Study – Summary:

Feminist Data Collection on Gender and Disability

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1 What is Feminist Data?

Organisations are increasingly using data to support their projects and initiatives. However, data are neither neutral nor objective, but rather the products of unequal social relations. The issue isn't just the absence of critical information on certain groups like persons with disabilities because even the data that does exist is often flawed, biased or incomplete. The answers we have are determined by the questions we ask and when those questions are biased, the data will also be biased. Yet, this is the very data that policymakers rely on to make crucial decisions.

Those in positions of power often determine what data is collected, how it is gathered and how it is used. However, like power itself, data is not always inclusive and accessible, often leaving marginalised groups out of the picture. This leads to significant gaps, where entire aspects of life remain undocumented.

2 Methodology

This study explored feminist data collection practices at the intersection of gender and disability using an exploratory qualitative approach with accessible semi-structured interviews. Fourteen expert participants were included: practitioners, researchers and advisors from advocacy groups, international development organisations and organisations of persons with disabilities (OPD), ensuring diverse representation across different roles and regions.

The interviews consisted of a set of 11 questions grouped into five core categories:

- The importance and impact of disaggregated data on gender and disability
- Challenges in intersectional data collection, on gender and disability
- Recommendations for improving data collection practices for gender and disability
- Ethical and data protection concerns
- General reflections on feminist data collection practices.

The responses were analysed using descriptive thematic analysis to identify themes and patterns within the five core categories.

3 Findings and Insights

Importance & Impact of Disaggregated Data on Gender and Disability

This section presents findings on the importance and impact of data disaggregated by gender and disability. Respondents (1) addressed why they believe collecting such data is important and (2) provided examples illustrating its potential or actual impact in their fields. Responses revealed four main themes:

Theme	Key Points
Identifying and addressing hidden gaps and inequalities	• Intersectional data reveals the unique and compounded experiences of individuals with intersecting identities - women and LGBTQI+ persons with disabilities face new and unique barriers that are hidden and unknown unless disaggregated. • Women and LGBTQI+ persons with disabilities face a heightened risk of experiencing violence and gender-based violence (GBV).
Strengthening advocacy, policy change and program design	• Evidence is needed to push for policy reforms, influence funding and drive systemic change. • Intersectional and disaggregated data on gender and disability enables targeted program design and resource allocation.
Improving service delivery and humanitarian response	• Critical for humanitarian and crisis response. Essential services cannot reach those most in need because without data, they are not known. • Essential for accessible service delivery in healthcare, justice, and education (e.g. sign language in courtrooms).

4 Challenges in Intersectional Data Collection

This section presents findings on challenges in collecting intersectional data on gender and disability. Respondents discussed difficulties in obtaining intersectional data, challenges in collecting data in rural areas, and the reasons for limited data collection.

The key challenges identified by respondents include:

- **Lack of interest and priority.** Disaggregated data on gender and disability is not prioritised by many organisations and international development agencies. Therefore, it is often missing.
- **Low participation.** There is limited engagement from international organisations and NGOs that request data but are unresponsive when invited to participate in research.
- **Limited funding and resources.** Organisations often lack access to funding for collecting, analysing and using disaggregated data, particularly on gender and disability.
- **Technological barriers.** Online surveys and digital tools exclude marginalised groups who lack internet access, digital literacy, or accessible technology.
- **Data invisibility due to stigma.** Women and LGBTQI+ persons with disabilities often remain invisible due to stigma, social exclusion, and communities hiding persons with disabilities.
- **Gender and social norms.** Male-dominated disability organisations lead to an under-representation of women with disabilities in disability advocacy. At the same time, women with disabilities are often underrepresented in women's rights spaces.
- **Rural data collection challenges.** Rural areas present difficulties in data collection due to logistical barriers, stigma, and lack of access to education and technology.
- **Lack of representation.** General lack of representation of women and persons with disabilities in data collection practices.

5 Data Collection Frameworks

Respondents were asked what frameworks or guidelines their organisations use to ensure gender and disability are included in data collection.

Data Collection Practices	Framework Description
No formal framework	• Half of the respondents (50%) reported that their organisation lacks formal frameworks or guidelines for collecting intersectional data on gender and disability.
International frameworks	• 29% of respondents use international frameworks such as the Convention on the rights of persons with disabilities (CRPD) and the Sustainable Development Goals (SDGs), but these do not guide how to collect intersectional data.
Use of Washington Group Questions	• 14% of organisations use the Washington Group Questions for disability data, but these tools do not include a gender lens, which limits their usefulness for intersectional data collection.
Conceptual informal models	• 7% use frameworks such as the socioecological model or feminist conceptualisations.

6 Recommendations for better Data Collection on Gender and Disability

Recommendation	Recommended Actions
Increase representation of women and LGBTQI+ persons with disabilities in data collection	• Include women and LGBTQI+ persons with disabilities in research design, decision-making, data collection and analysis. This ensures their perspectives are included and prevents gaps. • Hire local researchers and women with disabilities from the data collection area. • Increase representation of women, LGBTQI+ and persons with disabilities in international development agencies, particularly in disability-related research efforts. • Increase representation of women and LGBTQI+ persons with disabilities in disability projects.
Strengthen participation and accountability in data collection	• Ensure broader participation in data collection by actively encouraging all relevant stakeholders and requiring individuals to contribute to studies within their organisation. • Partner and collaborate with local OPDs and organisations of women with disabilities to improve outreach in remote and rural areas. • Train researchers in gender and disability sensitivity as well as cultural competency.
Improve data collection methods and accessibility	• Use easy-to-read language and accessible formats for data information and data collection. • Integrate gender and disability perspectives into data collection systems with specific questions about women and LGBTQI+ persons with disabilities. • Ensure survey tools are accessible for persons with various disabilities by working with OPDs representing women with diverse disabilities to design inclusive tools and surveys.
Strengthen data protection and ethical standards	• Adopt strict data protection laws that reflect disability and gender issues to ensure privacy and protection of vulnerable groups. • Develop clear and secure confidentiality protocols for data collection, storage, and sharing and include an intersectional perspective. • Provide regular training for researchers, service providers and stakeholders on privacy, ethical data handling and risks faced by vulnerable groups like women and LGBTQI+ persons with disabilities.

7 Summary

This study explores feminist data collection at the intersection of gender and disability, based on interviews with 14 experts across advocacy, development, and disability sectors. It finds that data is not neutral, those in power shape what is collected, often excluding marginalized groups like women and LGBTQI+ persons with disabilities.

Disaggregated data is essential for exposing hidden inequalities, informing policy, improving service delivery, and strengthening advocacy. Yet, major challenges remain in feminist data collection: lack of funding, low organisational interest, limited participation from global actors, stigma, technological barriers, rural access issues, and underrepresentation of women with disabilities as well as LGBTQI+ persons with disabilities in both research and leadership.

Participants stressed the need to include women and LGBTQI+ persons with disabilities in every stage of the research process, from design to analysis. They also called for accessible methods, stronger partnerships with local OPDs, and better ethical and privacy standards. Without inclusive data practices and an intersectional lens critical experiences and needs will continue to be overlooked in policy and programming.

You can read the entire **study here**.

Imprint

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