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When Ables Speak for Disables: Identifying Barriers for Women with Disabilities in Nepal

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Abstract

This paper critically evaluates how the shortcomings in existing policies have been affecting women with disabilities in Nepal and proposes comprehensive reforms to address these gaps. Despite Nepal's legal commitments, the current public policies continue to create barriers to the full participation of women with disabilities. Consequently, the research identifies key policy gaps and recommends actionable reforms by incorporating insights from policy sociology, which examines how social structures and power dynamics influence policy formulation and implementation. The study highlights the intersectionality of gender and disability, demonstrating how these factors compound the marginalization of women with disabilities. The findings are based on reviews of policy research conducted in 2021 and 2022 in collaboration with organizations led by women with disabilities. The research advocates for the establishment of a dedicated commission, the revision of policies to align with international standards, and the strengthening of legal frameworks to combat discrimination. Ultimately, this study underscores the need for transformative policy reforms to enhance the rights and inclusion of women with disabilities in Nepal, addressing both systemic and intersectional issues to foster a more equitable society.

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Keywords: Ableism, intersectional barriers, Nepal, policy, policy barrier, women with disabilities.

Introduction

This paper proposes sensible and inclusive disability-friendly policies and calls for the appraisal of the existing policies that are discordant for women with disabilities. The paper intends to identify policy gaps relating to barriers faced by women with disabilities and recommends policy reforms to resolve these gaps. In Nepal, women with disabilities² are among the populations seriously impacted by the unfitted and unreliable public policies, which led to their acute social, economic, and political marginalization. Despite Nepal ratifying the United Nation (UN) Convention on the Rights of Persons with Disabilities (CRPD) and the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), current policies still serve as institutional and policy barriers that hinder the full participation of women with disabilities in their daily lives.

My understanding of these barriers deepened while conducting a policy review for the research projects undertaken by two disability rights-based organizations led by women with disabilities: the Blind Women's Association of Nepal (2021) and the Nepal Disabled Women's Association (2022). My interest in learning about the lives of women with disabilities led me to sociologically make a sense of the relationship between "people" and "policies" and to analyze these links through the prism of "policy sociology." After all, public policies are the reflection of social realities and are socially constructed (Fischer, 2009). They reflect the decisions of the state about "who gets what, where, when, and how" (Bach, 2012). In the same context, by examining how power dynamics and social structures have shaped policy decisions, policy sociology provides a window to identify how disabled women have been marginalized or excluded from the decision-making processes that directly affect them. By delving into the process of the formulation, implementation, and evaluation of policies, the domain of policy sociology not only investigates how policies are put into practice on the ground (where disability intersects with other social identities including gender, class, and race) but also advocates for policy reforms by analyzing policy processes and outcomes.

From the perspective of policy sociology, understanding the specific challenges faced by women with disabilities in Nepal is crucial for several reasons. Firstly, it

¹ The author declares that this paper is an original work and has not been published elsewhere. The errors and mistakes that may appear in the paper are the sole responsibility of the author.

² In this article, I refrain from abbreviating women with disabilities in accordance with the norms set by the disability rights activists.

³ Michael Burawoy (2005) has categorized the field of sociology into four interconnected domains: professional, critical, policy, and public. These categories are developed by responding to two critical questions "knowledge for whom" and "knowledge for what." Policy sociology aims to provide solutions to problems. Burawoy argues that the knowledge generated by policy sociology has to be practical and useful leading to policy interventions.

provides a nuanced perspective on the intersectionality of gender and disability. contributing to broader discourses on social justice and human rights. Secondly, it underlines how ableism as a pervasive force has shaped the policy landscape in Nepal. Ableist attitudes and beliefs underpin many of the institutional and policy barriers faced by women with disabilities. These attitudes manifest in various ways, from overt discrimination to subtler forms of bias that influence policy priorities and resource allocations. The influence of ableism on policy-making is evident in the limited representation of people with disabilities, especially women, in decision-making processes. This framing based on the intersection of ableism and patriarchy, influences how policies are conceived, often leading to paternalistic approaches that do not empower women with disabilities or recognize their agency. Against this backdrop, coupled with theoretical perspectives and empirical findings, this paper argues that understanding of disability needs to be connected with the intersections of barriers that persons with disabilities experience. To make this argument clear, I have presented a visual representation and description of how barriers interact with other social identity-makers of women with disabilities. This argument is further elaborated by highlighting how the invisibility of women with disabilities is shaped by the intersection of ableism and patriarchy. Alongside, the diverse perspectives on disability studies followed by empirical findings of the policy review are discussed in the paper.

The paper is divided into ten sections. The first four sections present background and social context followed by theoretical perspectives on understanding the institutional and policy barriers experienced by women with disabilities. The first section presents the status of persons with disabilities in Nepal, examining their socio-economic status. The paper then presents an overview of the policy of disability in Nepal. This is followed by a definition of disability examining the four barriers that persons with disabilities experience. The paper then delves into the exploration of the intersection of ableism and patriarchy. The second half of the paper comprising the other five sections links the context and argument of the intersection of ableism and patriarchy by presenting the findings of the study. Illustrating the findings, I also discuss how women with disabilities remain largely invisible within the existing policies. I then move on to discuss how the Government of Nepal has failed to establish the Commission on Persons with Disabilities. The paper then moves on to discuss the lack of policy interventions to remove social barriers, followed by the challenges of legal mechanisms to criminalize discrimination against persons with disabilities. The paper ends with recommendations for policy reforms and institutional changes to better address the needs of women with disabilities.

Persons with Disabilities in Nepal

Persons with disabilities constitute one of the most marginalized and vulnerable communities globally (Fisher et al., 2023). The United Nations estimates that over a billion people in the world live with some form of disability (UNDP, 2014). Similarly, the World Health Organization (WHO) estimates that nearly 15% of the world's population have some or other form of disability, which makes them the largest global minority (WHO, 2021). Among them, 80% of Persons with Disabilities live in developing countries like Nepal (UNESCO, 2020), highlighting their significant presence among the world's poorest and most at-risk populations, susceptible to violence, disasters, and health challenges (UNDP, 2014).

Over the past two decades, there has been a notable increase in the number of persons with disabilities. In Nepal, the census data reveals a steady rise: from 0.46% in 2001 to 2.2% in 2021, a trend linked to factors such as the prolonged armed conflict. The Truth and Reconciliation Commission (TRC) documented 60,298 complaints of human rights violations during this period, including disabilities caused by conflict (Human Rights Watch, 2024). Despite this, there remains a lack of disaggregated data on disability globally, including in Nepal (Abualghaib et al., 2019) which complicates understanding of the specific impacts on different groups within the disabled community, such as by gender. Other contributing factors to the increasing disability rates include disasters and the rising number of road accidents (Sánchez et al., 2019). The global COVID-19 pandemic further exacerbated vulnerabilities among persons with disabilities in three main ways: increased health risks, reduced access to essential healthcare and rehabilitation services, and adverse social impacts from pandemic control measures (Shakespeare et al., 2021).

Girls and women with disabilities face additional vulnerability due to the intersection of disability and gender. Two studies conducted by organizations led by persons with disabilities in Nepal show that women with disabilities are further disadvantaged in times of pandemic due to unequal access to relief materials. The online survey conducted by the Blind Women Association of Nepal (BWAN) in December 2020 showed that women with disabilities experienced loss of livelihood, food insecurity, and lack of sharing spaces and mobility restrictions along with reduced access to basic health services. Respondents also reported experiencing severe mental/psychological stress (BWAN, 2020). A similar study carried out by the Nepal Disabled Women Association (NDWA) aiming to study access to relief materials during the pandemic, showed that 80% ofgirls and womenwith disabilities, particularly those with multiple disabilities faced challenges in receiving the relief materials (NDWA, 2021).

Limited small-scale studies show that persons with disabilities in Nepal experience various forms of discrimination at home and face barriers to accessing their basic rights of education, health, and freedom of expression. Approximately 68.2% of persons with disabilities have no access to education, 85% have no access to healthcare facilities, and 77.8% have no employment to earn their living (Paudel et al., 2017). Girls and women with disabilities in Nepal experience further challenges. The status of girls and women with disabilities in Nepal is also shaped by other forms of class, caste, and regional inequalities.

Evolution of Disability Policies in Nepal

The declaration of the International Year of Disabled Persons (IYDP) in 1981, followed by the UN Decade of Disabled Persons (1983-1992), maked a pivotal moment for the recognition of the rights of persons with disabilities in Nepal. In 1982, Nepal drafted the Protection and Welfare of the Disabled Persons Act (PWDPA), the first policy document addressing disability (NLC, 1982).

Critics, however, argue that the PWDPA adopted a welfare-oriented approach rather than a rights-based one and was insensitive to gender issues. With the restoration of democracy in 1990, Nepal witnessed a burgeoning disability rights movement, enriched by the participation of women leaders with disabilities. This period saw an increasing acknowledgment of the distinct needs and challenges faced by girls and women with disabilities within both disability and women's rights movements.

Nepal ratified the Convention on the Rights of Persons with Disabilities (CRPD) on December 27, 2009, followed by the optional protocol on May 7, 2010. The CRPD is a binding international instrument that holds ratifying states accountable for promoting and safeguarding the rights of persons with disabilities. Central to its principles is gender equality, as articulated in Article 6, which mandates states to implement measures - legislation, policies, and programs - to ensure the rights of girls and women with disabilities. In 2017, Nepal introduced a new policy, "The Act Relating to Rights of Persons with Disabilities" (ARPD), crafted through extensive consultations with Disabled People's Organizations (DPOs) and stakeholders. This policy aimed to align with the CRPD and replace the earlier welfare-oriented approach (NLC, 2017).

Chapter 4 of the ARPD, titled "Additional Rights of Women and Children with Disabilities," specifically acknowledges the rights of girls and women with disabilities. It emphasizes their reproductive rights and mandates the Nepalese government to enact provisions that protect their health and rights, considering their unique circumstances and ensuring an environment conducive to the potential utilization of their knowledge and skills (NLC, 2017). Despite these legislative developments, women with disabilities remain largely absent and invisible in policy discussions. Hence, I explore this issue, highlighting the urgent need for meaningful inclusion and representation in disability policies and practices.

Understanding Disability and Barriers

Definitions of disability have evolved significantly, shaped by both the disability rights movement and academic discourses. At the forefront of this evolution is the debate between the medical and social models of disability. The medical model traditionally views disability as a personal tragedy, reducing individuals to their bodily impairments. Proponents of this model, typically medical professionals without lived experiences of disability, have dominated the discourse.

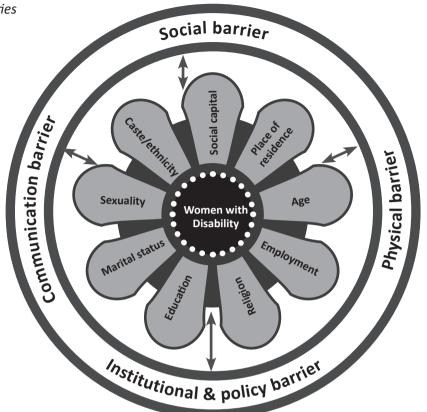
In contrast, the social model gained prominence from the 1970s onward, alongside the global disability rights movement. It contends that disability arises not solely from physical impairments but from societal barriers and discrimination rooted in ableism (Swain et al., 2003). Tom Shakespeare, a leading figure in disability studies, advocates moving beyond the binary of medical versus social models. He argues for theories that embrace the embodied experiences of persons with disabilities (Shakespeare, 2004). Shakespeare's perspective is ivnformed by feminist critiques, such as those by Jenny Morris (1991), which argue that the social model neglects the personal dimensions shaped by impairment, gender, and other social identities. Moreover, Shakespeare asserts that the social model fails to fully acknowledge the everyday challenges faced by persons with disabilities. including physical and mental difficulties compounded by social exclusion.

On the contrary, I adopt the definition of disability outlined in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) of 2006. This definition underscores disability as an evolving concept resulting from the interaction between impairments and societal attitudes and environmental barriers, which hinder full and equal participation in society (United Nations, 2006). This paradigm shift challenges previous notions that limited disability to purely medical and physical aspects. Central to this understanding is the concept of barriers, as articulated by the World Health Organization (WHO, 2021), which defines them as environmental factors restricting contributing to disability. Barriers encompass both visible and invisible forms; visible barriers include physical obstacles, while invisible ones like stigma and discrimination deeply affect persons with disabilities.

Here, I synthesize seven types of barriers—attitudinal, communication, physical, policy, programmatic, social, and transportation—from the Disability and Health Data System (DHDS) maintained by the Centers for Disease Control and Prevention (CDC, 2019). To streamline this discussion, I further merge these into four categories: social barriers, physical barriers, communication barriers, and institutional and policy barriers. These barriers operate synergistically, particularly impacting women with disabilities due to intersections with other identities such as caste, ethnicity, religion, and geography.

For instance, a six-year-old girl with a visual disability living in a hilly region encounters multiple barriers to education. Her family's attitudes towards education (social barrier) determine her access, compounded by physical challenges in reaching the nearest school (physical barrier). Even if accessible, the school may lack adequate resources for teaching students with visual impairments (institutional and policy barrier, communication barrier), and she may face discrimination from teachers and peers (social barrier). These complex intersections are illustrated in Figure 1 revealing how understanding and addressing these multifaceted barriers is essential for crafting inclusive policies that empower all persons with disabilities, particularly underscoring the unique challenges faced by women and girls in diverse contexts.

Figure 1: Author's Adaptation Intersectional Barriers Experienced by Women with Disabilities



Intersection of Abelism and Patriarchy

As a researcher studying disability in Nepal, my previous works are deeply rooted in the social model of disability. While preparing this paper, my inquiry was guided by a fundamental question: who formulates policies concerning women with disabilities? The answer became clear: predominantly the ableist (able-bodied individuals) lacking lived experiences of disability. This realization prompted me to delve deeper into understanding how non-disabled perspectives are shaped by the ideology of ableism.

Exploring the pervasive invisibility of women with disabilities in policies, I began to discern how institutional and policy barriers in Nepal are compounded by the intersection of ableism and patriarchy. I will attempt to briefly explore both concepts, followed by the evolvement of policies to address the needs of the persons with disabilities, and specifically women with disabilities in Nepal.

The world we inhabit is profoundly influenced by the ideology of ableism. Fiona Kumari Campbell, a leading scholar in disability rights, defines ableism as "a

network of beliefs, processes, and practices that construct a particular type of self and body—the "corporeal standard"—projected as perfect and typical of the species, and therefore essential and fully human" (2012, p. 213). In simpler terms, ableism molds people's perceptions to view individuals with disabilities as inherently "less than" those without disabilities, warranting differential treatment. This includes perpetuating harmful stereotypes, misconceptions, and generalizations about persons with disabilities. Ableism also encompasses the practice of "othering," relegating individuals with disabilities to the status of "different" and "other" (Mike-Meyer, 2016).

I draw extensively from Campbell's pioneering work in policy sociology for two reasons. Firstly, she is instrumental in integrating the perspective of ableism into disability discourse. Secondly, her clear definitions and delineation of ableism provide invaluable tools for policy-makers and advocates alike. Campbell (2012) identifies four core tenets of ableism:

- Normalcy and Naturality: Ableism dictates what is deemed normal and natural in society, often marginalizing persons with disabilities and characterizing their bodies as abnormal and objects of pity.
- **Idealized Citizenship:** Persons with disabilities are viewed as burdens on societal systems, contributing little to the economy or society—a reflection of charity-based welfare models.
- **Self-autonomy and Independence:** Ableism glorifies independence, shaped by capitalist and patriarchal ideologies, disregarding the interdependent nature of human society where mutual support is vital.
- Forced Segregation: Those deemed outside the norm are segregated and excluded from mainstream society, evident historically in practices like institutionalization and segregation in educational and residential settings.

These ableist perspectives are commonly held by non-disabled individuals, influencing their daily realities (Chaturvedi, 2020), including policy-makers in Nepal, who predominantly lack disabilities themselves. Therefore, I argue that policies in Nepal are formulated through an ableist lens.

While ableism is well understood, its intersection with sexism and patriarchy is less explored. Patriarchy, a system of power relations between genders, operates through both implicit (social norms) and explicit (laws, policies) mechanisms to perpetuate inequality. Patriarchy legitimizes male dominance and privilege over women (Walby, 1999), typically understood within a gender binary framework. To fully grasp the position of women with disabilities in society, an intersectional approach is essential, viewing patriarchy as a system that intersects with other forms of inequality such as class, race, and disability (Karioris, 2014). Based on this perspective, I argue that women with disabilities face dual oppression within an ableist and patriarchal society.

In Nepal, policies concerning persons with disabilities are largely crafted by able-bodied individuals with an ableist worldview. Disability rights movements in Nepal have contested this paradigm, advocating for policy reforms to protect the rights of persons with disabilities. However, Nepal remains deeply patriarchal and misogynistic, where preferences for sons are prevalent and women are systematically undervalued. Consequently, the rights and needs of women with disabilities are largely overlooked in national policies (with a few exceptions in disability-specific policies). This exclusion and silence regarding women with disabilities in policy-making are shaped by ableism and misogyny, which heavily influence the policy landscape in Nepal. I will expand on this argument while discussing the ongoing invisibility of women with disabilities in policy discourse.

Invisibility of Women with Disabilities

In this section, I present findings on the policy review studies I have undertaken. It is evident that in the policy landscape, women with disabilities are largely invisible, even in the ones that are considered women-centric.

Table 1 presented below has been developed through the use of word count in each specific policy document. The words used for the word count are as follows: disability, persons with disabilities, and women with disabilities, showing the following results:

Table 1: Representation of Women with Disabilities in Policy Documents

Policy document	Frequency of keywords used			
	Disability	Persons with disabilities	Women with disabilities	Women
Safe Motherhood Act (2018)	2	0	0	39
Sexual Harassment at Workplace Act (2015)	0	0	0	0
Education Act (1971)	1	0	0	1
Human Trafficking Act (2007)	0	0	0	0
The Right to Employment Act (2018)	0	0	0	1
Gender Policy (2021)	1	0	0	92
10 Year Disability Plan (current)	1,129	31	58	238
15th Periodic Plan (2019/20-2023/2024)	41	0	152	29
National Policy for Disaster Risk Reduction (2018)	1	1	0	1
Domestic Violence Act (2009)	0	0	0	4

Source: Author's research for BWAN (2021).

Table 1 shows that women with disabilities experience institutional and policy barriers in addition to other barriers. These policy barriers further translate into a lack of programmatic interventions and programs for women with disabilities. The table shows that except for a ten-year disability plan, girls and women with disabilities are not mentioned in any of the federal acts and policies. This invisibility and silencing of women with disabilities in the policy itself minimize their inclusion in interventions and programs informed by them. It can be argued that the mention of women with disabilities alone is not a guarantee of their inclusion; however, it can be seen as a first step in that direction.

This invisibility in policies like "The Right to Employment Act, 2018," denies girls and women with disabilities the economic rights including the right to work, and the right to an adequate standard of living (NLC, 2018). In March 2021, Nepal introduced the National Gender Equality Policy on the occasion of International Women's Day to institutionalize a gender-responsive governance system in three tiers of government. The policy acknowledges the need to make special provisions for the marginalized and minorities, including those with disabilities. However, the act does make correct use of the term "Apangata Bhayeka Mahila," to denote women with disabilities. Except for this brief acknowledgment of diversity among women, the policy conceptualizes Nepali women as neutral, and devoid of social identities, including disabilities. From the standpoint of girls and women with disabilities this policy is simultaneously gender insensitive and non-inclusive to persons with disabilities.

These are significant examples of institutional and policy barriers experienced by women with disabilities. After discussing these policy gaps, I further discuss possible directions of policy change needed to address the institutional and policy barriers.

Lack of Commission on Persons with Disabilities

One of the primary challenges exacerbating institutional and policy barriers is the absence of a dedicated constitutional body to coordinate and oversee the rights of persons with disabilities. Many countries that have ratified the CRPD have established autonomous commissions on disability. But Nepal currently lacks such a commission. While the newly formed National Inclusion Commission has recognized disability as a priority area, it regrettably lacks representation from the disability community. This omission stands against the fundamental principle of the disability rights movement: "Nothing about us, without us." Thus, the commission must include members, who are representative of persons with disabilities, particularly women with disabilities.

Chapter 9 of the ARPD (2017) provides for a Steering Committee and Coordination Committee, outlined in section 38, tasked with coordinating, monitoring, and promoting activities related to the rights, facilities, services, and protection of persons with disabilities. Disability rights activists have repeatedly called for the establishment of an autonomous disability commission, a demand that has largely

gone unheeded. To effectively mainstream the rights of persons with disabilities. the government must take immediate action, including:

- a) Appointing persons with disabilities, including at least one woman with a disability, to the National Inclusion Commission; and
- b) Establishing the National Commission of Persons with Disabilities in Nepal, ensuring meaningful representation of women with disabilities. Furthermore, it is crucial to include women with disabilities in every commission and constitutional body responsible for human rights, gender equality, and social inclusion.

To date, women with disabilities have been conspicuously absent from key commissions such as the National Women's Commission and the National Human Rights Commission. These steps are essential to address the institutional and policy barriers that women with disabilities continue to confront.

Lack of Policy Interventions to Address Intersectional Barriers

Nepal underwent a shift to federal governance in 2017, creating new opportunities for marginalized groups to engage politically and access state services through local governments (Rai, 2019). A crucial role of local government is the authority to develop policies tailored to local needs and realities. However, marginalized groups, including persons with disabilities, have minimal opportunities to participate in decision-making processes that shape local policies in Nepal.

Janak Rai (2020) delves into the legislative processes within local governments under federalism, highlighting that elected representatives often perceive law making as a complex, bureaucratic process. There is a glaring lack of recognition among local officials that law making should be participatory and inclusive of rights holders such as persons with disabilities (Rai, 2020). This underscores a key reason for the institutional and policy barriers faced by women with disabilities: their exclusion from decision-making processes that were ironically crucial for designing policies that directly impact their lives.

Lack of Criminalization of Discrimination against Persons with Disabilities

Non-Discrimination stands as one of the fundamental principles outlined in the CRPD, compelling signatory states to ensure that persons with disabilities have the right to live a dignified life free from discrimination. This principle is further elaborated in Article 5 on Equality and Non-Discrimination. The Constitution of Nepal (2015) similarly guarantees the rights of persons with disabilities to live without discrimination. Article 15 explicitly prohibits discrimination in any public or private sphere based on caste, tribe, community, profession, occupation, or physical condition. Likewise, Article 42, addressing the Right to Social Justice, affirms that citizens with disabilities have the right to dignity, equal access to public services, and to be recognized as part of the diverse fabric of society (NLC, 2015).

Disability policies in Nepal align with ARPD, CRPD, and the Constitution of Nepal, including robust provisions against discrimination. Section 8 of Chapter 3 on the Rights of Persons with Disabilities mandates that "no person with a disability shall be subjected to discrimination based on disability or deprived of personal liberty" (UN. 2006). However, there is a lack of provision criminalizing discrimination against persons with disabilities. Disability rights advocates could draw inspiration from the experiences of the Dalit community in Nepal, who successfully campaigned for the criminalization of discrimination and untouchability under the Caste-Based Discrimination and Untouchability (Offence and Punishment) Act, 2068 (2011) (NLC, 2011). A similar amendment is called for in the National Penal Code Act, 2017 (NLCL, 2017). These legal reforms empower Dalits to report and seek justice for discriminatory acts based on caste.

Despite the existing policies in Nepal aimed at safeguarding the rights of persons with disabilities and preventing discrimination, there remains a crucial gap in criminalizing discriminatory behaviors against them. Advocacy efforts by disability rights organizations are essential to push for amendments to the National Penal Code Act (2017) to criminalize discrimination against persons with disabilities (NLC, 2017). This initiative will necessitate a robust advocacy campaign to ensure legal protection and justice for persons with disabilities facing discrimination.

Policy Recommendations

Adopting a perspective rooted in policy sociology, I present several key policy recommendations aimed at improving both policy formulation and practical implementation. Firstly, the Nepali government must urgently establish a Commission on Persons with Disabilities, ensuring meaningful representation and leadership roles for women with disabilities. Despite the progress achieved through ratifying the CRPD and formulating the ARPD, sectoral policies remain insufficiently disability-friendly. Thus, secondly, these policies need to be revised to align more closely with the provisions outlined in the CRPD and ARPD. Thirdly, all organizations advocating for the rights of persons with disabilities should prioritize efforts toward criminalizing discrimination against this community. Above all, this effort necessitates a robust advocacy campaign aimed at amending the National Penal Code Act (2017) to criminalize discrimination based on disability explicitly (NLC, 2017).

These recommendations, however, underscore the critical need for legislative and policy changes that uphold the rights and dignity of persons with disabilities in Nepal, fostering a more inclusive and equitable society.

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