

Disability Inclusion Helpdesk Report No: 102

Query title	Safe and ethical data collection on disability inclusion in Gender Based Violence (GBV) programming
Authors	Katy Chadwick and Maria Vlahakis
Date	29th November
Query	<ul style="list-style-type: none"> > Produce guidelines on safe and ethical data collection on disability inclusion in GBV programming. > Include overview of challenges and risks associated with data collection. > Include case studies of how well this has been done in programming.
Enquirer	FCDO Disability Inclusion Team and Ending Violence Team

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Introduction

In the [Disability Inclusion and Rights Strategy](#), FCDO commits to greater visibility of persons with disabilities through quality comprehensive data and evidence, as well as programmes that are fully inclusive of women and girls with disabilities.

Reliable data related to the lived experiences and views of persons with disabilities is essential, both in terms of fulfilling rights and in providing much needed information for policies and programmes, and to expose the scale of systemic exclusion and discrimination persons with disabilities face. Disability disaggregated data from GBV programmes is important to better understand the differential patterns, prevalence and impacts of GBV in relation to the women and girls with disabilities who are predominantly affected by GBV; the barriers and gaps they might face in accessing services and support; how violence prevention and response programmes can be inclusive of their needs; and which violence prevention and response strategies are most successful (and for whom). Data collection can also help to identify and manage any risks and backlash that might occur during programming.

However, without proper attention to detail, and ensuring that data is collected in a safe and ethical way, there are significant risks to collecting data both on disability and GBV that could compromise safety of, and further stigmatise, already marginalised groups, risk re-traumatisation of people who have already experienced violence and discrimination, and generate a poor evidence base from which to inform policy and programming. Data collection should therefore be approached with care, and only undertaken when a minimum set of ethical standards can be met, and when the data collected has a practical purpose.

This guidance note on safe and ethical data collection on disability inclusion in GBV programming follows on from a guidance note on the safe and ethical collection of data on disability. It adds specifics around the additional considerations for collecting data on GBV, including in emergency contexts. It is designed to be of use to practitioners, particularly FCDO staff, and their implementing partners. It highlights 9 key steps in ensuring safe and ethical data collection on disability for GBV programming, and a number of tools, resources and programmatic examples that can be drawn on for further support.

Methodology

This guidance note has been developed as a rapid research enquiry through the Disability Inclusion Helpdesk. It draws on desk-based research and two interviews with global disability practitioners. The guidelines were validated and tested to ensure they are relevant and useful for practitioners through interviews with four Women's Rights Organisations (WROs) and Organisations of People with Disabilities (OPDs) based in Ghana, Mozambique, Indonesia and Mali, two practitioners working with global disability organisations, and a consultation with the GBV Area of Responsibility (AoR).

Secondary research: Secondary data sources included publicly available data identified through internet searches. The following criteria was used:

- > Focus: Publications that focus specifically on data collection on disability inclusion in GBV humanitarian programming are limited, and the search was widened to include publications which focused on at least two areas out of: disability inclusion; GBV programming; safe and ethical data collection; and humanitarian programming.
- > Time period: 2013 – Present.

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- > Language: English.
- > Publication status: Publicly available material.
- > Geographical focus: Global.

There were also limitations to the research. Firstly, the secondary research was rapid in nature. Secondly, whilst some consultation with OPDs and WROs was included, due to the time limited nature of the enquiry it wasn't possible to conduct a comprehensive co-creation process. Best practice in developing programmatic guidance would involve more consultation and co-creation with those at the frontline of working with and collecting data and information with and on persons with disabilities.

Additionally, it was also necessary to make some decisions about what was in and out of scope for the guidance note. In the review process there were requests to provide additional guidance on informed consent and assent with children and young people, how to approach advocacy for better provision of disaggregated, disability-inclusive data both at a national level, and within the humanitarian system, and how to approach the analysis and integration of data into programming. Whilst each of these topics would be a valuable addition, and are touched on within this guidance, it was not possible to provide detailed guidance on each of these topics within the scope of this note, and these might all be considered as potential topics for future guidance.

Understanding the social context of disability, and differing risks of violence

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) defines persons with disabilities as those who have long-term physical, mental, intellectual, or sensory impairments, which, when in interaction combined various other barriers, may hinder their full and effective participation in society on an equal basis with others. This may, for example, impact on how well persons with disabilities can access and use resources (including services for survivors of violence) and restrict their ability to fully participate in community activities.

Persons with disabilities are 16% of the world's population and 80% of persons with disabilities live in low and middle-income countries (LMICs) (WHO, 2023). An estimated 19% of women across the world have a disability, compared to 12% of men, and in the majority world, women constitute three quarters of persons with disabilities (What Works, 2017). In longer term conflict settings, the total percentage of people with disabilities is likely to be far higher – for example in Syria 25% of people aged over the age of 12 have a disability (Relief Web, 2021). Of the estimated 135 million people who need humanitarian assistance globally, 20 million have an impairment (Barth CA 2019).

People with disabilities, and especially women and girls with disabilities, experience multiple and intersecting forms of discrimination, based on their gender and disability status, as well as their other identities including ethnicity and race, class, religion, age, and sexual orientation (Women's Refugee Commission, 2016). These intersections can shape their status and power in relationships, households, and communities.

There is considerable evidence that women and girls with disabilities are significantly more likely to experience all forms of violence than women without disabilities and men with disabilities, with intimate partner violence (IPV) being the most common form of violence they experience (Stern et al., 2020). Risk of experiencing violence increases with the

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severity of disability. Women and girls with disabilities are also more likely to experience longer term consequences as a result of violence.

Women and girls with disabilities are also at higher risk of disability-specific forms of violence – this could include emotional abuse, denial of care or medication, or being neglected or refused support. Because women and girls with disabilities may be more reliant on others for support, they are also more likely to stay in abusive situations for longer and have fewer options for seeking safety. Women and girls with disabilities who live in institutions for example, are often isolated and reliant on the staff at the institution for their day-to-day care, increasing their risk of violence. A report from the European Parliament found that almost 80% of women with disabilities had experienced violence, and that for women living in institutions, this violence was most often perpetrated by staff and caregivers. Violence can also exacerbate a pre-existing disability or lead to a new impairment – this is especially the case for mental health conditions such as anxiety, depression, and Post Traumatic Stress Disorder (PTSD) (What Works, 2017).

Women and girls with disabilities may have increased difficulties recognising, defining, or describing abuse, especially when information on abuse is not provided in accessible formats. Even when women and girls do report abuse, they are less likely to be believed due to discrimination and stigma (Interview, WROs and OPDs, 2023). This is particularly the case for women and girls with intellectual disabilities and/or psychosocial disabilities and mental health conditions.

The risks of disability-specific forms of violence and gender-based violence also increase in times of stress and crisis – for example, women with disabilities have faced violence in refugee camps where they were forced to exchange sex for food rations (Interview, Humanitarian Expert, 2023). A paper by the Women’s Refugee Commission (WRC) (2016) documented that a common negative coping strategy employed by displaced families of adolescent girls with disabilities was to lock them up or restrain them.

Collecting quality data and evidence on disability inclusion in GBV programming contributes to meeting the four protection standards in humanitarian action¹.

However, persons with disabilities are often overlooked in needs assessments, and rarely consulted in humanitarian programme design. This can reduce their access to services and increase their risk of experiencing violence (WRC, 2016). A rapid review of the inclusion of persons with disabilities and older people in GBV humanitarian interventions conducted in 2019 found that of the 26 programmes included in the review only 8 (30%) integrated assessments on the GBV needs of people with disabilities and older people. There is also little evidence that initial needs assessments then influenced or informed greater disability inclusion in programming or Humanitarian Needs and Priorities Plans (Elrha and VOICE, 2019a; Interview, Disability Inclusion Humanitarian Expert, 2023).

Good quality data collection on disability inclusion throughout the programme cycle, and effective use of that data, can help to set more ambition for inclusive programming. This includes collecting data on GBV, disability and other related factors at baseline, integrating monitoring and learning on GBV and disability throughout the life cycle of the programme, regularly reporting against key inclusion indicators, and then adapting programming to be more inclusive and effective based on this data. This guidance note sets out key steps to integrating disability data collection into the life cycle of GBV programming.

¹ The four humanitarian standards are **meaningful access, safety, dignity, participation, and accountability**

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Steps to guide data collection on disability inclusion in GBV programming

Step 1: Assess the need for, and safety of, data collection, and understand context

It is important to collect quality data to tailor programmes, reduce the risk of leaving people behind, and to contribute to building a more comprehensive evidence base on disability inclusive GBV programming. However, there are also occasions when data is collected needlessly, where the type of data being collected has little practical application, or where, in fragile contexts and crisis settings, primary data collection on GBV prevalence (outside of data collected on response) comes with large associated risks, and minimal advantage.

It is also important to understand the context, the specific ways that disability is understood in that context, and how that may impact on the ability to collect representative and comprehensive data. For example, in some contexts, understandings of disability may focus on physical impairments, excluding others. In certain contexts, stigma may mean that there is a reluctance to disclose disability at all. People with disabilities may also be hidden by their families, making it more difficult to access them (Interview, Practitioners, 2023).

As part of planning for data collection, it is important to consider:

- > **why** data is being collected and **from whom**
- > **how** the data will be collected safely and ethically
- > **what** the data will be used for and what the risks are
- > **who** will have access to and use the data, and **how** it will inform programming going forward.
- > **whether** women and girls with disabilities in communities understand why data collection is happening and are supportive of the process
- > **how** the specific context might impact on the scope and type of data it is feasible to collect

A key gap identified is that many persons with disabilities have very limited access to appropriate services, especially in emergency contexts (Interviews, OPDs, WROs, Experts, 2023). In this case, data collection could help to identify which services are most needed, and what key barriers exist for persons with disabilities to access those services, and then help to inform specific actions to make those services inclusive of the needs of persons with disabilities.

Once the ‘why’ has been understood, it is important to investigate whether the data already exists, and whether secondary analysis of existing data sets will provide the information you need. The Inter-Agency Standing Committee (IASC) guidelines highlight that reliable data could already be available via censuses, administrative databases, or collected by specialised non-governmental organisations (NGOs) or OPDs (IASC, 2019).

If it is determined that existing data is not sufficient, and that collecting data is useful to the programme, there is a need to determine whether it is safe and ethical to collect the data. Collecting data on people’s experiences of disability, and on people’s experiences

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of GBV, are both sensitive topics, which will often rely on people sharing personal information about their lives. As such, they should always be approached with care, and with reference to agreed international standards. In some contexts, where there is heightened stigma around disability and/or GBV, data collection could bring additional risks, and be perceived as a threat (Interview, WRO, 2023). It is therefore essential to design any data collection process with careful consideration of the specific context, and in close collaboration with women led OPDs. It is also essential to ensure that women and girls with disabilities in the community are informed about the process, understand why data collection is happening, and are supportive of the process. If the data being collecting is part of a larger research study, there is also a need to obtain approval from the relevant local ethics committee. Practitioners also highlighted that having accurate and up to date information is essential for their advocacy and programming work. It's therefore important to continue to collect data, and to put in appropriate protections, rather than not collecting data at all (Interview, OPD, 2023)

Agreed international standards for gathering data on GBV and on disability

The World Health Organization (WHO) have published two comprehensive guides to ethical and safety recommendations for gathering data on violence against women, and monitoring sexual violence in emergencies, which are widely used in GBV research and data collection:

- > [Ethical and safety recommendations for intervention research on violence against women.](#)
- > [The inter-agency standards for Gender Based Violence in Emergencies programming \(standard 14 on the collection and use of survivor data\)](#)
- > The National Disability Authority in Ireland have published [ethical guidelines for research on people with disabilities](#), and the London School of Hygiene and Tropical Medicine (LSHTM) have summarised the steps for ethical consideration in disability research in [this article](#) and in an [online course on global disability: research and evidence](#).

In an emergency context it is also important to consider at which stage of the emergency data collection is safe and appropriate. In certain emergency situations it is more difficult to collect data on people with disabilities and pre-crisis data is often not reliable. Additionally, it is recommended that data on GBV prevalence is not collected in crisis settings, due to the additional risks this can pose. However humanitarian actors should be delivering inclusive programming regardless of whether new data can be collected or existing data can be relied upon (Interview, Disability Inclusion Humanitarian Expert, 2023).

It is important to be aware of the possible risks in collecting data, and the potential for challenges related to community perceptions of disability. These include the risk of re-traumatising people who have already experienced violence or discrimination, raising expectations of assistance and support when it is not easily available, putting people at further risk of violence or backlash for participating (especially if confidentiality has not been well maintained), and participants experiencing assessment fatigue (LSHTM, 2020; UN Women and SDDirect, 2020).

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Step 2: Promote the leadership of women with disabilities, consult and collaborate with OPDs and WROs

Women with disabilities will be uniquely able to identify effective ways to prevent and respond to violence against women and girls with disabilities, and to identify barriers to inclusive programming (What Works, 2017). It is important to ensure that ‘nothing about us without us’ is not an empty phrase (Interview, OPD, 2023). Women with disabilities are best placed to identify exactly what they need, especially given the specific nature of each disability (Interview, OPD, 2023). They will also be uniquely placed to create a safe and comfortable environment to speak with other women and girls with disabilities about their own experiences. One group who have been implementing Sphere community-based monitoring, found that women and girls with disabilities were more comfortable sharing their experience when women and girls with disabilities were data collectors (Interview, OPD, 2023). It is important to think about the diversity of research and data collection teams, and work with persons with disabilities, especially women, as team members and team leads, and wherever possible involve people with disabilities as co-researchers (using peer-led methodologies).

Collectively, OPDs and WROs will also have comprehensive information about local context and realities, specialist knowledge of GBV response services and effective prevention strategies, and the needs of persons with disabilities. Bringing these specialist groups together to plan for safe and ethical data collection offers an opportunity to pool specialist knowledge on planning for data collection that is inclusive, safe, and non-stigmatising. This might include working together on issues such as what types of questions are appropriate, where it is safest and most accessible to conduct interviews and focus group discussions, what type of language and terminology is most appropriate and non-stigmatising for both survivors of violence and for people with disabilities, and how best to use and apply the data to programming once it has been collected.

It is important for WROs and OPDs to be brought into the process from the beginning, with enough time to review tools, and to make the changes needed for accessibility (such as editing surveys, providing appropriate translations etc). Practitioners in the validation interviews emphasised how too often they are brought in far too late, when it is not feasible to make the needed changes (Interview, OPD and WRO, 2023). Women with disabilities, OPDs and WROs and women-led groups should always be fairly compensated for their time and acknowledged as equal partners and contributors in data collection and programming.

Collaboration and leadership in practice

In Rwanda, the *Indashyikirwa* programme team worked with the National Council of Persons with Disabilities to develop inclusive communication materials to illustrate the intersections of gender, disability, and violence. These materials were used to guide facilitated community activism, raise awareness of disability rights and to challenge disability related stigma and discrimination (Stern et al., 2019). In Lebanon, following trainings for violence against women and girls (VAWG) agencies, the agencies contacted local OPDs for information on girls with disabilities and guidance on how to develop strategies to reach them (Elrha and VOICE, 2019a).

Step 3: Decide on what data to collect and how to collect it

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The IASC (2019) Guidelines note that quality humanitarian programming should be built on an understanding of the requirements and priorities of persons with disabilities during a crisis. The guidelines highlight that this understanding is developed by identifying the population of persons with disabilities;

1. Analysing the risks that persons with disabilities face (including GBV risks), and the factors that contribute to those risks as well as the impact on individuals.
2. Identifying barriers that impede persons with disabilities from accessing and using humanitarian assistance, including GBV services, and the accommodations that are needed; and,
3. Understanding the roles and capacities of persons with disabilities in the humanitarian response.

Projects that have been collecting data on disability in GBV programming often combine quantitative data and qualitative data. A recent learning paper on disability inclusive GBV programming found that **it is important to disaggregate GBV data across gender, age, and disability** (including by impairment type and severity) which can help to show the differential impacts of programme activities on diverse women and girls with disabilities across the life cycle of the programme (End Violence against Women and Children Helpdesk, 2022). Other characteristics should be included as relevant in the context.

Quantitative data can be used to identify the number of persons with disabilities in an affected population, to assess the proportion of accessible services, to prioritise needs and risks, and to understand how these needs and risks vary across different demographics. It can also be used to measure whether change is occurring and the scale of that change. (IASC, 2019; UN Women and SDDirect, 2020). Quantitative service level data is a particular need and gap (Interview, Disability Inclusion Humanitarian Expert, 2023)

The Washington Group Short Set on Functioning (WG-SS) is one of the most widely used quantitative tools for collecting disability inclusion data. Their use is also promoted in the FCDO Disability Inclusion and Rights Strategy. The [WG-SS](#) includes six questions and four response categories of severity. They focus on core functional domains of seeing, hearing, walking, cognition, self-care, and communication. They take approximately two minutes to administer and have been designed so that they can be added to a range of tools such as census or service user questionnaires. Findings can be disaggregated and analysed in conjunction with other demographic and household data (Washington Group, 2018). The enhanced short set includes questions relating to psychological functioning.

There has been an important shift in the collection of data during needs assessment stage, with the WG-SS being much more widely used, however more preparation and training is needed to ensure they are used effectively (Interview, Disability Inclusion Humanitarian Expert, 2023). Humanity and Inclusion's factsheet on the do's and don'ts of using the Washington Group Questions emphasises the need to ask questions with respect, not to directly mention the word disability, and ensuring translations have been done in advance and are not provided 'on the go' (Humanity and Inclusion, 2018).

When collecting data on children and young people under 18, the child functioning model is one of the most widely used tools. However, a shorter version of this tool is not available, which can make it more difficult to incorporate into data collection, especially in humanitarian settings (Interview, Disability Inclusion Humanitarian Expert, 2023).

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Disability inclusive programming on GBV requires data on disability inclusion alongside data on GBV. There are a number of standardised quantitative measures available to assess experiences of GBV and related attitudes. Quantitative surveys often adapt items from the World Health Organization’s multi-country study on women’s health and domestic violence against women, and the RESPECT framework also provides guidance around developing monitoring and evaluation strategies for VAWG, including suggested indicators for each of the seven RESPECT strategies.² It is considered good practice to include standard questions from these surveys on: personal demographic data (including gender, age, disability status); household socio-economic data including composition, income, assets etc; attitudes about gender equality and specific types of violence against women (VAW); experience of various specific forms of VAW, and help-seeking behaviours and access to services (for women). Example 3 in the ‘data collection in practice’ box below, highlights how IPV, disability and mental health measurements were all included in the data collection process.

Qualitative data can be used to collate the views and priorities of persons with disabilities, to better understand risks, barriers and enabling factors, to understand how and why change is happening over time, and to monitor for any unintended consequences of programming. (IASC, 2019; UN Women and SDDirect, 2020). Qualitative data can also be particularly helpful in involving women and girls with disabilities in data collection to inform better service provision, and for the development of disability inclusive policies on GBV (Interview, OPD, 2023). There are a number of examples of using qualitative methods to support more inclusive data collection, and approaches used could include interviews, focus groups, community mapping, the use of vignettes, peer research and other creative approaches such as photography or narrative approaches. Some practitioners also highlighted the importance of spending time in the community, and community observation as an important qualitative data gathering approach (Validation interview, WRO, 2023). Examples one and two from the ‘data collection in practice’ box highlight ways that narrative approaches, photography, and vignettes have been used to better capture the views and experiences of people with disabilities.

Data collection in practice – collecting quantitative and qualitative data to understand the intersection of gender, disability, and violence

Example 1: Participatory approaches Researchers at the Institute of Development Studies, in collaboration with NGOs and OPDs, used a narrative approach to document the experiences of persons with disabilities during the COVID-19 pandemic. Participants were interviewed two months apart about their experiences of the pandemic and to share their recommendations for future action during crises (Wickenden et al., 2021). In a peer research project in Jordan, working with young persons with disabilities, participants identified key challenges in their lives, and proposed solutions, and were then invited to use a series of photos to capture these (Banioweda, 2019).

² The RESPECT women; preventing violence against women framework was developed by WHO and UN Women, and outlines seven interrelated intervention strategies to prevent VAW – these are 1, relationship skills strengthened 2, Empowerment of women 3, Services ensured 4, Poverty Reduced 5, Environments made safe 6, Child and adolescent abuse prevented 7, Transformed attitudes, beliefs and norms.

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Example 2: The ‘Safe at home’ programme is a family violence programme model to prevent and respond to violence against women and children at home in a humanitarian setting. Baseline data collected for the programme included both qualitative and quantitative measures that looked at the intersection of gender, disability, and experiences of violence. Quantitative data surveys collected included six items from the WG-SS to assess disability status, and past month experiences of IPV were assessed using adapted questions from the WHO multi-country study on VAW. Qualitative data was then collected through semi-structured interviews and the use of vignettes showing a hypothetical family to elicit beliefs about community norms related to family violence and disability. In one vignette the family is shown living with the husband’s older sister with a physical impairment and three children, one of whom also had a physical impairment, and questions were asked to assess perceptions of disability across a life course. The study provided insights towards the drivers and frequencies of violence against women as it relates to disability and older age identities, and women with disabilities reported higher levels of IPV compared to women without disabilities (Scolese et al., 2020).

Example 3: In a study on disability, violence and mental health amongst Somali refugee women, symptomatic scales were used to assess anxiety, depression and PTSD in the two weeks prior to interview, alongside measurements of IPV and disability (Hossain et al., 2020).

It is important to how to appropriately adapt the qualitative method to support inclusive access for the different communication profiles of participants, not just the method used (Kenny, N., Doyle, A., & Horgan, F. 2023). The GBV and Disability Toolkit (summarised in box below) has a number of qualitative tools, and considerations for their inclusive use, which can be used to gather GBV and disability inclusive data.

‘Building Capacity for Disability Inclusion in Gender-Based Violence Programming in Humanitarian Settings: A Toolkit for GBV Practitioners’ (Ending Violence against women and children helpdesk, 2022)

The [GBV and Disability Toolkit](#) was developed by the Women’s Refugee Commission and International Rescue Committee. It is the result of a two-year project entitled *Building Capacity for Disability Inclusion in GBV Programming in Humanitarian Settings* conducted in humanitarian settings in Ethiopia, Burundi, Jordan and the Northern Caucasus in the Russian Federation.

This toolkit was created with the input and participation of persons with disabilities and GBV practitioners to support GBV staff to build disability inclusion into their work and strengthens the capacity of GBV practitioners to use a survivor-centred approach when providing services to survivors with disabilities. The tools are designed to complement existing guidelines, protocols and tools for GBV prevention and response. The toolkit includes a number of practical tools that can be used to gather qualitative data about disability inclusion for GBV programming. These include a group discussion guide, an individual interview tool, a reflection tool for GBV practitioners, and a guide to documenting stories of change.

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Step 4: Invest in the training of staff, consultants, interpreters and enumerators

Staff and others involved in collecting data may have limited experience of disability inclusive programming, and/or of GBV programming. This might either limit inclusive engagement (for example, nervousness about using the wrong terminology might prevent them from including persons with disabilities in discussions), or risk unintentional harm being caused during the data collection process (for example, by asking intrusive, stigmatising or embarrassing questions) (Interview, OPD, 2023). It is important to invest in preparation and training for the team, to use values-based questions during the hiring practice, and to allocate adequate time in the project timeline. This training might include use of language; accessibility needs; communication strategies; understanding definitions of disability; challenging bias and stereotypes; understanding root causes of GBV and disability-related violence; and making appropriate referrals. It could also include the proper use of specific tools such as the WG-SS. It's also important (as referenced in step 2) to involve people with disabilities in both collecting and analysing data on disability.

There are also important considerations for preparing interpreters – for example not all words will have a corresponding sign in local sign languages, and meanings can get lost. Interpreters and enumerators need training on using non-stigmatising language, and access to word libraries (Interview, OPD, 2023). This needs to be prepared in advance.

There are several resources available that can support the development of comprehensive training for teams – for example the [GBV blended curriculum](#) developed by the International Rescue Committee (IRC) provides guidelines on working with GBV survivors with disabilities, [the WRC-IRC toolkit on GBV and disability](#) has a training module on GBV and disability, and training resources on using the WG-SS are available through Humanity and Inclusion's [disability data in humanitarian action programme](#).

Step 5: Establish safe and appropriate referral pathways

Collecting data on GBV, disability and other related topics may lead to disclosure and raise expectations of support when there are limited services available. Developing a plan for disability-inclusive referrals (i.e., mapping services to identify referral pathways which are accessible and inclusive for persons with disabilities) and how to meet increased demand for support, is essential before any data collection takes place. It is also important to provide clear guidance on legal obligations (for example any mandatory reporting requirements in particular contexts).

A study in the Philippines that looked at how referral pathways could be more inclusive of women with disabilities showed that services need to be physically accessible, but also need to address additional barriers, such as stigma (W-DARE, 2018). This includes raising awareness of the service, finding out whether women can leave the house to attend the service, providing accessible transport, and sensitising service staff (including guards) about the needs and rights of women with disabilities, as well as providing accessible communication materials and information (Ending Violence Against Women and Children Helpdesk, 2022).

Before collecting disability inclusion data for GBV programmes, adapt existing GBV Standard Operating Procedures (SOPs) to strengthen case management and referral pathways for persons with disabilities (disability inclusive case management and referral), and ensure that everyone involved in the collection of data has access to the referral

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pathways, and has received training on how to refer people to the services they need. It is important to identify trusted support systems for persons with disabilities in the community, as persons with disabilities may not have the same support services or trusted relationships in a community as persons without disabilities (SDDirect, 2022). It is also important to make sure that any information provided about locally available services is made accessible for people with a range of impairments. UNFPA have written [global guidelines](#) on the provision of inclusive and accessible services related to gender-based violence and sexual and reproductive health and rights for women and young people with disabilities.

In Malawi, the *Tithetse Nkhanza!* programme created posters to present referral pathways visually to make information about services available to low-literate audiences and included pictures of survivors with disabilities (Bangura and Bishop, 2021). In Lebanon, UNICEF and the WRC developed complimentary guidelines on safe identification and referrals, including a “Do’s and Don’ts List” in line with the SOPs, an informed consent flow chart with signposts for when to trial different communication methods and involve supervisors, and tips on when to refer to disability service providers (Elrha and VOICE, 2019a).

Step 6: Gain informed consent and assent

It is always essential to gain informed consent from participants you are gathering data from. This step is particularly crucial for women with disabilities, who may have previous experiences of not being listened to, and their opinions not being considered (Interview, OPD, 2023). An informed consent process has three key steps:

1. Providing all information and options to the participant in a way that is accessible and understandable to them,
2. Determining if they can understand the information and the implications of their participation,
3. Ensuring their decisions to take part are fully voluntary and not coerced.

Determining the capacity to consent of persons with disabilities can be more complex, however it is important to not make assumptions about a person’s capacity to consent. Speak directly to the person with disability, even if a caregiver, translator or other third party is present. It is also important to ensure consent is checked before, during and after data collection as consent is an evolving process and may vary at different stages. Those collecting data should provide clear and accessible information at the beginning, consent forms in accessible formats, emphasise that participation is fully voluntary, that they can also opt out at any point during the process (and/or ask to skip questions), and that participation will not have any impact on the services available to them. All information should be communicated to the person in a way they understand.

A [tip-sheet](#) from the Safeguarding Resource and Support Hub (RSH) provides information on differentiating between consent and assent, with a particular focus on taking children and young people through the assent process. The WRC-IRC [toolkit on GBV and disability](#), referenced in step 4), also includes tools for gaining informed consent, for working with caregivers, and for identifying the skills and capacities of persons with disabilities.

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Step 7: Ensure privacy and confidentiality

It is important that the privacy and confidentiality of participants is well respected and maintained during data collection. This is particularly important when data is being collected on sensitive topics such as GBV. In one-to-one interviews and surveys with an enumerator, people participating should be given privacy where they cannot be easily overheard or seen using sign language. In some cases, participants with disabilities may be accompanied by a support person or interpreter to the interview (often a family member), and in these cases it is important to consider what information is appropriate to ask in front of a family member. It is also important to keep in mind the risk that people providing care/accompaniment could also be perpetrators themselves. It might be useful to provide the option to the participant of using an external interpreter (Interview, Disability Inclusion Humanitarian Expert, 2023). In focus group discussions it is also important to consider which questions are appropriate to ask in a group setting, especially where participants are known to each other.

It is also essential to refer to guidelines on safe and ethical data management (such as storing data securely). This includes considering how to protect the anonymity of participants when writing about findings, by making sure that the number of identifying characteristics cited in examples (e.g., referring to specific communities, specific disabilities, age of participants, sexual orientation etc.) could not lead to identification of individuals.

Step 8: Provide appropriate, accessible space and materials

It is important to plan for accommodation considerations for a diverse range of persons with disabilities. This includes people with a range of different impairments and other identity characteristics. Consider whether there are additional barriers for women who might experience time poverty due to working a 'double day' of paid work and care responsibilities. It is also important to consult with people with disabilities about what accommodations would help to support their participation. This could include (LSHTM, 2020; Humanity and Inclusion, 2018):

- > Ensuring the accessibility of venue and checking whether there are ramps for people with physical impairments,
- > Providing accessible transport to the venue,
- > Considering home visits, where safe and confidential,
- > Providing extra time in interviews for participants,
- > Providing information and communication materials in accessible formats – this could include providing them in braille, large print, or easy read formats, having sign language interpretation, or having questions written down and provided in advance.

Good care should be taken with data collection to ensure respectful language and processes are adhered to (and that these are outlined clearly as part of the training process). This includes using 'person first' and non-stigmatising language, and contextualising language by checking with OPDs and/or people with disabilities about locally used and preferable language. Questions asked of people during interviews and focus groups should be respectful of participant's lived experiences and have been carefully thought through to avoid the risk of triggering past traumas.

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Step 9: Apply the data to programming

Data collected during monitoring and evaluation should always be used and applied in all stages of the programming cycle. Once data has been analysed, it is important to share findings with participants in accessible formats, and to ask for feedback and validation of findings. Those involved in data collection should bring programme partners together at regular intervals through the programme cycle to discuss monitoring findings and ideas for adapting programming to be more effective and inclusive, as well as advocating for integrating inclusive data collection practices.

Programme Phase	Tips for applying the data
Scoping/design phase	<ul style="list-style-type: none"> ✓ Provide opportunities to use data gathered to inform intentional design of more inclusive programming ✓ Test and validate findings with partners and community members before the start of implementation
Implementation	<ul style="list-style-type: none"> ✓ Provide regular updates to community members, programme participants and programme partners and validate data findings with them ✓ Ensure easily accessible feedback loops ✓ Bring partners together to use data to adapt programming at regular intervals
Monitoring:	<ul style="list-style-type: none"> ✓ Integrate inclusive data collection practices into the programme monitoring tools, logframes and results frameworks ✓ Update programme tools when gaps in data collection are identified ✓ Use data effectively to ensure that programming is more inclusive and effective
Closure	<ul style="list-style-type: none"> ✓ Share findings with participants in accessible formats ✓ Use data gathered to inform advocacy and policy work

Spotlight on practice: Inclusion of women and girls with disabilities in GBV services in Bidi Bidi Refugee Settlement (Elrha and VOICE, 2019b)

Overview: The National Union of Women with Disabilities in Uganda (NUWODU) implemented a project that focused on monitoring the protection needs and capacities of women and girls with disabilities, strengthening their access to services, fostering their participation in programme initiatives, and piloting the IASC Disability Guidelines.

Partners: NUWODU, formed a coalition with the National Union of Persons with Disabilities in Uganda (NUDIPU) and Restoration and Hope for Refugees (REHORE),

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How it was done:

- Training provided for all coalition staff members on GBV and disability, including the use of rights-based language when referring to persons with disabilities and survivors of violence.
- Consultative meetings with refugee women and girls with disabilities in Bidi Bidi refugee settlement to identify GBV risks, barriers to accessing GBV services and suggested strategies to make GBV prevention and response activities more accessible to them.
- Consultative meeting with GBV service providers operating in the settlement to identify their concerns and capacity development needs in reaching and supporting survivors with disabilities.
- Based on these meetings the team advocated for adaptations to data collection processes in the settlement, so that information could be disaggregated and analysed according to age, gender, and disability in the future.
- Women and girls with disabilities were involved in monitoring and evaluation and collected “Stories of Change”
- WGWD also participated in, and facilitated forums, for exchange of information, learning and coordination, including the “Persons with Specific Needs Working Group” and the Ministry of Gender, Labour, and Social Development forum GBV actors meeting.

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Helpdesk reports: The Disability Inclusion Helpdesk is funded by the UK Foreign, Commonwealth, and Development Office (FCDO), contracted through the Disability Inclusion Team (DIT) under the Disability Inclusive Development Inclusive Futures Programme. Helpdesk reports are based on between 3 and 4.5 days of desk-based research per query and are designed to provide a brief overview of the key issues and expert thinking on issues around disability inclusion. Where referring to documented evidence, Helpdesk teams will seek to understand the methodologies used to generate evidence and will summarise this in Helpdesk outputs, noting any concerns with the robustness of the evidence being presented. For some Helpdesk services, in particular the practical know-how queries, the emphasis will be focused far less on academic validity of evidence and more on the validity of first-hand experience among disabled people and practitioners delivering and monitoring programmes on the ground. All sources will be clearly referenced.

Helpdesk services are provided by a consortium of leading organisations and individual experts on disability, including Social Development Direct, Sightsavers, ADD International, Light for the World, Humanity & Inclusion, BRAC, BBC Media Action, Sense, and the Institute of Development Studies (IDS). Expert advice may be sought from this Group, as well as from the wider academic and practitioner community, and those able to provide input within the short timeframe are acknowledged. Any views or opinions expressed do not necessarily reflect those of FCDO, the Disability Inclusion Helpdesk or any of the contributing organisations/experts.

For any further request or enquiry, contact enquiries@disabilityinclusion.org.uk

Suggested citation:

Chadwick, K. and Vlahakis, V. (2023) *Safe and ethical data collection on disability in GBV Programming*, Disability Inclusion Helpdesk Research Report No. 102. London, UK: Disability Inclusion Helpdesk.