



# The right to health: An examination of health care access for women with disability in Nepal

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## 1. Introduction

The World Health Organization's (2022) Global Report on Health Equity for Persons with Disabilities estimates that about 16 per cent of the world's population (or approximately 1.3 billion people) live with some form of disability. The same report indicates that 80 per cent of people with disability<sup>1</sup> globally are located in the Global South (WHO, 2022), and an estimated three-quarters of them are women. These figures show a substantial increase in the percentage of people with disability worldwide in the last decade as a result of different demographic and epidemiological changes (WHO, 2022). However, despite the strength of these figures, empirical and theoretical research on disability in the Global South remains scarce (Grech, 2016). Although there are now signs of an increase in disability research conducted in low- and middle-income countries, theorising on disability in the Global South remains rather limited (Katsui & Swartz, 2021). The issue of access to health care for people with disability in South Asia is no exception.

People with disability have essentially the same health needs as any other person, encompassing the need for health promotion, preventive care, diagnosis, treatment, and rehabilitation. They may also have additional specific health needs arising from their impairments and other determinants of health, such as poverty, discrimination and stigmatisation, violence, and social exclusion (UN, 2018; WHO, 2022). The right to health, as a fundamental human right, is recognised in a range of human rights instruments at both the regional and international levels and encompasses a broad spectrum of freedoms and entitlements<sup>2</sup> (UN,

2000; UN, 2018; WHO, 2022). People with disability are protected by the same legal instruments and frameworks that uphold the right to health as any other person. However, there are specific provisions aimed at ensuring their full enjoyment of this right, most notably the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Article 25 of the Convention is of particular relevance, declaring that "(...) persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability" (UN, 2006). Article 25 also highlights the responsibility of the signatory states as guarantors of the provision of health services to people with disability. In a nutshell, the Convention requires states to provide equal access to health care for people with disability and to prevent discriminatory practices that limit or impede such access. The CRPD thus distances itself from the medicalisation of disability and advocates for the recognition of people with disability as rights-holders, rather than mere recipients of protection or welfare (UN, 2018). By highlighting the need to remove barriers that hinder or limit the full and equal enjoyment of the right to health for all people with disability, the Convention is aligned with the social model of disability.

According to the World Health Organization (2021), people with disability face several barriers to accessing health care that can be classified into four main categories: *attitudinal*, *physical*, *communication* and *financial*. Table 1 below provides a brief summary of the main barriers identified for each category.

As noted above, on a purely formal level, there are several legal instruments aimed at ensuring that people with disability have access to quality health care and fully exercise their right to health. However,

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<sup>1</sup> In accordance with WHO (2020) criteria, we use the term "people with disability" instead of "persons with disabilities", as this term denotes that disability is a universal human experience.

<sup>2</sup> *Freedoms* include the right to non-discrimination, the right to make decisions affecting one's own health and bodily integrity, the right to free and informed consent, the right to be free from non-consensual medical treatment and experimentation, and the right to be free from torture and cruel, inhuman, or degrading treatment or punishment. *Entitlements* include the right to essential primary health care and the right to access essential medicines. The right to health also extends to the underlying determinants of health, such as access to safe drinking water; adequate sanitation; adequate food, nutrition, and housing; healthy working and environmental conditions; and access to health-related education and information (UN, 2018, p. 5).

**Table 1**  
Barriers to accessing health care.

Category	Main barriers
<i>Attitudinal</i>	Stigmatising and discriminatory practices by health care providers; Limited knowledge and lack of training on disability issues among health care personnel
<i>Physical</i>	Unequal distribution of health care facilities (i.e., concentration of health services in urban centres); Limited accessible transport options; Inadequate infrastructure and equipment of health care facilities
<i>Communication</i>	Lack of health care information in accessible (e.g., Braille) and easy-to-follow formats; Limited availability of sign language interpreters
<i>Financial</i>	Lack of or limited resources to afford health care services and associated costs (e.g., transport and medication)

Own representation based on WHO (2021).

despite the existence of such normative imperatives, few countries provide adequate quality health services for people with disability, who continue to face significant barriers to accessing health care (WHO, 2021). Or to put it another way, “(...) the world is still far from realizing the right to the highest attainable standard of health for persons with disabilities” (WHO, 2022, p. 6). It follows that formal equality does not necessarily translate into substantive social equality, and that the right to health—as a fundamental social right—may be jeopardised for people with disability (Knight, 2014).

Despite the growing number of empirical studies on the subject, disability in the Global South continues to be undertheorised. To contribute to narrowing this research gap, this article aims to investigate the barriers to health care access faced by women with disability in Nepal. The case selection reflects the fact that Nepal has a relatively comprehensive set of legal and policy instruments aimed at protecting the right to health of people with disability; however, the full realisation of this right is often hampered by significant health inequities. This article uses empirical data from 25 qualitative interviews with women with disability and interprets them considering Amber Knight’s theoretical formulations on disability and vulnerability. Through a necessary theoretical reflection on how disability rights pan out in practice (Grech, 2016) and how formal equality translates (or not) into substantive equality, this article aims to contribute to the further theorisation of disability among women in South Asia.

This paper is divided into seven sections: the first section presents the state of research on access to health care for people with disability in low- and middle-income countries and identifies the main factors limiting access to health services for women with disability. The second section addresses the issue of access to health care for people with disability in the Nepali context and the barriers that women with disability face in exercising their right to health in the country. The third section introduces some theoretical considerations on disability and vulnerability and the political implications of addressing disability as a public welfare concern. The fourth section outlines the methods used to gather empirical evidence on women with disability’s access to health care in Nepal. The fifth section presents the research findings on the barriers to accessing health care faced by women with disability in Nepal. The sixth section discusses these research results in light of the theoretical framework. Lastly, the main strengths and limitations of this research are presented in the seventh section, followed by a conclusion in the eighth section.

## 2. State of research: access to health care for women with disability in the Global South

Over the last decade, there has been a significant increase in the number of studies—both qualitative and quantitative—addressing the issue of access to health care for people with disability, which can be partially attributed to the increased visibility given to the subject since the publication of the World Report on Disability and the launch of the

WHO Global Disability Action Plan 2014–2021: Better Health for All People with Disabilities (Hashemi et al., 2022). However, many of these studies tend to focus on high-income countries, while existing research in low- and middle-income countries is still limited and usually carried out on a small scale (Baart & Taaka, 2018; Bright & Kuper, 2018; Clemente et al., 2022). Furthermore, there are few systematic reviews available that aim to identify barriers to access to health care for people with disability, rendering it particularly difficult to obtain a comprehensive overview of existing knowledge and evidence in this area of research.

Two recent review studies (Baart & Taaka, 2018; Hashemi et al., 2022) examining the situation of access to health care in low- and middle-income countries have sought to contribute to filling these research gaps. The results of both studies indicate that barriers to access can be classified thematically into two broad categories: those related to the demand side (i.e., people with disability seeking access to health care services) and those related to the supply side (i.e., health care providers). On the demand side, Baart and Taaka (2018) identify four major barriers: lack of information about the availability of health services; additional costs associated with accessing health care; limitations in terms of mobility; and stigmatisation and marginalisation embedded in the negative attitudes of families and communities towards people with disability. On the supply side, they point to three significant barriers: the negative attitude of health care staff; communication barriers between service providers and patients with disability; and the inaccessibility of health facilities and equipment in health centres (Baart & Taaka, 2018). Hashemi et al. (2022) point to a complex and dynamic interplay between three broad sets of constraints that impact both the demand for and supply of health care: cultural beliefs and attitudinal barriers; informational barriers; and practical and logistical barriers. They also draw attention to the fact that intersections between various socially constructed categories (such as socio-economic status and gender, to name but a few) often reinforce such barriers (Hashemi et al., 2022).

In this regard, another recent systematic review (Matin et al., 2021) examines the nature and complexity of the barriers that women with disability face when trying to access health care services internationally. Following the conceptual framework of access to health care proposed by Levesque et al. (2013), the main findings of the study were categorised into five dimensions: approachability, acceptability, availability, affordability, and appropriateness. In terms of approachability, four factors limit access to health services for women with disability: poor knowledge, negative experiences, lack of transparency, and lack of health information—the latter being a barrier that is evident in high-income countries as well as in low- and middle-income countries. In the acceptability dimension, multiple barriers are encountered, including insufficient social support, erroneous assumptions, discriminatory attitudes, stigma, violence and abuse, and social isolation. Regarding availability, lack of physical access to transport systems and buildings, inaccessible equipment, or lack of assistive devices in health facilities are factors that negatively impact access to health care for women with disability, especially in low- and middle-income countries, where such deficiencies are a major obstacle. In the affordability dimension, poverty, unemployment, financial dependency, lack of health insurance and high costs of certain services (e.g., transportation) are the main barriers to the utilisation of health services. Finally, in terms of appropriateness, low levels of health literacy, the lack of communication tools in health care settings and the lack of necessary skills and competencies among health care providers constitute significant barriers for women with disability (Matin et al., 2021).

These findings are also in line with the results of the scoping review by Clemente et al. (2022), who classify barriers to health access for people with disability according to the same five dimensions. The authors further point out that these dimensions of access are not independent, but on the contrary, they are interrelated and can influence each other. Additionally, and consistent with the findings of Baart and

Taaka (2018) and Hashemi et al. (2022), they note the presence of barriers on the part of health service users (such as communication failures between professionals and patients, financial constraints, attitudinal issues, poor service provision, and organisational and transport barriers) and on the side of health care providers (such as lack of training for professionals, health systems failures, physical barriers, lack of resources, and language barriers). The authors conclude that the numerous barriers identified –in addition to substantially limiting access to health care– generate and perpetuate inequalities that result in the further social exclusion of people with disability (Clemente et al., 2022).

It is clear that the situation of access to health care for people with disability –and particularly for women with disability– in the Global South is complex, with numerous barriers to overcome to ensure that they can exercise their right to health on an equal basis. The following section reviews the existing literature on the topic in the Nepali context to gain a better understanding of the factors limiting women with disability's access to health care in the country.

### 3. State of research: access to health care for women with disability in Nepal

At present, existing data and statistics on people with disability in Nepal are extremely scarce, confusing, and even contradictory (Eide et al., 2016; Poudyal et al., 2018; USAID, 2017). In addition, and as observed in other low- and middle-income countries, research efforts in this field are incipient. Empirical evidence on the situation of people with disability is therefore limited, particularly with regard to access to health care. Moreover, following Devkota et al. (2017), the specific issue of access to health care services for women with disability remains an under-researched subject in the country.

Nepal is a signatory of the UNCRPD and has multiple constitutional, legislative, and public policy instruments aimed at the protection and promotion of the rights of people with disability<sup>3</sup>. Both the 2015 Constitution of Nepal and the country's disability policies aim to ensure freedom from discrimination on the basis of gender and disability (Acharya, 2020). Yet there are significant implementation gaps that translate into substantial barriers to the exercise of the right to health, especially for women with disability. Acharya (2020) further points out that existing disability provisions<sup>4</sup> in the country are either not gender-sensitive or are ineffectively enforced, leading to the violation of the rights of women with disability.

A qualitative study on disability inclusion in access to primary health care points out that in addition to the well-known environmental barriers (such as lack of transportation and poor quality of services provided), there are other barriers that widely affect access to health care for people with disability: the social environment and dependence on third parties to visit health facilities; stigmatisation by families and communities; lack of income or financial resources; out-of-pocket payments; lack of public awareness about disability; and lack of information about government support systems (Van Hees et al., 2015). Further studies (Eide et al., 2016; Mahato & Paudel, 2015) also point to a lack of awareness among patients with disability –as well as health workers– of free health care services, which have been constitutionally guaranteed since 2007<sup>5</sup>. Mahato and Paudel (2015) argue that the lack of

dissemination of information about free health care programmes by hospitals results in a very low utilisation of such services and a heavy reliance on out-of-pocket payments, which substantially limits access to health care services for those without health insurance or the necessary financial means.

While the financial disadvantage of people with disability is perceived as one of the main barriers in the Nepali context (Van Hees et al., 2015), there are additional factors that hinder access to health care. Several studies investigating the provision of maternal health services for women with disability in the country (see for example Devkota et al., 2017; Devkota et al., 2018; Morrison et al., 2014) also highlight a number of shortcomings in terms of accessibility and availability. These comprise the inadequacy of health facilities regarding physical infrastructure; the long distances to health facilities; the unequal distribution of health centres between rural and urban areas (with a clear urban bias); the inadequate budget allocation in the health sector; high transport costs; the poor state of roads; long waiting times; shortages of equipment and supplies; and lack of adequately trained health personnel. Inefficiencies in the health system, poor implementation of health sector policies and mismanagement of available resources are also identified as major factors contributing to the problem (Devkota et al., 2018). Finally, regarding acceptability and the presence of attitudinal barriers, some studies (see for example Devkota et al., 2017; Devkota et al., 2018; Devkota et al., 2019) report mixed findings. However, there is evidence of prevalent negative attitudes and behaviours towards women with disability on the part of health service providers –for example, stemming from inadequate public and professional knowledge about disability– which result in experiences of discrimination, stigmatisation, and exclusion, and undermine access to health care (Devkota et al., 2017, 2018, 2019). It was also found that existing disability provisions fail to address the intersection of disability with other relevant social categories (such as gender or caste), leading to further discrimination and marginalisation of women with disability (Acharya, 2020).

Despite the limited empirical evidence, the available findings are consistent with the research results from other low- and middle-income countries discussed in the previous section. Data from Nepal indicate the presence of attitudinal, physical, communication and financial barriers on both the supply and demand sides. The interrelationship and interaction of these barriers hinder the utilisation of health services and thus compromise full and equal access to health care for people with disability.

This review of the existing literature on the topic shows that empirical and theoretical research on disability remains rather limited in the Global South, with Nepal being no exception. Particularly striking is the insufficient theorisation of disability (Grech, 2016; Katsui & Swartz, 2021), which represents a significant problem in addressing barriers to health care in an informed and contextualised way. To contribute to a stronger theoretical anchoring of the topic, our empirical data on access to health care for women with disability in Nepal will be analysed and interpreted in light of the theoretical framework presented below.

### 4. Theoretical framework: Disability and vulnerability

The language of vulnerability is common among social movements, human rights advocates and institutions, whose discourse draws attention to the existence of vulnerable populations or groups in need of protection (Butler et al., 2016). Among these groups, people with disability are often considered 'especially' vulnerable, implying that their chances of being subject to harm are greater, and therefore require special support or services to protect them or enable them to protect themselves from potential harm (Scully, 2013). While appealing to the specific vulnerability of certain groups can be seen as an effective means of promoting the development of policy strategies aimed at reducing exposure to risk or harm (Grech, 2021), such targeting can also have unintended consequences. As Jackie Leach Scully (2013) points out,

<sup>3</sup> For a detailed account of these instruments, see Adhikari K. P. (2019). Realizing the Rights of Persons with Disability in Nepal: Policy Addresses from the Health, Education and Livelihoods Perspectives. *Nepalese Journal of Development and Rural Studies*, 16, 23–34.

<sup>4</sup> For a relevant and detailed thematic analysis of the disability provisions in place in Nepal, see Acharya, T. (2020). *Sex, Gender and Disability in Nepal. Marginalised Narratives and Policy Reform*. London and New York: Routledge.

<sup>5</sup> The 2007 Interim Constitution of Nepal effectively addresses health as a fundamental right and states that every citizen has the right to free basic health care (Mishra et al., 2015).

such an operation reinforces the notion that whereas some people require special protections, the norm of human life is to be –or to aspire to be– invulnerable.

This fiction of invulnerability regards vulnerability as an accidental trait –often associated with passivity, lack of agency, and susceptibility to harm– that is typically disavowed and projected onto others with whom one disidentifies (Cano Abadía, 2020). Understanding vulnerability in these terms results in the dichotomisation of populations into two distinct groups: the invulnerable ones and the vulnerable "others" who need extraordinary treatment and special protections that the former do not (Scully, 2013). In other words, when people with disability are thought of as a separate class of people –as a vulnerable "them" distinct from an invulnerable "us"<sup>6</sup>– disability issues are mistakenly understood as the special interests of a specific subset of the population (Knight, 2014).

This article addresses the issue of barriers to access to health care for women with disability in Nepal by building on Amber Knight's theoretical efforts. Knight (2014) posits that a political appeal to a shared human vulnerability has the potential to deconstruct the able/disabled binary that still hinders addressing disability as a shared matter of political planning and public welfare. To this effect, Knight draws on the work of Judith Butler, who argues for a new bodily ontology that allows for a rethinking of vulnerability. According to Butler, the human body is fundamentally fragile, insofar as every physical body is exposed to injury and mortality. This fragility can be understood as the universal condition of primary vulnerability, also called *precariousness*. It is however possible and necessary to distinguish between this universal condition of vulnerability and its particular experience, as human vulnerability is affected by power relations. In this sense, Butler contends that while human lives are universally vulnerable, precariousness is unequally distributed and thus experienced in particular ways. This unequal distribution is called *precarity* and refers to a condition politically induced by the interplay of various forms of oppression, such as sexism and ableism (Knight, 2014).

Knight (2014) aims to demonstrate that the denial of our shared vulnerability ultimately affects both people with and without disability, contributes to the stigmatisation of impaired people, and leads to the inadequate design of social welfare policies. The disavowal of human vulnerability perpetuates the idea that people with disability require "special" protections or services, constraining the creation of political and social arrangements beneficial to all, including people with disability and other marginalised groups. This analysis of vulnerability points to the responsibility of states to take an active role in the equitable distribution of precariousness through the universalisation of social rights (Knight, 2014). As mentioned above, formal equality –embodied, for example, in anti-discrimination legislation advocating for equal protection and rights– does not automatically translate into substantive social equality (Knight, 2014). In fact, legal instruments are severely limited in their capacity to combat the structural inequality that exposes certain groups to precarity. This is especially evident in the case of access to health care for people with disability, as they continue to face substantial barriers in exercising their right to health. As Knight (2014) suggests, an appeal to vulnerability allows us to think of disability not just as a discrimination issue, but as a public welfare issue, since vulnerability to illness and disability are constant and universal. In this way, the debate on barriers to access to health care may be shifted from the realm of individual discrimination to the realm of social policy

<sup>6</sup> The binary opposition "us" versus "them" (Said, 1978) is a core concern of the postcolonial canon. Said (1978) originally employed this terminology to refer to the othering process by which the difference between the familiar (the West, the colonisers, "us") and the strange (the East, the colonised, "them") was promoted. The analysis recovered here draws on reflections from post-colonialism, accounting for the consequences of legitimising the representation of people with disability as the "vulnerable other".

planning and development. Perhaps this shift could ensure the full realisation of the right to health of people with disability and address the precarity to which they are exposed.

## 5. Research methods and procedures

This paper's qualitative data collection process was carried out in two phases, which took place in November 2021 and November 2022. The first exploratory phase aimed to identify barriers and enablers to the social, economic, and political inclusion of women with disability in Nepal. To this end, ten semi-structured in-depth interviews were conducted using photo elicitation<sup>7</sup>. Having recognised the relevance of specific issues (such as gender-based violence or access to health care) in the experience of the interviewees, we decided to carry out a second data collection to address them more thoroughly. The results obtained during the first phase were thus complemented by 15 additional semi-structured in-depth interviews.

The selection criteria focused primarily on adult women with disability. To explore the intersection of disability with other social categories, the sample was sought to present a diverse set of characteristics (in terms of age, ethnicity, caste, and urban/rural residence). In the first phase of data collection, a total of 10 women with different forms of disability (i.e. physical impairment, sensory impairment or mental illness<sup>8</sup>) were interviewed. The selection and recruitment of participants were carried out by four local organisations of people with disability (OPDs) together with CBM International: the National Indigenous Disabled Women Association Nepal (NIDWAN), the Blind Women Association Nepal (BWAN), the Nepal Disabled Women Association (NDWA) and the National Mental Health Self-Help Organisation (KOSHISH). In the second phase, a total of 15 women with different forms of disability (i.e. physical or sensory impairment) were interviewed. Participants were selected and recruited through snowball sampling, i.e., through some of the women interviewed in November 2021.

A total of 25 qualitative interviews were conducted, each lasting between 60 and 90 minutes. The interviews were conducted face-to-face in agreed-upon locations that were safe and convenient for the participants (i.e. in their homes or in accessible venues). Open-ended questions were asked to explore participants' personal experiences and subjective views, which allowed for the emergence of unforeseen topics. All data and information were to be kept anonymous at all times, with a guarantee provided to respondents in advance. Participation in the study was voluntary and written consent was obtained from all respondents after careful explanation of the study<sup>9</sup>.

The 25 interviews were recorded, transcribed and translated from Nepali into English –where necessary– and then coded and categorised using MAXQDA and following the principles of grounded theory (GT). GT was chosen as a qualitative data analysis method partly because it offers useful strategies to develop theoretical analyses (Charmaz & Thornberg, 2021) based on systematically collected and analysed data (Noble & Mitchell, 2016). GT's inductive nature allows for the

<sup>7</sup> Photo elicitation is a method that involves using photographs or other visual aids in an interview to prompt verbal discussions and generate data and knowledge (Glaw et al., 2017). In the first research phase, photographs taken by the participants served as a starting point for the qualitative interviews but are not included in this article.

<sup>8</sup> *Physical impairment* denotes any condition or limitation affecting a person's physical functioning, mobility or bodily systems. *Sensory impairment* refers to a condition in which one or more of the senses (such as sight or hearing) are significantly diminished or absent. *Mental illness* is understood as any condition affecting a person's thinking, emotions, and/or behaviour.

<sup>9</sup> Regarding the consent process for respondents with mental illness, it is pertinent to clarify that these women suffer from chronic major depression and were fully capable of giving their consent to participate in the research after a detailed explanation of the purposes.

researcher's assumptions to be challenged and the views and concerns of the social actors involved in the research process to be heard (Strauss & Corbin, 1996). GT is thus well suited to capture and interpret individuals' subjective experiences and perceptions of reality (Cullen & Brennan, 2021). The process of coding and data analysis involved sensitivity and reflexivity, and the research team critically reviewed and discussed the derived interpretations to enhance credibility (Foley & Timonen, 2015).

## 6. Results

The state of research presented above indicated that the barriers restricting access to health care for people with disability are numerous and reinforced in their interaction with socially constructed categories such as gender, caste, or socio-economic status.

The results of our research show that two main factors compromise the full enjoyment of the right to health of women with disability in Nepal: on the one hand, *lack of accessibility* (in terms of availability of health care services, daily living aids and assistive devices, and infrastructure) and, on the other hand, multiple instances of *discrimination and stigmatisation* (related to disability, ethnicity, caste, and gender).

### 6.1. Lack of accessibility

Regarding lack of accessibility, our results mainly indicate a lack of or restricted access to quality health care as a consequence of the shortage of health professionals trained in disability issues, the uneven distribution of health care centres across the country (with a marked deficit in rural areas) and the high costs of health care (which include not only the costs of treatment but also costs linked to access to health care, such as transport). Most of the women interviewed particularly emphasised the financial difficulties they face in paying for the necessary treatments and medications, given the often precarious economic situation in which they find themselves:

*"The cost [of the treatment] was around 4000 US dollars in 4 years, which is a very big amount for us farmers. There is a women's group and cooperatives and financial institutions where we save around 500 Rupees (less than 4 USD) a month. I am in 5 such cooperatives. And I took loans of about 50'000 Rupees (approx. 383 USD) ... Some of my relatives helped me with loans. [We] sometimes sold our cattle and we took a loan. So, all this helped to fund my treatment." (Heena, 45 years old, mental illness)*

Although the Nepali Constitution guarantees free health care services since 2007, several respondents claimed to be uninformed about these programmes or unable to benefit from them. When asked about this, one of the interviewees said:

*"First of all, we don't have access to information. [...] The government is not paying so much attention, in fact not paying attention at all. They only give some facilities to us in the government hospitals, but it is not enough because the government hospitals are not that good in Nepal. And not every treatment is available there. So, for those types of treatment, we have to go to private hospitals and the case is the same there." (Laxmi, 24 years old, visual impairment)*

As these women's accounts show, financial barriers are further exacerbated for those who live far from Kathmandu, where most of the country's hospitals and health centres are located:

*"And more so we need access to medication, and it is very difficult to just get anti-depressants without a doctor's note. So, we have to come to Kathmandu all the time and that adds to the financial burden as well. So, it is a major barrier." (Heena, 45 years old, mental illness)*

Indeed, restricted access to quality health care takes a heavy toll on the long-term health and well-being of these women, as one respondent noted:

*"To begin with, the illness in itself is small and manageable with proper treatment on time. But because we didn't have access to doctors, it became big over time." (Binsa, 23 years old, mental illness)*

Our results also indicate that women with disability experience restricted access to the daily living aids and/or assistive devices that they require. Many interviewees reported that the provision of these devices (such as Braille devices, prostheses, or wheelchairs) in the country is scarce and that they have to resort to imported devices:

*"I am a prosthesis user. [...] The prosthetics that we have access to in Nepal are very basic. But the ones abroad are more advanced, and one can even run with it. Having that would enable me to run around as well and feel less bad about my situation." (Sanjana, 26 years old, physical impairment)*

Another respondent stressed that the devices they require are not guaranteed to be free of charge, thus becoming a financial burden:

*"This [showing a picture] is the prosthesis that I use to support my legs. Most people can't get this. Only 2 or 3 hospitals provide this. [...] To get this made, I had to pay 25'000 Rupees (approx. 191 USD). The government and the handicapped industry give it to the hospitals for free, but they make us pay for it. Many people cannot pay for it. But we need it, as we cannot walk without it." (Shubhu, 24 years old, physical impairment)*

In addition, our results show that inadequate infrastructure is another major barrier to access to health care for women with disability:

*"It [the hospital] is not very accessible. I have to park my wheelchair outside and then I go in using my hands." (Devna, 39 years old, physical impairment)*

Even when infrastructural accessibility conditions are guaranteed in some health care facilities, attitudinal barriers are still present:

*"Most health centres are not accessible to me. I mostly go to places that are accessible nowadays. The last one I visited was [hospital name] where there is a wheelchair facility, and the toilets are also disability friendly. There is also a parking space for four-wheeler scooters. But there are times, even in that hospital when the doctors question me and ask me why I came alone." (Ehani, 38 years old, physical impairment)*

The inadequacy of infrastructure is not only related to health care facilities but also, for instance, to transportation and roads, as several interviewees explained:

*"The main problem I have been facing is with transportation, the public vehicles. They don't want to take us in their vehicles as they have to give one space and give us a discount. And that for them is making less money from one seat. So, it is a type of loss, and they are not considerate. This is a major issue and people need to be strict with the concerned policies." (Anushka, 23 years old, visual impairment)*

*"When I started going out of my hostel, around the time I started losing my vision, I realised the complexities of our surroundings. There were so many potholes in the road, bricks were randomly thrown about, and all these things make life more complicated for us." (Kasmitha, 26 years old, visual impairment)*

As can be seen, women with disability in Nepal face multiple barriers (touching on the dimensions of availability, affordability, and appropriateness of access to health care) that interact with and are reinforced by the instances of discrimination and stigmatisation presented below.

### 6.2. Discrimination and stigmatisation

Regarding the multiple instances of discrimination and stigmatisation, our findings show that they significantly restrict access to health care for women with disability in Nepal throughout their lives. The

testimonies of the interviewees give an account of how these experiences negatively impact (either directly or indirectly) their exercise of the right to health both during childhood and adulthood. Most respondents stressed that disability continues to be highly stigmatised in Nepali society, resulting in experiences of discrimination that compromise their access to health care. Our results show that already from an early age, many women with disability are ostracised and thus systematically excluded from the social, economic, and political spheres. During childhood, for instance, the stigma associated with disability leads children with impairments to remain isolated in their homes, severely compromising their access to education and health. The stigmatisation of disability also contributes to social isolation during adulthood, as many interviewees pointed out:

“Anytime I step out of my house, I feel people judging me and pitying me. It makes me feel further depressed. So, I hate going out.” (Chimini, 24 years old, visual impairment)

Negative attitudes and behaviours are as prevalent in the immediate environments (such as family or friendship circles) as in recreational, educational, work, and political settings. Take labour participation as a case in point: Given the lack of disability awareness and the resulting discrimination, women with disability face significant difficulties in accessing paid work, as one interviewee noted:

“People have a preconceived notion that persons who are disabled will not be able to work and don’t give us jobs. [...] They just look at our faces and decide that we can’t work.” (Anushka, 23 years old, visual impairment)

As such, attitudinal barriers to labour market integration frequently lead to a lack of financial means to access health care services (i.e., they become a financial barrier).

As far as experiences of discrimination and stigmatisation by health care providers are concerned, our research presents (in line with other studies conducted in the country) mixed findings. On the one hand, some interviewees reported good experiences in their encounters with health care providers and even highlighted the good treatment they received from nurses and doctors. On the other hand, however, our results show the presence of attitudinal barriers that undermine access to health care for women with disability. In many cases, discriminatory and/or stigmatising attitudes and behaviours go hand in hand with a lack of knowledge about disability issues, as one respondent pointed out:

“They [doctors] do not know how to handle us and how to behave with us. Sometimes even nurses do not know. They are educated, but they are not educated in terms of awareness”. (Laxmi, 24 years old, visual impairment)

Also in line with the lack of knowledge and awareness, some of these women (especially those whose impairments are less visible) reported disbelief on the part of health workers:

“I don’t go much for check-ups. But when I go and show my [disability] card, they question my disability and that is not right”. (Aarati, 28 years old, physical impairment)

As can be seen, concerning the acceptability dimension, the presence of attitudinal barriers translates into experiences of discrimination and stigmatisation that undermine access to health care for women with disability in Nepal. We have sought to show that the restriction of such access does not stem exclusively from the negative attitudes and behaviours towards these women that prevail in the health care sector. Multiple instances of discrimination and stigmatisation in other spheres also significantly compromise their access to health services and the full enjoyment of their right to health. Interviewees’ testimonies show how discrimination and stigmatisation –both during childhood and adulthood– negatively impact their access to health care. Systematic exclusion from the social, economic, and political spheres (resulting from barriers to inclusion in community, educational and work settings, to name but a few) not only affects the mental and physical health of

women with disability but also significantly reduces their possibilities of accessing health care. Our results thus show that attitudinal barriers interact in complex ways with several other factors (such as financial and physical inaccessibility), limiting access to health services for women with disability in Nepal and undermining their well-being.

## 7. Discussion

As Grech (2016) rightly pointed out, theorising on disability in the Global South remains weak, and the intersection of disability with other social categories continues to be underexplored. In order to contribute to narrowing these gaps, this section analyses the empirical data collected in relation to the proposed theoretical framework. In line with Grech (2016) it is our understanding that situated theorising of disability –in all its complexity and heterogeneity– is a necessary reflective exercise for informed, contextualised, responsible and responsive development practice. In other words, theorising disability can potentially contribute to an improved design of social policies that accommodate the needs and perspectives of people with disability to fulfil their social rights effectively. Following Amber Knight (2014), this section reflects on how the notion of a shared human vulnerability can enable disability to be addressed as an issue of shared public welfare. This insight could be valuable in improving access to health care for women with disability in Nepal to ensure their full enjoyment of the right to health.

Our research found –in line with other empirical studies on the topic– that women with disability in Nepal face multiple barriers when trying to access health care. Our results show that *lack of accessibility and discrimination and stigmatisation* are the main factors limiting the full enjoyment of the right to health of women with disability in Nepal. Financial, physical, and attitudinal barriers have been identified as the main hurdles that –both individually and in their interaction– significantly restrict access to health care for women with different types of impairments. The continued presence of these barriers reveals the limitations of specific legislative instruments in guaranteeing the social rights of women with disability –as, in this case, the right to health.

It has been noted that Nepal has a relatively comprehensive set of legal and constitutional provisions aimed at protecting the rights of people with disability and ensuring equal access to them as their non-disabled peers. However, our data reveal a gap between formal or normative equality and substantive equality. In other words, the recognition of the rights of people with disability does not necessarily translate into the full exercise of these rights. As a report of the UN Committee on the Rights of Persons with Disabilities (2018) points out, this is partly due to inadequate and/or insufficient implementation of existing anti-discrimination legislation, policies, and programmes. A central concern relates to the multiple and intersectional discrimination that people with disability continue to face in Nepal (on grounds of caste or ethnicity, for example), and to the situation of women and girls with disability.

As our research shows, the discrimination and stigmatisation experienced by women with disability in Nepal is indeed a factor hindering their access to health care, but not the only one. In line with Knight’s (2014) argument, what is evident is that anti-discrimination legislation does not ensure the effective removal of barriers that restrict the social rights of people with disability in the Nepali context. While these instruments are of fundamental relevance for advancing the full participation of people with disability in civil society, they are limited in their capacity to ensure the necessary transformations to tackle the precarity to which they are exposed (Knight, 2014).

To return to what was mentioned in the theory section, thinking about the distinction between universal human vulnerability and its particular experience (i.e., between precariousness and precarity) allows us to recognise the dynamics that affect it. Precariousness is not only unequally distributed between people with and without disability, but also among people with disability based on their gender, ethnicity, religion, caste, socio-economic status, or geographic location, among

many others. The testimonies of the women interviewed show the heterogeneity of their experiences and the different degrees of precariousness to which they are exposed.

However, our findings still indicate that health care access is generally compromised for women with disability in Nepal. This raises the question of the politically induced nature of the precarity to which they are exposed, disadvantaged in comparison to their non-disabled peers. Following Knight's (2014) argument, this research corroborates that existing instruments for eradicating discrimination against people with disability (and, in particular, women with disability) fall short of guaranteeing the full exercise of their social rights, including access to health care. This is partly due to their limited capacity to address the lack of accessibility resulting, for example, from the uneven distribution of health care centres across the country, the high costs of health care, or the inadequate infrastructure of health facilities, transport, and roads. Although anti-discrimination instruments address the issue of accessibility in formal and discursive terms, this does not translate into effective changes that remove the barriers to access to health care discussed here. That is, while constraints in the dimensions of availability, affordability, and appropriateness of access to health care are reinforced by discrimination and stigmatisation, they must also be addressed independently. As Knight (2014) suggests, disability should not be thought of exclusively as a discrimination issue, but also as a public welfare issue.

In this respect, recognising our shared human vulnerability provides a good starting point for creating fairer social and political orders that do not in practice relegate the rights of people with disability. Perhaps the idea that all human beings are likely to experience some kind of disability at some point in their lives (Knight, 2014) will allow us to allocate the necessary resources and political will to ensure the fundamental rights of people with disability, such as the right to health. In other words, shared vulnerability could be a solid basis for meaningful political solidarity aimed at dismantling the web of inequalities that constrains the exercise of rights (Knight, 2014). This analysis points to the fundamental role of the state in mitigating precarity through a genuine universalisation of social rights (Knight, 2014) from which all can benefit regardless of socio-economic status, gender, caste, ethnicity, geographic location, or disability, among others. The case of access to health care is illustrative in this respect: taking measures to remove the barriers identified in our research (such as the lack of health care centres in rural areas or the high costs of medical treatment) would not only be beneficial for women/people with disability but for the population as a whole.

## 8. Strengths and limitations

The main strength of this research lies in the inclusion of marginalised voices to address an under-researched and under-theorised topic in the Nepali context. The chosen qualitative approach allowed us to delve deeper into the lived experiences of women with disability and was well-suited to explore the intersection of disability with other relevant social categories. It is acknowledged that the main limitation of this research lies in the limited generalisability of the results, given the sample size and characteristics. While our findings provide valuable insights regarding access to health care for women with disability, they are specific to the Nepali context and predominantly reflect the experiences of physically disabled women living in urban areas. Further empirical and theoretical research efforts (particularly in remote areas of the country) are needed to advance the full realisation of the rights of women with disability.

## 9. Conclusion

The limited access to health care for women with disability in Nepal is of great concern to both academics and practitioners, as this situation represents a breach of a fundamental human right, namely the right to

health. As we have sought to demonstrate in this article, women with disability face numerous and interrelated barriers when trying to access health care in the country. Both the lack of accessibility and the multiple instances of discrimination and stigmatisation severely restrict the possibilities of the women interviewed to access quality health services, which has a detrimental impact on their well-being. Nevertheless, as we argue, it is necessary to address this situation as a matter of public welfare and not as a problem that affects only a limited group of individuals. As our results show, the precarity to which women with disability are exposed is not only a consequence of the discrimination they experience, but also a product of various forms of oppression (such as ableism, sexism, or racism, to name a few) that place certain populations on the margins. In this sense, we agree with Knight (2014) that anti-discrimination instruments have a limited capacity to distribute precariousness more equitably.

Our research has shown that access to health care –as a social right– is not guaranteed for women with disability despite the existence of multiple constitutional, legal, and public policy provisions in place in the Nepali context. The available literature on the subject also reports a gap between formal equality and the effective exercise of rights, which is suggested to be partly due to the inadequate or incomplete implementation of disability policies and programmes. While we agree a priori with this assessment of the situation, more empirical and theoretical research efforts are needed to gain a better understanding of the problem and inform the design of social policies that accommodate the needs and perspectives of women/people with disability. It is even possible to argue, in line with Knight (2014), that this is a necessary step away from the erroneous view that disability issues are only of concern to a small and distinct segment of the population. Understanding that no one is exempt from acquiring a disability –given our primary human vulnerability– can lead to the health needs of people with disability no longer being considered "special" or "extraordinary". In this way, the reluctance of a political system to allocate the necessary resources to meet the so-called "special" needs of people with disability could potentially be countered (Knight, 2014).

In this regard, it is crucial not only to redouble disability research efforts but also to adopt participatory approaches to openly listen to and learn from people with disability and their environments. Prioritising their voices in research is necessary to recognise that context, cultures, religions, ideologies, and circumstances construct and frame the experience of disability (Grech, 2016). Capturing the complexity and heterogeneity of the disability experience (as well as the way disability intersects with other relevant social categories) is the critical starting point for adequately addressing the needs of people with disability. This is precisely what we have attempted to do in this article, given the still persistent paucity of reliable data and limited theorising on disability in South Asia. In this case, gaining a better understanding of the reality of women with disability in Nepal can contribute to bridging the research gaps identified and accommodating their needs and perspectives in policy planning and implementation. Regarding barriers to health care, addressing them as a public welfare issue (and not exclusively as a discrimination issue) can be beneficial not only for women with disability, but potentially for the whole population. Ensuring truly universal access to health care is the first step in helping to improve health outcomes and increase levels of well-being for women with disability, thus ensuring the full realisation of their right to health.

## Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ssm.2023.100315>.

org/10.1016/j.ssmqr.2023.100315.

## References

- Acharya, T. (2020). *Sex, gender and disability in Nepal. Marginalized narratives and policy reform*. London and New York: Routledge.
- Baart, J., & Taaka, F. (2018). Barriers to healthcare services for people with disabilities in developing countries: A literature review. *Disability, CBR & Inclusive Development*, 28(4), 26–40. <https://doi.org/10.5463/dcid.v28i4.656>
- 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. <https://doi.org/10.3390/2Fijerph15091879>
- Butler, J., Gambetti, Z., & Sabsay, L. (2016). Introduction. In J. Butler, Z. Gambetti, & L. Sabsay (Eds.), *Vulnerability in resistance* (pp. 1–11). Durham and London: Duke University Press.
- Cano Abadía, M. (2020). The fiction of invulnerability. Silence and otherness in francoist Spain. *Redescriptions: Political Thought, Conceptual History and Feminist Theory*, 23(2), 138–150. <https://doi.org/10.33134/rds.341>
- Charmaz, K., & Thornberg, R. (2021). The pursuit of quality in grounded theory. *Qualitative Research in Psychology*, 18(3), 305–327. <https://doi.org/10.1080/14780887.2020.1780357>
- Clemente, K. A. P., Silva, S. V. da, Vieira, G. I., Bortoli, M. C. de, Toma, T. S., Ramos, V. D., & Brito, C. M. M. de (2022). Barriers to the access of people with disabilities to health services: A scoping review. *Revista de Saúde Pública*, 56, 64. <https://doi.org/10.11606/s1518-8787.2022056003893>
- Cullen, M. M., & Brennan, N. M. (2021). Grounded theory: Description, divergences and application. *Accounting, Finance & Governance Review*, 27. <https://doi.org/10.52399/001c.22173>
- Devkota, H. R., Kett, M., & Groce, N. (2019). Societal attitude and behaviours towards women with disabilities in rural Nepal: Pregnancy, childbirth and motherhood. *BMC Pregnancy and Childbirth*, 19, 20. <https://doi.org/10.1186/s12884-019-2171-4>
- 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. *Reproductive Health*, 14, 79. <https://doi.org/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), Article e0200370. <https://doi.org/10.1371/journal.pone.0200370>
- Eide, A. H., Neupane, S., & Hem, K. G. (2016). *Living conditions among people with disability in Nepal*. Oslo: SINTEF.
- Foley, G., & Timonen, V. (2015). Using grounded theory method to capture and analyze health care experiences. *Health Research Services*, 50(4), 1195–1210. <https://doi.org/10.1111/1475-6773.12275>
- Glaw, X., Inder, K., Kable, A., & Hazelton, M. (2017). Visual methodologies in qualitative research: Autophotography and photo elicitation applied to mental health research. *International Journal of Qualitative Methods*, 16(1). <https://doi.org/10.1177/1609406917748215>
- Grech, S. (2016). Disability and development: Critical connections, gaps and contradictions. In S. Grech, & K. Soldatic (Eds.), *Disability in the Global South. The critical handbook* (pp. 3–20). New York: Springer.
- Grech, S. (2021). Critical thinking on disability and development in the Global South. In R. Lewis Brown, M. Maroto, & D. Pettinicchio (Eds.), *The oxford handbook of the sociology of disability* (pp. 135–154). Oxford: Oxford University Press. <https://doi.org/10.1093/oxfordhb/9780190093167.013.9>
- 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 & Rehabilitation*, 44(8), 1207–1220. <https://doi.org/10.1080/09638288.2020.1817984>
- Katsui, H., & Swartz, L. (2021). Research methods and practices of doing disability studies in the Global South. *Scandinavian Journal of Disability Research*, 23(1), 204–206. <https://doi.org/10.16993/sjdr.841>
- Knight, A. (2014). Disability as vulnerability: Redistributing precariousness in democratic ways. *The Journal of Politics*, 76(1), 15–26. <https://doi.org/10.1017/s0022381613001266>
- Levesque, J. F., Harris, M. F., & Russell, G. (2013). Patient-centred access to health care: Conceptualising access at the interface of health systems and populations. *International Journal for Equity in Health*, 12, 18. <https://doi.org/10.1186/1475-9276-12-18>
- Mahato, P. K., & Paudel, G. S. (2015). Access to free health-care services for the poor in tertiary hospitals of western Nepal: A descriptive study. *WHO South-East Asia Journal of Public Health*, 4(2), 167–175. <https://doi.org/10.4103/2224-3151.206686>
- Matin, B. K., Williamson, H. J., Karyani, A. K., Rezaei, S., Soofi, M., & Soltani, S. (2021). Barriers in access to healthcare for women with disabilities: A systematic review in qualitative studies. *BMC Women's Health*, 21, 44. <https://doi.org/10.1186/s12905-021-01189-5>
- Mishra, S. R., Khanal, P., Karki, D. K., Kallestrup, P., & Enemark, U. (2015). National health insurance policy in Nepal: Challenges for implementation. *Global Health Action*, 21(8), Article 28763. <https://doi.org/10.3402/2Fgha.v8.28763>
- Morrison, J., Basnet, M., Budhathoki, B., Adhikari, D., Tumbahangphe, K., Manandhar, D., Costello, A., & Groce, N. (2014). Disabled women's maternal and newborn health care in rural Nepal: A qualitative study. *Midwifery*, 30(11), 1132–1139. <https://doi.org/10.1016/j.midw.2014.03.012>
- Noble, N., & Mitchell, G. (2016). What is grounded theory? *Evidence-Based Nursing*, 19(2), 34–35. <https://doi.org/10.1136/eb-2016-102306>
- Poudyal, N., Banskota, M., Khadka, D., & Ojha, G. (2018). *Disability in Nepal: Taking stock and forging a way forward*. Kathmandu: Disability Research Centre Kathmandu University.
- Said, E. W. (1978). *Orientalism*. New York: Pantheon Books.
- Scully, J. L. (2013). Disability and vulnerability: On bodies, dependence, and power. In C. Mackenzie, W. Rogers, & S. Dodds (Eds.), *Vulnerability: New essays in ethics and feminist philosophy* (pp. 204–221). Oxford: Oxford University Press.
- Strauss, A. L., & Corbin, J. (1996). *Grounded theory: Grundlagen qualitativer sozialforschung*. Weinheim: Beltz/Psychologie Verlags Union.
- United Nations (Un). (2000). *Substantive issues arising in the implementation of the international covenant on economic, social and cultural rights*. Geneva: United Nations.
- United Nations (Un). (2006). *Convention on the rights of persons with disabilities*. Geneva: United Nations.
- United Nations (Un). (2018). *Report of the Special Rapporteur on the rights of persons with disabilities*. Geneva: United Nations.
- United States Agency for International Development (USAID). (2017). *Reading for all: Disability inclusive education for Nepali children*. Kathmandu: USAID.
- Van Hees, S., Cornielje, H., Wagle, P., & Veldmann, E. (2015). Disability inclusion in primary health care in Nepal: An explorative study of perceived barriers to access governmental health services. *Disability, CBR & Inclusive Development*, 25(4), 99–118. <https://doi.org/10.5463/dcid.v25i4.373>
- World Health Organization (WHO). (2020). *Disability: People with disability vs persons with disabilities*. Retrieved from <https://www.who.int/news-room/questions-and-answers/item/people-with-disability-vs-persons-with-disabilities>. (Accessed 16 May 2023).
- World Health Organization (WHO). (2021). *Disability fact sheet*. Retrieved from <https://www.who.int/news-room/fact-sheets/detail/disability-and-health>. (Accessed 24 July 2022).
- World Health Organization (WHO). (2022). *Global report on health equity for persons with disabilities*. Geneva: World Health Organization. Licence: CC BY-NC-SA 3.0 IGO.