Study:

Feminist Data Collection on Gender and Disability

Abstract

This study explores how organisations collect and use data on gender and disability, with a focus on feminist approaches. Based on interviews with experts from advocacy groups, research institutes, NGOs, organisations of persons with disabilities (OPDs), and international development agencies, it highlights key challenges such as limited funding, low prioritisation, stigma, and barriers in rural areas for disability and intersectional data. Without disaggregated data, especially regarding gender and disabilities, important inequalities remain hidden and unaddressed in policy, services, development cooperation, and humanitarian response. The findings also show that many organisations do not have clear frameworks for collecting data on persons with disabilities, as well as intersectional data. Also, data protection practices vary widely. The report puts forward practical recommendations such as the involvement of women with disabilities in research, improving the accessibility of data tools, encouraging full, equal and meaningful participation of OPDs and other stakeholders, and strengthening ethical and data protection standards. Overall, it makes the case for more intentional, inclusive and accessible data practices so that no one is left out of the picture.

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Introduction

Social impact organisations are leveraging data more and more to support their projects and initiatives. Its use extends across various sectors such as healthcare, rural development, and agriculture. Despite good intentions, bias exists in current data collection practices, often leaving women and girls with disabilities invisible. Furthermore, data is often collected, analysed, and interpreted in ways that can even amplify existing inequalities. As a result, intentional efforts are needed to ensure women and girls with disabilities are included in all data. Rethinking every aspect of the data collection process is essential to enhance inclusivity and accessibility.

This study explores how organizations currently collect intersectional data on gender and disability, the challenges they encounter, and the strategies they use to improve data quality. Through interviews with experts and practitioners, the study highlights both barriers and best practices in gender sensitive and intersectional data collection on disability.

The report is structured as follows: The Background section provides an overview of feminist data collection on disability and its significance. The Methodology outlines the research approach. The Findings present insights from interview responses.

Finally, the findings and recommendations are summarised in a framework to chart a path forward on intersectional data on disability and gender.

1. Background

Data feminism is a term coined by Catherine D'Ignazio and Lauren F. Klein in 2020 that offers a new way of thinking about data and ethics, both in its applications and limitations, by drawing on lived experience.

Data feminism goes beyond simply collecting data about gender; it critically examines traditional data collection practices by considering power dynamics and privilege. It challenges binary thinking and acknowledges the complex ways in which factors like gender, race, disability, class, and geography intersect to shape people's experiences and opportunities. [1] By doing so, a feminist data approach uncovers important insights that might otherwise be hidden.

Data holds significant power in today's world. It has been leveraged to uncover injustices, enhance, e.g. healthcare and social services. At the same time, it has been used for discrimination and surveillance. This dual potential for both positive and negative impact raises critical questions: Who is creating data science? Who benefits from it? And whose interests does it truly serve? [2]

[1] International Women's Development Agency (IWDA), 2022. *Data is a feminist issue*. Available at: https://iwda.org.au/data-is-a-feminist-issue/ [Accessed 10 March 2025].
[2] D'ignazio, C. and Klein, L.F., 2023. *Data feminism*. MIT press.

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. This leads to significant gaps, where entire aspects of life remain undocumented, particularly those affecting women and girls, people of colour, Indigenous communities, LGBTQI+ individuals and persons with disabilities. The issue isn't just the absence of critical information; even the data that does exist is often flawed, whether biased, incomplete, or discriminatory. Yet, this is the very data that policymakers rely on to make crucial decisions.[1]

> "The problem isn't only that some women are missing from the record altogether. It's also that the data we do have — data that policymakers depend on — is bad. You might even call it sexist. We like to think of data as being objective, but the answers we get are often shaped by the questions we ask. When those questions are biased, the data is too."
>
> ***Melinda Gates*** [3]

The concept and idea of data feminism asserts that data are not neutral nor objective, but the products of unequal social relations. This context is essential for conducting accurate, ethical analysis that includes everyone. [2]

2. Current data collection practices and challenges

> "What gets counted counts."
>
> **Joni Seager, Feminist Geographer**

Traditional data collection methods, such as censuses and labour force surveys, often exclude certain groups, for example, women with disabilities, due to biases and a lack of inclusivity. These biases can be in the form of defining the problem that the data will attempt to solve, the design, the phrasing of survey questions, as well as how, where, and to whom those questions are asked. These gaps must be addressed to enable a feminist approach to data, ensuring all populations are represented accurately, in particular persons with disabilities, where there may be additional accessibility challenges.

The way research questions are defined, along with the overall approach, is itself a source of bias. For example, in many low-income countries, data on women primarily centres on reproductive health because their primary role in society is seen as being a wife and mother. As a result, other critical aspects of their lives, such as economic participation and education, receive far less attention, creating significant gaps in data and understanding.

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[3] Gates, M., 2019. *2019 Annual Letter*. Gates Notes. Available at: https://www.gatesnotes.com/2019-Annual-Letter [Accessed 10 March 2025].

Furthermore, when it comes to persons with disabilities, many labour force surveys fail to ask about disability status, or if they do, they don't disaggregate the results by both gender and disability. This kind of biased data collection means that data on the employment experiences of women with disabilities is either missing or lumped in with men with disabilities or women with no disabilities.

When we look at commonly used methods such as surveys, the design plays a crucial role in shaping data collection, often reinforcing gender biases. For example, national labour force surveys will typically ask questions only about a person's primary activity. For many women in low-income countries, the response is "housewife," with no follow-up questions that could potentially capture other sources of income.[4]

Additionally, the lack of disaggregation is another challenge in current data collection practices. We don't know how much most women or women with disabilities earn or what they own because, in many countries, income and assets are reported at the household level. Since the husband is considered the head of the household, all earnings and assets attributed to the wife are credited to him. Without disaggregating data, intrahousehold inequalities remain hidden, making it difficult to see disparities in asset ownership and economic contributions.[5] Disaggregating by factors such as sex, age, disability, and income quintile is essential for identifying these inequalities and ensuring that policies address the unique needs of different household members. [4] [5]

However, many studies exclude certain groups altogether, making disaggregation impossible. For example, many studies do not even have a category for persons identifying outside of the binary gender classification or do not ask about a person's disability. Unless gender and other identity categories are expanded, included, and incorporated into data collection practices, many lived experiences, especially instances of gender-based violence against LGBTIQ+ persons and women with disabilities, will remain unrecorded.

To answer many complex questions, especially with regards to such issues where we have limited data or understanding, artificial intelligence (AI) has been used and seen as a powerful tool. While AI has great potential, they can amplify existing inequalities, when algorithms are trained on biased data. Since algorithms learn from historical data, any biases present in that data get embedded in the model and influence its decisions.[2] [6]

When data is informed by intersectional feminism, it has the immense power to create a more equitable and sustainable future for everyone, everywhere. This means collecting and analysing data that reflects how different aspects of identity, such as gender, disability, and class, interact and affect people's lives, then removing the data collection biases discussed above. There is a growing movement of gender equality and gender data advocates calling for and collecting inclusive data that reflects the diversity of people's lives and experiences, including persons with disabilities and diverse genders such as the LGBTQI+ communities.

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[4] Feminist AI, 2021. *Feminist Data Collection: Building a Vision of an Inclusive System*. Available at: https://feministai.pubpub.org/pub/feminist-data-collection/release/1 [Accessed 10 March 2025].
[5] UN Women, 2021. Module 5: Methods for Data Collection and Estimation. [Accessed 10 March 2025].
[6] Sinders, C., 2020. Feminist data set. *Clinic for Open Source Arts. Feminist-Data-Set-Final-Draft-2020-0517.pdf*

3. Methodology

This study aimed to better understand feminist data collection practices, focusing on the intersection of gender and disability. Recognising the complexity and sensitivity of this area, an exploratory qualitative approach was used. Accessible semi-structured interviews were chosen as the primary method for data collection, allowing participants to openly discuss their experiences, perspectives, and recommendations.

A total of 14 expert participants were included in the study based on their knowledge, experience, and involvement in feminist data collection or work related to gender and disability. Participants included practitioners, researchers, and advisors from advocacy groups, international development organizations and organisations of persons with disabilities, ensuring diverse representation across different roles and regions.

The interviews consisted of a set of 11 carefully designed questions. Questions were grouped into five core categories to explore specific areas:

- 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.

Interviews were conducted remotely via video conferencing platforms, allowing participation from different geographical regions and ensuring accessibility. Additionally, participants were given the option to respond using Voiceform, an online voice-survey tool, to enhance accessibility and encourage inclusive participation. All interviews were recorded with participants' consent, transcribed, and subsequently anonymised to protect participant confidentiality. Anonymity and confidentiality were maintained by removing identifiable information from all transcripts, and all sensitive data were securely stored and managed.

To analyse the responses, a descriptive thematic analysis was used. Interview transcripts were reviewed and analysed to identify themes and patterns within each of the five core categories. These themes were then summarized and illustrated using direct quotes from participants, ensuring their voices and insights were accurately represented.

4. Findings and insights

4.1. Importance and impact of disaggregated data on gender and disability

This section presents the findings from expert responses regarding the importance and impact of data disaggregated by gender and disability. Respondents were asked two specific questions:

(1) Why they believe collecting data on gender and disability is important, and
(2) to provide examples illustrating its potential or actual impact in their fields.

Responses revealed four main themes:

Theme 1: Identifying and addressing hidden gaps and inequalities

Many respondents highlighted that disaggregated data reveals the unique and compounded experiences of individuals with intersecting identities, in the case of this study, women with disabilities who face multiple layers of discrimination. Women with disabilities face new and unique barriers that are hidden and unknown unless we specifically look at the intersection of gender and disability.

One OPD representative explained the depth of this challenge:

> "Persons with disabilities, of course, face barriers, but women with disabilities face compounded barriers simply because of these structural and social barriers. When you are a person with a disability, there's stigma, there's accessibility, but when you're a woman with a disability…your disability has compounded barriers because of, for instance, preferential gender roles. Women with disabilities have barriers, but they're expected to perform their gender roles, or they are often abandoned or are not considered worth support."
>
> **Learning and Community Engagement Officer, International Organisation of Persons with Disabilities (OPD)**

This perspective highlights how structural inequalities and gender expectations combine to deepen the exclusion of women with disabilities, making them more vulnerable to discrimination and social isolation.

> "We only know about disability and gender; we forget that there are very interesting and different experiences when these two intersect. Women with disabilities face much greater discrimination and exclusion than men."
>
> **Researcher, Advocacy group**

This respondent emphasised the limitations of data that treats gender and disability as separate, overlooking the realities at their intersection.

> "It's just double discrimination if you think… Women in Sub-Saharan Africa, women with disabilities, they're so far away from any form of support, let alone careers. There's much too little evidence of this out there."
>
> **Researcher, Disability Research Institute**

This comment points to the extreme exclusion and double discrimination faced by women with disabilities in under-resourced regions and the urgent need for more evidence on the intersection of gender and disability.

Other respondents pointed out that women with disabilities face heightened risks of violence, including gender-based violence (GBV) and exclusion. They emphasised that disaggregated data is crucial in making these issues more visible, as women with disabilities face different challenges and violence:

> "We found that women with disabilities are significantly more likely to face GBV and rape than women without disabilities."
>
> **Researcher, Person with a disability**

> "In South Africa it has been very important to show that women are much more likely to be abused when having a disability and more likely to be raped and more likely to be unemployed and not get an education."
>
> **Researcher, Disability Research Institute**

In theme 1, experts emphasis that there is a sense of generalisation on only gender or disability issues, forgetting to focus and collect necessary data on the intersecting groups of women with disabilities.

Theme 2: Strengthening advocacy, policy change, and program design

Several respondents emphasized that disaggregated data is a powerful tool for advocacy. It provides evidence that can be used to push for policy reforms, influence funding and drive systemic change. Additionally, it informs program design, ensuring that initiatives are data-driven and effectively address the needs of marginalized groups.

> "Data should ideally be disaggregated by various aspects of an individual's identity, including age, geographical setting, gender, and so on. This helps us to advocate more compellingly for the specific needs of particular sub-groups, and to compare access or outcomes across different identity markers."
>
> **Researcher, Disability Research Institute**

This respondent highlights how data disaggregation enables more targeted advocacy for specific communities and their specific needs:

> "Collecting disaggregated data on gender, age, and disability is essential for creating targeted and effective policies. In countries like Pakistan and others in the Global South, where disparities can be more pronounced, this data helps identify the specific needs of different groups within society. By understanding these nuances, governments and organizations can allocate resources more effectively, ensuring that budget distributions and development plans address the most vulnerable populations."
>
> **Person with a disability, International NGO**

> "It [data] helps to create initiatives, many of the international NGOs and governments do initiatives and campaigns, but they are inaccurate and wrong, and the resources are poorly allocated because they don't have any data."
>
> **Researcher, Advocacy group**

These respondents have a shared frustration with poorly designed programs and highlight how the absence of data often leads to ineffective or misplaced efforts. They emphasise that if there is no accurate data, the understanding of what needs to be done is lacking, hence initiatives and campaigns are often not effective.

Other respondents have noted that concrete data is crucial for making a case for legal and policy reforms:

> "Azerbaijan looked at policy financing operations… and then found that there were significant barriers under the labour law that prohibited women from working in 674 jobs. We advised the government on how to reform the labour code by providing good examples of why it's good for the economy. There was a woman it was her childhood dream to be a train conductor, but she couldn't do that under the old labour code, so now she became the first female train conductor in Azerbaijan."
>
> **Head of Research, International Development Agency**

This example illustrates how data-backed advocacy can directly influence labour law reforms and open opportunities for women previously excluded from certain jobs.

> "Integrating data collection efforts with national policies is important in our work: To enhance the inclusiveness and effectiveness of programmes, particularly for women and girls with disabilities. To improve accessibility and cultural sensitivity, using community-based data collectors."
>
> **Programme design lead, International Development Agency**

This respondent illustrates the importance of a system-level view, where data is embedded into national planning to ensure inclusion from the start.

The respondents' feedback and examples in theme 2 illustrate that when disaggregated data is available, it strengthens the case for policy reforms, program design, and equitable resource allocation that actors would otherwise not even be aware of.

Theme 3: Improving service delivery & humanitarian response

Respondents noted that disaggregated data plays a crucial role in humanitarian efforts, disaster response, and public services. Without it, essential services were unable to reach those most in need because they simply did not know.

> "In 2023, Malawi faced climate crisis. The Cyclone Freddy severely hit the country. My organisation conducted a study on the impact on women and girls with disabilities. The study observes that there are gaps in the disaster management response towards women and girls with disabilities that needs to be filled. […] the country lacks data for women and girls with disabilities on disaster risk management and response"
>
> **International Development Agency**

> "In the recent floods, we faced significant challenges in identifying how many individuals required support, particularly those with disabilities. Shockingly, there was no available data on the types of disabilities or the number of affected individuals… After facing these gaps, we took legal action and filed a petition in court to include a more comprehensive set of questions regarding disabilities in future censuses. The aim was to ensure that all individuals with disabilities are properly identified and accounted for, enabling more accurate data collection and better-targeted humanitarian response efforts during crises like floods."
>
> **International Development Agency**

These respondents illustrate how the lack of disability data during crisis response meant that essential services could not be provided to those who needed them because they were simply not identified.

> "Disaggregated data enables the design of inclusive and equitable humanitarian support strategies. It allows policymakers to assess who is being left behind and where interventions are needed most. This is especially important in post-crisis or resource-constrained environments."
>
> **Programme design lead, International Development Agency**

This respondent emphasises how data can guide humanitarian response efforts to be more inclusive and better targeted, especially when resources are limited.

Some participants also highlighted the risks of inaccurate data collection in humanitarian contexts and even in the justice system. This often not only leads to a lack of services that are required, but also a lack of accessibility within provided services. For example, we see that in Thailand, there is a lack of accessibility in the judicial system:

> "We have found…there are about 4,000 deafs in prisons, but we don't know their genders, we don't know their age, and we don't know in which prisons, we don't know this, we just know that its 4,000. In prison deafs, don't have any access to any necessary service for disabilities because there is no system, there is not enough sign language interpreters in the justice system. There is no procedural accommodations policy to ensure accessibility. There is no support, there is no informed consent, etc."
>
> **Founder, Organisation of Persons with Disabilities**

This example highlights how the absence of disaggregated data leads to inaccessibility in the justice system and a complete lack of accessible services and procedural protections.

> "It is important to identify differences in access to services that might differ based on gender in addition to disability, particularly for maternal health and SRHR."
>
> **Researcher, Advocacy Group**

This respondent further highlights how the absence of disaggregated data also leads to the inaccessibility of services for women. There is a need to understand how gender and disability interact to affect access to specific services, such as sexual and reproductive healthcare. A field were discrimination of women with disabilities is still very active. These experiences underscore the critical need for disaggregated data to ensure that no vulnerable group is overlooked in times of disaster or in the long-term planning of public policies and humanitarian aid. Data gaps directly impact access, and lead to lack of aid and services. Disaggregated data on e.g. gender and disability critical for disaster response, program design and inclusive planning.

Theme 4: The complete absence of data is a barrier in itself

A great deal of respondents noted that the biggest issue is not just the lack of action, but the fact that data is missing entirely. Respondents emphasise that they often require disaggregated data on women with disabilities, but that it's simply not available.

> "I think the fact that it's [data] missing is the problem, that it's not readily available to be able to be used. Like when we're talking about how important it is to have intersectionality and to say, X amount of women are affected by this, but X amount of women who are disabled or who come from this area or experience this, have this amount of barrier or this amount of discrimination, essentially live in poverty. You know, these kinds of like evidence stories that come out of it. I think the lack of that means that we're not using it well enough."
>
> **Gender Advisor, International Development Agency**

Other respondents have pointed to the lack of institutional prioritisation of data collection, which contributes to ongoing gaps. And where disability is deprioritised. We also see that some respondents have noted that although there is a request and need for data, there is a lack of participation and action to make it possible:

> "We needed it a lot in many cases but never had it. I request it from the organisation often, and everyone wants data, but they don't take part in data collection. For example, I'm the researcher, we do lots of studies, and the advisors of other organisations never have time to take part in studies. They come to me and request data, but when I invite them to take part in our surveys or interviews, they are not there."
>
> **Researcher**

Key insights:

Disaggregated data is essential for identifying hidden inequalities. Without breaking down data by gender and disability, the unique barriers faced by women with disabilities, LGBTQI+ persons with disabilities, and others remain invisible.

Lack of disaggregated data limits understanding of gender-based violence. Women with disabilities face higher risks of abuse and exclusion, but without accurate data, the scale of the problem remains unclear, and they do not receive the necessary support.

Data gaps prevent informed decision-making. The lack of gender- and disability-disaggregated data makes it difficult to assess the needs of women with disabilities, leading to ineffective interventions.

Advocacy and policy change rely on intersectional data collection. Collecting and using disaggregated data has the potential to strengthen legal reforms, funding allocation and the development of inclusive and gender inclusive policies and programs.

Disaggregated data supports legal and policy reforms. Gender- and disability-specific data has led to changes in labour laws and improvements in access to employment. But there is more to do.

Humanitarian response, development cooperation and service delivery are hindered by the absence of disaggregated data. Without accurate data, humanitarian response and development cooperation, e.g. on disaster relief and social services fail to effectively reach persons with disabilities in all their diversity, e.g. LGBTQI+ or women with disabilities.

Demand for data is high, but participation in collection is low. Organizations frequently request disaggregated data e.g. by gender and disability, but do not invest in its collection, leaving persistent gaps.

4.2. Challenges in feminist data collection

This section presents the findings from expert responses on the challenges of collecting intersectional and disaggregated data on gender and disability. Respondents were asked about specific difficulties they encountered in obtaining such data, as well as their challenges faced in rural areas, and why they believe it is not being widely collected. The findings highlight systemic barriers at multiple levels, including institutional neglect, financial limitations, societal stigma, and logistical obstacles in rural settings. Addressing these challenges is crucial to ensuring that data collection efforts accurately reflect the lived experiences of persons with disabilities, particularly women.

Theme 1: Lack of interest and priority

A recurring challenge is the overall lack of priority given to collecting disaggregated data on gender and disability and women with disabilities in general. Many respondents noted that even when disability-related data is collected, it is often not sufficiently disaggregated or completely excludes a gender lens to reveal the unique barriers faced by women with disabilities:

> "People are not interested, and at development agencies, civil society org, etc., they are not interested. Mostly development agencies do this research [on gender], but they don't consider disability as an issue. […] We talk about gender but apparently, no woman has a disability? In my opinion, women with disabilities are the most disadvantaged and marginalised group globally."
>
> **Researcher**

> "Disability is still not on the radar, disability is such a non-topic on the global scale and there's so many people who have personal acquaintances and relationships with persons with disabilities, but this is a topic which is never in the media which doesn't have any lobbying."
>
> **Head of Research, International Development Agency**

International organisations and development agencies often request data but according to many researchers in this study, these organisations are unresponsive when asked to participate in data collection efforts. It was a recurring complaint from respondents that international organisations and other relevant organisations in this field seem not to be interested enough in doing something about the lack of data.

> "People from INGOs and government agencies do not want to take part. For every 100 invitations I send, I get 5 responses."
>
> **Researcher**

> "The international development agencies are always asking for more data, but they don't want to take part in research. They are highly unresponsive when conducting any kind of research."
>
> **Researcher, Advocacy Group**

These insights suggest that despite the growing demand for data, the actual investment and participation in disaggregated data collection remain limited. Without concrete commitments, these gaps in understanding and representation will persist.

Theme 2: Lack of funding and resource constraints

If the topic is not a priority for many, there will also be a lack of funding and resources to collect any data. Many organizations have emphasised that they would like to collect more data such as organisations of persons with disabilities, but they do not have access to funding limiting their ability to collect comprehensive disaggregated data:

> "In my country there is a big disability empowerment fund...but women with disabilities cannot access the fund because the law set the condition of receiving funds to go to the national associations of person with disabilities. […] my association of women with disability that I am the general secretary cannot access the fund."
>
> **Founder, Organisation of Persons with Disabilities**

This respondent illustrates how both legal and funding structures can exclude organisations representing women with disabilities, leaving them unable to collect or contribute to data collection efforts.

> "There's sadly not a lot of money and demand for this kind of work."
>
> **Head of Research, International Development Agency**

We have seen that intersectional data is often not viewed as a priority. This lack of interest contributes to limited funding for disaggregated and intersectional data collection.

Resources can also be a great challenge. We often think that technology can be of great help, but in most countries, persons with disabilities, especially women, do not have that kind of access:

> "Online surveys have been a great way to collect data, however, the entire set of respondents on an online survey that presents only people who are technology adapters and who have access to technology."
>
> **Learning and Community Engagement Officer, International Organisation of Persons with Disabilities (OPD)**

> "Most participants are not on social media or unable to be on a regular basis, so getting participants in such areas is a challenge."
>
> **Researcher**

These respondents point to how reliance on digital tools can exclude people who do not have consistent access to technology and highlight practical recruitment challenges for surveys in digitally disconnected communities.

They underscore that without adequate funding and resources, the collection of gender- and disability-disaggregated data remains difficult, contributing to persistent data gaps. Without increased investment, efforts to improve data accuracy will remain stagnant.

Theme 3: Data invisibility and social barriers

Many respondents pointed out that people with disabilities, particularly women, are often "invisible" in data collection due to stigma, social exclusion, and systemic neglect. These respondents emphasise how invisibility in society directly translates into invisibility in data systems:

> “The government doesn’t provide any data on women or disabilities. Just finding the data they collected especially from census and new areas are near impossible to find. More so people with disabilities are invisible, they are hidden by families.”
>
> **Researcher**
>
> “It’s hard to collect data on a group that is invisible because people don't consider them as important.”
>
> **Researcher, Advocacy group**
>
> “If the society is not seeing them in the first place, a data scientist is going to have a very hard time bringing visibility to them as well.”
>
> **Gender Advisor, International Development Agency**

Some respondents noted that stigma within families and communities directly affects data collection, making it difficult for researchers to reach marginalized individuals:

> "They hide them, families are ashamed, and persons with disabilities are fearful of exposure."
>
> **Researcher, Advocacy group**

> “In addition, they are sometimes hidden away "for their own protection" or because of shame. This makes it harder for them to leave home and makes it harder for researchers to meet them.”
>
> **Gender Advisor, International Development Agency**

These respondents highlight how family-level stigma leads to physical and social isolation, creating barriers to identifying and reaching people in research.

When it comes to women with disabilities, discrimination based on social norms for gender and disability lead to multiple discrimination. The gender barriers in society are often not that different to the gender barriers in the disability movement.

> "Disability associations are mostly managed and directed by men."
> **Founder, Organisation of Persons with Disabilities**

> "Disability inclusion efforts are often led by men; these are the same gender barriers in the disability movement which is the men are usually the ones representing and speaking up while women have to take care of children or are kept behind by social norms that don't allow them to come out of the house. And then again in women's rights group, women with disabilities are not represented or considered."
> **Head of Research, International Development Agency**

This points to the double exclusion that women with disabilities face, both within the disability movement and within the gender movement. These responses highlight how gender norms and social exclusion make it nearly impossible to gather accurate data on women with disabilities and making their voices count. Without intentional efforts to counteract these barriers, their experiences remain undocumented and overlooked.

Theme 4: Challenges in rural data collection

Data collection in rural areas presents unique barriers, including stigma, cultural misconceptions, and limited access to resources. This is the case in most settings, however in rural areas it is different and often more pronounced. The study shows that cultural stigma plays a significant role as well as the logistic barriers:

> "The stigma and discrimination attached to disability remain significant challenges, particularly in rural areas, where disabilities are often hidden or not acknowledged due to deeply ingrained stereotypes. This lack of visibility leads to marginalisation, making it harder for individuals with disabilities to access support, services, and opportunities."
> **Programme design lead, International Development Agency**

Many respondents noted that when in communication with someone from a rural area, it is difficult to collect data due to the social barriers. These social barriers also mean that individuals do not have the same access to resources that will allow them to participate in research.

> "Families often don't want you to speak to their disabled family members or they talk on their behalf thinking they are cognitively unable to take part in the research or speak for themselves."
> **Researcher**

This respondent highlights how social norms and the perceptions of persons with disabilities lead to exclusion or family members speaking on the behalf of persons with disabilities. Reasons are for example:

> "Language barrier and educational barriers of participants."
>
> **Researcher**

> "Most women especially in the rural setting are illiterate and do not demand for their rights."
>
> **Representative, International Development Agency**

These responses show how exclusion in rural areas lead also to limited education, infrastructure and access to support tools. Many women are illiterate or have language barriers.

> "All data collection in rural areas is more challenging. In my setting, persons with disabilities[7] living in rural settings have even poorer access to the means for participation, like assistive devices and sufficient healthcare services."
>
> **Researcher**

> "Geographical barriers: Remote and rural areas pose logistical challenges for data collection efforts."
>
> **Representative, International Development Agency**

These findings highlight that rural areas pose distinct challenges for collecting disaggregated data on gender and disability. Social stigma, logistical barriers, and limited access to technology and education make women with disabilities invisible in research.

Other observations

An overarching challenge that came out in the study is that there is a lack of representation of persons with disabilities, and in particular, women and LGBTQI+ with disabilities. Respondents have emphasised that there is a lack of representation of women with disabilities even within disability organisations. Further intersectionality aspects like the situation of LGBTQI+ with disabilities were not mentioned at all from participants, which shows that there is even more need for disaggregated data on this topic.

Respondents noted a lack of women and women with disabilities in leadership roles within statistical offices and data collection frameworks. This underrepresentation results in blind spots in data priorities, reinforcing the exclusion of gender and disability issues from mainstream data collection efforts.

Another key observation was the disconnect between international researchers and local communities, particularly in rural areas. Respondents noted that when researchers from Western countries such as the US, Germany, and France conduct studies in African, Asian or

[7] Due to sensitive language, this term has been changed from the original interview.

Latin American regions, local communities often feel uncomfortable engaging with them. Language barriers and cultural differences make participation difficult.

Another factor to consider came from one of the respondents who disclosed that he/she had a disability. The respondent emphasised that collecting data as a researcher with disabilities was difficult because the research design was not accessible. Additionally, it was mentioned that persons with disabilities often face stigma and discrimination when conducting interviews.

Key insights:

Lack of interest and priority. Disaggregated data on gender and disability, particularly for women with disabilities or LGBTQI+ with disabilities is not prioritised by many organisations and international development agencies.

Low participation. Researchers emphasised that there is a lack of engagement from international organisations and NGOs that request data but are unresponsive when invited to participate in research efforts.

Limited funding and resources. Organisations that want to collect data lack access to funding. Without financial support, efforts to collect, analyse, and use disaggregated data remain minimal.

Technological barriers in data collection. While online surveys and digital tools are often used for data collection, they exclude marginalised groups who lack internet access, social media presence, digital literacy or the tools used are often not accessible.

Data invisibility due to stigma and social exclusion. Women and LGBTQI+ with disabilities remain largely invisible due to stigma and social exclusion based on social norms about gender, and communities hiding persons with disabilities.

Gender and social norms. The disability rights movement itself mirrors broader gender inequalities, with disability organisations often being male dominated. Women with disabilities are underrepresented in both disability advocacy and women's rights spaces.

Challenges in rural data collection. Rural areas present unique difficulties due to logistical barriers, stigma and prejudices, as well as a lack of access to education and technology.

Representation. We see that there is a general lack of representation of women and persons with disabilities in data collection practices as well as disability organisations.

4.3. Data collection and data protection – Ethical Frameworks

This section seeks to give an overview on the current data collection practices used by organisations to collect disaggregated data by gender and disability, as well as the approaches they use to protect sensitive information. The goal is to understand what frameworks or guidelines, if any, organisations rely on to ensure inclusivity in data collection and to identify the existing measures used to safeguard data privacy and security.

Respondents were asked two key questions:

- What frameworks or guidelines (if any) does your organisation use for data collection to ensure that gender and disability are included?
- How do you ensure that sensitive data is well protected?

By examining these responses, this section maps out the current landscape of intersectional data collection practices, highlighting gaps in institutional policies and ethical safeguards.

Current Data Collection Practices

Findings reveal that organizations do not follow a single standardised approach to collecting intersectional data. While some refer to established international frameworks, others operate without structural frameworks or guidelines.

- Seven of the respondents (50%) indicated that their organisation does not have any formal framework for collecting intersectional data on gender and disabilities. Some noted that while they acknowledge the importance of intersectional data collection, they have yet to develop a systematic approach or guideline for their organisation.
- Four respondents (29%) reported making use of international frameworks, such as the Convention on the Rights of Persons with Disabilities (CRPD)[8], the Sustainable Development Goals (SDGs)[9], the AU Agenda 2063[10], and CEDAW[11]. However, these frameworks do not provide specific methodologies or guidelines for intersectional data collection.
- Two respondents (14%) indicated that they use the Washington Group Questions[12] on Disability Statistics, a widely recognised tool for disability-related data collection. However, this tool does not explicitly incorporate a gender perspective, resulting in a gap in achieving intersectional data collection.

[8] United Nations. 2006. *Convention on the Rights of Persons with Disabilities*. Treaty Series 2515 (December): 3.
[9] UN General Assembly, *Transforming our world: The 2030 Agenda for Sustainable Development*, A/RES/70/1, 21 October 2015. [accessed 15 July 2025]
[10] African Union AU Commission (2015). Agenda 2063: The Africa We Want. African Union, Addis Ababa.
[11] UN General Assembly, *Convention on the Elimination of All Forms of Discrimination Against Women*, 18 December 1979, United Nations, Treaty Series, vol. 1249, p. 13.
[12] Washington Group on Disability Statistics. (n.d.). *Washington Group short set of questions on disability*. United Nations Statistics Division.

- One respondent (7%) mentioned drawing from feminist or socioecological conceptual models, but this does not constitute a structured framework for data collection.

The table below summarizes the data collection frameworks reported by respondents:

Current Data Collection Practices	Respondents	Quote Examples Given
No formal framework	7	"This is so new that we don't have anything as of yet. It is something we are actively now trying to advocate for."
International frameworks	4	CRPD, SDGs, African Disability Protocol, AU Agenda 2063, CEDAW, Maputo Protocol.
Use of Washington Group Questions	2	"Washington group questions for survey data collection. No specific frameworks or guidelines for gender."
Conceptual informal models	1	"Frameworks such as the socioecological model or feminist conceptualisations."

These findings highlight significant inconsistencies in data collection practices. While some organizations reference global frameworks, they often lack structural frameworks or guidelines for intersectional data collection. The absence of a framework or any type of guidelines can result in intersectional data not being prioritised or not collected at all.

Current data protection practices

Alongside data collection guidelines, organisations were asked about the approaches they use to protect sensitive data. The responses indicate a wide range of approaches, from compliance with international data protection standards to a lack of formal safeguards.

- Six respondents (43%) indicated that their organization has formal data protection measures in place. These include compliance with the General Data Protection Regulation (GDPR)[13], secure storage methods, and ensuring informed consent. Some organizations limit the amount of data collected and implement strict retention policies to reduce risks.
- Four respondents (29%) reported having no formal data protection measures in place that relate to disability inclusion and gender. Their responses indicate that no policies exist within their organization for securing sensitive data.

[13] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation).

- Three respondents (21%) expressed doubt or scepticism about whether data can ever be fully protected. They noted that, despite best efforts, ensuring complete security is difficult or impossible.
- One respondent (7%) referenced the ethical principles of the Do No Harm approach, rather than providing specific data security measures.

The table below summarizes the data protection practices reported by respondents:

Data Protection Measures	Respondents	Example Quotes Given
Have formal data protection measures on intersectional data on gender and disability	6	"Follow GDPR; separate identifiable information from research data; secure data sharing protocols."
No data protection measures on intersectional data on gender and disability	4	"None"
Believes data cannot be fully protected	3	"Not sure it can be."
Ethical approach	1	"Do No Harm principle"

Key Insights:

Half of the respondents (50%) of organisations **lack formal frameworks and guidelines for intersectional data collection** on gender and disability.

Existing frameworks do not fully address intersectionality as well as gender and disability together. While 29% of respondents use international guidelines such as CRPD and SDGs, these frameworks do not provide guidelines on collecting intersectional data.

Some organisations use recognised tools, but with limitations. The Washington Group Questions (14%) are widely used for disability data but do not integrate a gender lens, limiting their effectiveness on intersectional data collection.

Data protection practices vary widely. While 43% of respondents implement security measures such as GDPR compliance and secure storage, 29% reported having no formal protections in place.

Concerns exist about data security. 21% of respondents believe sensitive data cannot be fully safeguarded, highlighting risks in current data management practices.

5. Recommendations for better data collection on gender and disability

5.1. Increase representation of women with disabilities and LGBTQI+ persons with disabilities in data collection

Many respondents emphasized the importance of directly involving women with disabilities in all aspects of data collection, design, and decision-making to ensure accuracy and representation.

- It is important to include women with disabilities in the design and decision-making process as well as the data collection and analysis process, as they are often excluded. This allows the perspective of women with disabilities to be included in the data collected on them to ensure there are no gaps or blind spots
- Local researchers and women with disabilities from the area where the data is being collected should be hired within the research teams. Sending researchers from abroad or high-income countries can lead to cultural and communication barriers.
- Representation of persons with disabilities needs to be increased in international development agencies, especially in research efforts related to persons with disabilities.
- More female representation is needed in disability projects and groups, as organisations of persons with disabilities often exclude women.
- Representation of LGBTQI+ persons with disabilities is needed.

5.2. Strengthen participation and accountability in data collection

Many experts highlighted that while international development agencies request data, they often do not participate in data collection efforts. This lack of involvement weakens the quality and effectiveness of research.

- Ensure broader participation by actively informing and encouraging all relevant stakeholders in a study, particularly those working in the field, to participate.
- Require individuals from an organization to participate in its own study to ensure those working in the field contribute their insights.
- Partner and collaborate with community leaders and local organisations of persons with disabilities as well as women with disabilities to effectively reach and involve communities in remote and rural areas, taking their knowledge and connections into account.
- Train researchers in disability sensitivity and cultural competency to ensure accurate and respectful data gathering to enhance and increase participation.
- Funding intersectional data collection is essential to avoid reproducing existing power structures and to uncover hidden inequalities.

5.3. Improve data collection methods and accessibility

Experts have emphasised that data collection practices are not always accessible and do not always reach remote and rural communities that we seek to collect data on. Making data collection tools more inclusive will ensure that women and LGBTQI+ persons with disabilities are accurately represented and included.

- Ensure that easy to read language and easy to understand formats are used, especially in rural areas where education levels are often lower.
- Improve data collection systems by integrating a gender and disability perspective and including questions specifically about women with disabilities as well as LGBTQI+ with disabilities.
- Make survey tools more accessible by ensuring they accommodate individuals with disabilities to improve inclusive data collection in rural areas.
- Ensure participants understand the research and have access to the findings by clearly explaining the study's purpose and publishing reports in accessible formats for those who participated.
- To develop an effective data collection strategy, consult with organisations representing women with diverse disabilities as well as LGBTQI+ persons with disabilities. This ensures that data collection tools are accessible, inclusive, and respectful of their needs.

5.4. Strengthen data protection and ethical standards

Organisations need to adopt stricter data protection measures to safeguard the privacy and rights of marginalised individuals.

- Adopt and enforce strict data protection laws and policies to ensure the privacy and protection, especially of vulnerable groups, such as LGBTQI+ persons with disabilities, women with disabilities and GBV survivors, to ensure that their participation does not expose them to additional harm.
- Develop clear and secure confidentiality protocols for data collection, storage, and sharing.
- Provide regular training for researchers, healthcare providers and stakeholders on privacy, ethical data handling, and the risks faced by vulnerable groups, such as LGBTQI+ persons with disabilities and women with disabilities.

6. Study Summary

This study examines how organisations currently collect data on gender and disability, with a focus on inclusive and feminist approaches. Through interviews with experts from advocacy groups, NGOs, research institutions, and international development agencies, the research explores how gaps in data leave many individuals, especially women with disabilities, unseen and unsupported.

Findings show that disaggregated data by gender, disability and other identity factors is often missing or incomplete. This makes it difficult to understand the compounded barriers faced by women with disabilities, including increased rates of poverty, violence, unemployment, and exclusion from basic services. When data does exist, it often lacks intersectionality, treating gender and disability as separate rather than overlapping categories.

Respondents noted that institutional disinterest, limited funding, and stigma contribute to ongoing data gaps. Data collection is especially difficult in rural areas, where cultural norms and logistical barriers further exclude women with disabilities. Even within the disability movement and women's rights spaces, women with disabilities remain underrepresented.

The study also finds inconsistencies in the frameworks and tools used to collect data. Many organisations operate without any structured approach and even widely used tools fail to fully account for gender. Ethical and data protection practices vary, with some respondents expressing doubt that sensitive data can be adequately safeguarded.

Overall, the study highlights how existing data systems reinforce invisibility and exclusion and why intentional, intersectional approaches are needed to change that.

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