Access and quality of women with disabilities' maternal healthcare

Laura Herren, Francesca Lanzarotti, Savo Noori, Hridaya Raj Devkota, Sara Hillman, Kate Roll

Introduction

Globally, women with disabilities' right to maternal healthcare is not fully met. Despite the existence of the United Nations Sustainable Development Goals (SDGs) which strive for good health, well-being, and gender equality, these women remain politically and socially marginalised. The UN Population Fund (UNPFA) reported that Nepali women with disabilities have limited healthcare access[1] which is exacerbated during pregnancy. In addition to infrastructural barriers, this puts women at risk of obstetric violence and maternal mortality. Previous reports illustrate women with disabilities' inadequate maternal healthcare experiences, and this research brief adds updated status in a post-federalisation context of Nepal and the current decentralised healthcare system.[2]

This policy brief reports on women's experiences from various stakeholders' perspectives. It highlights the importance of adjusting policies to address the healthcare gap and driving collective action for inclusive and responsive maternal healthcare provision.

Research Background

- The data from Nepal's Census 2078 reported that 2.2% of the Nepali population has a disability, of which 46% (or approximately 299,893) of them are women.[3]
- Women with disabilities have reported that social barriers, like negative disability stereotypes, and environmental barriers, like transport and hospital infrastructure, limit their access to maternal healthcare.[4]
- Despite policies such as the National Guidelines for Disability Inclusive Health Services, 2019, implementation has been reported made difficult, partially due to the role un-clarity between different level governments in Nepal's recent federal system.
- Even with the implementation of programs like "The Safe Motherhood" and "Skilled Birth Attendant", healthcare providers still lack adequate maternal healthcare knowledge and clinical skills, particularly to address the needs of women with disabilities.[5]

"The facilities provided to people with disabilities are not enough. The disability sector is put in low priority, but we have to empower them, we have to protect them."

- A local municipality leader

Policy brief

Access and quality of women with disabilities' maternal healthcare

Reach Alliance

UCL

Data Source

The information from this policy brief comes from a qualitative case study which holistically captured multiple perspectives on the access and quality of maternal healthcare for women with disabilities in Dakshinkali and Nagarjun - two municipalities in Kathmandu, Nepal. The data from this case study has since been included in peer-reviewed publications.[7,8]

The data includes semi-structured interviews with 12 women with visual and physical disabilities of varying severity who had been pregnant within the last five years. Interviews were also conducted with 12 policymakers at various governmental levels including deputy mayors and ministry leads, and 7 doctors, nurses or midwives. Focus group discussions were conducted with Female Community Healthcare Volunteers and mothers without disabilities to triangulate and provide a comparative perspective. The data was analyzed using a thematic analysis to identify the overarching themes between the groups.

PARTICIPANT GROUP	CATEGORY	NUMBER OF PARTICIPANTS
Women with disabilities		**12**
	Disability related to vision	5
	Physical disability	7
Healthcare providers		**7**
	Medical officer	2
	Nurse	3
	Executive health director	2
Policymakers		**12**
	National government representatives	1
	Municipal government representatives	7
	Association and community group representatives	4
Focus group discussions		**3 groups**
	Women with disabilities in Raamkot	6 participants
	FCHV in Raamkot	6 participants
	FCHV in Dakshinkali	5 participants
TOTAL:		**48**

Results

Women with disabilities in Nepal face significant barriers to accessing maternal healthcare, rooted in societal stigma, infrastructural challenges, healthcare-related barriers, and weak policy implementation. While progress has been made, these barriers limit their ability to receive equitable and inclusive care.

Social Barriers

Family and community support play a vital role in shaping maternal healthcare experiences. Some women described receiving encouragement and practical help, particularly from husbands, which made pregnancy easier. However, healthcare providers often perceived families as unsupportive, citing neglect and stigma. Stigma and stereotypes, such as misconceptions about passing on disabilities to children, added to these challenges. One participant worried,

"Sometimes I thought that either my baby will also be born disabled like me or not"

- A woman with visual disability

Societal attitudes often viewed disability as punishment, further marginalizing these women.

Environmental Barriers

Long travel to reach health facilities, poor road conditions, and inaccessible public transportation posed significant barriers. Buses were often inaccessible, and passengers rarely offered support, further complicating travel. Once at healthcare facilities, infrastructural barriers persisted. Many lacked ramps, elevators, and accessible toilets, making them difficult for women with physical disabilities to navigate. A policymaker acknowledged,

"The facilities provided to disabled people are not enough. Although newer buildings have seen improvements, older facilities remain largely inaccessible"

- A Municipality leader

Healthcare Provider Barriers

Healthcare providers and service users expressed different opinions during the interaction. While some women received supportive care, others felt dismissed or neglected. Providers often lacked training in disability-specific maternal care. One noted,

"People with disabilities need specialized care, and if we counsel the patient in a way we do without disabilities, their needs might not be met"

- A medical doctor

Communication barriers were common, with providers relying on family members to convey information, limiting women's autonomy. Few providers used alternative communication methods or tools, further isolating women with sensory disabilities.

Policy and Systemic Barriers

Despite supportive policies, implementation remains inadequate due to insufficient budgets, poor coordination, and low prioritization of disability-inclusive care. A policymaker remarked,

"There are many policies regarding the rights of disabilities but lack effective implementation"

- A OPD leader

Women with disabilities and healthcare providers reported minimal involvement in policy-making, leading to gaps in addressing specific needs. Some participants noted that the focus on financial allowances overshadowed efforts to improve the quality of healthcare services.

Policy Implications

To address the systemic barriers faced by women with disabilities in accessing quality maternal healthcare, targeted policy actions are essential. Recommendations focus on improving infrastructure, financial support, staff training, inclusive governance, and localized implementation.

- Enhance Accessibility: Disability-friendly healthcare infrastructure must be prioritized, including ramps, elevators, accessible hospital beds, Braille signage, and sign language interpreters. Consistent enforcement of disability-inclusive design standards across healthcare facilities is vital.
- Expand Financial Support: Financial barriers remain a significant challenge. Policymakers should strengthen the enforcement of subsidies, such as healthcare discounts and transport allowances for women with disabilities. Collaborations with NGOs and private sector entities can help fund essential improvements.
- Improve Staff Training: Healthcare providers require comprehensive disability-awareness training to address specific maternal healthcare needs. Mandating disability-inclusive curricula in medical education and offering continuous professional development will enhance service delivery. Employing individuals with disabilities in healthcare roles can further improve care quality.

- Increase Awareness: Public education campaigns and accessible information dissemination are necessary to bridge knowledge gaps about disability-inclusive maternal healthcare. Empowering women with disabilities to advocate for their healthcare rights is equally important.
- Promote Inclusive Policymaking: Actively involving women with disabilities in healthcare policy design and implementation ensures their needs are accurately represented. Stakeholder workshops can facilitate meaningful contributions and drive more inclusive decisions.
- Strengthen Local Governance: Local governments are best positioned to implement tailored solutions. Strengthening their capacity through adequate resource allocation, training, and adherence to federal guidelines will enhance accountability and responsiveness.

These recommendations align with Nepal's obligations under the UNCRPD, fostering a healthcare system that respects and upholds the dignity of women with disabilities while addressing critical gaps in maternal healthcare.

Conclusion

Nepalese policymakers must prioritize addressing systemic barriers to maternal healthcare for women with disabilities. This includes enforcing disability-friendly infrastructure standards, enhancing financial support mechanisms, and mandating comprehensive disability-awareness training for healthcare providers. Additionally, integrating women with disabilities into policy development processes and strengthening local governance structures are critical to ensuring tailored, community-specific solutions. These measures, aligned with Nepal's obligations under the UNCRPD, are essential for establishing an equitable, inclusive healthcare system that upholds the dignity and rights of women with disabilities.

References

1. Devkota HR, Murray E, Kett M, Groce N (2018) Are maternal healthcare services accessible to vulnerable groups? A study among women with disabilities in rural Nepal. PLoS ONE 13(7): e0200370. https://doi.org/10.1371/journal.pone.0200370
2. Rajendra K, Kirti MT, Alison M, Nashna M, Bharat B & Dharma SM. (2022) Policies and actions to reduce maternal mortality in Nepal: perspectives of key informants, Sexual and Reproductive Health Matters, 29:2, 1907026. https://doi.org/10.1080/26410397.2021.1907026
3. "Disability Data from Nepal Census 2022," National Federation of the Disabled - Nepal (NFDN). 4 April 2023. Retrieved from: https://nfdn.org.np/news/disability-data/#:~:text=Nepal%20Census%202078%20says%202.2,%2C%202.0%25%20have%20some%20disability
4. Dhungana, BM. (2006). The lives of disabled women in Nepal: vulnerability without support. Disability & Society, 21(2), 133–146. https://doi.org/10.1080/09687590500498051
5. Rajbhandari R, Rai S, Hathi S, Thapa R, Rai I, Shrestha A. The quality of skilled birth attendants in Nepal: High aspirations and ground realities. PLoS One. 2019 Apr 4;14(4):e0214577. https://doi.org/10.1371/journal.pone.0214577
6. Herren, L, Lanzarotti F, Noori S, Sara H, and Kate R. 2023. "Maternal healthcare for Women with Disabilities in Nepal: access and Quality." Vancouver: The Reach Alliance. https://reachalliance.org/wp-content/uploads/2023/11/Nepal-Final.pdf
7. Lanzarotti F, Herren L, Noori S, Devkota H, Roll K, & Hillman, S. (2024). The role of stigma on the pregnancy experiences of women with disabilities in Kathmandu: a qualitative study. Disability & Society, 1–25. https://doi.org/10.1080/09687599.2024.2411526
8. Herren L, Noori S, Lanzarotti F, Devkota HR, Hillman S, Roll K. Improving the Maternal Healthcare Quality for Women with Disabilities in Nepal, 04 December 2023, PREPRINT. https://doi.org/10.21203/rs.3.rs-3686354/v1