

# Disability Inclusion in Primary Health Care in Nepal: An Explorative Study of Perceived Barriers to Access Governmental Health Services

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## ABSTRACT

**Purpose:** *Persons with disabilities face additional barriers in accessing primary healthcare services, especially in developing countries. Consequently the prevalence of secondary health conditions is higher among this population. This study aims to explore the perceived barriers to access primary healthcare services by persons with disabilities in the Western region of Nepal.*

**Methods:** *10 primary healthcare providers and 11 persons with disabilities (physically or visually impaired) were selected by non-governmental organisations from the hilly and lower areas. Based on the International Classification of Functioning and the health accessibility model of Institute of Medicine, semi-structured interviews were conducted and analysed using analytical induction.*

**Results:** *In general, healthcare providers and persons with disabilities reported similar barriers. Transportation and the attitude of family members and the community were the main **environmental barriers**. Even with assistive devices, people still depend on their families. **Financial barriers** were lack of funds for health expenses, problems in generating an income by persons with disabilities themselves, and the low socio-economic status of their families. **Personal barriers**, which affect help-seeking behaviour in a major way, were most often mentioned in relation to financial and socio-environmental barriers. Low self-esteem of the person with disability determines the family's attitude and the motivation to seek out healthcare. Lastly, poor public awareness about the needs of persons with disabilities was reported.*

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**Conclusions:** Besides the known physical environmental barriers, this study found several environmental, financial and personal barriers that also affect access to primary healthcare. In particular, the attitudes of families and poor financial conditions seem to be interrelated and greatly influence help-seeking behaviour.

**Implications:** There is a definite need to educate primary healthcare providers who work at the community level about disability-related health conditions, and train them to diminish barriers to access health services. In addition, the government support system for persons with disabilities should be revised and implemented accordingly. Lastly, further research is needed to understand the interaction between the reported barriers that influence the inclusion of persons with disabilities in healthcare.

**Key words:** persons with disabilities, accessibility, barriers, primary healthcare

## INTRODUCTION

Compared to persons without disabilities, persons with disabilities face additional barriers in accessing primary healthcare services and health promotion activities (Beatty & Dhont, 2001; Beatty et al, 2003; World Health Organisation, 2011). Research shows that persons with disabilities have greater medical vulnerability and a higher prevalence of secondary health conditions than the general population (Kinne et al, 2004; Drainoniet al, 2006; Trani et al, 2011). Therefore, access to primary healthcare services is even more important to persons with disabilities.

Persons with disabilities develop similar health problems as the general population (World Health Organisation, 2011). However, misconceptions about the health of persons with disabilities exist, and lead to the assumption that they do not require equal access to health promotion and disease prevention (World Health Organisation, 2011). Even in countries where resources and knowledge about inclusion and accessibility are available, persons with disabilities encounter barriers to use primary healthcare services. A study by Stillman et al (2014) found that persons with physical impairments receive fewer preventive interventions and health assessments in primary healthcare centres than able-bodied persons. As a result, persons with disabilities tend to underutilise preventive healthcare services (Drainoni et al, 2006; Trani et al, 2011). This leads to neglect of preventable diseases (Ormond et al, 2003; Drainoni et al, 2006; Tomlinson et al, 2009).

## **Situation in Nepal**

The health status in Nepal is poor due to the high prevalence of preventable infectious diseases, caused by poor sanitation, malnutrition, illiteracy, poor access to clean water and poor quality of healthcare (Zaidi et al, 2004). Low utilisation of healthcare services by the general population could be due to distance, lack of medicines, unavailability of staff, lack of finances and opening hours of the facility (Yadav, 2010; Paudel et al, 2012).

## **Inclusion of Persons with Disabilities**

Disability inclusion is a construct that was initially developed in the educational sector. Inclusion is based on the social model of disability (Shakespeare, 2002), which uses human rights as a starting point to explain disability. Persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability (United Nations, 2012). Possible perceived barriers that might hinder this right to inclusion in primary healthcare include environmental, financial and personal challenges. On all levels, those barriers might lead to social exclusion and prevent the process of inclusion (Nuwagaba et al, 2012).

## **Objective**

The aim of this study is to gain a better understanding of the perceived barriers faced by persons with disabilities in accessing primary healthcare services in Nepal. The study also explores environmental, financial and personal barriers from the perspectives of primary healthcare providers and persons with disabilities.

## **METHOD**

### **Setting and Study Design**

This qualitative study was conducted in both the lower (Terai) and the hilly areas of Nepal, namely Rupandehi district and Tanahun district respectively.

### **Sampling**

Participants were recruited with the help of non-governmental organisations working in these geographical areas. The method of purposive sampling (Boeije,

2006) was used to select primary healthcare providers from several health posts within the district, and persons with a physical or visual disability living in the same area.

## **Participants**

Twenty-one (21) participants were recruited from the two target groups - 9 healthcare providers working in primary healthcare and 11 persons with disabilities, all living or working in Rupandehi district (lower area) and Tanahun district (hilly area). One president of a Disabled People's Organisation (DPO) was also included.

Inclusion criteria were as follows:

- For the healthcare providers - either the manager of the sub-health post (SHP) or health post (HP) - also referred to as health facility- or one of the staff members. These participants would have had at least 1 year of experience in this health post and a minimal education level of CMA (Community Medical Auxiliary: a diploma in primary healthcare).
- For the persons with disabilities –those with either a visual impairment or a physical impairment, who were consequently faced with mobility challenges due to their inability to see or who had walking difficulties or were using an assistive device (wheelchair, prosthesis, crutches or walker). The participants would have to be at least 18 years old and living at home.

## **Data Collection**

Semi-structured interviews were used. Interviews were conducted by the researcher (not a native Nepali-speaker) and a local Nepali interpreter. The interpreter had a public health background and was trained extensively. Interviews were conducted at the work stations of healthcare providers and at the homes of persons with disabilities.

## **Instrument**

A topic list was developed based on a healthcare model to identify barriers and the International Classification of Functioning, Disability and Health (ICF), a classification of health and health-related domains (World Health Organisation, 2001). As functioning and disability are related to the person in a context, ICF also includes a list of personal and environmental factors. Those factors are used

as categories to classify possible barriers. The Institute of Medicine or IOM (1993) sets forth a conceptual framework for classifying perceived barriers to access healthcare services, that is useful for thinking about functional limitations and their relationship to such barriers. The IOM framework identified three broad categories of barriers: structural, financial, and personal/cultural, of which financial barriers are separately mentioned, unlike the ICF model. Since this framework provides items for financial barriers and the study takes place in a developing context where financial resources are often limited, it was decided to use this category as an addition to the framework of the ICF. Thereafter, a meeting between the researcher and disability experts took place to examine the topic list on its feasibility for the Nepalese setting. The topic list was adapted during data collection and analysis, while comparing the answers of participants with the original theoretical framework.

**Environmental** barriers are defined as impediments to healthcare services, which directly relate to availability, concentration, location, or organisational configuration of healthcare services and the physical environment. The social environment around the person with a disability is also incorporated. As described in other studies, attitudes, local stigmatisation and misconceptions of persons with disabilities (Noseket al,1995; Nakabuye et al, 2006) influence help-seeking behaviour.

**Financial** barriers may restrict access by inhibiting the ability of persons to pay for needed healthcare services or transportation. There is a bi-directional link between poverty and disability (Ghai, 2009; Sen, 2009). According to Peters et al (2008) and Yeo (2001) poverty may increase the likelihood of disability for a person with an existing health condition. Once a person has a disability, he/she faces increased barriers to accessing healthcare services, education, employment, and other public services.

Lastly, **personal** barriers may inhibit persons with disabilities from seeking medical attention (IOM, 1993). The Health Belief Model and Hidden Distress of Stigma Model were used to elaborate health beliefs and stigmatisation (Scambler, 1998; Abraham & Sheeren, 2005).

## Data Analysis

The procedure of analytical induction was used during data analysis (Boeije, 2006). The code tree with codes, categories and themes is presented in the Appendix.

## Ethical Considerations

Approval for the study was given by NHRC before the start of data collection. Every participant was asked to give informed consent, with a letter written in Nepali. Participants were not given any incentive to take part in the research.

## RESULTS

The perceived barriers of both groups will be presented separately, to show reports from two different perspectives. Differences in reports are presented in Table 1.

**Table 1: Major differences in the reports of Healthcare Providers and Persons with Disabilities**

<b>Transportation</b>
Healthcare providers think that giving out wheelchairs helps persons with disabilities to visit the health post. Persons with disabilities report that even with a wheelchair they still depend upon others to visit the governmental health facility.
<b>Quality of care</b>
Healthcare providers mention they need more specialised knowledge about disabilities.  Persons with disabilities do not mention this as a reason not to visit the centre; they mention more basic needs that are lacking in the health centre; lack of staff, lack of variance in medicine, getting low doses of medicine compared to the private services, and no positive experiences in the past.
<b>Stigma by family and community</b>
Healthcare providers report a high level of stigmatising behaviour of both family members and community members.  Persons with disabilities, who are interviewed in their homes, report positive attitude of their close neighbours and family members in helping them with practical tasks around the house.
<b>Public awareness on disability</b>
All healthcare providers opt for more public awareness on disability issues.  The participants with disabilities who were higher educated also mentioned the need for more public awareness activities; the participants with lower education levels did not report this.

<b>Financial situation</b>
Both groups agree this barrier is one of the major ones. They all agree on the dependence of persons with disability on their family and their financial situation. There were different reports about the governmental support system which implies a lack of transparency of this system.
<b>Self-stigma by persons with disabilities</b>
Healthcare providers all report hesitation and shame on the part of the person with disability to move outside. Responses of the society are reported as the reason. Persons with disabilities report that their hesitation is based on the responses of healthcare providers and inconvenient situations (for example, incontinence).

## **Barriers perceived by Healthcare Providers**

### 1. Environmental barriers

#### a) Transportation

Bus transportation was only used when the health facility was near the main road. Healthcare providers reported both discriminatory and helpful behaviour of bus personnel. For example, some bus drivers do not stop for persons with disability; however, they sometimes offer a seat or help to carry these people into the bus. Distance is a great barrier; hence persons with disabilities and caregivers prefer to visit the medical shop which is closer. All healthcare providers stated that family members prefer to visit the health facility on behalf of the person with disability, since it is a burden for them to carry the person. Even when they are given a wheelchair, persons with disabilities totally depend on their family members to visit the health facility.

#### b) Physical environment

The road condition was cited as a barrier in the hilly area, especially during the rainy season. All healthcare providers, from both the lower and the hilly areas, mentioned that the health facilities are not disability-friendly, in terms of the path leading to the building, ramps, and accessible treatment room and mobility devices. They are willing to treat the persons with disabilities outside; however, privacy is a problem.

### c) Quality of care

Healthcare providers reported that persons with disabilities prefer other health facilities like medical shops and the hospitals in the cities. The reasons they mentioned were the unavailability of the health worker and their own limited knowledge about disability-specific conditions. They also reported that other healthcare providers used the health facility for private business and that people in the community believed that the variety and dosage of medicines given were better in the medical shop (privately owned by a healthcare provider).

### d) Community-based health services

In the hilly area, community health workers conducted home visits, which seemed more urgent due to the topographic condition. These community health workers live closer to the community and assist the health worker at the health facility.

### e) Social environment (family and community)

Most healthcare providers reported that stigmatising behaviour of the family and community was a barrier for persons with disabilities who seek health care. The families' busy schedules, money problems and poor awareness of the needs of persons with disabilities were responsible for the delay or denied them the opportunity to seek out health care. Although this barrier was mentioned, healthcare providers also reported a general improvement in the stigmatising behaviour of the family and the community.

## 2. Financial barriers

All healthcare providers clearly cited the poor financial condition of persons with disabilities as the major barrier to their use of healthcare facilities, both for primary and secondary/tertiary care.

*"The first reason for not coming to the health post is the lack of money. And for using secondary health care facilities, money is already finished. So they don't go for further treatment due to the financial barrier"- Healthcare provider.*

Healthcare providers reported that because persons with disabilities were unemployed, they lacked financial resources to take care of their own health.

They also mentioned there was a poor grading system to determine levels of disability that would entitle one to receive a disability card and subsequent



benefits. It was pointed out that the money did not always reach the beneficiaries, but might remain with the village development committee or with the family.

### 3. Personal barriers

#### a) Knowledge

Most healthcare providers reported that they wanted more training on disability-related issues. The majority of them mentioned the importance of health education to increase knowledge about general public health issues among persons with disabilities.

*“Being a health worker, I give health education and refer them for tertiary treatment. I used to provide public awareness and also suggest family members not to hate the disabled persons”- Healthcare provider.*

#### b) Communication

Healthcare providers reported difficulties in communicating with persons with disabilities, especially with those who were not able to hear and speak. They also indicated that persons with disabilities who were able to speak hesitated to tell the health worker their problems, and preferred to ask their caregivers to report their health complaints.

#### d) Health beliefs

All healthcare providers perceived that people with disabilities were more susceptible to infectious diseases, diarrhoea, hits/bruises, malnutrition, skin diseases and other conditions.

#### e) Self-stigma by persons with disabilities

The behaviour of persons with disabilities themselves was also reported as a barrier to seeking healthcare services. According to healthcare providers, persons with disabilities hesitate to go outside and face the community. It was reported that these people had low self-esteem and would not speak out and explain their problems to the health worker at the health facility.

### 4. Additional theme

#### a) Public awareness of disability

In both topographic areas, healthcare providers reported the lack of general public awareness of disability as a barrier to the use of health services by persons with disabilities.

## **Barriers perceived by Persons with Disabilities**

### 1. Environmental barriers

#### a) Transportation

By and large, persons with disabilities reported about their dependence on others when visiting the health facility. The main reasons for the visually impaired were the unfamiliar environment, and for physically impaired wheelchair users the long distances and bad roads. A wheelchair would make them independent only if their houses and the health facility were near a paved road; otherwise, the wheelchair made it easier for family members to transport them. Distance was another barrier; therefore, persons with disabilities preferred the medical shop or asked family members to collect their medicine. Public transportation was perceived as a barrier because bus personnel would not stop for them, as persons with disabilities do not have to pay bus fare and consequently, privately owned bus companies cannot make a profit.

#### b) Physical environment of health facility

Only a few persons with disabilities reported that the health facilities were not built in a disability-friendly way. Instead, the indoor facilities to transfer themselves and positioning for physical examination were mentioned as a barrier. In general, this was not perceived as a major barrier.

#### c) Quality of care

Persons with disabilities reported the unavailability of the medicines they specifically needed at the governmental health facility. Also, in the private medical shop they received a higher dosage of medicine, which cured their illness faster. Furthermore, they felt they were treated better by the health worker in the private facility, because they paid for the service.

#### d) Social environment (family and community)

Persons with disabilities did not report bad attitudes of the family and community. On the other hand, when people understood their position and condition, there was love and affection. Family members hesitated to take the person with disability to the health facility only due to their busy time schedules.

## 2. Financial barriers

Most persons with disabilities reported that a major barrier in seeking health care was their limited financial resources. Participants who did not generate income indicated that they had to rely on assistance provided by the community, on receiving gifts of money, or had to offer to pay in instalments. Moreover, minimal financial support from the government and the non-transparency of policies about the disability fund were a major concern.

*“My husband refused to take me to the Village development committee to take the disability fund. He used to tell me, your fund is being eaten by some of the persons”* - Person with disability.

Few participants utilise the discounts provided for use of public transport services. This was largely attributed to lack of awareness of the discounts and lack of policy implementation.

## 3. Personal barriers

### a) Health beliefs

Persons with disabilities reported their traditional health beliefs which were related to bad spirits, God’s protection and the role of faith healers. The tendency was to first visit the traditional healer, and thereafter visit the health facility when they were not cured. In general, knowledge about hygiene, healthy food and general check-ups appeared to be connected with the educational level of the person. Also, bad experiences at a particular health facility would make a person hesitate to go there again.

### b) Self-stigma by persons with disabilities

Persons with disabilities mentioned that anticipating possible negative reactions of others created fear of moving about outside, though they did not hesitate to move around in their own familiar neighbourhood. They reported self-blame and guilt about being a burden to their family.

*“I don’t want them to carry me. I don’t want to give them more burden, this is the same for moving me to the health facility”* - Person with disability.

## **Barriers perceived by the Disabled Persons’ Organisation (DPO)**

The chairperson of one DPO was interviewed, and reported about their public awareness activities which were also focussed on the local government. According

to this chairperson, the three major barriers are transportation, financial resources and attitude of family members. In general, awareness of disability-related issues is improving in the community. However, the behaviour of the community and family members towards persons with disabilities continues to be discriminative.

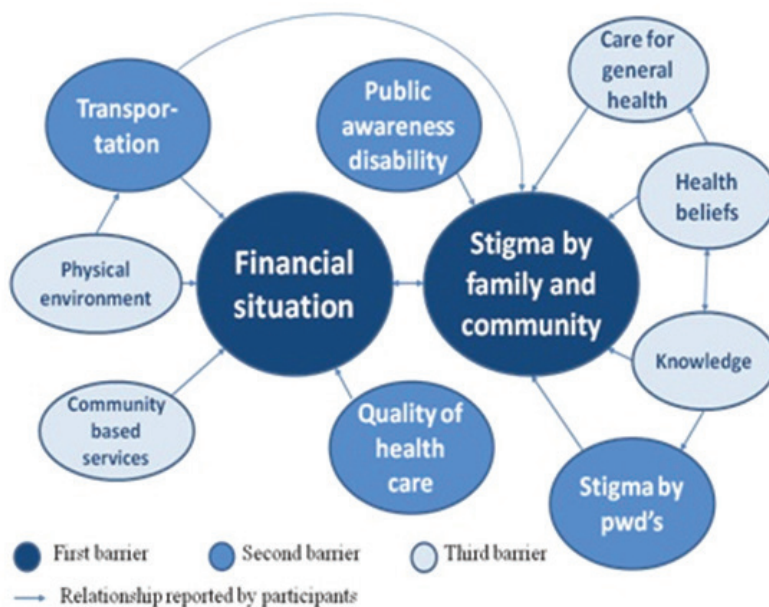
Persons with disabilities are invited to meetings of the DPO. However, those who are not able to reach the place where the meeting is held do lack knowledge and empowerment skills.

The chairperson underlined the importance of the governmental support system (disability card) and advocated for free services up to secondary healthcare level.

### Severity and Relationship between Perceived Barriers

Most participants mentioned barriers according to the order of severity and how those barriers were interrelated. A schematic overview of all barriers, in terms of importance and their relationships, is presented in Figure 1.

**Figure 1: Overview of Barriers and their Relationships**



Pwds = persons with disabilities

## DISCUSSION

Among the environmental barriers, transportation and social environment are the most prominent ones. Many persons with disabilities do not reach the health facility. Transportation in Nepal is generally challenging due to bad road conditions, long distances to main roads and the rainy season. In line with other studies in Nepal and other developing countries, distance was found to be a barrier to access public services, for both persons with and without disabilities (Yadav, 2010; Nuwagaba et al, 2012; Paudel et al, 2012). Healthcare providers believe that wheelchairs would diminish the transportation barrier, while persons with disabilities report that having a wheelchair does not mean there is no transportation barrier (Scovil et al, 2012).

The other major environmental barrier was the stigmatising behaviour of the family and community (enacted stigma) (Scambler, 1998). This barrier seemed strongly related to transportation and, even more, to financial barriers. Since persons with disabilities travel with their family members, these family members are also exposed to the community. They try to hide the disability from the community due to enacted (social) stigma (Weiss et al, 2006). Concerning the financial barrier, persons with disabilities generally are highly dependent on their relatives for transport and money (Gautam, 2009; Wasti et al, 2012).

When further treatment is required (secondary health services which are not free of cost), the chief barrier is limited financial resources. Money needed to pay health services directly is defined as out-of-pocket payment and does not provide any financial protection, as for example with a health insurance, which increases the risk of poverty (Peters et al, 2008). In addition, persons without disability often do not recognise that persons with disabilities can make positive and meaningful contributions to the economy and the society (Mosharaff, 2004), resulting in a low rate of income generation among persons with disabilities (Nuwagaba et al, 2012). Participants reported varied information about the government support system.

Healthcare providers reported that more specific knowledge about prevention and treatment of secondary conditions, communication with persons with disability, and knowledge of rehabilitation treatment and referral systems were needed, as found in another study (Berry et al, 2009). The need to provide optimum healthcare for persons with disabilities was confirmed in other studies (Lightfoot, 2003; Drainoni et al, 2006; Francis & Adams, 2010). Also, considering

that persons with disabilities have a higher susceptibility to infectious diseases and secondary conditions, health promotion activities should be inclusive of them (Kinne et al, 2004; Parish & Huh, 2006).

With regard to personal barriers, persons with disabilities hesitate to seek healthcare and to ask their relatives for support. They have negative perceptions about themselves (felt stigma). As reported by Steward et al (2008), enacted stigma (by family or community) highly influences felt stigma. Moreover, felt stigma seems to provoke a negative attitude towards help-seeking behaviour (Wrigley et al, 2005), which implies that persons who are stigmatised and who also feel stigmatised will be less likely to seek healthcare.

## CONCLUSION

This study gives a comprehensive picture of perceived barriers that affect the access to primary healthcare services for persons with disabilities in Nepal. Healthcare providers and persons with disabilities showed similar perceptions about most barriers, which implies that the problem is understood well. In addition to well-known environmental barriers like lack of transportation, long distances and the poor quality of care, this study found the following barriers which largely affect the access to care:

- Social environment and the dependence upon others to visit the health facility;
- Stigma by the family and the community –refusal to take the person to the health facility and not providing support for transportation or health expenses;
- Out-of-pocket payment;
- Lack of income;
- A poor disability grading system to obtain government support;
- Lack of awareness or incorrect information about government support systems;
- Self-stigma which has an effect on help-seeking behaviour;
- Lack of public awareness about disability, which influences social participation.

The financial barriers and attitude of the family seem interrelated. The impact of one barrier on other barriers and help-seeking behaviour seems far-reaching and complex.

## IMPLICATIONS

The lack of knowledge about the prevention and treatment of secondary conditions and general health problems faced by persons with disabilities shows that there is a great need for training government primary healthcare providers. Training should also be provided to general healthcare organisations, especially in government facilities. Findings of this study can be used to create awareness about barriers faced by persons with disabilities. Beneficiaries of training should be primary healthcare providers who work at the community health facility and community health workers who come across many people within the community. With well-trained health personnel, the Nepalese government could work on the right to the enjoyment of the highest attainable standard of health (Article 25) and providing training for stakeholders on accessibility issues (Article 9), as stated in the UN Convention on Rights of Persons with Disabilities, signed by Nepal in 2008 (United Nations, 2012).

In the light of the poor social security system for persons with disabilities in Nepal, the first recommendation is to revise the disability grading system and train the medical officers who allocate grades to individuals with disability. The system should also ensure that the funds reach the beneficiaries. Second, reorganising healthcare facilities to be inclusive will require inputs from those who are familiar with, and affected by, current barriers. If healthcare providers and persons with disabilities are involved in the planning and decision-making process, then the system will be more responsive. As a result, persons with disabilities will be more likely to access and utilise health services, leading to better health outcomes.

Social initiatives such as income generation and health education activities should be inclusive for persons with disabilities and their families, so as to reduce stigmatisation and increase help-seeking behaviour. This could be done by disabled persons' organisations, healthcare providers and non-governmental organisations, by including persons with disabilities in their mainstream programmes. Current initiatives to improve societal attitudes should be encouraged to enhance social participation.

## Limitations

Though this study was carefully designed and conducted, there were some limitations. Interviews with persons with disabilities were conducted in their home environment. It was culturally and practically not possible to create an environment with total privacy and separate from family members. Therefore, a response bias may have influenced the reports by persons with disabilities, especially regarding the attitude of their family members. This could explain the differences in reports, presented in Table 1. Due to limitations in time and availability of interpreters, the data was translated and coded by one researcher and one interpreter. The analysis of the interviews was not double-checked. Lastly, the conclusions are based on a small group of participants, especially the group of persons with disabilities among whom a wide variety of disabilities is not represented.

This study explored a broad range of barriers to access healthcare. The relationship between barriers was greatly emphasised by the participants. Further research on those relationships and their in-depth systems is needed to enhance effective access to primary healthcare.

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The authors declare that they have no competing interests.

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## Appendix

### Code tree barriers to use Primary Health Care

Barriers General	Category	Public awareness of disability and health
<b>Environmental</b>	<b>Transportation</b>	Using devices
		Dependency for transportation
		Using bus (getting inside- seat- ask bus to stop)
		Family member gets medicine
		Distance
	<b>Physical environment</b>	Geography of area
		Disability-friendly environment
		<b>Quality of care</b>
	Better treatment non-government	
	Continuity and monitoring of health post	
	Medicine types and dose availability	
	Care capacity of health facility	
	<b>Community- based services</b>	Benefits, costs. social involvement
		Community services
	<b>Financial</b>	Money for health expenses
Disability fund and discount		
Money generation and management		
Income (children/partner/land)		
Paying for services by loan		
<b>Personal/ Cultural</b>	<b>Knowledge</b>	Awareness of health facility
		Receiving/giving health education
	<b>Health beliefs</b>	Spiritual beliefs and treatment
		Severity of illness
		Susceptibility
		Benefits for visiting hp
		Care for general health

	<b>Behaviour family community</b>	Behaviour community members
		Attitude of family members
		Enacted stigma family
		Busy schedule family
	<b>Behaviour person with disability</b>	Anticipated stigma by person with disability
		Internalised stigma of person with disability
		Experienced stigma of person with disability
		Expression of the problem by person with disability
		Raising voice and self-confidence
<b>Facilitating factors</b>	<b>Demographic</b>	Educational level
		Severity of disability
		Living situation
	<b>Time constraint</b>	Time constraint health care provider
		Priority order and attention
	<b>Behaviour of hcp</b>	Knowledge of health care provider
		Attitude of health care provider
		Showing respect - language
		Enacted stigma health care provider