

Negotiating Rights, Enabling Voices: Disability Inclusion and Governance Participation Among Marginalized Women in Nepal

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Abstract

This study investigates the landscape of disability inclusion and the participation of marginalized women with disabilities in local governance processes in Nepal. Drawing on an extensive field-based assessment across 15 municipalities in three provinces—Madhesh, Karnali, and Sudurpaschim—the study combines quantitative survey data from 180 respondents and qualitative insights from key informant interviews and focus group discussions. Despite progressive national laws such as the Act Relating to Rights of Persons with Disabilities (ARPD, 2017), and international commitments under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006), many women with disabilities remain excluded from meaningful participation in governance, decision-making, and access to essential services. The research identifies significant gaps in legal awareness, administrative barriers to disability ID cards, and low representation in planning and budgeting processes. Anchored in the Capability Approach, the Social Model of Disability, and Intersectionality Theory, this study argues for a recalibration of local governance practices that centers voice, agency, and rights. Findings suggest that despite the existence of OPDs and advocacy networks, structural and attitudinal barriers continue to undermine effective inclusion. The paper concludes with policy recommendations focused on improving service delivery, legal empowerment, and institutional inclusion.

Keywords: Dalits with disabilities, intersectionality, structural violence, marginalization, disability and caste, human rights

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Introduction

Disability inclusion has emerged as a pivotal concern in global development discourse, particularly following the adoption of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2006. This landmark treaty catalyzed a shift from charity-based or medicalized understandings of disability toward a rights-based model, emphasizing agency, autonomy, dignity, and equal participation (United Nations, 2006). The convention underscores the obligation of state parties to ensure that persons with disabilities (PWDs) can access the same rights and opportunities as everyone else—including participation in public life and decision-making at all levels of governance.

For Nepal, this global movement intersects with its own socio-political transformation. The promulgation of the Constitution in 2015 and the subsequent shift to federal governance devolved substantial power to 753 local governments or Palikas. This decentralization aims to bring governance closer to communities, with increased responsiveness and inclusivity in service delivery. However, this transition has also revealed capacity limitations at the local level, including inadequate awareness of disability rights, inconsistent implementation of national laws, and a lack of disaggregated data on persons with disabilities—particularly women. Nepal’s 2017 Act Relating to Rights of Persons with Disabilities (ARPD) sought to address these challenges by aligning national policies with the UNCRPD, yet implementation remains fragmented, poorly resourced, and inconsistently monitored.

Women with disabilities—especially those from disadvantaged caste and ethnic groups such as Dalits, Janajatis, and Madhesis—face multiple and intersecting forms of discrimination. These intersecting identities lead to compounded vulnerabilities, as structural inequalities tied to gender, disability, caste, and geography collide. Crenshaw’s (1989) concept of intersectionality provides an effective analytical lens to understand these layered exclusions. While Nepal has adopted progressive gender and disability policies, such provisions often fail to meaningfully address the realities of women situated at the margins of both systems.

This marginalization has far-reaching implications—not only in terms of individual wellbeing but also for democratic governance and inclusive development. A society that excludes women with disabilities from decision-making undermines its own ability to deliver equitable and responsive policies. Despite local governments being constitutionally mandated to ensure representation and participation, evidence suggests that women with disabilities are often absent from public forums, ignored in planning processes, and overlooked in budget allocations. These exclusions reflect not only policy gaps but also entrenched social attitudes that frame women with disabilities as passive recipients of care rather than active rights-holders.

In light of these challenges, this paper draws upon a baseline study conducted by KOSHISH, a national self-help organization working in mental health and disability, in collaboration with FWDN and supported by UN Women. The research was undertaken in 15 Palikas across three provinces—Madhesh, Karnali, and Sudurpaschim—and employed both quantitative and qualitative methods. The survey component included 180 respondents selected from marginalized groups, while the qualitative component involved 30 Focus Group Discussions (FGDs) and 15 Key Informant Interviews (KIIs) with OPD leaders, government representatives, and community members.

The objectives of the study were threefold:

1. To assess the level of awareness about disability rights among women with disabilities.
2. To evaluate the extent of their participation in local governance and access to services.
3. To identify barriers and enablers to inclusion, and generate evidence-based recommendations for policy and programming.

By situating these findings within broader theoretical frameworks—namely the Capability Approach (Nussbaum, 2011), the Social Model of Disability (Oliver, 1996), and Intersectionality Theory (Crenshaw, 1989)—this paper aims to unpack the complex dynamics of exclusion and propose strategic interventions to realize the rights of women with disabilities in Nepal.

Literature Review

The academic and policy literature on disability rights and inclusive governance reflects a growing recognition of the need for systemic transformation to achieve equality for persons with disabilities (PWDs). Globally, the UNCRPD (2006) has been instrumental in setting normative standards by reframing disability as a matter of human rights rather than medical pathology or charity. The convention obliges states to promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity (United Nations, 2006).

Despite this progress at the normative level, translating international commitments into practice remains a major challenge, particularly in low- and middle-income countries (LMICs). As Meekosha and Soldatic (2011) argue, many countries in the Global South face institutional, economic, and cultural obstacles that hinder meaningful implementation. In the context of South Asia, deeply embedded social hierarchies—such as caste, patriarchy, and ableism—interact to marginalize persons with disabilities, especially women.

Nepal's ARPD (2074 BS) represents a major step in aligning national law with the UNCRPD. The ARPD recognizes disability as a cross-cutting issue and guarantees a wide range of rights, including access to education, employment, healthcare, social protection, and political participation (Government of Nepal, 2017). Yet empirical studies suggest that awareness of these legal provisions remains low among intended beneficiaries, and the infrastructure for delivering services is underdeveloped. According to Lord and Stein (2018), laws without operational mechanisms, dissemination strategies, or accountability frameworks fail to yield substantive change.

The situation is particularly acute for women with disabilities (WWDs), who experience multiple and intersecting forms of exclusion. Research shows that WWDs are more likely to live in poverty, have lower literacy rates, face domestic violence, and experience barriers to healthcare and justice (Groce & Kett, 2014). Dhungana (2006) found that in Nepal, disabled women often lack support networks and are stigmatized by both the disability movement and the women's movement—being perceived as “invisible” in each.

The concept of intersectionality, introduced by Crenshaw (1989), provides a useful framework to understand these overlapping forms of oppression. Intersectionality highlights how systems of power—such as casteism, sexism, and ableism—do not act independently but combine to reinforce disadvantage. This is especially relevant in the Nepali context, where the interplay of caste, ethnicity, gender, geography, and disability produces unique patterns of marginalization.

Another body of literature focuses on the role of Organizations of Persons with Disabilities (OPDs) in promoting inclusion and holding duty-bearers accountable. According to the WHO and World Bank (2011), OPDs are crucial intermediaries between the state and disability communities, offering peer support, advocacy, and service delivery. However, their effectiveness is often constrained by a lack of financial resources, training, and institutional recognition. Lang and Murangira (2009), studying disability advocacy in Uganda, emphasize that meaningful participation requires not only legal inclusion but also material and technical support for OPDs.

From a theoretical standpoint, several frameworks inform the analysis of disability inclusion. The Social Model of Disability, developed by Oliver (1996), asserts that disability is not inherent in the individual but arises from societal barriers—whether physical, institutional, or attitudinal. This model has been influential in shifting focus away from impairments and toward environmental and policy structures that hinder participation.

Complementing this, the Capability Approach, articulated by Amartya Sen and further developed by Martha Nussbaum (2011), provides a human development perspective on inclusion. The approach emphasizes the expansion of individual freedoms, opportunities, and the actual ability to pursue a life one has reason to value. It argues that real inclusion must address both structural enablers and individual capabilities.

Finally, Intersectionality Theory serves as a critical lens to examine how social categories interact to shape power relations and access to resources. In the context of this study, it helps explain why women with disabilities from Dalit or Janajati communities are more likely to face exclusion than their upper-caste or male counterparts, even when legal protections are in place.

Together, these theoretical frameworks offer a multidimensional understanding of exclusion and inclusion. They also inform the study's analytical approach, which seeks to identify not only the barriers but also the institutional and community-level enablers that can advance the rights of women with disabilities in Nepal.

Methodology

This study employed a descriptive mixed-methods approach to examine the level of disability inclusion within local governance systems in Nepal, particularly focusing on women with disabilities (WWDs) from marginalized groups. The rationale for this approach was to integrate numerical trends with lived experiences, thus capturing the complex, layered realities of social inclusion and exclusion. Combining quantitative and qualitative methods enabled triangulation, improved validity, and helped explore both the structural and cultural dimensions of disability rights at the local level.

Study Area and Population

The study was conducted in 15 municipalities (Palikas) across three provinces—Madhesh, Karnali, and Sudurpaschim—chosen based on geographic diversity, population density, and socio-political marginalization indicators. Each province reflects unique socio-cultural dynamics and infrastructural capabilities, which makes comparative analysis meaningful.

The population of interest was women with disabilities aged 18 and above, particularly those belonging to Dalit, Janajati, and other underrepresented caste and ethnic groups. The target was

to reach individuals who had direct or indirect interactions with local government offices or service systems.

Sampling Strategy

A purposive sampling technique was employed to select 180 respondents. The Krejcie and Morgan (1970) sample size formula was used to determine the minimum number of participants required for statistical confidence based on an estimated population of 300 eligible individuals across the study areas. The final sample exceeded this minimum, with proportional allocation across Palikas to ensure representation by disability type and region.

Participants were identified through local Organizations of Persons with Disabilities (OPDs), ward offices, and community referrals. Additional screening ensured inclusion of women with physical, sensory, mental, and multiple disabilities.

Quantitative Data Collection

Quantitative data were collected through structured surveys administered using the KOBO Toolbox digital platform. Enumerators were equipped with tablets and conducted interviews face-to-face, ensuring accessibility based on the respondent's comfort—whether at home, OPD centers, or public venues.

The questionnaire was developed in consultation with OPD leaders and experts in disability rights. It was translated into Nepali and localized dialects, then pre-tested in a similar non-sample municipality. Revisions addressed linguistic clarity, cultural sensitivity, and response flow.

Key sections of the survey included:

- Demographic details
- Awareness of legal frameworks (ARPD, CRPD)
- Access to services and entitlements
- Participation in governance and public forums
- Affiliation with OPDs and advocacy experience

Enumerators received two days of training on disability-sensitive data collection, ethical considerations, and use of KOBO Toolbox. Data collection was conducted over a period of four weeks.

Qualitative Data Collection

The qualitative component comprised 30 Focus Group Discussions (FGDs) and 15 Key Informant Interviews (KIIs) across the 15 Palikas. FGDs were conducted separately with WWDs and local OPD representatives to create a safe space for open discussion. Each FGD had 6–8 participants and was moderated using a semi-structured guide.

KIIs targeted municipal officials (e.g., mayors, chief administrative officers), ward-level social mobilizers, and disability rights advocates. The interviews explored perceptions of inclusion, awareness of policy mandates, challenges in service delivery, and institutional practices.

All qualitative interactions were recorded (with consent), transcribed, and translated into English for analysis.

Data Analysis

Quantitative data were cleaned and analyzed using SPSS (Version 25). Descriptive statistics such as frequencies, cross-tabulations, and percentage distributions were generated to examine relationships between variables such as:

- Gender and legal awareness
- Province and access to disability ID cards
- Disability type and participation in planning

Qualitative data were analyzed using thematic coding. Two independent coders developed codes inductively from the transcripts, followed by consolidation into broader themes such as:

- Structural exclusion
- Identity recognition
- Organizational engagement
- Municipal accountability

Findings from both methods were synthesized in the results and discussion sections.

Results

This section presents the findings derived from both the quantitative and qualitative components of the study conducted across 15 Palikas in the Madhesh, Karnali, and Sudurpaschim provinces of Nepal. The results are organized thematically according to the major domains of inquiry: demographic characteristics, awareness of disability rights, access to services, participation in governance, and engagement with Organizations of Persons with Disabilities (OPDs). Where relevant, comparative insights across province, gender, and type of disability are provided to highlight intersectional dimensions of inclusion and exclusion.

Demographic Profile

Of the total 180 respondents, a significant majority (79%) were women, in line with the study's focus on women with disabilities (WWDs), while the remaining 21% were male participants. Notably, 61% of all participants belonged to historically marginalized Dalit and Janajati communities, underscoring the intersectional approach of the research.

In terms of provincial representation:

- Madhesh Province: 35%
- Sudurpaschim Province: 34%
- Karnali Province: 31%

Reported types of disability included:

- Physical impairments: 43%
- Sensory impairments (visual and hearing): 24%
- Mental or intellectual disabilities: 15%
- Multiple disabilities: 18%

Educational attainment levels were notably low:

- 56.1% of respondents were illiterate
- 23.3% had completed primary education
- Only 6.1% had completed secondary education or higher

These demographic patterns highlight the intersection of disability, caste, gender, and educational exclusion—factors that compound vulnerabilities in access to services and civic participation.

Awareness of Disability Rights (ARPD & CRPD)

The study found that awareness of legal rights among respondents was alarmingly low. Only 47.2% of the participants reported having heard of the Act Relating to the Rights of Persons with Disabilities (ARPD, 2017), and a mere 31% were familiar with the UN Convention on the Rights of Persons with Disabilities (CRPD).

Among those who had heard of the ARPD:

- Only 40.6% could articulate one or more provisions of the Act
- Awareness levels were somewhat good in Karnali Province than the Madhesh Province

Qualitative evidence from FGDs revealed that legal literacy was minimal even among those possessing disability ID cards. Respondents described an almost complete lack of information dissemination by local authorities:

“I have a disability ID, but I don't know what the law says about my rights. We were never told.” (FGD participant, Doti)

“We don't know the name of the law. We just heard that some people with cards got benefits.” (FGD participant, Sarlahi)

These narratives emphasize the disjuncture between legal frameworks and the lived realities of women with disabilities, particularly in rural and remote areas.

Access to Services and Disability Identification Cards

Access to disability ID cards—a prerequisite for entitlements and services—was relatively high, with 76% of respondents reporting that they had received a card. However, satisfaction with the process and the outcome was significantly lower:

- Only 32% of respondents believed that their disability category on the card was accurate
- Many felt they had been placed in lower categories than deserved, resulting in fewer benefits
- The application process was widely reported as inaccessible, confusing, and costly

Provincial differences were notable:

- Respondents in Sudurpaschim Province had greater card coverage, but also expressed higher dissatisfaction
- Participants from Madhesh Province reported greater delays and more bureaucratic hurdles

Commonly cited barriers included:

- Physically inaccessible municipal buildings
- Uninformed or insensitive municipal staff
- Lengthy and expensive travel for documentation and follow-up

“They told me to bring proof from the hospital. I went twice, but they didn’t accept it. It’s expensive to go again.” (FGD participant, Jumla)

These findings illustrate not just logistical hurdles but also systemic insensitivity to the needs and realities of women with disabilities.

Participation in Local Planning and Governance

Despite the emphasis in national policy on inclusive governance, actual participation by WWDs in local decision-making was found to be extremely limited:

- Only 24% of respondents had ever participated in a local planning meeting
- Of these, fewer than half reported that they had been able to speak or that their contributions had been taken seriously

A recurring theme in both interviews and FGDs was tokenistic inclusion. WWDs were frequently invited as an afterthought, and often their involvement lacked substance or continuity.

“They call us only when there’s a donor project. Otherwise, we are not asked anything.” (KII, OPD Leader, Bardiya)

“We go, sit, and come back. Decisions are already made.” (FGD participant, Surkhet)

Differences across provinces were evident:

- Madhesh Province reported higher levels of participation, largely due to stronger OPD networks and advocacy presence
- Karnali Province saw minimal engagement, attributed to geographical remoteness, limited mobility options, and the absence of proactive inclusion by local governments

Role of Organizations of Persons With Disabilities (OPDs)

Only 28% of respondents reported being a member of a formal OPD. Membership patterns were shaped by geography and social capital:

- OPD engagement was higher in urban Palikas
- WWDs associated with OPDs exhibited greater awareness of their rights, and were more confident engaging with municipalities

Nevertheless, structural constraints undermined the impact of OPDs:

- Many were underfunded, with little or no support from municipal budgets
- Only 17% of key informants said that OPDs were regularly consulted in local planning processes

“We submitted a proposal for accessible toilets. It was ignored because the Palika said we are not ‘officially recognized’.” (OPD Leader, Janakpur)

“We have many members, but no budget. We rely on volunteers.” (FGD respondent, Kailali)

These findings suggest that while OPDs have the potential to be powerful vehicles for advocacy and inclusion, their ability to influence governance outcomes is heavily contingent on formal recognition, institutional support, and consistent resourcing.

Discussion

This section interprets the study’s findings through the lens of the Capability Approach, Social Model of Disability, and Intersectionality Theory. The results paint a layered picture of legal, institutional, and socio-cultural exclusion that limits the agency and participation of women with disabilities (WWDs) in Nepal. Each of the main themes is examined in light of relevant academic frameworks to identify both structural patterns and potential entry points for reform.

Legal Identity and Rights Awareness

The study reveals a critical gap in awareness of disability rights laws, with less than half of the respondents familiar with the ARPD and even fewer aware of the CRPD. This lack of knowledge undermines the ability of WWDs to assert claims, challenge injustice, or participate meaningfully in public life. It confirms Lord and Stein’s (2018) assertion that legal recognition is insufficient unless coupled with widespread dissemination and community education.

From the lens of the Capability Approach (Nussbaum, 2011), legal knowledge is not just an informational asset but a capability in itself—essential for agency, choice, and self-determination. Without it, women with disabilities are denied the freedom to function as civic actors. They may receive welfare services passively but remain unable to negotiate their rights proactively, especially in the governance domain.

Moreover, the findings underscore the need for local government actors themselves to be sensitized to disability rights frameworks. Several officials interviewed lacked even basic understanding of ARPD provisions, reinforcing the gap between national legislation and decentralized action.

Barriers to Accessing Services

Although the majority of respondents held disability ID cards, widespread dissatisfaction with categorization accuracy, application difficulty, and unequal treatment was reported. Many respondents believed they had been misclassified in a lower disability category—resulting in reduced entitlements. Others reported repeated travel and expense for bureaucratic tasks.

According to the Social Model of Disability (Oliver, 1996), individuals are not disabled by their impairments but by social and institutional barriers. This was clearly reflected in the data. A respondent with a mobility impairment who was denied support not because of her condition, but because of inaccessible government offices and uninformed staff, is emblematic of how systems themselves perpetuate exclusion.

These findings also point to procedural injustice—where people are formally included but structurally excluded. Without accessible grievance redress mechanisms or oversight of ID card assessments, inclusion is performative rather than substantive.

Structural Exclusion in Local Governance

Participation in planning processes is a key indicator of democratic inclusion. Yet the results show that WWDs are systematically excluded from public forums, often invited late or not at all. Even when present, they are rarely given opportunities to speak or influence outcomes.

The data corroborates Crenshaw's (1989) theory of intersectionality, showing how multiple identities—gender, disability, caste, and geography—interact to produce compounded disadvantages. Women with disabilities from Dalit and Janajati backgrounds were especially underrepresented and silenced in governance settings. Their absence is not merely an oversight—it reflects deep-rooted structural bias in how institutions define participation and whose voices are considered legitimate.

The study also demonstrates that current participatory mechanisms in Palikas are often tokenistic. Invitations to WWDs or OPDs occur only during donor-funded projects or special events. This undermines the principles of ongoing, institutionalized inclusion that the Constitution of Nepal mandates.

The Role and Challenges of OPDs

Organizations of Persons with Disabilities (OPDs) have the potential to act as powerful intermediaries between WWDs and the state. Respondents with OPD affiliations had higher levels of awareness, self-confidence, and participation. However, the study found that OPDs themselves face institutional exclusion, insufficient funding, and limited technical capacity.

Lang and Murangira (2009) argue that unless OPDs are empowered as equal stakeholders in governance processes, they risk becoming marginalized alongside the communities they represent. The current practice of project-based engagement—where OPDs are consulted only when donor funding mandates it—creates dependency and erodes the continuity of advocacy.

Institutional integration of OPDs in Palika planning, budgeting, and monitoring is critical. This involves not only providing financial resources but also establishing legal mandates for their participation, regular consultations, and accountability mechanisms.

In summary, the findings reveal that exclusion operates across legal, institutional, and cultural domains. Rights may exist on paper, but unless capabilities are developed, systems are reformed, and intersectional inequalities are addressed, women with disabilities will remain marginalized in Nepal's governance structures.

Conclusion and Recommendations

This study underscores the urgent need to advance disability inclusion in Nepal's local governance systems. Despite the presence of progressive legal frameworks such as the Act Relating to Rights of Persons with Disabilities (ARPD, 2017) and international commitments like the UNCRPD, the lived experiences of women with disabilities reveal enduring exclusion, limited agency, and unequal access to resources and decision-making platforms.

The findings illustrate that while services like disability ID cards are available, they are often delivered through bureaucratically inconsistent and structurally inaccessible processes. Additionally, awareness of rights is limited, both among WWDs and the municipal actors

responsible for upholding them. The participation of WWDs in local planning remains low, often symbolic, and rarely empowered. While Organizations of Persons with Disabilities (OPDs) have made progress in advocacy and capacity building, their roles remain insufficiently institutionalized and under-resourced.

From a theoretical perspective, this research affirms the value of applying a multi-lens approach:

- The Social Model of Disability explains how institutional and infrastructural constraints—not impairments—generate exclusion.
- The Capability Approach emphasizes the importance of enhancing the real freedoms and agency of WWDs.
- Intersectionality Theory reveals how caste, gender, geography, and disability intersect to deepen marginalization.

Together, these perspectives highlight the need to move beyond surface-level inclusion toward substantive, institutional, and community-rooted empowerment.

Recommendations

Based on the evidence and analysis, the following policy and programmatic actions are recommended:

1. **Launch disability rights literacy campaigns**
Develop inclusive, multilingual, and accessible information materials about the ARPD and CRPD. Disseminate through community radios, ward offices, and women’s groups. Include visual and audio materials for persons with sensory impairments.
2. **Reform and standardize the disability ID card process**
Ensure transparency and equity in disability classification. Establish mobile disability assessment units in remote areas. Train Palika staff on disability evaluation procedures and create feedback mechanisms for appeal.
3. **Invest in inclusive education and digital empowerment**
Expand literacy and digital training programs for WWDs. Partner with OPDs and NGOs to create learning hubs and accessible training centers, particularly in rural areas.
4. **Institutionalize OPD participation in local governance**
Mandate OPD representation in municipal planning, budgeting, and monitoring committees. Provide annual grants to recognized OPDs and facilitate capacity-building initiatives to enhance their technical and advocacy skills.
5. **Enforce inclusive service delivery guidelines in Palikas**
Develop and implement a “Code of Disability-Inclusive Practice” for local government offices. Include accessibility audits, staff sensitization modules, and community scorecards to track inclusion performance.

These actions require collaborative efforts between federal, provincial, and local governments, as well as civil society, donors, and OPDs. Real change will come not from isolated projects, but from a long-term commitment to rights, participation, and justice.

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