



# Exploring the Intersection of Disability and Sexual and Reproductive Health: Reported Needs for Women's Access to Care



**Jene Shrestha<sup>1</sup>, Rekha Khatri<sup>1</sup>, Meghnath Dhimal<sup>2</sup>, Indira Basnett<sup>1</sup>, Meena Paudel<sup>3</sup>, Tikadevi Dahal<sup>3</sup>, Manish Prasai<sup>1</sup>, Sabitri Sapkota<sup>1\*</sup>**

<sup>1</sup> Possible

<sup>2</sup> Nepal Health Research Council

<sup>3</sup> Nepal Disabled Women Association

\*Senior Author

# Background

- Around 16% of the world population has some form of disability; women comprise more than half of it globally (WHO, 2023)
- In Nepal, 2.2% of people are living with disabilities, and almost half of them are women with disabilities (Census, 2078)
- Few studies in Nepal to understand the sexual and reproductive health care needs of women living with disability
- Limited innovative strategies and interventions to address their SRH needs, integrating lived experiences and adapting co-designing process

Original Research

BMJ Global Health

## From words to actions: systematic review of interventions to promote sexual and reproductive health of persons with disabilities in low- and middle-income countries

Shaffa Hameed <sup>1</sup>, Alexander Maddams <sup>1</sup>, Hattie Lowe <sup>1</sup>, Lowri Davies <sup>1</sup>, Rajat Khosla <sup>2</sup>, Tom Shakespeare <sup>1</sup>

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### ABSTRACT

**Introduction** Persons with disabilities have the same sexual and reproductive health and rights (SRHR) as non-disabled persons. Yet they face numerous barriers in their access to sexual and reproductive health services and their rights are often not met. Evidence on SRHR for persons with disabilities is sparse, particularly evaluations of interventions demonstrating 'what works.' This systematic review assessed interventions to promote SRHR for persons with disabilities in low- and middle-income countries.

**Methods** We searched for qualitative, quantitative or mixed method observational studies representing primary research, published between 2010 and 2019, using MEDLINE, Embase, PubMed, Global Health and CINAHL Plus. Search strings were compiled for different elements of SRHR and for all forms of disability. 24,919 records were screened, leading to over 380 relevant papers, most of which were descriptive, focussing on needs and barriers to SRHR needs being fulfilled. Of the 33 full-text articles assessed for eligibility, 18 were included in the synthesis. All included studies were assessed for bias and quality

### Key questions

#### What is already known?

- Fifteen per cent of the global population—one billion people—are people with disabilities, with the same need for sexual and reproductive health and rights as non-disabled people.
- People with disabilities lack access to sexual and reproductive health (SRH) services and face violations of their human rights due to factors that range from inaccessible facilities, to communication barriers and negative attitudes.
- There is strong research and descriptive evidence documenting barriers and facilitators to SRH and rights (SRHR) attainment for people with disabilities.

#### What are the new findings?

- Relatively few studies evaluate interventions and their effectiveness in promoting SRHR for people with disabilities.
- Most interventions are set in upper-middle income contexts, urban areas and have tended to focus sole-

# Objectives

Assess the needs of women with disabilities in accessing SRH services, thereby informing the co-design of interventions to address them

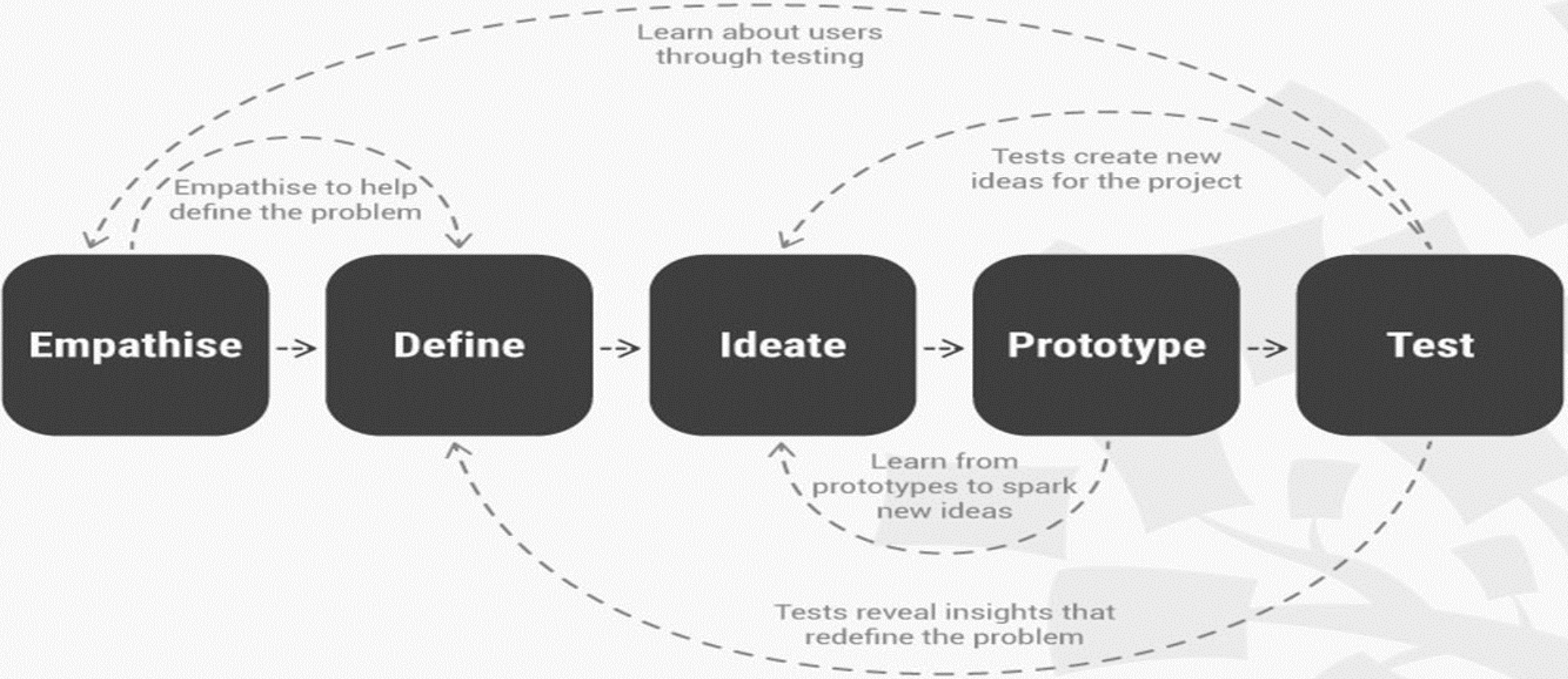


# Methodology

- Participatory approach
- 5-step human-centered design
- Focusing on lived experiences of physical, hearing, and visual disability
- Kathmandu, Morang, Dhanusha and Kanchanpur
- Data analyzed thematically

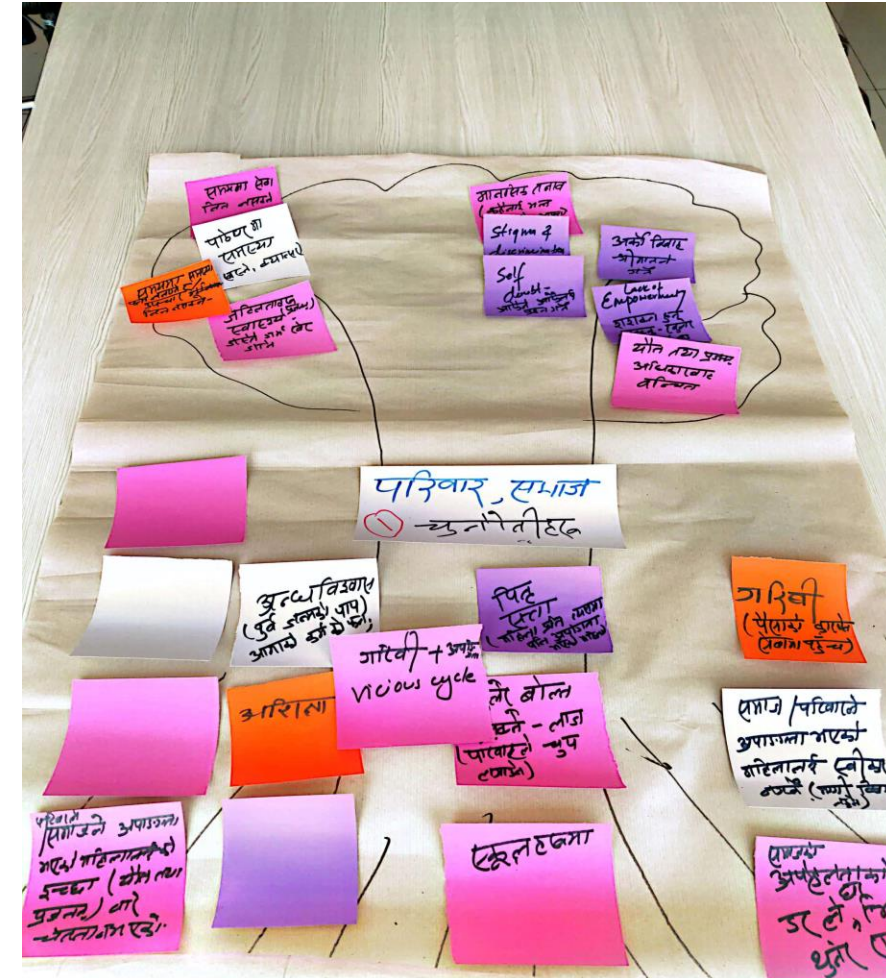


# DESIGN THINKING: A NON-LINEAR PROCESS



# Methodology (contd.)

Human centered design	Activities
Empathize	Data collection with those with lived experiences, relevant stakeholders using participatory methods
Define	Rapid analysis of findings from empathize phase to define the identified needs and barriers
Ideate	Brainstorm to co-create list of potential ideas for interventions to address the identified needs/barriers
Prototype	Finalize the intervention to be tested



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# Participants

Categorization of disability (varied severity)	No of session	Study Area
Women with hearing disability (n=22)	2	Kathmandu, Morang
Women with physical disability (n=36)	3	Kathmandu, Dhanusa Kanchanpur
Women with visual impairment (n=26)	3	Kanchanpur, Kathmandu Morang
Stakeholders (n=17)	2	Kanchanpur, Kathmandu
Mixed group	1	Kanchanpur
Total	11	

# Results

## Identified six themes to summarize the SRH needs of women with disability

1. Acceptance and recognition of SRH needs of women living with disabilities from family and society
2. Access to SRH related information
3. Accessible health facilities
4. Respectful care and services at health facilities
5. Safe spaces
6. Communication and navigation systems



Photo taken with participants' consent 8



# Theme 1- Acceptance and recognition of SRH needs by family, society including schools

- Family and society's ignorance/apathy towards SRHR needs of people with disability (no conversation around desires for marriage and kids; stigma and discrimination)
- Lack of family support (no provision of sanitary products, restricted mobility, considered as liability)
- General lack of understanding about disability (diversity within disability, exclusion in curriculum)

*“Our family members don't acknowledge our sexual needs. They question why we need these things. They advise against getting married, questioning our ability to take care of ourselves, let alone a baby. They believe our children will have to beg to survive.”*

- Woman with visual impairment; empathize session, 3

*“We are also interested in marriage and sexual relations, but we face judgment from others when we discuss these topics”*

- Woman with physical disability; empathize session 9

## Theme 2- Access to information about SRH for women with disability

*“At first, one of my friends didn't want a child. She was unaware of family planning services. She opted for abortion each time she became pregnant. However, when she eventually desired to conceive, she encountered difficulties”*

- Woman with hearing impairment; empathize session, 2

- Inaccessible SRH information including Comprehensive Sexuality Education (more so for hearing disability )
- Lack of awareness of sexual needs resulting in internalized stigma, fear, anxiety, confusion
- Limited terms of SRH within sign language

# Theme 3- Accessible health facilities (Physical)

*'Sometimes, there are doors that wheelchairs cannot pass through, gaps between pathways, and broken roads. There are no clear directions to follow, and even when there are toilets with disabled signs, they may be locked'*

- Woman with wheel chair user; empathize session, 1

- Limited understanding of disability-friendly infrastructure (focused on ramps only)-beds, bathrooms, delivery rooms, equipment
- Lack of information to navigate HFs in accessible forms (Braille, audio, larger fonts)
- Lack of prioritization to women with disabilities (long waiting hours/crowded)
- Lack of friendly transportation services to and from health facilities (esp. for persons with physical and visual impairment)
- Unaffordable healthcare services
- Lack of prioritized implementation or operationalization of related guideline

# Theme 4- Respectful care and services at health facility

- Judgmental attitudes and lack of sensitivity among staff at health facilities resulting in trust issues
- Lack of awareness and training to health care workers on respectful care and services, more on disability-friendly care delivery
- Privacy and confidentiality; Unavailability of professional sign language interpreters and support person (within the health facility )
- Male service providers
- Lack of policy and guidelines and prioritized implementation

*“---due to my small height, the doctors at the hospital scolded my sister-in-law for allowing me to get pregnant. They said I shouldn't have gotten married and that it was dangerous for my life to become pregnant. However, after undergoing surgery, I successfully gave birth to a baby weighing 3000 grams”*

- Woman with physical disability; empathize session, 4

# Theme 5- Safe spaces for women with disability

- Broader societal understanding /attitude towards women in general and WWDs resulting in violence
- Difficulty navigating social physical spaces (due to lack of disabled-friendly infrastructure
- Ineffective response system for justice for violence survivors

*“She used to call him brother. Once, he called her to go visit. According to her, she went with him and drank water. She doesn’t remember anything after that; she was sent home later. Now, she is 6-7 months pregnant. She met that boy, and the relationship happened unconsciously. The phone number of that person is off, and she can’t reach him. Although the mistake is made by both, only females have to suffer. She was scared to go to the police; they are afraid of their reputation in society”*

- Woman with visual impairment; empathize session, 3

*“We should also be aware of how to protect ourselves from sexual violence. Understanding these kinds of situations can be immensely helpful. Recognizing such behaviors of the perpetrators, and knowing what to do if we find ourselves in such situations is crucial”*

- Woman with hearing impairment; empathize session, 2

# Theme 6- Communication and navigation support systems

- Inability to identify or communicate about the perpetrators (especially for women with visual and hearing)
- Lack of disability-friendly patient navigation system in health facilities
- Unavailability of professional (ethical conduct ) Sign Language Interpreters
- Communication barrier

*'In cases involving deaf individuals, we faced challenges conducting counseling sessions, even with the assistance of their mothers'.*

- Service provider, OPD, Empathize session, 10

*"I had gone to pharmacy because of stomach ache; I was given medicines. I didn't know I was pregnant and I wasn't asked either. Later, I gave birth to an unhealthy baby [with cleft lip and palate]".*

- Woman with hearing disability; empathize session, 7

# Take home message

- Participants with lived experience offer valuable insights that help to comprehend the nuances of existing gaps
- Coordinated efforts to create safe and respectful care for women with disabilities beyond sensitization and creating awareness is required



Photo taken with participants' consent

# WHAT NEXT?

- Identifying potential solutions
- Co-designing a prototype



# Acknowledgments



- Research participants
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- Sign language interpreters
- Captioners



# Thank you!

An early-career researcher with a strong aspiration to make significant contributions to the framework of mixed-method approaches in the field of global health. Currently, working at Possible, co-leading and codesigning interventions aimed at enhancing the sexual and reproductive health of women living with disabilities, with a specific focus on those who have firsthand experience with these challenges.



Jene Shrestha

[Jene@possiblehealth.org](mailto:Jene@possiblehealth.org)