or family members to take me to the hospital, I can hardly get up on my own, I cannot go anywhere. My brothers usually take me on their motorbikes but if I am seriously ill, they call an ambulance too."

Not only people with mobility challenges, but people with low vision or blindness also expressed a similar need of requiring someone to travel to the health facility. Ram, who was accompanied by his daughter throughout the interview shared:

"I don't have mobility issues and the hospital is not that far, but I am not confident to walk alone. My daughter guides me if I am going to the nearby health post or else, I go with my wife."

A 56-year-old female informant who hardly left home due to her physical disability resulting from polio reported being more dependent upon her family members with her growing older.

"Though it would take me a while, I used to walk to the health facility alone for minor health issues until the age of maybe 40, but it is very difficult nowadays. I need someone to support me walk. Sometimes they even carry me on their back."

## 4.1.2 Health infrastructures: Accessibility and inclusivity

Many of the physical infrastructures including the health facilities in the Sindhupalchok district were severely damaged by the earthquake of 2015. Most health facilities were renovated rather than reconstructed. Also, many of them have semi-permanent buildings. This poses an additional obstacle to creating an accessible environment for individuals with disabilities. The Health Coordinator of Balephi Rural Municipality explained:

"We have ten health facilities in the municipality. Two of the buildings being constructed are disability friendly, the old ones are not. The major challenge is still the physical infrastructure. Budget is limited so all physical infrastructure cannot be replaced to meet the disability friendly standards."

Most of the health coordinators believed that the infrastructures built after the earthquake were more disability-friendly than the older ones since the design was either decided by the government or had to be approved by the government. However, a few were a bit skeptical. The Health Coordinator of Barhabise Municipality explained:

"Three health facilities are being reconstructed right now in the municipality. The building designs must follow the guidelines and mandates developed by the federal government. I assume that the building will be disability friendly. For now, I don't understand the layouts very well. So, let's see how disability-friendly the building will turn out, after the completion."

### Lifts and elevators

Most of the health posts in the wards of the municipalities were reported to be single storied and thus no additional barrier was created in the absence of elevators and lifts. The district hospital and a few of the municipal hospitals, however, were two storied and it was assured by the health coordinators that the second floor was usually allocated for administrative purposes and if required, patients with disabilities were accommodated on the first floor.

38-year-old Sita with a moderate disability shared:

"It is uncomfortable if I have to use stairs or else, I am fine with the buildings and structures of the health posts here."

## Wheelchair accessibility

The informants with mobility issues and the health coordinators had major concerns about wheelchair accessibility. They confirmed that most health facilities have wheelchairs as well as ramps for wheelchairs for easy mobility inside the health facilities. However, it was evident that the focus of the coordinators was primarily on physical disabilities when considering the concept of disability-friendly buildings. The representative from Lisankhupakhar Rural Municipality of Sindhupalchok shared the following opinion:

"The facilities being constructed now are disability friendly. Most health facilities can be accessed through wheelchairs. They have ramps for wheelchairs suitable for people with impairments."

In the health facilities, I could observe that the doors were wide enough to accommodate wheelchairs, but these did not follow a standard and the same was the situation for the ramps constructed to link the parking and the buildings. Out of the four health facilities I observed thoroughly, the health center of Helambu did not pass the standards for wheelchair accessibility and also did not have guard rails.

When inquiring about accessibility for persons with blindness or low vision, none of the health facilities could give a positive response. One of the Health Coordinator from a comparatively urban area, Barhabise Municipality shared:

"I don't think any of our health facilities at the municipality or any government health facilities in the whole country are appropriate for people with blindness. The general understanding of disability friendly these days is the places accessible with wheelchairs."

The interview participants with blindness confirmed the lack of blindness pathways in the health facilities. Hari, a 48-year-old male informant with blindness said,

"No, I don't think I have ever used the pathways in any of the health facilities here. I usually am guided by one of my family members or friends who takes me to the health facility. Now

that we are talking about the pathways, I think that health facilities should have them. I wonder if the new health posts being constructed will have pathways."

In times or places with no arrangements for wheelchair accessibility and a lack of caretakers, the informants with disabilities reported having been assisted by the support staff to navigate their way inside the health facilities.

Though a greater emphasis was given to wheelchair accessibility, the Health Coordinators realized that it was not enough as one of them from a Rural Municipality shared:

"Without necessary physical infrastructures, it is not possible to provide disability-friendly services. With the limited resources we have, we tried at least to make the health facilities accessible with wheelchairs, to begin with."

## The toilets

In the buildings recently constructed, the toilets had ramps and side assist handles. Out of the four health facilities observed, three had modern style commode toilet seats which are believed to be more comfortable than the Indian style toilets. Though the three health facilities had commode toilets and ramps, the space to turn around the wheelchair seemed to be very limited.

observed that there their Indian style



In one of the other health posts, I Figure 4: Toilet observed in a health facility in Melamchi Municipality

toilet was added hand support in two sides modified to make it comparatively easier for patients to get up and sit down easier (see Figure 4 for reference). The other practice observed in one of the households was a plastic chair cut a hole in the seat to make it resemble a commode with hand support when placed over the traditional Indian style toilet (see Figure 12.

## Waiting areas and parking

Most of the health facilities in the districts were built in spacious areas with enough parking space. Though there were no designated parking spaces, the premises could accommodate up to four or five four wheelers: cars and ambulances easily.

Similarly, the waiting areas had no specific accommodation for people with disabilities, but the observed health facilities had a wide area where wheelchairs could be placed and suitable for moving around.

# The ticket/ registration counter

Most informants with disabilities found that the height of the registration counter was acceptable to their needs. Especially people in wheelchairs reported being able to easily communicate at the counter. However, for people with speech and hearing impairments, the difficulties were in communication rather than physical obstacles.

For convenient access to health services after reaching the health facilities, Participant Shiva suggested, "There is a need to have a competent staff to help people like us and the elderly, right after they enter the health facility to provide them with the support they need."

# The furniture and the equipment

Since the informants with disabilities only visited the health posts for basic health services, the was no need for hospitalization, but they reported lying in bed while getting a few checkups and for saline water or medicine injections.

I observed that though 2-3 beds (in hospital settings) were usually dedicated to the treatment of people with disabilities, most of the beds were simple without adjustment functions. The beds were almost 2.5 ft and were provided with a separate tiny stair to climb. They were not easily movable (with wheels) Figure 5: One of the six height adjustable either. This was the same for all patients with or beds of Chautara District Hospital



climb. They were not easily movable (with wheels) Figure 5: One of the six height adjustable either. This was the same for all patients with or beds of Chautara District Hospital without disabilities. In the district hospital, which provided more specialized services, there were six beds that could be lowered and adjusted as per the needs of the patients as seen in Figure 5.

The lack of appropriate beds was reported by the informants. Kumari, an informant from Sunkoshi Rural Municipality who had visited the nearby health post a month ago explained:

"I had to be carried and placed in the bed for the checkup. In other conditions, I would have only required support to lie in bed but this time I was really sick and had no energy to even try. This could have been difficult for any other patients as well, not only for me because of my disability."

### 4.1.3 Communication and information dissemination

Informants with speech, hearing and vision related disabilities faced additional challenges in the health system when it comes to communication and information dissemination.

### Communication

The participants with hearing and speech impairment specifically faced the challenge of effectively communicating with the health professionals and thus required an accompaniment for accessing the health services. A 28-year-old informant with a speech and hearing disability explained:

"If the wounds are visible like a cut, it is okay for me to go to the health post on my own but if I have other issues, it is difficult to explain, and I would prefer my family's company."

Another participant with hearing and speech disability who knows sign language and is also a teacher in the Deaf School in Barhabise also preferred to visit the health facility with his family members as they know the sign language.

"Without my children, I won't be able to clearly communicate my problem to the health personnel. My daughter or my mother usually goes with me. The problem with communication starts right after I reach the entrance. I have to tell them my name, age, etc. while getting the tickets. That is difficult. I can sign but the staff there cannot understand. I sometimes write my information for them. The problem is the same while seeing the doctor. I might not always be able to write about my health problems and they don't know how to sign."

In my observation, I found that none of the health facilities had translators for those with hearing and speech impairments.

In contrast, informants with other disabilities did not have significant barriers to communicating at the health facilities. However, they still expressed that they feel more confident and at ease talking about their health problems when they have someone assisting them.

### Information dissemination

Not only for the direct communication between the service providers and the patients, but people with disabilities also often lacked access to essential information. Effective information dissemination is crucial to ensure that they can access and understand important healthcare related content. It is common for the government to share health promotion and disease prevention related information through brochures, pamphlets, and posters. However, as an interview participant with complete blindness explained, none of this information was available in braille.

"I don't think such information in braille is available anywhere in Nepal and we are talking about these small health facilities of Sindhupalchok and even if such information is available in braille, think about how many people with blindness can actually read."

I also had questions about how the informant with disabilities receives health-related information. Informants shared their methods of accessing health information highlighting the diverse sources they rely on. It was evident that people with different types of disabilities require different types of information sources.

" I listen to the radio most of the time and our friends help circulate any important information. Our way of communication is via voice, so it is easy but for others with hearing and vocal disabilities, it could be very difficult."- Informant with blindness.

It was fascinating to observe how technologies such as a smartphone could be made user-friendly. During one of the interviews, Ram, who is a teacher and a musician and is completely blind, took his phone out to find out the time. I could observe that he had his phone in text-to-speech mode. This simple adaptation allowed him to receive audible information without the help of anyone.

It was comparably easier for participants who could read to receive this sort of information. They were commonly found using social media and the internet and newspapers to be informed. In contrast, participants who could not read were mostly dependent upon their family members and friends for receiving any sort of information.

To get insights on information dissemination from the government side, I asked the health coordinators their strategies and ways of broadcasting health related information. In addition to the traditional method of newspaper publications, posters and radio, social media was found to be actively used. Many municipalities had their own Facebook page where they regularly post and assume that it reaches their audiences. Alongside, Female Community Health Volunteers (FCHVs) who are often recognized as the pillars of the Health System in Nepal, were believed to be the most reliable source of information dissemination.

"Our strongest and most reliable medium of health information is still our FCHVs. They are in every tole [ward] to deliver health messages at the grassroot level. We also disseminate information on Facebook and our website and those who can read can have access to it. We also have posters patched in every junction". — Health Coordinator Jugal Rural Municipality

Though there were no distinct strategies used to increase access to health information among persons with disabilities, the local level of government believed that none of them had been deprived of receiving important information. The dissemination of information through various means and methods was believed to reach every group of the population in one way or the other.

However, during my observation in the field, I noted that there was no practice of displaying information in the lobby or waiting areas, using announcements to inform people with blindness to get by inside the facilities or providing braille versions of written information. Also, the size of signage in the doors and any information painted on the walls of the health facilities depended upon the space availability rather than the consideration of people with low vision.

## 4.1.4 Affordability

The government provided free basic health services through public health institutions. For the services that require the patients to pay such as for outpatient tickets in hospitals, bed charges during hospitalization, medicines (other than the free essential medicines) and laboratory services, usually the services are provided with certain discounts or even free for people with disabilities. The Health Coordinator of Tripurasundari Rural Municipality claimed: "We have lab services and X-rays in some of our health facilities. People with disabilities do not have to pay for these services."

However, the informant Ram, who confirmed what other informants told, had a different experience:

"The provision of having a free allocated bed for patients with disabilities is not implemented well. Many of the health staff do not understand many of the provisions for us and we are forced to pay. I have been paying the same amount as normal people."

Only at the registration counter of the district hospital, a board was installed (as shown in Figure 6) that informed about the provisions of free health services and requested the patients with disabilities to show their disability ID card as proof to receive the free health service.

However, apart from the few cases where people with disabilities had to pay, the primary cost associated with receiving health services in the municipality seemed to be the travel cost and the caregiver's time.



primary cost associated with receiving health Figure 6: The information board at the registration area of Chautara District Hospital

In addition, many factors such as the need for specialized treatment, lack of medicines and adequate human resources often cause the residents of the district to seek health services from the private health sector. Consequently, out-of-pocket payment is common among people with disabilities as well.

## Disability Allowance

People with disabilities receive a monthly allowance from the government based on their disability grades. Individuals with profound and severe disabilities were reported to receive NRs. 4000 (approx. 30.24 USD) and NRs. 2133.33 (approx. 16.13 USD) per month respectively. The amount is hardly sufficient for the people to survive. A woman with a severe physical disability explained,

"The allowance hardly makes anything better. Imagine getting two thousand rupees [approx. 15 USD] when the minimum monthly wage announced by the government for a living is seventeen thousand [approx.128 USD]."

### National Health Insurance

The Government of Nepal has implemented health insurance programs throughout the nation for every group of the population. For every family of five, insurance is provided with NRs. 3500 (approx. 26.32 USD) annually. With an increase in one family member, the insurance amount increases with NRs. 1500 (approx. 11.28 USD) annually. However, for people with disabilities and their families, the insurance is covered by the government. The participants interviewed in this study were unfortunately not a part of the national insurance program. Some of the informants were unaware of how the insurance system works while some were skeptical about its practicality.

"Even though I work in a hospital setting and I am aware that there is health insurance, I am not confident if it is feasible. I will have to go to the health institutes specified by the insurance plan. It won't cover my expenses if I need to receive services somewhere else like in private clinics." - Informant who works in a hospital setting

# Municipalities' initiatives

A few municipalities had initiated their own financial support system. Helambu Rural Municipality was found to implement a financial risk protection program to financially support the vulnerable population. The Health Coordinator of Helambu Rural Municipality elaborated:

"We have provisions to help people financially from our public health support program and say for example if someone with a disability needs a specialized treatment, we financially support them to receive it even from health institutions outside the municipality or the district."

Similarly, a few municipalities like Sunkoshi Rural Municipality and Lisankhupakhar Rural Municipality provided financial and medical support for health problems not covered by the package of free basic health services to vulnerable populations including people with disabilities.

"Whenever we are made aware of the need of any individuals with disabilities, the municipality sets up a meeting and allocates NRs. 10-15,000 [approx. 75.56-113.34 USD] for the person." - Health Coordinator of Tripurasundari Rural Municipality

# Community based rehabilitation (CBR) program for economic status improvement

The health coordinators reported having observed unequal access to health services among people with disabilities based on their economic status. Those belonging to higher income households had greater access as compared to those from low-income households.

The health coordinators believed that improving the economic status of persons with disabilities would make it easier for them to access health services. They emphasized the importance of livelihood programs for uplifting their living standard. The Health Coordinator of Panchpokhari Thangpaldhap Rural Municipality emphasized: "With increased income, they can buy the assistive device they need and get better and specialized treatment. They won't have to depend on their family either."

To improve the economic status of people with disabilities, the government of Nepal has implemented a community-based rehabilitation program (CBR) under the Women and Children Division. The health coordinators mentioned the implementation of CBR in every municipality through other external development partners.

The Health Coordinator of Jugal Rural Municipality explained that the municipality calls for proposals and the local non-government organizations bid for the program implementation. This sort of program has helped people with disabilities to improve their living. Participant Bishnu from Helambu Rural Municipality shared,

"I have 8 goats right now; the municipality gave me 5 last year. I even sold two of them when I got admitted to the hospital. Though these goats haven't made me rich, it has helped me be occupied and contribute to the family's income."

Though the CBR program was to be conducted every year, a few of the municipalities like Barhabise Municipality could not implement CBR this year. The Health Coordinator explained, "This could have something to do with the financing. Budgets for CBR are low and activities are limited."

### THEME II: Health Service Delivery- Perspective of the healthcare sector

The findings related to the provision and organization of health services by the municipalities and their health division are presented under the theme "Health Service Delivery". It focuses mainly on the implementation of health services to meet the needs of people with disabilities as

perceived by actors in the health sector. The findings are further supported by the experiences of persons with disabilities.

## 4.2.1 Prioritization of persons with disabilities

According to the health coordinators who are responsible for providing services, people with disabilities were treated equally, and they were provided with the same health services as people without disabilities in the municipality. The Health Coordinator of Sunkoshi Rural Municipality said:

"All general services are free in our municipality for everyone, be it for people with or without disabilities. In the health division, we don't have rules to provide services to some and skip some groups, we believe that every citizen should have access to health services."

Though the division views every citizen to have equal rights to health and treat everyone the same, the health coordinators seemed to prioritize the vulnerable population including individuals with disabilities. With prioritization, they mostly meant providing services first to people with disabilities.

"When anyone with disabilities visits the health facilities, we make sure that they don't have to wait in long queues. We are guided by the health system to provide service to people with disabilities and other vulnerable groups with greater priority." – Health Coordinator, Rural Municipality

It was also reported that people with mild and moderate disabilities were usually treated the same as those without disabilities with an assumption that they do not face more challenges than the other group of the population utilizing the health services.

For the community health programs where the federal government sets a target of 100% achievement such as for immunization coverage, the local level health system made sure that no one was left behind.

"Even if we might not have people with disabilities as a separate target population for health programs, we not only include them but also prioritize them. For a safe motherhood program, if a mother or the child has a disability, they are not excluded but served with priority to the extent possible." – Health Coordinator, Barhabise Municipality

However, according to people with disabilities using the services, prioritization was not the same for all. Ram who usually visits the district hospital whenever needed said, " The provision of not to be in the queue is not implemented properly, due to the lack of awareness. Some patients in line want us to be in the queue and some do not."

Another interview participant who has completed his master's degree in education and has several years of work experience in the development sector linked prioritization to the level of awareness among persons with disabilities. He explained:

"If I go to any health facilities, I will be prioritized to receive the health services because I can speak and ask them about my rights but what if someone from the rural area goes for the services, who will make them aware of their rights?"

## Home visits for health services

The health divisions of most municipalities in the district reported an additional effort to serve people with disabilities through home visits. Especially during the recent COVID-19 pandemic, the health professionals were recommended by the health coordinators to vaccinate people with disabilities who were not able to visit the health facilities and other vulnerable groups at their homes.

The Health Coordinator of Helambu explained that the home visit is not the mandate of the government and added:

"The government guideline is "provide maximum services" but it doesn't say anything about how. It is up to the municipality to decide. By any chance, if anyone with disabilities could not get the service, we do the home visits through our Female Community Health Volunteers (FCHVs) and ward representatives and take necessary steps."

Balephi Rural Municipality, the only municipality which did not practice door-to-door service during emergencies like in COVID-19 pandemic reasoned that:

" There might have been instances where few healthcare providers have offered home services based on their personal relationship with the patients but there is no formal policy provision regarding the home services at the moment."

Informants with disabilities also confirmed receiving vaccines at their homes for COVID-19. 58-year-old Narayan said:

"The doctor from the health post came here [at home] and gave me the vaccine. It was nice because it is difficult for me to go to the health post, and I would have probably skipped."

## 4.2.2 Disability targeted health programs

The disability targeted health programs or health services were minimal in the district. As the Health Coordinator of Barhabise Municipality stated:

"There are no programs for the targeted group and the lack of awareness on why targeted programs are needed creates additional challenges."

However, there were priority programs designed by the federal government like maternal and child health programs, of which one of the objectives is to prevent pregnancy- and nutrition-related disabilities. The Health Coordinator of Chautara Sangachokgadi Municipality explained:

"There are many disabilities that can be prevented like polio and many other disabilities that can be diagnosed during pregnancy. So, we are highly focused on disability identification during pregnancy."

The Health Coordinator had previously worked in a non-government organization, well recognized for working with disability related issues within the country. The coordinator reported having learnt more about disability related issues and aims to implement his learnings now in his municipality. He added having carried out a few programs to identify and treat early disabilities and elaborated:

"We have an eyesight-saving campaign as well in the municipality, mainly for school-going children. We identify the issue, prescribe them glasses and in cases of surgery or other corrective actions, we have a separate fund in the municipality."

Occasionally, the municipalities were found to organize physiotherapy kind of programs marking special days like International Disability Day. Indrawati Rural Municipality, which was one of those having such programs explained:

"We recently organized physiotherapy sessions in many of the wards of this municipality. We need external resources to organize such events. This makes it challenging to organize such sessions regularly."

The municipality authorities also claimed to organize occasional disability-related health camps and distribute assistive devices such as wheelchairs and walking sticks in the community. One participant mentioned assistive technology support:

"They sometimes distribute assistive devices like wheelchairs and walking sticks. I got one at a similar event. Other than that, I don't know about the specialized health camps or any other health-related events for us."

The assistive devices were mostly distributed by non-government organizations (NGOs) in coordination with the health division and the women and children division of the district. No budgets were strictly allocated by the federal government for the availability of assistive devices and specialized health camps at the municipality and ward levels. Thus, the local levels usually depended upon external support for such activities or depended on their internal revenue generation.

### 4.2.3 Capacity of the health personnel

The health coordinators had a sound understanding of disability as a condition which aligns with the definition and explanations of the Nepal Government. Most health coordinators preferred explaining disabilities in terms of their severity rather than the types of disabilities.

It was common among health professionals to apply for the position of health coordinators from any health background and 10 out of the 12 health coordinators had an educational background in a technical subject such as Health Assistants and Auxiliary Health Workers. Most of them had previously worked as service providers in health facilities before being appointed as health coordinators.

Health coordinators felt that they had limited skills to be working as managers of health. One of the informants shared: "I am a technical person to serve a health post, there are challenges to work on the managerial parts."

At the health facilities, it was reported that none of the staff were trained to accommodate the needs of people with disabilities. Few municipalities reported having an orientation to prioritize vulnerable populations like in the Panchpokhari Rural Municipality, where the Health Coordinator explained: "We orient the health personnel about the targeted/ vulnerable groups and their prioritization, but they are not further trained."

In the district, there were NGOs like Community Development and Environment Conservation Forum which trained the Female Community Health Volunteers (FCHVs) to identify early signs of disabilities in newborns and children. The volunteers would then notify the respective municipality which would then take necessary actions such as treatment, corrective surgery, or rehabilitation.

# 4.2.4 Health workers' attitudes and support

The Health Coordinators were confident about the positive attitudes and willingness to provide maximum support to the patients with disabilities at any health facility. One of the Health Coordinators assured:

"We have several people with speech and hearing impairments in our catchment area. Though most of the time they come with a family member, sometimes when they visit the facility alone, our service providers, despite not knowing the sign language, try their best to understand their problem and help them. I did the same when I was working in a health post a few years back as a service provider. I assume and expect the same from other health service providers."

A mixed response was received from the participants with disabilities. Though they were satisfied with the care they were receiving from the healthcare workers regarding their health problems, a few of the participants complained of poor understanding of their need to get help and not receiving the needed support until they reached the check-up room.

"If I reach the premises of the health post alone, I have to wait for someone to assist me through the gates and rooms. The health professionals try to unsee me so that they don't have to guide me. They think that it is the support staff's job and I have to wait until the support staff comes." – Participant from Sunkoshi Rural Municipality with a physical disability.

In general, people with disabilities found the behaviour and attitudes of the service providers positive. They repeatedly emphasized their improved use of language. They felt respected as every other patient. Rita from Jugal Rural Municipality said:

" Their behavior [health workers'] has improved quite a lot these days. They do not use terms like disabled and any other undignified words like "lulo", "langado", "andho". They

are not allowed to use such undignified words as well. Over the year I have felt a noteworthy change in terms of language."

Regarding the word-use by both groups of participants interviewed, the term "normal people" was often used to indicate people without disabilities. Though they used the more dignified expression "people or persons with disabilities" almost exclusively, referring to the other group as "normal" in casual conversations was common.

## THEME III: Planning disability inclusive health services: The administrative level

The third theme "Planning disability inclusive health services" includes the findings about the administrative process in developing disability inclusive healthcare systems. It highlights the lack of disability related data, the role of the Women and Children Division in the municipality, the participation of people with disability in the planning process, the challenges and opportunities of the new government and the disability inclusiveness in the municipal policies.

## 4.3.1 The lack of disability-related data

According to the interviewed Health coordinators, disability-related data is not being collected and reported by any level of health divisions in Nepal. When asked about the reporting system used in the health facilities, the Health Coordinator of Melamchi Municipality echoed the responses of other health coordinators:

"In the Health Information Management Systems (HMIS), we need to report the data of our service users based on their age group and ethnicity but there is no requirement to report the disability related status. You can see that even in the updated sheet for HMIS reporting.

The need to have disability related data in the health sector was realized well by the health coordinators. As the Health Coordinator of Jugal Rural Municipality said: "We need to know how many people with disabilities are receiving the basic health services and how we could improve their access to health services."

Since the HMIS reporting system is followed by public health facilities at all levels, the Health Coordinator of Chautara Sangachokgadi believed that simply adding a section where the disability status of the service receiver can be recorded in the HMIS reporting sheet could be a solution.

However, he added that this must be done by the federal government, as the local level of government does not have such authority.

### 4.3.2 Role of the Women and Child Welfare Division

The Women and Child Welfare Division in the municipality is responsible for the welfare of vulnerable populations in Nepal, including people with disabilities (PWDs). The Disability Coordination Committee has been established under this division and the division is responsible for the identification of people with disabilities to ensure their rights. It was also found that the Women and Child Welfare Division plays an important role in advocacy. The Women and Child Welfare Division is also responsible for distributing assistive devices and implementing community-based rehabilitation (CBR) programs for people with disabilities.

The health coordinators believed that the Women and Child Welfare Division had a lot of responsibilities but were often not given priority in the administrative planning.

The Health Coordinator of Tripurasundari Rural Municipality shared:

"Our "Women and children division" has had a vacant position for the last 4 years and some other department has taken few of its responsibilities. So, maybe that is why the welfare programs for vulnerable groups are not managed well. But we might have someone coming soon to fill the position, so let's see."

Similarly, the Health Coordinator of Helambu Rural Municipality said:

"There is no women and children division in Helambu municipality right now, its responsibilities have been transferred to the health division. I am still new in these matters, and I have not been into it in detail."

So, although there was a special administrative unit meant to be responsible for disability and inclusion, it did not seem to be operational.

### Disability Identity (ID) Cards

Nepal Government started the distribution of disability identity cards in 2009 to bring persons with a disability under the social security system of the country. As reported by the informants, the ID card is the only legal document that qualifies the person to be eligible for disability related services such as social allowance, free basic healthcare, and discounts in transportation.

The Women and Children Welfare division is primarily responsible for the identification and distribution of disability ID cards to people with disabilities in the municipality. In addition to the individuals applying for disability ID cards independently, the Women and Children Welfare Division also reported organizing health camps in coordination with the Health Division.

During fieldwork, it appeared that only the persons with profound and severe disabilities received the monthly cash allowance from the social security system and this was often observed as the only direct benefit among the people with disabilities and their families. According to the health coordinators, among the persons with either mild or moderate disabilities, only those well aware of the benefits came for the registration/renewal of their disability cards.

The Health Coordinator of Lisankhupakhar Rural Municipality elaborated:

"Most people in the municipality have mild or moderate disabilities. When we have health camps for card distribution, these groups often leave their cards with us saying that if they are not getting any allowance what's the use of it? We try to make them aware of the advantages of the card for the discounts in transportation and healthcare and also for their eligibility for livelihood programs."

The other challenge as observed at the administrative level is that people wanted to upgrade their disability ID card to a higher level of disability for receiving the allowance. The Health Coordinator of Barhabise explained this phenomenon more in-depth:

"People in other categories want to have a card representing the profound or severe level of disability, pressurizing the local government. And because the Health Division is assumed to have a close relationship with the medical personnel that recommends or determines their level of disability, we are often asked for favors."

## 4.3.3 PWDs' participation in the health planning

Agreeing with the notion "Nothing about us, without us", the health divisions and the whole municipality, in general, had made attempts to ensure the participation of people with disabilities in program planning and meetings.

The Health Coordinator from one of the urban Municipality explained:

"During the ward and municipal level programs, people with disabilities are encouraged to participate and have their say. Usually, a committee member from the ward or Municipality Disability Coordination Committee represents the group. Though we might not be able to hear every group of people with disabilities with different types of disabilities, we try to ensure their participation.

According to the informants, even with the regular attempts to involve people with disabilities in the planning and discussion process at the municipality, the transportation and geological difficulties were reported to make their participation challenging. This applied even to the regular committee meetings as the coordinator from Lisankhupakhar Rural Municipality explained:

"The transportation is difficult, there is only one bus that brings them here [in the municipality] and if they miss it, they have to walk. They leave their discussions in the middle to catch their bus. To return from the municipality office is very difficult for those with disabilities. In my experience, the transportation issue has hindered them from advocating for their rights even in the municipality."

### 4.3.4 Disability inclusiveness in municipal policies

At the local level of government, the municipalities have the authority to develop their own disability inclusive policies and plans in adherence to the national policies and guidelines. However, not many municipalities in the district had developed their own health policies and implementation plans that emphasize disability inclusion.

Moreover, even if the plans, policies, and guidelines get contextualized in the municipalities, they are often not updated on their websites. I did a thorough search on the government websites of the 12 municipalities under study and found that 10 municipalities of the district had their directives for ID Card distribution made available on their respective websites. Other than the directive, there were several legal documents that were meant to aid people with disabilities and improve their access to health services, as described in the following paragraphs.

### Gender Equality and Social Inclusion (GESI) Strategy

Since the federal government had repeatedly emphasized developing the Gender Equality and Social Inclusion (GESI) Strategy at every local level, the municipalities of the Sindhupalchok

district also had it prepared. Though every Health Coordinator assured that their municipalities had prepared the GESI strategy, only six municipalities had made it available on their respective websites (see Figure 20 for reference).

The GESI strategy though did not have specific plans and approaches for people with disabilities, they were addressed as a part of the broader vulnerable population. Among the many other divisions of the municipality, the Health Division was also identified as a primary actor in ensuring GESI. One of the objectives of the GESI strategy was to increase access to health services among the vulnerable group of populations.

The common strengths identified by the municipalities in their GESI strategies were the increased attention of GESI in the municipality's plans & guidelines and the inclusion of vulnerable groups in the planning process while the most common challenges identified were the lack of GESI analysis in the municipality's plans and policies. It was also repeatedly mentioned that the municipalities lacked specified budget allocations for vulnerable populations.

Moreover, the municipalities were required to prepare a GESI audit report every year. One or two audit reports were updated on two (Melamchi and Chautara Sangachokgadi) municipality's websites, but no continuity was observed. For instance, the Chautara Sangachokgadi Municipality had an audit report for the fiscal year 2015/16 only. One reason for the irregularity in the GESI audit as stated in the audit report of Melamchi Municipality can be the lack of resource allocation for the audit. 13

### National Health Insurance Implementation guideline

Although according to the Health Coordinators, national health insurance was implemented in all municipalities, its implementation guideline was found available only in Chautara Sangachokgadi Municipality. According to the implementation plan of Chautara Sangachokgadi Municipality, people with severe disability were included in the national health insurance, whose costs were covered by the Municipality. <sup>14</sup>

https://www.melamchimun.gov.np/sites/melamchimun.gov.np/files/documents/Melamchi%20%20MUN%20GESI%20Strategy%20final.pdf

<sup>12</sup> https://chautarasangachowkgadhimun.gov.np/en/node/58

<sup>13</sup> 

<sup>&</sup>lt;sup>14</sup> https://chautarasangachowkgadhimun.gov.np/ne/act-law-directives

As per its annual plan, Balephi Rural Municipality didn't have any specific strategy to include people with disabilities in the national health insurance. Notwithstanding, the encouraging of the general population to enroll in the programs was planned to contribute to 25% enrollment in wards 1,2,3, and 4. <sup>15</sup>

# Financial Assistance Fund Operation and Management Guidelines

Helambu Rural Municipality developed Financial Assistance Fund Operation and Management guidelines in 2018 to provide immediate support to the needy, which included people with disabilities. The Municipality had the provision to provide financial support to NRs. 10,000 (approx. 75.56 USD) to NRs 1,00,000 (approx. 755.56 USD) depending upon the need and context. Panchpokhari Thangpaldhap Rural Municipality followed a similar approach to providing financial support. 17

Tripurasundari Rural Municipality had a specific guideline to provide a monthly treatment allowance of NRs 5000 (approx. 37.78 USD) to people with profound or severe disability due to their spinal cord injury. Other municipalities also had emergency fund operations prepared, but they did not contain specific provisions to address the needs of any of the vulnerable groups in their respective municipality.

## Ambulance service operation guideline

Jugal Rural Municipality, Indrawati Rural Municipality, and Helambu Rural Municipality were the only municipalities whose ambulance operation guideline was available on their websites.

Indrawati Rural Municipality had, as reported by the Health Coordinator areas still not connected to the main roads to the city. The rural municipality had a Municipality level hospital at Nawalpur and had designed ambulance services to bring patients to that hospital. According to the Ambulance service operation guideline, the patients were charged anywhere between NRs. 1500 (approx. 11.31 USD) to NRs. 6500 (approx. 49 USD) depending upon the distance. However, people with disabilities were offered a 50% discount. Similarly, the Jugal Rural Municipality offered a 30% discount for people with disabilities and any other vulnerable group of the

<sup>15</sup> http://www.balephimun.gov.np/budget-program

<sup>16</sup> https://www.helambumun.gov.np/procedure

<sup>17</sup> https://www.panchpokharithangpalmun.gov.np/act-law-directives?page=1

<sup>18</sup> https://www.tripurasundarimunsindhupalchowk.gov.np/act-law-directives

<sup>&</sup>lt;sup>19</sup> https://www.indrawatimun.gov.np/act-law-directives

population <sup>20</sup> while Helambu rural municipality's guideline did not specify any provisions for people with disabilities or any other vulnerable groups.<sup>21</sup> Thus, such support for people with disability varied from municipality to municipality.

# Standards related to building construction

Though most municipalities had their building construction-related standards set up, none of them had the mandate to make it disability friendly. The standards mostly included the location/ space, approval procedures and requirements based on the type and use of buildings. Even though there were standards specified for health facilities like polyclinics, no criteria to make it disability friendly was provided.

#### Health Acts

Though certain municipalities like the Melamchi Municipality and Lisankhupakhar Rural Municipality had Health Acts developed for the municipality, the act focused mainly on mandates of treatment and services based on the types of health facilities. Acts of both the municipalities had, however, mentioned that the basic standards as decided by the federal government should be followed and these emphasized improving access to those usually unreachable. <sup>22</sup>, <sup>23</sup>

## The Municipality's Plan

All the municipalities had made their yearly plans available on their websites and from these plans and programs, it appeared that the municipalities were committed to promoting disability inclusiveness. The major activities outlined in their plans included increasing access to health services and implementing targeted activities for people with disabilities. Also, the plans recognized the need to create disability-friendly public infrastructures. Though budgets have been allocated for these activities, the specific strategies and implementation guidelines were not clearly specified.

For instance, Barhabise Municipality's program plan for FY 2022/23 included providing free health services to vulnerable populations including those with disabilities at the Barhabise Primary

<sup>&</sup>lt;sup>20</sup> https://www.jugalmun.gov.np/act-law-directives

<sup>21</sup> https://www.helambumun.gov.np/procedure?page=1

<sup>&</sup>lt;sup>22</sup> https://www.melamchimun.gov.np/act-law-directives?page=2

<sup>&</sup>lt;sup>23</sup> https://www.lisankhupakharmun.gov.np/act-law-directives?page=7

Health Centre which is upgrading as a hospital. It also promises to implement disability targeted programs, although specific details were not provided. <sup>24</sup>

Municipalities were also found developing periodic plans which included people with disabilities. Helambu Rural Municipality had developed a periodic plan for 3 years from FY 2022/23- FY 25/26 that emphasized uplifting the living standards of vulnerable groups including people with disabilities. Also, an equal focus on making public physical infrastructures like schools and health facilities disability friendly was recorded.<sup>25</sup> Similarly, the five-year periodic plan of Jugal Rural municipality (2022/23-2027/28) highlighted making disability-friendly physical infrastructures to increase access to public services. <sup>26</sup>

# 4.3.5 New government: New opportunities

The current local government in Nepal is in its first year of the five-year cycle and the elected local level authorities were new at the time of my fieldwork. They bore the authority and responsibility of formulating plans and policies for their respective municipalities. The health coordinators had their concerns about the understanding of their local level authorities that could impact the inclusion of disability-friendly development initiatives.

The Health Coordinator of Bhotekoshi Rural Municipality said:

"We have a sound understanding of the needs of people with disabilities and their inclusion. Our local government authorities should be aware of disability inclusion. They are the ones responsible for change. They should know the government's policies, acts and regulations for vulnerable groups like people with disabilities and adapt it to our context."

In the areas where the local authorities were more aware of the need for disability inclusive healthcare, the municipalities even had their budget set aside for improvements in healthcare. The Health Coordinator of Chautara Sangachokgadi municipality shared their enthusiasm with an example:

"In the next budgeting, we have requested the municipality to focus on certain things and they have agreed to listen and work on them. Disability prevention and rehabilitation will

<sup>&</sup>lt;sup>24</sup> https://barhabisemun.gov.np/act-law-directives

<sup>25</sup> https://helambumun.gov.np/publications

<sup>&</sup>lt;sup>26</sup> https://www.jugalmun.gov.np/plan-project

be our primary focus. The mayor's vision aligns with the health section, and this has made things easier."

The health coordinators had mixed expectations from the newly elected local level authorities. For instance, one of the Coordinator of Barhabise Municipality expressed:

"The new government is still new and does not know how everything functions. So, let's see if anything starts happening from next year."

Others, like the Health Coordinator of Balephi Rural Municipality, perceived limited changes with the new government. Lisankhupakhar Rural Municipality had even fewer expectations:

"I feel like whoever is elected, the government officials view women, children, elderly and people with disabilities as a separate class of citizens [not in a positive way] and they don't prioritize these groups. I have seen that though the policies are formed in the municipality, it does not include them. So, despite the high demand for the rights of people with disabilities, the improvement is quite limited."

In light of these observations, the Health Coordinator of a Rural Municipality recommended that the Federal Government introduce policies and guidelines for all levels of governance to follow:

"For example, the government can specify certain budgets for people with disabilities and ask the local authorities to use them for their targeted welfare programs. If the budgets keep on being allocated as a bucket fund for the local level authorities to identify their own priority programs, they might never see the need to prioritize the needs of people with disabilities in the health system."

#### **Summary**

The findings arranged in these three main themes with sub-themes suggest that the people with disabilities living in the Sindhupalchok district face numerous challenges in accessing health services within their own district. While there are noticeable efforts by the local government to ensure equitable health services to people with disabilities, there is a wide gap, particularly in terms of transportation, communication, and infrastructure, that hinders access to health services. Several other factors were found interconnected that could affect their access. The findings will be further analyzed in the next chapter for a deeper understanding and discussion of their implications.

#### **CHAPTER V: DISCUSSION**

## 5.1 Discussing some of the assumptions prior to the study

At the outset of my research, I held an assumption that the health sector in Nepal had undergone significant changes in response to the country's efforts to rebuild after the 2015 earthquake.

The earthquake had a devastating impact on 12 districts, including Sindhupalchok, where many buildings were destroyed or severely damaged. Across the country, a total of 446 public health facilities were completely destroyed and an additional 765 health facilities were partially damaged (NPC, 2015). In Sindhupalchok district alone 84 public health facilities i.e., 80% of the health facilities were damaged by the earthquake (NPC, 2015; Ulak, 2015). In addition to the national government's effort to immediate response and rehabilitation, numerous development agencies worked to rebuild the district. For instance: in the month following the earthquake (June 2015), international donors pledged approximately 3 billion USD for the country's recovery from earthquake (Mullan, 2015).

I initially believed that most health facilities in Sindhupalchok had been reconstructed, with a few being renovated. However, it was reported that only 58% of the buildings that collapsed during the earthquake were reconstructed during the two first years (Gautam, 2017). In line with the report by Gautam (2017), I observed during the fieldwork that many of the health facilities were still in the construction phase. Moreover, most facilities were renovated or got additional rooms rather than being completely reconstructed.

After the massive destruction of public health facilities, the Government of Nepal decided that the buildings that were to be constructed should be disability-friendly (NPC, 2015). My initial assumption was that the development agencies supporting Nepal would follow policies and practices promoting disability inclusive development in their reconstruction and renovation efforts of health facilities. However, similar to the National Federation of Disabled Nepal (NFDN) assertion "about the urgent need to address the needs of people with disability in Nepal (Paudel et al., (2016), my findings suggest that such efforts were limited. While ramps and wider doors were added to improve accessibility for individuals with mobility issues, there were few specific measures to enhance accessibility for persons with disabilities beyond these basic adaptations.

#### 5.2 Main findings and their implications

In the following, I discuss my findings according to the three main themes focusing on i) administrative level: federalism and its implications, ii) perceived accessibility challenges and iii) health service provisions respectively.

## 5.2.1 The Administrative level: Federalism and its implications

Federalism has shifted significant decision power to the local level of governance, including municipalities and their health divisions, enabling them to develop their own health plans, policies, and strategies for implementation (Acharya, 2018).

Moreover, because the local level government authorities could decide their priorities (Thapa et al., 2019), the development of local level plans and policies in the current scenario depended upon the needs, interests, and understanding of the local level authorities. Thus, there is a high chance that some matters get higher attention than others. In addition, the health coordinators had opportunities to put forward their proposal to make the health services more disability inclusive and increase access to health services. Thus, the prioritization of disability inclusiveness also depended upon the knowledge, practice, interest, and understanding of the health coordinators.

#### Bound to federal laws

The Local Government Operation Act gave autonomy to the local level governments to develop their own plans and policies. These should align with the federal and provincial laws and as Acharya discussed (2018), most of the municipalities of Sindhupalchok district were found adapting the "model laws" that the federal government formulated. This limited the contextualization of such legal provisions and an analysis of the capacity of the municipality to execute them as suggested by Acharya (2018) and Thapa et al. (2019).

Moreover, consistent with the discussion by Acharya (2018) and Thapa et al. (2019), the health coordinators reported a lack of clarity among the local level authorities about their power and limitations when it came to the formulation of local policies and acts.

## **Resource Constraints**

In my study, constraints were frequently mentioned in the documents of the Sindhupalchok district and budget constraints were reported by the health coordinators. According to the literature, this was also reported in many other local level governments in the nation (Acharya, 2018; Thapa et al., 2019).

The Local Government Operation Act <sup>27</sup> has outlined a comprehensive list of functions that the local governments are responsible for such as health, education, and infrastructure development (Thapa et al., 2019). However, the act did not ensure that the local governments have access to sufficient and sustainable revenue to fulfill their responsibilities (Acharya, 2018). This seems still to be true today, when budget constraints may lead to the de-prioritization of several matters including the inclusion of persons with disabilities in health service planning and delivery.

The interviews with the health coordinators also signified the gap in technical capacity, human resources, knowledge and skills to disseminate local laws among the local level authorities, something that also has been pointed out by Acharya (2018). According to the informants of the study, enhancing such capacities of the local government can ensure that the relevant and real needs of the health sector are planned and prioritized.

#### The role of the federal government

According to the health coordinators, few health programs and health services, such as immunization and vaccinations, and programs strictly advised by the federal government were implemented with greater priorities. This strategic approach aligns with the highlights by Thapa et al. (2019), wherein the conditional budget allocation from the federal government in the health sector at the local level was found useful in overcoming the issue of de-prioritization. If the federal government could set indicators for disability inclusion in healthcare (through both the targeted activities and mainstreaming) that the local levels must report to the federal level, the chances of applied disability inclusion may be higher.

# Multidimensional needs requiring multi-sectoral approaches

Access to health services among the informants with disabilities was found influenced by multiple factors such as socio-economic status, and this is confirmed by other studies. For instance,

<sup>27</sup> 

 $<sup>\</sup>underline{https://mofald.gov.np/sites/default/files/News\_Notices/\%E0\%A4\%B8\%E0\%A5\%8D\%E0\%A4\%A5\%E0\%A4\%BE\%E0\%A4\%A8\%E0\%A5\%80\%E0\%A4\%AF-$ 

<sup>%</sup>E0%A4%B8%E0%A4%B0%E0%A4%95%E0%A4%BE%E0%A4%B0-

<sup>%</sup>E0%A4%B8%E0%A4%9E%E0%A5%8D%E0%A4%9A%E0%A4%BE%E0%A4%B2%E0%A4%A8-

<sup>%20%</sup>E0%A4%90%E0%A4%A8%20.pdf

informants in the study had varied educational and income status and this affected their access to health services differently something confirmed by the findings of Eide et al. (2016) in four African countries (Sudan, Namibia, Malawi, and South Africa), Harrison et al. (2020) in Malawi and Devkota et al. (2018) in Nepal, who systematically relate degree of education and economic status the access to health services among persons with disabilities. In Sindhupalchok district, the reported lack of disability-friendly public transportation and the need for out-of-pocket expenses for specialized treatments, medicines, and equipment posed a great challenge for people with disabilities to access healthcare, despite the free primary healthcare services available in the district.

Thus, as recommendations drawn from Hashemi et al.'s (2022) study from low and middle-income countries, and in line with critical disability theory (Hosking, 2008), the multidimensional challenges faced by individuals with disabilities require a multi-sectoral approach that involves collaboration among different sectors such as health, education, transportation, and employment, for example.

As recommendations drawn from the study by Hashemi et al.(2022) and the approach suggested by critical disability theory (Hosking, 2008) addressing the multidimensional challenges faced by individuals with disabilities requires a multi-sectoral approach that involves collaboration among different sectors such as health, education, transportation, and employment.

## 5.2.2 Accessibility challenges

The current study's findings are mostly aligned with the general transportation, communication, inaccessible infrastructures, and affordability related challenges faced by people with disabilities while accessing health services.

#### Transportation barriers

The transportation barriers faced by the informants of the current study resemble the difficulties encountered by individuals in other regions of Nepal, as evidenced by studies conducted in the Western region of Nepal (Van Hees et al., 2015) and among women of Rupandehi district of (Hridaya Raj Devkota et al., 2018). Both studies found that there was a lack of disability-friendly public transportation and good roads to travel to the nearest health facilities. Additionally, being a disaster-prone area, the roads of Sindhupalchok district were frequently washed out, creating additional barriers in transportation.

# Accessibility inside the health facilities

As for the participants with physical impairments and vision related impairments, they mostly faced challenges in mobility and accessible infrastructure such as the availability of ramps. The experiences of the informants with mobility challenges of the current study resemble the findings of several previous studies such as those by Binder-Olibrowska et al. (2022), Hashemi et al. (2022), Hridaya Raj Devkota et al. (2018) and Torsha et al. (2022). Our informants reported structural barriers encountered by people with mobility impairments, such as with diagnostic equipment, and process barriers like procedural accommodation and flexibility, which are also discussed by Kroll, Jones, Kehn and Neri (2006).

The current study examined the physical accessibility of health facilities in the Sindhupalchok district and most results aligned with a study carried out in Brazil (Pinto et al., 2021). Similarly, the current study showed that the newly built health facilities and the ones providing secondary healthcare services like the municipal hospital and the district hospital had better accessibility compared to the health centers in the community. However, in contrast to the study in Brazil, the health facilities observed in this study were spacious. On the other hand, the health facilities of Sindhupalchok showed limited effort in terms of elevators and toilets similar to a study in Bangladesh (Torsha et al., 2022).

In the current study, we found that there is still room for improvement to make a health facility disability friendly, as the health facilities in Sindhupalchok appear to be improving at a slow pace, only beginning with making the health facilities accessible with wheelchairs and ramps. A study carried out in Rupandehi, Nepal by Devkota et al. (2018) reported that none of the health facilities under study had accessible buildings. The focus on ramps and wheelchair accessibility in the health facilities of the district resembles the findings of a study in Southern India (Nischith et al., 2018) as most health facilities in the district were reported to have ramps for wheelchairs, according to the study participants.

## Communication and Information dissemination

Effective communication plays an important role in ensuring the quality and right to health services among any group of the population. Healthcare providers need to understand and address the healthcare needs of their patients with disabilities. Communication barriers hinder access to appropriate care and limit the people with disabilities to rightly express their concerns.

The communication barrier in this study was reported significantly higher among the informants with hearing and speech disabilities, mirroring the findings reported by Van Hees et al. (2015). This reported communication barrier also significantly aligned with the findings of the literature review by Kuenburg et al. (2015) who found that persons with hearing and speech related impairments often had no one to translate for them in the health facilities and reported the health personnel lacking the knowledge of sign language. Additionally, persons with disabilities' right to information gets compromised if they cannot read or have vision related impairments as most health information is disseminated in written form.

Despite the varied socio-economic status and severity of the informants with disabilities, most of them were comfortable using their smartphones. This presents a significant opportunity to leverage smartphone technology to enhance access to healthcare services for this group of the population as most smartphones offer a range of features and applications that can be tailored to their unique need. Similar to the findings of Jahan et al. (2020), smartphones gave some level of autonomy to the participants and made information accessible through text-to-voice feature. This underscores the potential for smartphones to be used as assistive device that empowers persons with disabilities to have control over their access to information and communication.

#### Need of an accompanier

Both the informants with disabilities and health coordinators explained that the lack of disability inclusive health facilities and services forced individuals with disabilities to rely on their families and friends even for basic needs such as moving around and communications, as well as accessing services and facilities. The finding is consistent with the study conducted in the Western region of Nepal by Van Hees et al. (2015) which had outlined similar infrastructural barriers.

Dependency was also found related to several other factors such as the type of impairments, disability, distance to health facilities, accessible buildings and infrastructures, and education/awareness of both the service provider and the people with disabilities.

# The diversity of needs, challenges, and resources in disability

As emphasized by Hosking (2008), persons with disabilities are a diverse group with varied experiences and needs, making a one-size-fits-all approach ineffective. For instance, informants

with mobility challenges in the current study faced challenges due to the inaccessible building while those with speech and hearing related impairments faced communication difficulties.

In our study, informants emphasized the need to enhance wheelchair accessibility in health facilities, and a similar emphasis was found in a study in Bangladesh (Torsha et al., 2022). Since mobility issues were the most recognized disability in the district (GoN, 2023), such efforts show positive initiation to inclusion. However, other types of disability, such as blindness and people with hearing impairments have not received as much attention, which can lead to the exclusion and marginalization of individuals with other needs.

Thus, as stated by Hosking, treating disability as a monolithic category can lead to a lack of attention and resources directed towards individuals with less recognized disabilities. It is therefore important to value the diversity of disabilities and ensure that all individuals have access to the resources and accommodations they need to live full and meaningful lives (Hosking, 2008).

## 5.2.3 Health service provisions

While many studies carried out in Nepal reported insufficient or low quality of care and dissatisfaction towards the attitudes of the health workers, such as in studies by Devkota, Murray, Kett, & Groce (2017) and Shiwakoti et al. (2021), the informants of the current study were mostly satisfied and reported a positive attitude change encountered when receiving services.

The readiness of the service providers to prioritize persons with disabilities was mostly appreciated by the informants with disabilities. The findings reflect a pragmatic approach to providing health services to persons with disabilities. With limited resources and contextual demands, the service providers and the office helpers of the health facilities were reported by the informants to assist and accommodate the needs of persons with disabilities as per the availability of the resources. This approach however could foster the charity model of disability as the service providers and the helpers may view the persons with disabilities as people who first and foremost require support (Retief & Letšosa, 2018b). However, it may also be that health workers' norms evolve towards thinking more according to a human right approach, and the right of any person to receive proper health care.

Our study reports insufficient training and orientation of service providers, something that corresponds to other studies globally, as reported in the comprehensive review by Dassah et al.

(2018). The absence of such training potentially hinders the capacity of service providers to effectively communicate with and offer quality services to persons with disabilities.

Additionally, the "person first language" as suggested by person-centered care perspectives and by critical disability theory (Hosking, 2008) was reported to be in practice, something that can be attributed to the increased awareness/ advocacy programs of the government and of the non-government organizations. The interviews with health coordinators also indicated an increased awareness about the needs and rights of persons with disabilities among health professionals. The health coordinators also had a sound understanding of disability as a condition rather than a misfortune. Despite this, I could hear even persons with disabilities talking about persons without disabilities as "normal", a wording implying that individuals with disabilities are not comparable to "able-bodied" (Hosking, 2008; Retief & Letšosa, 2018b), thus potentially perpetuating the belief that disability is something abnormal or inferior. This signifies that though the model of disability has been shifted from a medical model to a social and right-based model, the medical model of disability that views persons with disabilities as those deviating from "normal" is still deeply rooted in Nepalese society (Retief & Letšosa, 2018b).

# 5.3 Limitations of the study

Though the study was conducted with the intention of reducing biases and errors, it is important to acknowledge certain limitations that emerged during the research process, as presented below.

#### a. Participant selection

Initially, informants with disabilities were recruited based on the recommendations from an NGO and through snowballing by fellow informants. This approach may have unintentionally favored individuals who had more access to public services, and who also had a better educational and economic situation. This may have skewed the findings, most probably an overestimation of the positive aspects of the healthcare system as perceived by the informants.

Additionally, the study aimed to understand the perspectives of informants with disabilities in general, accessing mostly the basic health services from the public health facilities in their municipality/ district. However, there were instances where service utilization was very low among the 10 informants. This aspect of the study design posed challenges in obtaining detailed and

varied results as focusing on specific health problems or more participants with particular disabilities could have provided more targeted and specific findings.

## b. Information bias

The research is mainly based on the responses of the two groups of participants: people with disabilities and health coordinators from various municipalities. For both groups, it could only be assumed that their answers were truthful. The social desirability of health workers to present themselves in a favorable light could have resulted in over representation of some topics and under representation in some areas. For instance, the health coordinators might have been inclined to highlight their effectiveness in delivering health services, showcasing their competence.

It is essential to acknowledge that the relationship between myself and the research assistant, and particularly with the health coordinators, could have influenced their responses. Though I did not feel that the informants were uncomfortable, the presence of both me and the research assistant could have impacted the comfort level of participants in disclosing information to two persons instead of one.

Additionally, the responses could also be affected by the recalling bias. There were instances where the participants had to recall events in the past and respond. Their ability to remember specific details or events could have been compromised.

#### c. Researcher bias

One important aspect of qualitative research is the possible influences of researcher bias. As a primary researcher, I bring my own understanding, experiences, and perception to the research topic. Similarly, the research assistant may also possess their own biases. As researchers, we employed measures such as reflexivity and positioning where we consistently reflected on our preconceptions and biases throughout the research. Nonetheless, there might have been areas where I influenced the data collection and interpretation. For instance, my familiarity with the context of the Sindhupalchok district and by extension, its healthcare provisions, could have led to subconsciously emphasizing responses that aligned with my preexisting viewpoints. To mitigate such biases, I time and again reminded myself about my preconceptions and positioning and reevaluated some methodological steps.

#### d. <u>Self-developed data collection tools</u>

I developed two interview guides (one for each group of informants) and one observation guideline for the health facilities. The interview guides were developed with extensive literature reviews and pre-tested among two participants of each group and kept improving during and along the interviews, it is important to acknowledge that the concerns regarding their overall validity and reliability may pertain.

The self-developed observation checklist also has some limitations that should be acknowledged. There were no clear standards made available within the governmental documents of Nepal regarding what constitutes a disability-friendly health facility. In the absence of such explicit guidelines, the guideline was developed based on a combination of other existing documents, literature, and reports, with guidance from my supervisors. The observation mostly aligned with the findings from the interviews with the informants. Nonetheless, there is a chance that the checklist may not have accurately captured all the intended phenomenon.

# e. <u>Translation and interpretation of interviews and legal documents</u>

One limitation of this study is the translation and interpretation of the interviews and the legal documents. The study was conducted in Nepal and all the interviews were conducted in Nepali and then the interviews were translated and transcribed. Even though Nepali is the national language, it was not the first language for many of the informants with various ethnic backgrounds. It is also important to realize that two of the interviews were conducted with sign language and then translated. There could have been a loss of information on how those responses were expressed in Nepali. Moreover, there were instances where the direct translation of Nepali to English would not make sense and there could have been a loss of meaning during translations.

The same was true in the context of the analysis of legal documents. They were written in Nepali and though the likelihood of missing meanings was minimal, the interpretation of texts could have potential omissions or errors.

#### f. The use of critical disability theory

As anticipated, the critical disability theory played an important role in helping understand disability inclusiveness in healthcare and the interaction of various physical, attitudinal and systematic factors (Hosking, 2008). However, the comprehensive nature of the theory led me to explore each dimension only to a certain extent.

While the study managed to cover various dimensions including the physical barriers, the political influences and service delivery, I could not delve deeply into any of the single dimensions. Consequently, the outcomes yielded to be more general.

## **5.4 Trustworthiness of the study**

Guba's construct of trustworthiness has been acknowledged and implied by many researchers to ensure the trustworthiness of a qualitative study (Hanson, Ju, & Tong, 2019; Shenton, 2004). I discuss the trustworthiness of the data based on Guba's four components, namely: credibility, dependability, confirmability, and transferability, as discussed by Shenton (2004).

## Credibility and dependability

Credibility refers to the extent to which the research findings and judgements made by the researcher are trustworthy (Enworo, 2023; Shenton, 2004), whereas dependability refers to the reliability and stability of data over time and conditions of the study. Though credibility and dependability slightly differ from one another, they are closely connected according to Lincoln and Guba and usually ensuring credibility contributes to ensuring dependability (Shenton, 2004).

As cited by Enworo, Guba and Lincoln argue that credibility is achieved through prolonged engagement, triangulation, peer debriefing, persistent observation, negative case analysis, referential adequacy and member checks (2023). Likewise, dependability is enhanced when the research process is logical and transparent, which is further attained through credibility and triangulation (Enworo, 2023). By adhering to these principles, I ensured that the current study is dependable and credible.

To understand the context, I stayed in the study area for two months as well as I knew it from previous times. I developed familiarity with the area, the working modalities of the health facilities and the municipalities and lifestyles of the study population. This also helped me establish trust and build relationships with the participants.

The authenticity of the research was a concern throughout the study, specifically during interviews. As suggested by Shenton (2004), I applied certain measures to help ensure honesty during the interviews. Before beginning to conduct interviews, I and my research assistant discussed the importance of allowing the participants to be authentic in their responses. I made sure that the participants understood the purpose of the interview and assured them that there were no right or wrong answers to the questions being asked.

We gave participants enough time and space to respond and reflect freely during the interviews. We patiently waited, repeated, and paraphrased questions whenever necessary. We avoided asking leading questions and restricted ourselves from providing any positive or negative feedback after their answers. Additionally, to make sure that the participants were responding to what they wanted to communicate, we would confirm their answers by asking "So you said ....., is this correct?"

The findings from the in-depth interviews were enriched with the observations of the health facilities and the analysis of legal documents of the municipalities facilitated the triangulation of the data and aided in understanding a more real scenario. Additionally, through interviews with two distinct groups of informants (health coordinators as health service managers and people with disabilities as service utilizers), we were able to capture different perspectives and experiences related to disability inclusive health services which further helped in verifying the findings and enhancing the credibility of the research.

## **Transferability**

According to Creswell (2014a), qualitative studies do not intend to generalize the study findings to individuals or sites outside those under study. However, as Stake and Denscombe (as cited by Shenton, 2004) argue, although each case is unique, it still represents a broader group, and some generalization is not entirely impossible.

The current study is based on the findings of one district with distinct geographical features. Nevertheless, this kind of geographical setting is common in many other districts of Nepal. Additionally, the government health system and the local government structures of the municipalities and the rural municipalities of the Sindhupalchok district resemble many other districts in Nepal. Thus, the study findings can be helpful to understand the situation in other districts as they share a background similar to the Sindhupalchok district. Nevertheless, it is important to note that the individual experience of people with disabilities in accessing health services in their municipality may vary and that 10 informants were not many. Also, the inclusivity of the legislation in specific municipalities may depend upon unique circumstances (such as the availability of funds) that are not transferable.

To ensure transferability in the present study, I have supported the findings with a detailed description of the context, location and people studied. Since transferability also depends upon

being transparent about analysis and trustworthiness, I have applied measures to ensure trustworthiness as discussed earlier.

# Confirmability

Confirmability as discussed by Shenton (2004) is associated with the researcher's concern for objectivity in the research and it is the degree to which the findings and interpretations are not influenced by the researcher's perspectives, biases or preconceptions. To avoid my own biases, I practiced reflexivity throughout the research. I was conscious of evaluating whether the data I collected, transcribed, and interpreted were trustworthy. I ensured that I was not biasing the responses of my informants during the interviews.

Additionally, a few other strategies were implemented to enhance the quality of the data. One such was the use of a member check which involved sharing the findings of the study with two participants with disabilities and a health coordinator. The member check allowed for their input and validation of the accuracy of the findings based on their experience.

Peer debriefing was another strategy I employed. During the translation- transcription and analysis of the data, regular discussions with the research assistant were held to ensure consistency and alignment in identifying matching patterns and themes. Moreover, the study underwent a peer review process by another student researcher who was also conducting a similar kind of qualitative study. The critical feedback on the methodology, analysis and interpretation received from the peer review contributed to enhancing the quality, trustworthiness, and confirmability of the study. Regular discussions with my supervisors also played a significant role in improving the confirmability of the study.

#### **CHAPTER VI: CONCLUSION**

This section concludes the major findings of the study in terms of the research objective. The study aimed to recognize the opportunities and challenges of developing a disability inclusive healthcare system and services in the municipalities of Sindhupalchok district, and the findings of this study are summarized below.

# Challenges in achieving disability inclusive healthcare at the local (municipal) level

One of the prime challenges identified in the study is related to the external factors that impact individuals with disabilities' access to healthcare. The limitations within the transportation, communication, financial resources, and other infrastructures within health facilities require them to depend on their family members or caretakers even for general healthcare. The government of Nepal has defined disability in terms of people's ability to perform their tasks independently but apparently, the current government provisions do not support the autonomy of those with disabilities in receiving even general health services. Thus, disability inclusive development is crucial for ensuring disability inclusive healthcare.

Furthermore, the study revealed that the healthcare workers and the managers of the health system at local levels were not trained or oriented to effectively accommodate the needs of people with disabilities. For quality and accessible services, it is essential to incorporate disability related training and orientations in their on-the-job training programs to address the diverse needs of individuals with hearing and speech disabilities.

Another crucial obstacle lies in the lack of awareness among people with disabilities about their health rights and their entitlements. This knowledge gap can impact their access to healthcare resources and support. Though a gradual change in the attitude and language used for individuals with disabilities themselves and by health professionals was observed, the provision of dignified care remains an ongoing challenge that requires continued advocacy efforts.

Additionally, the lack of data-driven planning poses a significant challenge in achieving disability inclusive healthcare. The health system lacks the recording and reporting of the service utilization data of people with disabilities and without the segregated disability related data, their health needs can only be assumed. Availability of such data is crucial in designing effective health programs and ensuring equitable access to healthcare.

Lastly, the current health system faces the challenge of deprioritization at the local level. Besides the priority programs enforced by the federal government, decision making powers lie with the local level authorities and this introduces the risk of bias and potential inequalities in the planning and implementation of any healthcare initiatives. The extent to which the health services are made inclusive now relies heavily on the knowledge, interests, and perceived needs of the decision-making authorities at the municipalities. It is thus essential to aware the local level actors such as the elected bodies (Mayors and Chairpersons), health coordinators, women and children division, persons with disabilities and committees/organizations working for persons with disabilities on disability related issues and to establish a robust check and balance system to minimize personal biases and interests in the decision-making process.

The national constitution, policies, guidelines, and other legal provisions demonstrate a comprehensive and inclusive approach towards addressing the needs of people with disabilities in accessing healthcare, the challenge is in its contextualization and implementation by the local levels of the government. It has been observed that unless the federal government strictly enforces it and provides necessary resources, many of the policies and strategies remain unadopted or poorly implemented. Regular supervision and monitoring along with clear guidance would help bridge the gap between policy and practice.

Addressing these challenges, it would be possible to work towards achieving disability inclusive healthcare that caters to the unique needs of individuals with disabilities at the local level.

## Opportunities to ensure disability inclusive healthcare at the local level

There are three specific opportunities identified in the study that can contribute to enhancing healthcare accessibility for people with disabilities. Firstly, the use of technology, particularly smartphones, presents a promising opportunity. Important information can be disseminated through mobile applications and platforms that empower persons with disabilities to make informed decisions about their health while experiencing independence. Additionally, an online platform can provide them with opportunities to participate in the local level planning and decision-making processes, allowing their voices to be heard and taken into account and put their voice in the local level planning and decision-making events. However, it is important to be thoughtful of the competence of individuals using such technology.

Secondly, a critical opportunity identified in the present study is related to federalism. Federalism and the recent local level election have provided a lot of opportunities for ensuring disability inclusion in the health sector. The municipalities now can contextualize the policy and guidelines of the federal government and define their own priorities and standards of care. They can develop and implement strategies to make healthcare disability friendly as per the context's needs and available resources.

The third opportunity for disability inclusive healthcare also extends within the realm of federalism. The local levels have recently started practicing their power for the development of their respective municipalities. The primary focus at many local levels has been infrastructure development. This presents a timely opportunity to enforce disability inclusion and ensure that infrastructure such as roads, transportation and buildings is designed to meet the needs of individuals with disabilities.

#### The current status of disability inclusivity in healthcare at the local level

Despite the numerous challenges observed in the district, the study findings indicate commendable efforts and resilience displayed by the service providers, caretakers of the individuals with disabilities, Municipal Health coordinators and the municipalities as a whole in addressing the situation to the best of their abilities. The stakeholders have demonstrated a positive and pragmatic approach to navigating the limitations of the healthcare system to ensure that persons with disabilities receive the same level of care as those without disabilities.

A gradual slow pace of improvement is noticed, and this could be the appropriate time to reinforce the legal guidelines. A gentle push in the form of continued resources, support, capacity building and policy reinforcement is required to sustain and enhance the efforts of the stakeholders for improvements in disability inclusive healthcare. This will empower and enable these stakeholders to achieve truly accessible and inclusive healthcare catering to the unique needs of individuals with disabilities.

#### Recommendation for future research

For future research, a detailed assessment of the status of local level healthcare system and services based on WHO's measures would be effective to add to the challenges, successes, and gaps in disability inclusion. It is important to analyze other interrelated factors impacting disability

inclusion in health, such as disability ID card distribution, health insurance, and community-based rehabilitation.

Additionally, research that focuses on the scope of federalism and its implication for mainstreaming disability inclusion at all levels of government would contribute to a deeper understanding of the dynamics between the three tiers: federal, provincial and the local (Municipal) level of the government.

# **TABLES AND FIGURES**

# 1. Classification of disabilities as per the Government of Nepal

Table 4: Classification of Disabilities according to the problem and difficulty in any organ or system of the body, defined by the Government of Nepal (2017a).

S.N.	Classification of Disability	Description
1.	Physical disability	Problems in the operation of the physical parts, use and
		movement
2.	Disability related to vision	Includes blindness, low vision, and total absence of sight
3.	Disability related to hearing	Includes people who are deaf and have hard of hearing
4.	Deaf- Blind	Persons without both hearing and vision
5.	Disability related to voice	Includes difficulties raising and lowering the voice,
	and speech	trouble speaking clearly, and repeating words and letters.
6.	Mental or psycho-social	Inability to behave one's age and situation and delay in
	disability	intellectual learning, performing intellectual activities,
		problems in the brain and mental parts and awareness,
		orientation, alertness, memory, language, and calculation
7.	Intellectual disability	Problems in carrying out age or environment relative
		activity, due to the lack of intellectual development
8.	Disability associated with	A genetic condition that arises problems in the blood
	haemophilia	clotting due to the deflection in blood factors
9.	Disability associated with	Problem in the development of veins or tissues and
	autism	functionality thereof such as difficulty communicating,
		repetition of the same activity, difficulty in understanding
		& applying social rules and does not assimilate with
		others.
10.	Multiple disability	Having two or more types of disability mentioned above

# 2. Prevalence of disability in Nepal

Table 5: Prevalence and types of disability in Nepal according to Census 2021 (GoN, 2023)

Total 1	Population	29,164578
Total ]	persons with disability	647744
Disabi	llity prevalence	2.2%
S.N.	Disability by type	Percentage
1	Physical disability	37.1%
2	Low vision	17.1%
3	Blind	5.4%
4	Deaf	7.9%
5	Psycho-social disability	4.3%
6	Hard of Hearing	8%
7	Deaf and blind	1.6%
8	Speech impairment	6.4%
9	Intellectual disability	1.8%
10	Hemophilia	0.8%
11	Autism	0.8%
12	Multiple disability	8.9%

# 3. Type of government health institutes and their services at the local level

Table 6: Type of health institutes/ facilities and the service provided at different local levels of government (GoN, 2017b)

Level of	Type of health	Services provided
local	service	
government	delivery	
	institution	
Ward level	Health post and	Immunization, family planning, ante-natal care, normal delivery,
of Village or	Community	new-born care, nutrition counseling, Treatment of TB and other
urban	Health Unit	common communicable diseases and conditions, management of
Municipality		epidemic, basic mental health service, counseling, screening and
		primary treatment of non-communicable diseases, medicine
		distribution, pathology lab and other diagnostic services,
		promotion and prevention of eye/sight and dental problems
Ward of	Urban Health	Immunization; nutrition counseling; Promotion and prevention
Metropolitan	Promotion	and primary treatment of non-communicable diseases; Family
City / Sub	Center	planning; Adolescent reproductive and sexual health services;
Metropolitan		Psychosocial counseling; geriatric counseling; Health Inspection
City		Services to protect and promote the health and environment
Rural	Primary	Basic health services
Municipality	Hospital, Class	• Immunization, family planning, ante-natal care, normal
	В	delivery, new-born care, nutrition counseling, Treatment of TB
		and other common communicable diseases and conditions,
		management of epidemic, basic mental health service,
		counseling, screening and primary treatment of non-
		communicable diseases, medicine distribution, pathology lab and
		other diagnostic services, promotion and prevention of eye/sight
		and dental problems; and other diagnostic, curative, promotive,
		and preventive basic health services defined by the federal
		Ministry of Health.

		Social Service Unit
		Medical services
		Common gynecological and obstetric services
		• Out Patient Department (OPD) services;
		Comprehensive emergency obstetric and neonatal care
		(CEONC)
		Basic Surgery Services
		Primary treatment for eye/sight and dental problems
		• 24-hour emergency service.
Municipality	Primary	Basic health services
or Sub-	Hospital, Cl	
metropolitan	A	delivery, new-born care, nutrition counseling, Treatment of TB
or		and other common communicable diseases and conditions,
Metropolitan		management of epidemic, basic mental health service,
city		counseling, screening and primary treatment of non-
		communicable diseases, medicine distribution, pathology lab and
		other diagnostic services, promotion and prevention of eye/sight
		and dental problems; and other diagnostic, curative, promotive,
		and preventive basic health services defined by the federal
		Ministry of Health.
		Social Service Unit
		Medical services
		• Outpatient Service: General Medicine, Gynecology and
		Obstetrics, Pediatric and Orthopedic Services
		• 24-hour emergency service,
		• Treatment for eye/sight and dental problems,
		Comprehensive emergency obstetric and neonatal care
		(CEONC), specialized and major Surgery Services including
		Orthopedic Surgeries.

# 4. Relevant pictures from field observations



Figure 7: Settlement at Melamchi Municipality



Figure 8: Location of one of the health post observed during travel



Figure 9: Chautara District Hospital, Chautara Sangachokgadi Municipality



Figure 10: Helambu Health Centre, Helambu Rural Municipality



Figure 11: Nawalpur Primary Hospital, Indrawati Rural Municipality



Figure 12: Melamchi Municipality Hospital, Melamchi Municipality



Figure 13: OPD/ in-patient bed in Helambu Health Centre



Figure 14: Waiting area of Nawalpur Primary
Hospital



Figure 15: Disability-friendly Toilet of Nawalpur Primary Hospital



Figure 16: A plastic chair modified to use as a toilet seat



Figure 17: OPD/ in-patient bed in Helambu Health Centre



Figure 18: IEC corner at Chautara District Hospital

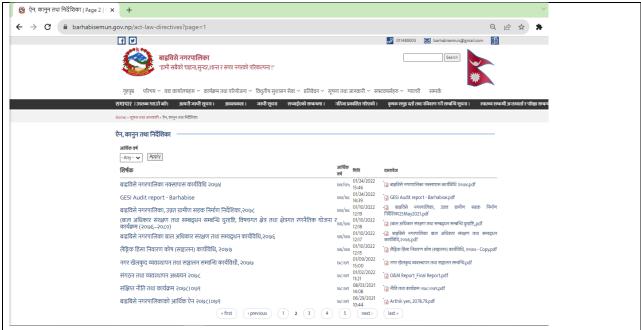


Figure 19: Website of Barhabise Municipality where the local laws, policies and information were published

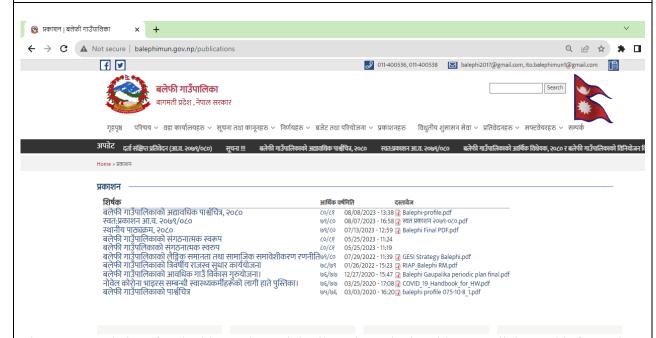


Figure 20: Website of Balephi Rural Municipality where the local laws, policies and information were published.

(The second publication displayed here is the implementation guideline of disability ID card distribution and the sixth one is the GESI strategy)

#### REFERENCES

- Acharya, K. K. (2018). Local Governance Restructuring in Nepal: From Government to Governmentality. *Dhaulagiri Journal of Sociology and Anthropology*, 12(0), 37-49. doi:10.3126/dsaj.v12i0.22178
- Arne H Eide, H. M., Mustafa Khogali, Gert Van Rooy, , Leslie Swartz, A. M., Karl-Gerhard Hem, Malcolm MacLachlan,, & Dyrstad, K. (2015). Perceived barriers for accessing health services among individuals with disability in four African countries. *PLoS One*, 10(5), e0125915. Retrieved from <a href="https://pubmed.ncbi.nlm.nih.gov/25993307/">https://pubmed.ncbi.nlm.nih.gov/25993307/</a>
- Arstein-Kerslake, A., & Black, J. (2020). Right to legal capacity in therapeutic jurisprudence: Insights from critical disability theory and the convention on the rights of persons with disabilities. *International Journal of Law and Psychiatry*, 68, 101535. doi:https://doi.org/10.1016/j.ijlp.2019.101535
- Attride-Stirling, J. (2001). Thematic networks: an analytic tool for qualitative research. *Qualitative research*, *I*(3), 385-405.
- Baral, R. (2018). Historical policy review on disability. *Research Nepal Journal of Development Studies (RNJDS)*, 1(1), 73-82.
- Bimali, I., Adhikari, S. P., Baidya, S., & Shakya, N. R. (2018). Impairment and Functional Status of People with Disabilities Following Nepal Earthquake 2015. *Kathmandu Univ Med J* (KUMJ), 16(64), 285-289.
- Binder-Olibrowska, K. W., Godycki-Ćwirko, M., & Wrzesińska, M. A. (2022). "To Be Treated as a Person and Not as a Disease Entity"-Expectations of People with Visual Impairments towards Primary Healthcare: Results of the Mixed-Method Survey in Poland. *Int J Environ Res Public Health*, 19(20). doi:10.3390/ijerph192013519
- Bowers, B., Esmond, S., Lutz, B., & Jacobson, N. (2003). Improving Primary Care for Persons with Disabilities: The nature of expertise. *Disability & Society*, 18(4), 443-455. doi:10.1080/0968759032000080995
- Briggs, A. M., Shiffman, J., Shawar, Y. R., Åkesson, K., Ali, N., & Woolf, A. D. (2020). Global health policy in the 21st century: Challenges and opportunities to arrest the global disability burden from musculoskeletal health conditions. *Best Practice & Research Clinical Rheumatology*, *34*(5), 101549. doi:https://doi.org/10.1016/j.berh.2020.101549
- Bright, T., & Kuper, H. (2018). A Systematic Review of Access to General Healthcare Services for People with Disabilities in Low and Middle Income Countries. *International Journal of Environmental Research and Public Health*, 15(9), 1879. Retrieved from <a href="https://www.mdpi.com/1660-4601/15/9/1879">https://www.mdpi.com/1660-4601/15/9/1879</a>
- BYAN. (2015). Nepal and Disability. Retrieved from <a href="https://www.byanepal.org/who-we-are/nepal-and-disability/">https://www.byanepal.org/who-we-are/nepal-and-disability/</a>
- Casebolt, M. T. (2020). Barriers to reproductive health services for women with disability in lowand middle-income countries: A review of the literature. *Sexual & Reproductive Healthcare*, 24, 100485. doi:https://doi.org/10.1016/j.srhc.2020.100485
- Corby, N., & Bermejo, R. (2022). *Inclusion of children and young people with disabilities in routine* general healthcare. Retrieved from <a href="https://www.unicef.org/media/127496/file/Disability\_Inclusion\_in\_Routine\_General\_Health\_Care">https://www.unicef.org/media/127496/file/Disability\_Inclusion\_in\_Routine\_General\_Health\_Care</a> Practice Guide 2022.pdf
- Creswell, J. W. (2014a). Qualitative Methods. In *Research design : qualitative, quantitative, and mixed methods approaches* (4th ed.

- International student ed. ed.). Los Angeles, Calif: SAGE.
- Creswell, J. W. (2014b). Research design: qualitative, quantitative, and mixed methods approaches (4th ed.; International student ed. ed.). Los Angeles, Calif: SAGE.
- Dassah, E., Aldersey, H., McColl, M. A., & Davison, C. (2018). Factors affecting access to primary health care services for persons with disabilities in rural areas: a "best-fit" framework synthesis. *Global Health Research and Policy*, 3(1), 36. doi:10.1186/s41256-018-0091-x
- Devkota, H. R., Murray, E., Kett, M., & Groce, N. (2017). Healthcare provider's attitude towards disability and experience of women with disabilities in the use of maternal healthcare service in rural Nepal. *Reprod Health*, *14*(1), 79. doi:10.1186/s12978-017-0330-5
- Devkota, H. R., Murray, E., Kett, M., & Groce, N. (2018). Are maternal healthcare services accessible to vulnerable group? A study among women with disabilities in rural Nepal. *PLoS One*, *13*(7), e0200370.
- Devlin, R. F., & Pothier, D. (2006). Critical disability theory: Essays in philosophy, politics, policy, and law: UBC press.
- DFID. (2000). *Disability, poverty and development*. Retrieved from United Kingdom: <a href="https://hpod.law.harvard.edu/pdf/Disability-poverty-and-development.pdf">https://hpod.law.harvard.edu/pdf/Disability-poverty-and-development.pdf</a>
- DoHS. (2020). *Annual Report: Department of Health Services 2057/76 (2018/2019)*. Retrieved from Nepal: <a href="https://dohs.gov.np/wp-content/uploads/2020/11/DoHS-Annual-Report-FY-075-76-.pdf">https://dohs.gov.np/wp-content/uploads/2020/11/DoHS-Annual-Report-FY-075-76-.pdf</a>
- Eide, A. H., Neupane, S., & Hem, K. G. (2016). *Living conditions among people with disability in Nepal*. Retrieved from Trondheim, Norway: <a href="https://www.sintef.no/globalassets/sintef-a27656-nepal-printversionfinal.pdf/">https://www.sintef.no/globalassets/sintef-a27656-nepal-printversionfinal.pdf/</a>
- Enfield, S. (2018). Mainstreaming disability and making WASH programmes inclusive.
- Enworo, O. C. (2023). Application of Guba and Lincoln's parallel criteria to assess trustworthiness of qualitative research on indigenous social protection systems. *Qualitative Research Journal, ahead-of-print*(ahead-of-print). doi:10.1108/QRJ-08-2022-0116
- Faeth, E. M. (2021). Agency, Power, and Disability: A Textual Analysis of The Silence Between Us. *Children's Literature in Education*, *52*(4), 433-448. doi:10.1007/s10583-021-09453-w
- Gautam, M. (2017). Only a quarter of damaged health facilities rebuilt. *The Kathmandu Post*. Retrieved from <a href="https://kathmandupost.com/miscellaneous/2017/04/05/only-a-quarter-of-damaged-health-facilities-rebuilt">https://kathmandupost.com/miscellaneous/2017/04/05/only-a-quarter-of-damaged-health-facilities-rebuilt</a>
- GoN. (2017a). *The Act Relating to Rights of Persons with Disabilities, 2074 (2017)*. Retrieved from Nepal: <a href="https://www.lawcommission.gov.np/en/wp-content/uploads/2019/07/The-Act-Relating-to-Rights-of-Persons-with-Disabilities-2074-2017.pdf">https://www.lawcommission.gov.np/en/wp-content/uploads/2019/07/The-Act-Relating-to-Rights-of-Persons-with-Disabilities-2074-2017.pdf</a>
- GoN. (2017b). *Nepal Health Infrastructure Development Standards 2017*. Retrieved from Ramshahpath, Kathmandu: <a href="https://www.nhssp.org.np/Resources/HI/HI\_Dev\_Standards\_2074BS\_Unofficial\_Translation\_Volume4.pdf">https://www.nhssp.org.np/Resources/HI/HI\_Dev\_Standards\_2074BS\_Unofficial\_Translation\_Volume4.pdf</a>
- GoN. (2019a). *The fifteenth plan (fiscal year 2019/2020/2023/24)*. Retrieved from Singhadurbar, Kathmandu: <a href="https://www.npc.gov.np/images/category/15th">https://www.npc.gov.np/images/category/15th</a> plan <a href="mailto:English">English</a> Version.pdf
- GoN. (2019b). *National Guidelines for Disability Inclusive Health Services, 2019*. Retrieved from Kathmandu,
  Nepal:
  <a href="https://www.nhssp.org.np/Resources/GESI/Disability%20Inclusive%20Guidelines%20English%20-%20FINAL-2019.pdf">https://www.nhssp.org.np/Resources/GESI/Disability%20Inclusive%20Guidelines%20English%20-%20FINAL-2019.pdf</a>
- GoN. (2023). *National Population and Housing Census 2021: National report*. Retrieved from Thapathali, Kathmandu: <a href="https://censusnepal.cbs.gov.np/results/downloads/national">https://censusnepal.cbs.gov.np/results/downloads/national</a>

- Groce, N. E. (2018). Global disability: an emerging issue. *The Lancet Global Health*, 6(7), e724-e725.
- Grue, J. (2019). Inclusive Marginalisation? A Critical Analysis of the Concept of Disability, Its Framings and Their Implications in the United Nations Convention on the Rights of Persons with Disabilities. *Nordic Journal of Human Rights*, 37(1), 3-17. doi:10.1080/18918131.2019.1589165
- Hall, M. C., & Zalta, E. N. (2019). Stanford Encyclopedia of Philosophy. *Critical disability theory*. Hanson, C. S., Ju, A., & Tong, A. (2019). Appraisal of Qualitative Studies. In P. Liamputtong (Ed.), *Handbook of Research Methods in Health Social Sciences* (pp. 1013-1026). Singapore: Springer Singapore.
- Harrison, J. A. K., Thomson, R., Banda, H. T., Mbera, G. B., Gregorius, S., Stenberg, B., & Marshall, T. (2020). Access to health care for people with disabilities in rural Malawi: what are the barriers? *BMC Public Health*, 20(1), 833. doi:10.1186/s12889-020-08691-9
- Hashemi, G., Wickenden, M., Bright, T., & Kuper, H. (2022). Barriers to accessing primary healthcare services for people with disabilities in low and middle-income countries, a Meta-synthesis of qualitative studies. *Disability and Rehabilitation*, 44(8), 1207-1220. doi:10.1080/09638288.2020.1817984
- Hosking, D. L. (2008). Critical disability theory. A paper presented at the 4th biennial disability studies conference at Lancaster University, UK, Sept. 2-4, 2008. *Journal of Consulting and Clinical Psychology*, 72(3), 467-478.
- Jackson, M. A. (2018). Models of Disability and Human Rights: Informing the Improvement of Built Environment Accessibility for People with Disability at Neighborhood Scale? *Laws*, 7(1), 10. Retrieved from <a href="https://www.mdpi.com/2075-471X/7/1/10">https://www.mdpi.com/2075-471X/7/1/10</a>
- Jahan, N., Barbareschi, G., Jan, C. A., Mutuku, C. M., Rahman, N., Austin, V., & Holloway, C. (2020). *Inclusion and Independence: The impact of mobile technology on the Lives of persons with disabilities in Kenya and Bangladesh*. Paper presented at the 2020 IEEE Global Humanitarian Technology Conference (GHTC).
- Kc, H. (2016). Disability Discourse in South Asia and Global Disability Governance. *Canadian Journal of Disability Studies*, 5(4), 25-62. doi:10.15353/cjds.v5i4.314
- Kroll, T., Jones, G. C., Kehn, M., & Neri, M. T. (2006). Barriers and strategies affecting the utilisation of primary preventive services for people with physical disabilities: a qualitative inquiry. *Health & social care in the community, 14*(4), 284-293.
- Kuenburg, A., Fellinger, P., & Fellinger, J. (2015). Health Care Access Among Deaf People. *The Journal of Deaf Studies and Deaf Education*, 21(1), 1-10. doi:10.1093/deafed/env042
- Kuper, H., Hameed, S., Reichenberger, V., Scherer, N., Wilbur, J., Zuurmond, M., . . . Shakespeare, T. (2021). Participatory research in disability in low-and middle-income countries: what have we learnt and what should we do? *Scandinavian Journal of Disability Research*, 23(1), 328-337.
- McClintock, H. F., Kurichi, J. E., Barg, F. K., Krueger, A., Colletti, P. M., Wearing, K. A., & Bogner, H. R. (2018). Health care access and quality for persons with disability: Patient and provider recommendations. *Disability and Health Journal*, 11(3), 382-389. doi:https://doi.org/10.1016/j.dhjo.2017.12.010
- Miller, C., & Albert, B. (2005). *Mainstreaming disability in development: Lessons from gender mainstreaming*. Retrieved from <a href="https://assets.publishing.service.gov.uk/media/57a08c5be5274a27b2001147/RedPov\_gen\_der.pdf">https://assets.publishing.service.gov.uk/media/57a08c5be5274a27b2001147/RedPov\_gen\_der.pdf</a>

- Mji, G., Braathen, S. H., Vergunst, R., Scheffler, E., Kritzinger, J., Mannan, H., . . . Visagie, S. (2017). Exploring the interaction of activity limitations with context, systems, community and personal factors in accessing public health care services: A presentation of South African case studies. *Afr J Prim Health Care Fam Med*, 9(1), e1-e9. doi:10.4102/phcfm.v9i1.1166
- MoF. (2022). *Budget Speech of Fiscal Year 2022/23*. Retrieved from Nepal: <a href="https://www.mof.gov.np/uploads/document/file/1656476715\_Budget%20Translation%20">https://www.mof.gov.np/uploads/document/file/1656476715\_Budget%20Translation%20</a> 031379%20cv.pdf
- MoHP. (2019). *National Health Policy 2019*. Retrieved from Ramshahpath, Nepal: <a href="https://publichealthupdate.com/national-health-policy-2019-nepal/">https://publichealthupdate.com/national-health-policy-2019-nepal/</a>
- MoHP, ERA, N., & ICF. (2022). *Nepal demographic and health survey 2022: Key indicators report*. Retrieved from Kathmandu, Nepal: https://dhsprogram.com/pubs/pdf/PR142/PR142.pdf
- Mullan, Z. (2015). Rebuilding Nepal. The Lancet Global Health, 3(11), e654.
- Nepal in data. (2018). Administrative map- Sindhupalchok, Province 3. Retrieved from <a href="https://nepalindata.com/resource/Administrative-Map---Sindhupalchok--Province-3/#">https://nepalindata.com/resource/Administrative-Map---Sindhupalchok--Province-3/#</a>
- Nickerson, C. (2022). Understanding Critical Theory. Retrieved from www.simplypsychology.org/critical-theory.html
- Nischith, K. R., Bhargava, M., & Akshaya, K. M. (2018). Physical accessibility audit of primary health centers for people with disabilities: An on-site assessment from Dakshina Kannada district in Southern India. *J Family Med Prim Care*, 7(6), 1300-1303. doi:10.4103/jfmpc.jfmpc 177 18
- NPC. (2015). *Post Disaster Needs Assessment*. Retrieved from Nepal: https://www.npc.gov.np/images/category/PDNA volume BFinalVersion.pdf
- Oliver, M. (1998). Theories in health care and research: theories of disability in health practice and research. *Bmj*, 317(7170), 1446-1449. doi:10.1136/bmj.317.7170.1446
- Padam Prasad, S., & Sharada Prasad, W. (2021). Opportunities and Challenges for effective implementations of Karnali Province Health Policy. *Europasian Journal of Medical Sciences*, 3(1). doi:10.46405/ejms.v3i1.312
- Paudel, Y. R., Dariang, M., Keeling, S. J., & Mehata, S. (2016). Addressing the needs of people with disability in Nepal: The urgent need. *Disability and Health Journal*, 9(2), 186-188. doi:https://doi.org/10.1016/j.dhjo.2016.01.004
- Pinto, A., Köptcke, L. S., David, R., & Kuper, H. (2021). A National Accessibility Audit of Primary Health Care Facilities in Brazil—Are People with Disabilities Being Denied Their Right to Health? *International Journal of Environmental Research and Public Health*, 18(6), 2953. Retrieved from https://www.mdpi.com/1660-4601/18/6/2953
- Public Health Update. (2020). Organogram and Reporting Mechanism of Nepalese Health System in Federal Context. Retrieved from <a href="https://www.publichealthupdate.com/organogram-and-reporting-mechanism-of-nepalese-health-system-in-federal-context/">https://www.publichealthupdate.com/organogram-and-reporting-mechanism-of-nepalese-health-system-in-federal-context/</a>
- RAP3. (2018). Sindhupalchok district profile.
- Retief, M., & Letšosa, R. (2018a). Models of disability: A brief overview. *Hervormde Teologiese Studies*, 74(1). doi: http://dx.doi.org/10.4102/hts.v74i1.4738
- Retief, M., & Letšosa, R. (2018b). Models of disability: A brief overview. HTS Teologiese Studies/Theological Studies, 74(1).
- Rocco, T. S. (2005). From disability studies to critical race theory: Working towards critical disability theory.

- Rogers, K. (2023). Disability inclusive health care has mountains to climb. *Devex*. Retrieved from <a href="https://devex.shorthandstories.com/disability-inclusive-health-care-nepal/index.html">https://devex.shorthandstories.com/disability-inclusive-health-care-nepal/index.html</a>
- Rohwerder, B. (2020). *Disability Inclusive Development Nepal Situational Analysis: June 2020 update*. Retrieved from UK: <a href="https://opendocs.ids.ac.uk/opendocs/bitstream/handle/20.500.12413/15510/DID%20Nepa1%20SITAN\_June%202020.pdf?sequence=1">https://opendocs.ids.ac.uk/opendocs/bitstream/handle/20.500.12413/15510/DID%20Nepa1%20SITAN\_June%202020.pdf?sequence=1</a>
- Sakellariou, D., & Rotarou, E. S. (2017). Access to healthcare for men and women with disabilities in the UK: secondary analysis of cross-sectional data. *BMJ Open*, 7(8), e016614. doi:10.1136/bmjopen-2017-016614
- Sapkota, S., Panday, S., Wasti, S. P., Lee, A., Balen, J., van Teijlingen, E., . . . Karki, J. (2022). Health System Strengthening: The Role of Public Health in Federal Nepal. *Journal of Nepal Public Health Association (JNEPHA)*, 7(1), 36-42.
- Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for information*, 22(2), 63-75.
- Shiwakoti, R., Gurung, Y. B., Poudel, R. C., Neupane, S., Thapa, R. K., Deuja, S., & Pathak, R. S. (2021). Factors affecting utilization of sexual and reproductive health services among women with disabilities- a mixed-method cross-sectional study from Ilam district, Nepal. *BMC Health Services Research*, 21(1), 1361. doi:10.1186/s12913-021-07382-4
- Sindhupalchok, D. (2023). Brief Introduction. Retrieved from <a href="https://dccsindhupalchowk.gov.np/en/brief-introduction/">https://dccsindhupalchowk.gov.np/en/brief-introduction/</a>
- Sztobryn-Giercuszkiewicz, J. (2017). Critical Disability Theory as a theoretical framework for disability studies. In (pp. 29-35).
- Thapa, R., Bam, K., Tiwari, P., Sinha, T. K., & Dahal, S. (2019). Implementing Federalism in the Health System of Nepal: Opportunities and Challenges. *Int J Health Policy Manag*, 8(4), 195-198. doi:10.15171/ijhpm.2018.121
- Torsha, N., Rahman, F. N., Hossain, M. S., Chowdhury, H. A., Kim, M., Rahman, S. M. M., . . . Rahman, A. (2022). Disability-friendly healthcare at public health facilities in Bangladesh: a mixed-method study to explore the existing situation. *BMC Health Services Research*, 22(1), 1178. doi:10.1186/s12913-022-08538-6
- Ulak, N. (2015). Nepal's earthquake-2015: Its impact on various sectors. *The Gaze: Journal of Tourism and Hospitality*, 7, 58-86.
- UN. (2006). *United Nations Convention on the Rights of Persons with Disabilities*. Retrieved from <a href="https://www.un.org/disabilities/documents/convention/convention-accessible-pdf">https://www.un.org/disabilities/documents/convention/convention-accessible-pdf</a>.
- UN. (2015). Consideration of reports submitted by States parties under article 35 of the Convention: Initial reports of States parties due in 2012 Nepal. Retrieved from <a href="https://documents-dds-ny.un.org/doc/UNDOC/GEN/G15/272/68/PDF/G1527268.pdf">https://documents-dds-ny.un.org/doc/UNDOC/GEN/G15/272/68/PDF/G1527268.pdf</a>?OpenElement
- UN. (2019). Disability and Development Report: Realizing the Sustainable Development Goals by, for and with persons with disabilities Retrieved from New York: https://social.un.org/publications/UN-Flagship-Report-Disability-Final.pdf
- UNHCR. (2023). Models of disability. Retrieved from <a href="https://www.unhcr.org/media/handout-2-models-disability">https://www.unhcr.org/media/handout-2-models-disability</a>
- Van Hees, S., Cornielje, H., Wagle, P., & Veldman, E. (2015). Disability inclusion in primary health care in Nepal: An explorative study of perceived barriers to access governmental health services. *DCID*, 25(4), 99.

- Veltman, A., Stewart, D. E., Tardif, G. S., & Branigan, M. (2001). Perceptions of primary healthcare services among people with physical disabilities. Part 1: access issues. *Medscape General Medicine*, 3(2), 18.
- WHO. (2011). *World report on disability*. Retrieved from Geneva, Switzerland: <a href="https://www.who.int/publications/i/item/9789241564182">https://www.who.int/publications/i/item/9789241564182</a>
- WHO. (2021). Disability and health. Retrieved from <a href="https://www.who.int/news-room/fact-sheets/detail/disability-and-health">https://www.who.int/news-room/fact-sheets/detail/disability-and-health</a>
- WHO. (2022). *Global report in health equity for persons with disabilities*. Retrieved from Geneva: https://www.who.int/publications/i/item/9789240063624
- WHO. (2023). Disability. Retrieved from <a href="https://www.who.int/news-room/fact-sheets/detail/disability-and-health">https://www.who.int/news-room/fact-sheets/detail/disability-and-health</a>
- Yin, R. K. (2009). Case study research: Design and methods (Vol. 5): sage.

## **APPENDIX**

## I. NSD notification

7/23/23, 1:07 PM

115D notification

Meldeskjema for behandling av personopplysninger



Notification form / Ensuring equitable healthcare for people with disabilities at local ... / Assessment

# Assessment of processing of personal data

 Reference number
 Assessment type
 Date

 818977
 Standard
 05.06.2023

#### Title

Ensuring equitable healthcare for people with disabilities at local level: A qualitative case study of Sindhupalchok, Nepal

#### Data controller (institution responsible for the project)

Universitetet i Bergen / Det medisinske fakultet / Institutt for global helse og samfunnsmedisin

#### Project leader

1. David Lackland Sam and 2. Graziella Emilia Henny van den Bergh

#### Student

Susmita Neupane

#### **Project period**

01.06.2022 - 31.08.2023

#### Categories of personal data

General

Special

#### Legal basis

Consent (General Data Protection Regulation art. 6 nr. 1 a)

Explicit consent (General Data Protection Regulation art. 9 nr. 2 a)

The processing of personal data is lawful, so long as it is carried out as stated in the notification form. The legal basis is valid until 31.08.2023.

#### Notification Form 🖸

#### Comment

Data Protection Services has assessed the change registered in the Notification Form.

Processing of personal data has been extended to 31.08.2023. We consider that the processing is still legal.

#### FOLLOW-UP OF THE PROJECT

We will follow up the progress of the project at the planned end date in order to determine whether the processing of personal data has been concluded

Good luck with the project.

## II. Approval from NHRC



## Nepal Health Research Council (NHRC)

Ref. No.: 4351

5 July 2022

#### Ms. Susmita Neupane

Principal Investigator

University of Bergen

Norway

Ref: Approval of thesis proposal

#### Dear Ms. Neupane,

This is to certify that the following protocol and related documents have been reviewed and granted approval through the expedite review process by the Expedited Review Sub-Committee meeting for it's implementation.

Protocol Registration No/ Submitted Date	254/2022 MT 5 June 2022		Sponsor Protocol No	NA	
Principal Investigator/s	Ms. Susmita Ne	eupane	Sponsor Institution	University of Bergen	
Title	Mainstreaming disability for inclusive health care in Sindhupalchok, Nepal: A qualitative case study of community-based health programs				
Protocol Version No	NA Vers		Version Date	NA	
Other Documents	Data collection tools     Informed consent form     Donor agreement letter     Work plan		Risk Category	Minimal risk	
Co-Investigator/s	Dr. David Lackland Sam     Dr. Graziella Van den Bergh				
Study Site	Sindhupalchok district of Nepal				
Type of Review	V	Expedited Full Board 3 July 2022	5 July 2022 to Ju 2023 Duration of Approval 5 July 2022 to 4 July 2023		

是:



## Nepal Health Research Council (NHRC)

Ref. No.: 4351

		This approval will be valid one year	
Total budget of research	NRs 5,11,400.00		
Ethical review processing fee	NRs 10,000.00		

#### **Investigator Responsibilities**

- · Any amendments shall be approved from the ERB before implementing them
- Submit progress report every 3 months
- · Submit final report after completion of protocol procedures at the study site
- Report protocol deviation / violation within 7 days
- · Comply with all relevant international and NHRC guidelines
- Abide by the principles of Good Clinical Practice and ethical conduct of the research

If you have any questions, please contact the Ethical Review M & E Section at NHRC.

Thanking you,

Dr. Pradip Gyanwali Member Secretary



# Nepal Health Research Council (NHRC) Estd. 1991

Ref. No.: 231

August 16, 2023

Ms. Susmita Neupane

Principal Investigator University of Bergen, Norway

Subject:

Approval of the requested amendment for a study entitled Mainstreaming disability for inclusive health care in Sindhupalchok, Nepal: A qualitative case study of community-based health programs (Reg. No. 254/2022, Approved on July 3, 2022)

Dear Ms. Neupane,

The Ethical Review Board of the Nepal Health Research Council received the amendment request for the above-mentioned study on July 12, 2023, for the addition of people with disabilities as a study population and interview guidelines. Accordingly, the update of the different sections of the proposal as per the amendments has been discussed and approved through the expedited review process on August 16, 2023.

Initially approved title: Mainstreaming Disability for inclusive health care in Sindhupalchok, Nepal: A qualitative case study of community-based health Programs

Updated Title: Ensuring Disability-inclusive Healthcare at the Local Level: A qualitative case study of Sindhupalchok, Nepal. This title will be used for further communications.

#### Approved documents

- Amendment request form
- Updated proposal
- Guidelines for data collections
- Progress report

If you have any queries, please feel free to contact the Ethical Review M&E section of the NHRC.

Thanking You!

Dr. Pradip Gyanwali

Member-Secretary

#### **III.** Informed Consent (English)

This is to inform you about your participation in a research project where the main purpose is to understand the current status along with the challenges and opportunities of disability inclusion in the healthcare system at local levels of government in Nepal. In this letter, I will give you information about the purpose of the project and what your participation will involve.

Title of the study: Ensuring disability inclusive healthcare at the local level: A qualitative case study of Sindhupalchok, Nepal.

The current study is a part of a master's thesis in Global Health, Faculty of Medicine, University of Bergen

**Benefit:** There is no direct benefit to the interview participants. Your participation may help identify the contextual information about disability mainstreaming in Nepal. This can add to the existing knowledge of designing and implementing disability inclusive health programs.

**Risk:** There are no anticipated risks associated with your participation in this study.

**Participation:** You are asked to participate because you are either a Municipality level Health Coordinator in one of the municipalities in the Sindhupalchok district or a person with disabilities residing in the district. The participation of you and/or your institute is completely voluntary and have the right to discontinue anytime and there will be no consequences for it. Also, you can demand for your data be deleted from the study.

**Frequency of contact:** You will be contacted only once for the in-depth interview. However, if any additional information is required from you, you will be contacted and your decision to further comply will be respected.

**Procedures:** Participation in this study involves document review, a face-to-face interview and observation. The municipality will be asked for legal documents like plans, and policies of the municipality that are related to health and disability inclusion.

The Health Coordinator and persons with disabilities will be asked for an in-depth interview of approx. 30 minutes which will be audio-recorded, and notes will be taken. The questions will be directed towards the implementation of the health projects and how disability inclusive it has or hasn't been.

In addition, a few project activities will be observed from a distance and notes will be taken. The municipality or the participants can ask for the transcript or the report from the research after completion.

Confidentiality: Data collected through this process will be highly confidential and will be used only for research purposes. None of the raw data will be shared beyond the researcher and the supervisors. None of the personal information will be published. Responses are anonymous and cannot be traced back to the respondent or the municipality. Also, the audio recordings will be deleted after the completion of the project.

#### Your rights

So long as you can be identified in the collected data, you have the right to:

- access the personal data that is being processed about you
- request that your personal data is deleted
- request that incorrect personal data about you is corrected/rectified
- receive a copy of your personal data (data portability), and
- send a complaint to the Data Protection Officer or The Norwegian Data Protection

  Authority regarding the processing of your personal data

#### Right to processing your personal data

We will process your personal data based on your consent.

Based on an agreement with the University of Bergen, NSD – The Norwegian Centre for Research Data AS has assessed that the processing of personal data in this project is in accordance with data protection legislation.

#### For more information:

If you have questions about the project, or want to exercise your rights, contact:

• University of Bergen via:

Student's Information:	Supervisor's Information	Supervisor's Information
Name: Susmita Neupane	Name: David Luckland Sam	Name: Graziella Emilia Henny van den Ber
Contact no.: (+47) 96802786,	Contact no.: (+47) 55583215	Contact no.:
(+977) 9851102284	Email id: david.sam@uib.no	Email id: <u>Graziella.Van.den.Bergh@hvl.no</u>
Email id: veb019@uib.no		

IV

- Our Data Protection Officer: Janecke Helene Veim at the University of Bergen
- NSD The Norwegian Centre for Research Data AS, by email <u>personverntjenester@nsd.no</u> or by telephone: +47 55 58 21 17.
- Ethical Review Board, Nepal Health Research Council (NHRC) by email: <a href="mailto:ethicalreviewb@gmail.com">ethicalreviewb@gmail.com</a> or by telephone: +977- 4254220 (ext no 125)

Yours sincerely, Susmita Neupane

(Student researcher)

#### **Consent form**

- i. I/We have read and understood the information provided about this research project in the information sheet
- ii. I/ We consent for the researcher to take notes and record audio during the interview. It can be transcribed by the researcher.
- iii. I/ We consent that the researcher can review our project activity related documents and can observe the implementation of our activities.
- iv. I/ We are aware that I/ we may withdraw ourselves or any information that I/ we provide for this project at any time
- v. In case of withdrawal, I/we understand that all relevant information will be destroyed
- vi. I/ we agree to participate in this research

Name of the Interviewee:		
Municipality:		
Date:		

#### IV. Informed Consent (Nepali)

## सुचीकृत मन्जुरीनामा

#### नमस्कार!

म सुस्मिता न्यौपाने,बर्गेन युनिभर्सिटी (University of Bergen), नर्वेमा विश्वव्यापी स्वास्थ्य (Global Health) मा मास्टर डिग्री पढ्दै गरेकी विद्यार्थी हुँ। तपाईलाई "स्थानिय तहमा अपाङ्गता समावेशी स्वास्थ्य सेवा सुनिश्चितता: सिन्धुपाल्चोक नेपालको एक गुणात्मक अध्ययन " विषयको अध्ययनमा स्वागत छ।

यस अध्ययनको मुख्य उद्देश्य नेपालको स्थानिय तहमा अपाङ्गता समावेशी स्वास्थ्य सेवा प्रणाली लागु गर्नको लागि अवसर र चुनौतीहरूको साथै साथै यसको वर्तमान अवस्था बुझ्नु हो। तपाईले यस अध्ययनमा भाग लिई तपाईको बिशेष अनुभव र बुझाई साटासाट गर्न अनुरोध गर्दछु। म तपाईलाई यो सुनिश्चितता दिन्छु, कि तपाईले प्रदान गर्नुभएको जानकारी गोप्य राखिनेछ र केवल अनुसन्धानको उद्देश्यको लागि मात्र प्रयोग गरिनेछ। यसकासाथै, अनुसन्धानको प्रत्येक चरणमा जानकारीको गोपनियता कायम गरिनेछ।

यस अन्तरवार्तामा तपाईको सहभागिता पूर्ण रूपमा स्वेच्छिक हुनेछ। यदि यस अध्ययन र अध्ययनका कुनै प्रश्नहरूको उत्तर दिन अप्ठ्यारो महसुस भएमा तपाई अन्तरवार्ता छोड्न र कुनै प्रश्नको उत्तरदिन नचाहेमा, सो को उत्तर नदिन तपाई स्वतन्त्र हुनुहुन्छ। तपाईको सहयोग र सहभागिताले नेपालमा अपाङ्गता मूलप्रवाहीकरणको बारेमा प्रासंगिक जानकारी पहिचान गर्न मद्दत गर्न सक्छ। यस अध्ययनले अपांगता समावेशी स्वास्थ्य कार्यक्रमहरूको तयारी (डिजाइन) र कार्यान्वयनको विद्यमान ज्ञानमा केही थाप योगदान दिनेछ।

## सहभागिता

यस अध्ययनमा अपाङ्गता भएका व्यक्तिहरु र पालिका स्तरका स्वास्थ्य शाखा प्रमुख हरु सहभागि हुनुहुने छ। तपाई/तपाईंको संगठनको सहभागिता पुर्णरूपमा स्वेच्छिक हुनेछ र तपाईलाई कुनै पनि समयमा यस अन्तर्वार्ता रोक्ने अधिकार छ।

## प्रक्रिया

यस अध्ययनमा कागजात अध्ययन र समीक्षा, आमने-सामने अन्तरवार्ता र स्वास्थ्य संस्था अवलोकन समावेश गरिएकोछ। नगरपालिका स्वास्थ्य शाखा संग अपाङ्गताको समावेशीता सम्बन्धि नगरपालिकाका योजना, नीतिलगायतका कानुनी कागजातहरु अध्ययनका लागि लिईनेछ।

स्वास्थ्य शाखा प्रमुख र अपाङ्गता भएका व्यक्तिहरूसंग लगभग ३०-४५ मिनेट अन्तर्वार्ताको लिईनेछ, जुन अडियो-रेकर्ड गरिनेछ र नोटहरू लिइनेछ।

प्रश्नहरू सरकारी स्वास्थ्य संस्थामार्फत कार्यान्वयन भएका स्वास्थ्य सेवाहरू कित्तको अपाङ्गता समावेशीता भए वा भएनन् भन्नेतर्फ निर्देशित हुनेछन् र केही गतिविध अवलोकन गरिनेछ र नोटहरू लिइनेछ। नगरपालिका वा सहभागीहरूले अनुसन्धान पूरा गरेपछि ट्रान्सक्रिप्ट वा प्रतिवेदन माग्न सक्नेछन।

## जोखिम

यस अध्ययनमा तपाईंको सहभागितासँग सम्बन्धित कुनै पनि अपेक्षित जोखिमहरू छैनन्।

## तपाई संगको सम्पर्क

तपाईलाई गहन अन्तर्वार्ताको लागि एक पटक मात्र सम्पर्क गरिनेछ। यद्यपि, यदि तपाइँबाट कुनै थप जानकारी आवश्यक परेमा तपाइँलाई सम्पर्क गरिनेछ र थप जानकारी लिने क्रममा तपाइँको निर्णयलाई सम्मान गरिनेछ।

## फाईदा

यस अध्ययनमा कुनै भौतिक फाईदाहरु प्रदान गरिने छैनन् तर तपाईको सहभागिताले अपाङ्गता भएका व्यक्तिहरूको लागी समावेशी स्वास्थ्य कार्यक्रम निर्माण गर्न मद्दत पुराउन सक्नेछ।

तपाईलाई अन्तरवार्ताको क्रममा केहि ब्यक्तिगत र गोप्य जानकारीले गर्दा केही असहज हुन सक्छ। यदि तपाईले कुनै पिन प्रश्नको जवाफ दिन नचाहेमा निदन सक्नु हुनेछ। यसका साथसाथै तपाईले कुनै पिन प्रश्नको जवाफ दिन नचाहेमा वा अन्तरवार्तामा भाग लिन नचाहेमा कुनै कारण प्रस्ट पार्न अवश्यक हुने छैन। यसको कुनै नकारात्मक परिणाम हुनेछैन। साथै, तपाईले आफ्नो तथ्यांक (डाटा) अध्ययनबाट मेटाउनको लागि माग गर्न सक्नुहुनेछ।

## गोपनीयता

यस प्रक्रिया मार्फत संकलित डाटा पुर्णरुपमा गोप्य हुनेछ र अनुसन्धान उद्देश्यका लागि मात्र प्रयोग गरिनेछ। कुनै पनि अप्रशोधित तथ्यांक (कच्चा डाटा) अनुसन्धानकर्ता र पर्यवेक्षकहरू बाहेक कसैलाई साझा (सेयर) गरिने छैन। कुनै पनि व्यक्तिगत जानकारी प्रकाशित गरिने छैन। साथै जवाफहरू बेनामी (नाम नखुलाईएको) बनाइनेछन् र उत्तरदाता वा संस्थामा उक्त तथ्यांक तथा जानकारी पुनः उपलब्ध गराउन सिकँदैन। साथै, अडियो रेकर्डिङ परियोजनाको अन्त्यमा मेटाइनेछ।

## तपाईंको अधिकार

तपाईसँग संकलित तथ्यांकमा तपाईंको निम्न अधिकार छः

- तपाइँको बारेमा प्रशोधन भइरहेको व्यक्तिगत डाटा पहुँच गर्ने।
- तपाईंको व्यक्तिगत तथ्यांक मेटाउन अनुरोध गर्ने।
- तपाइँको बारेमा गलत व्यक्तिगत तथ्यांक सच्याउन/सुधार्न अनुरोध गर्ने।
- तपाईंको व्यक्तिगत तथ्यांक को प्रतिलिपि प्राप्त गर्ने।
- तपाईंको व्यक्तिगत तथ्यांक को प्रशोधन सम्बन्धमा तथ्यांक सुरक्षा अधिकारी वा नर्वेजियन डाटा संरक्षण प्राधिकरणलाई उजुरी पठाउन

## तपाईंको व्यक्तिगत तथ्यांक प्रशोधन गर्ने अधिकार

हामी तपाईंको सहमतिमा आधारित तपाईंको व्यक्तिगत डाटालाई प्रशोधन गर्नेछौं।

बर्गेन विश्वविद्यालयसँगको सम्झौताको आधारमा, NSD – नर्वेजियन सेन्टर फर रिसर्च डाटा AS ले यो परियोजनामा व्यक्तिगत तथ्यांक प्रशोधन तथा संरक्षण कानून अनुसार भएको मूल्याङ्कन गरेको छ।

## थप जानकारिको लागि

यदि तपाइँसँग परियोजनाको बारेमा प्रश्नहरू छन्, वा तपाइँको अधिकार प्रयोग गर्न चाहनुहुन्छ भने, निम्न तरिकाबाट सम्पर्क गर्नुहोसः

## बर्गेन विश्वविद्यालयको लागि

विद्यार्थीको जानकारी सुपरभाईजरको जानकारी सुपरभाईजरको जानकारी

Name: Susmita Neupane Name: David Luckland Sam Name: Graziella Emilia Henny van den

Contact no.: (+977) Contact no.: (+47) 55583215 Bergh

9851102284 Email id: david.sam@uib.no Contact no.:

Email id: <u>yeb019@uib.no</u> Email id:

Graziella. Van.den. Bergh@hvl.no

- बर्गेन विश्वविद्यालयमा डाटा सुरक्षा अधिकारी: जेनेके हेलेन भेइम
- NSD नर्वेजियन सेन्टर फर रिसर्च डाटा **AS**, इमेल: <u>personverntjenester@nsd.no</u> वा टेलिफोन मार्फत (+47) 55 58 21 17
- नेपाल स्वास्थ्य अनुसन्धान परिषद् (NHRC) इमेल मार्फतः ethicalreviewb@gmail.com वा टेलिफोन मार्फत +977- 4254220 (एक्सटेनसन नः 125)

तपाईको, सुस्मिता न्यौपाने विद्यार्थी अनुसन्धानकर्ता

## सहमति फारम

- क) मैले /हामीले सूचना पानामा यस अनुसन्धान परियोजनाको बारेमा प्रदान गरिएको जानकारी पढेका छौं र बुझेका छौं।
- ख) म /हामी अन्वेषकलाई अन्तर्वार्ताको क्रममा टिपोटहरू लिन र अडियो रेकर्ड गर्न सहमति दिन्छौं। यो अनुसन्धानकर्ता द्वारा ट्रान्सक्रिप्ट गर्न सिकन्छ।
- ग) म/हामी अनुसन्धाताले हाम्रो परियोजना गतिविधि सम्बन्धी कागजातहरू समीक्षा गर्न र हाम्रा गतिविधिहरूको कार्यान्वयनको अवलोकन गर्न सक्ने सहमति गर्छौं।
- घ) म/हामीलाई थाहा छ कि म÷हामी आफैं वा मैले÷हामीले यस परियोजनाको लागि उपलब्ध गराएको कुनै पनि जानकारी कुनै पनि समयमा फिर्ता लिन सक्छौँ।
- ङ) फिर्ता लिने अवस्थामा, म/हामी बुझ्छौं कि सबै सान्दर्भिक जानकारी नष्ट गरिनेछ।
- च) म/हामी यस अनुसन्धानमा भाग लिन सहमत छौँ।

अन्तर्वार्ता दिने व्यक्तिः	
पालिका को नामः	
मितीः	

## V. Questionnaire guide for the interview with persons with disabilities (English)

(Inform	nation, consent, and Rapport building)
Name:	Age:
Addres	ss:
Educat	tion:
Occup	ation:
Family	v status:
Type a	nd grade of disability:
Trans	portation to nearest health facility
a.	Which is the nearest health center to your home? Do you go to the same health facility
	if you have any problems? If not, where do you usually go?
b.	How do you get to the health facility? Is there any difficulty in reaching the health
	institution? If yes, can you please elaborate?
c.	Do you go alone or with a friend? Who do you usually go with?
Exper	ience within the Health facility
d.	After you reach the health facility, how comfortable are you in receiving the heath service on your own? <ask about="" pathway,="" stairs,="" toilets="" wheelchairs,=""></ask>
Comm	nunication and receiving information
e.	How do you communicate with the health personnel? Do they understand or try to understand you?
f.	Are you able to read/ understand the written information inside the buildings?
g.	How doe you receive any sorts of health-related information? What source?
Health	service provision
h.	Are there any special provisions made available for you in health service delivery?
i. j.	Do you have to be in queue to receive any health services? How do you feel about your need being accommodated during the treatment process?
k.	Have you ever had health workers come to your home and provide you the health
	service?

#### Behaviour of health professionals

- a. How helpful are the health workers?
- b. Do you see any difference in their behavior because of your disability?

#### **Health expenses**

- n. How do you bear the expenses of the health institution? Do you get any discounts?
- o. Are you covered by the national health insurance program?
- p. Does the government's disability allowance cover your expenses?
- q. Have you received any benefits from the Community based rehabilitation (CBR) Program? If yes, please elaborate.
- r. Have you received any other services or facilities available to people with disabilities?

#### Participation in health service planning

- s. Are you a member of any organizations or committees of people with disabilities? If yes, please elaborate on the name and type of the organization/committee, your role, and its impact on your life?
- t. If not, have any of those organizations offered you any support? Please explain.
- u. Have you been involved in any health program planning or seminars by your ward or municipality? If so, what program and when?
- v. Can you give any examples of your involvement in any initiative you have taken in the field of disability?

### VI. Questionnaire guide for the interview with persons with disabilities (Nepali)

## अपाङ्गता भएका व्यक्तिहरुका लागि प्रश्न गाइड

नाम: उमेरः

ठेगाना:

शैक्षिक योग्यता:

रोजगार:

पारिवारिक स्थिति:

अपाङ्गताको प्रकार र वर्ग:

#### यातायात

- १. तपाईको घर बाट निजकै पर्ने स्वास्थ्य केन्द्र कुन हो? के तपाई केहि समस्या पर्दा सोही स्वास्थ्य चौकी जानुहुन्छ? होइन भने किन? कहाँ जानुहुन्छ त?
- २. स्वास्थ्य सेवा लिन जाने ठाउँ सम्म कसरी पुग्नुहुन्छ?
- ३. एक्लै जानु हुन्छ कि कोहि साथी संग? यदि साथी संग जानुहुन्छ भने को संग?
- ४. स्वास्थ्य संस्था सम्म पुग्न केहि कठिनाई हुन्छ? यदि हुन्छ भने कस्तो प्रकारको कठिनाई हुन्छ?

## स्वास्थ्य संस्था पुगेपछिको अनुभव

५. स्वास्थ्य संस्था भएको ठाउँ पुगेपछी, संस्था भित्र जान या स्वास्थ्य सेवा लिन कत्तिको सजिलो/ सहज महसुस गर्नुहुन्छ? किन? (ह्वीलचेयर, बाटो, सिढी, शौचालय बारे सोध्ने)

## सञ्चार र जानकारी प्राप्ति

- ६. तपाईं स्वास्थ्यकर्मीहरूसँग कसरी कुराकानी गर्नुहुन्छ ? के उहाहरूले तपाईंलाई बुझ्नुहुहुन्छ वा बुझ्न प्रयास गर्नुहुहुन्छ ?
- ७. के तपाइँ भवन भित्र लिखित जानकारी पढ्न/बुझ्न सक्षम हुनुहुन्छ?
- ८. कुनै पनि प्रकारको स्वास्थ्य सम्बन्धी जानकारी तपाइँ कसरी प्राप्त गर्नुहुन्छ ? स्रोत?

## स्वास्थ्य सेवा प्रवाह

- ९. के स्वास्थ्य सेवा प्रवाहमा तपाईका लागि कुनै विशेष व्यवस्थाहरू उपलब्ध छन् ?
- १०.के तपाई कुनै स्वास्थ्य सेवा लिन लाइनमा बस्नु पर्छ ?
- ११.उपचार प्रक्रियाको क्रममा तपाईंको आवश्यकतालाई समायोजन गरिएको बारे तपाईंलाई कस्तो लाग्छ ?

१२.के तपाईले कहिल्यै स्वास्थ्यकर्मीहरू तपाईको घरमा आएर तपाईलाई स्वास्थ्य सेवा प्रदान गर्नुभएको छ?

## स्वास्थ्यकर्मीको व्यवहार

- १३.स्वास्थ्यकर्मीहरू कत्तिको सहयोगी हुनुहुन्छ?
- १४.के तपाईंले आफ्नो अपाङ्गता को कारण उहाहरूको व्यवहारमा कुनै फरक पाउनुभएको छ?

## स्वास्थ्य खर्च व्यवस्थापन

- १५.स्वास्थ्य संस्थाको खर्च तपाइँ कसरी बेहोर्नुहुन्छ ? के तपाइँले कुनै पनि स्वास्थ्य सेवाहरू प्रयोग गर्दा कुनै छुट पाउनुहुन्छ?
- १६.के तपाई राष्ट्रिय स्वास्थ्य बीमा कार्यक्रममा आबद्ध हुनुहुन्छ?
- १७.के तपाईले सरकारी अपाङ्गता भत्ता पाउनु हुन्छ ? के यो तपाईको स्वास्थ्य खर्चको लागि पर्याप्त छ?
- १८.के तपाईंले सामुदायिक पुनर्वास (CBR) कार्यक्रमबाट कुनै फाइदाहरू प्राप्त गर्नुभएको छ? यदि छ भने, कृपया विस्तारित गर्नुहोस्।
- १९.के तपाईले अपाङ्गता भएका व्यक्तिहरूका लागि उपलब्ध अन्य कुनै सेवा वा सुविधाहरू प्राप्त गर्नुभएको छ?

## स्वास्थ्य सेवा योजनामा सहभागिता

- २०.के तपाई अपाङ्गता भएका व्यक्तिहरूको कुनै संस्था वा सिमतिको सदस्य हुनुहुन्छ? यदि हुनुहुन्छ भने, कृपया विस्तारित गर्नुहोस्। कृपया संगठन/सिमतिको नाम र प्रकार, तपाईको भूमिका, र यसले तपाईको जीवनमा पार्ने प्रभावबारे विस्तृत रूपमा बताउनुहोस्?
- २१. यदि तपाइँ त्यस्तो कुनै समिति वा संस्थामा संलग्न हुनुहुन्न भने, के ती संस्थाहरूले तपाइँलाई कुनै सहयोग प्रस्ताव गरेका छन?
- २२.के तपाइँ तपाइँको वडा वा नगरपालिका द्वारा आयोजित कुनै स्वास्थ्य कार्यक्रम योजना वा सेमिनार मा संलग्न हुनुभएको छ ? छ भने कुन कार्यक्रम र कहिले ?
- २३.स्वास्थ्य सेवामा पहुँच सुधार गर्न आफ्नो संलग्नताको कुनै उदाहरण दिन सक्नुहुन्छ?

#### VII. Questionnaire guide for the interview with Health Coordinators (English)

#### Question guide for the interview with Health Coordinators

Information, consent, and Rapport building

Name:

Municipality:

Permanent address:

Educational background:

Years of experience:

#### Disability and data

- a. How do you understand disability?
- b. Do you have disability-related data? What is the categorization based on?
- c. Do the health service institute and health programs record the segregated data of diverse disabilities? If not, why?

#### **Health infrastructures**

- d. Are the health infrastructures disability friendly? For instance: for people with mobility issues and people who are blind?
- e. Do all the health facilities in this municipality have ramps and pathways that can be used by those with blindness or low vision?
- f. Have any though been given to accommodate the specific needs of individuals with speech and hearing impairments?

#### Disability inclusion in health service provision

- g. What has been done to promote the health of Persons with disabilities (PWDs)?
- h. How accessible are the health promotion services for PWDs in the municipality?
- i. How are the needs of PWDs accommodated in healthcare programs?
- j. How do you disseminate the health information to persons with disabilities?
- k. Are there any targeted health programs for Persons with disabilities?
- 1. Any additional strategies developed to increase service utilization among PWDs? Such as to facilitate their transportation, communication, or financial aids.

n. How has it been (challenging, easy, complex...)? Is there anything that could have made the inclusion more effective? What is making the inclusion of disabilities complex and/or easy?

#### **Relevant training**

- o. Do you orient or train the health services providers on disability related matters?
- p. Are you trained on disability inclusion?
- q. Do you have any experiences on working with and for persons with disabilities?

#### Involvement of persons with disabilities in program planning

- r. What sort of policies do the municipality have that ensures equal access to health services for persons with disabilities?
- s. Have PWDs or organizations for persons with disabilities (OPDs) been involved during the planning process? Why or why not? Any challenges faced?
- t. Has OPD approached the municipality for the promotion of health services? If yes, how did the municipality respond?

#### Challenges and opportunities in ensuring disability inclusive health service

- u. What do you think are the challenges in providing disability inclusive health services in this municipality?
- v. Do you see any opportunities that can improve access to health services for persons with disabilities?
- w. What kind of governmental provisions would make disability inclusion more effective?

### VIII. Questionnaire guide for the interview with Health Coordinators (Nepali)

## नगरपालिकाको स्वास्थ्य संयोजकहरूको लागि प्रश्न गाइड

(अनुसन्धान सम्बन्धित जानकारी, सहमति र सम्बन्ध विकास)

नगरपालिकाको नाम:

स्वास्थ्य संयोजक को नाम:

स्थाई ठेगाना:

शैछिक योग्यता (background):

सो पलिकामा काम गरेको अनुभव (time period):

## अपाङ्गता सम्बन्धित तथ्याङ्क

- १) तपाईंको विचारमा अपाङ्गता भनेको के हो?
- २) के अपाङ्गता भएका व्यक्तिहरु यस पालिकाको लक्षित समूहमा पर्दछन?
- ३) यस पालिकामा कित संख्यामा अपाङ्गता भएका व्यक्तिहरु छन? यसको वर्गीकरण के मा आधारित छ? कस्तो किसिमको अपाङ्गताको संख्या बढी छ? यदी त्यस्तो कुनै डाटा छैन भने किन?
- ४) के स्वास्थ्य संस्था र स्वास्थ्य कार्यक्रमहरूले विभिन्न अपाङ्गताहरूको पृथक डाटा रेकर्ड (सन्कलन) गर्दछ?

## स्वास्थ्य पूर्वाधारहरू

- ५) यस पालिकाका स्वास्थ्य चौकीहरु अपाङ्गता भएका व्यक्तिहरुका लागि कित्तको पहुँचयोग्य छन्? के स्वास्थ्य चौकीहरु अपाङ्गमैत्री छन्? के अपाङ्गता भएका व्यक्तिहरु, स्वास्थ्य चौकी पुगेपछि, बिना अरुको सहयोग स्वास्थ्य सेवा लिन सक्छन?
- ६) गतिशीलता समस्या भएका र आँखा नदेख्ने व्यक्तिहरूका लागि कस्ता प्रावधानहरू छन्?
- ७) बोली र श्रवण सम्बन्धी अपाङ्गता भएका व्यक्तिहरूको विशेष आवश्यकताहरू समायोजन गर्ने कुनै प्रावधानहरू छन्?

## समावेशी स्वास्थ्य सेवा प्रावधान

- ८) अपाङ्गता भएका व्यक्तिको स्वास्थ्य प्रवर्द्धनका लागि यस पालिकामा के- कस्ता काम गरिएको छ ?
- ९) स्वास्थ्य प्रवर्द्धन सेवाहरू अपाङ्गता भएका व्यक्तिका लागि कत्तिको पहुँचयोग्य छन्?
- १०) स्वास्थ्य सेवा कार्यक्रमहरूमा अपाङ्गता भएका व्यक्तिहरूको आवश्यकतालाई कसरी समायोजन गरिन्छ?

- ११) अपाङ्गता भएका व्यक्तिहरुले कसिर स्वास्थ्य सूचनाहरु लिदै आएका छन्? स्वास्थ्य सचेतना कार्यक्रममा अपाङ्गता भएका व्यक्तिहरुको आवश्यकताहरू कसरी समावेस गरिएको छ?
- १२) के यस पालिकामा अपाङ्गता भएका व्यक्तिहरूका लागि लक्षित स्वास्थ्य कार्यक्रमहरू छन्?
- १३) स्वास्थ्य सेवा लिन जादा अपाङ्गता भएका व्यक्तिहरुलाई प्राथमिकतामा राखिने प्राबधान छ? कसरी?
- १४) अपाङ्गता भएका व्यक्तिहरु माझ सेवा उपयोगिता बढाउन कुनै थप रणनीतिहरू विकास गरिएको छ? जस्तै यातायात, सञ्चार, वा आर्थिक सहायताहरू सहज बनाउन
- १५) यसमा पालिकाको अनुभव कस्तो रहयो?के त्यहाँ समावेशीकरणलाई अझ प्रभावकारी बनाउन सक्ने ठाउँ छ?

## अपाङ्गता सम्बन्धित तालिम

- १६) के तपाईले स्वास्थ्य सेवा प्रदायकहरूलाई अपाङ्गतासँग सम्बन्धित विषयमा अभिमुखीकरण वा तालिम दिनुभएको छ?
- १७) के तपाइँ अपाङ्गता समावेशीकरण मा प्रशिक्षित हुनुहुन्छ?
- १८) के तपाइँसँग अपाङ्गता भएका व्यक्तिहरूसँग काम गरेको कुनै अनुभव छ?

## कार्यक्रम योजनामा अपाङ्गता भएका व्यक्तिहरूको संलग्नता

- १९) अपाङ्गता भएका व्यक्तिको स्वास्थ्य सेवामा समान पहुँच सुनिश्चित गर्ने नगरपालिकासँग कस्तो खालको नीति छ ?
- २०) योजना प्रक्रियामा अपाङ्गता भएका व्यक्तिहरु वा अपाङ्गता भएका व्यक्तिहरुका लागि काम गर्ने कुनै संस्थाहरू पनि संलग्न छन्?
- २१) के अपाङ्गता भएका व्यक्तिहरूका लागि काम गर्ने कुनै संस्थाले स्वास्थ्य सेवा प्रवद्र्धनका लागि पालिकामा सम्पर्क गरेको छ? यदि छन भने कस्ता सेवाहरूको लागि र पालिकाले कस्तो प्रतिक्रिया दियो?

## अपाङ्गता समावेशी स्वास्थ्य सेवा सुनिश्चित गर्नका लागि चुनौती र अवसरहरू

- २२) यस पलिकामा अपाङ्गता मूल प्रवाह कत्तिको सम्भव होला? के कस्ता कुराहरुले अपाङ्गत समावेशीकरणलाई जटिल र/वा सजिलो बनाउँदैछ? कसरी?
- २३) अपाङ्गता भएका व्यक्तिहरूको स्वास्थ्य सेवामा पहुँच सुधार गर्न सक्ने कुनै अवसरहरू देख्नुहुन्छ?
- २४) यस पालिकामा कुन प्रकारका सरकारी प्रावधानहरूले अपाङ्गता समावेशीकरणलाई अझ प्रभावकारी बनाउन सक्छ?

#### IX. Observation guide

Name of the Health facility: Address:

No. of floors: No. of beds available:

#### **Transportation**

- a. Is this health facility easily accessible by public transport?
- b. Is there enough parking available?
- c. Is there designated parking available for persons with disabilities?
- d. Is the parking lot wide enough to accommodate wheelchairs or other similar equipment?

#### Entrance related

- e. Are the entrances (main doors) wide enough for a wheelchair?
- f. Do people have to climb any stairs to reach the entrance? If so, are alternative ramps or lifts available for persons with disabilities?
- g. Can the doors be easily opened or closed by persons with any disability?
- h. Is there a separate line for persons with disabilities?

#### Registration and waiting area

- i. Is the registration desk / table suitable for persons with disabilities?
- i. Are there any signs or posters in braille or large print?
- k. Are waiting areas suitable for persons with disabilities?
- 1. Are chairs or seating areas comfortable and accessible to persons with disabilities?
- m. Are there accessible toilets for persons with disabilities nearby?

#### Examination and treatment rooms

- n. Are the testing and treatment rooms spacious enough to accommodate persons with disabilities and the equipment they use?
- o. Are the check-up/ treatment beds height adjustable?
- p. Are there accessible toilets for persons with disabilities near the examination/ treatment rooms?
- q. Are there any assistive technologies available to assist people with visual and hearing disabilities?
- r. Are there any treatment rooms or beds allocated for persons with disabilities? If yes, how many?

## Communication

- s. Are there any services available for people with sensory (visual and hearing) disabilities, such as sign language interpreters?
- t. Are any information booklets or documents provided in accessible formats in braille or large print?