

Key Considerations when Supporting Survivors with Disabilities

“At first I thought that I couldn’t be helpful to certain persons with disabilities because I am not a doctor, I couldn’t make their condition better, I couldn’t heal them. But then, once I took time to start to listen more, they were not asking for that type of help, they wanted to talk, they wanted assistance to support themselves, to be safer. I realized that I already knew how to support this person....Before I assumed that I didn’t, I assumed that talking to me wouldn’t change their situation at all. I should have listened more before, but now I do, I really listen first, before I try to make plans and try to fix things.” - IRC Community Mobilizer — Muyinga camp, Burundi

Persons with disabilities:

- include persons with physical, sensory (hearing and visual), intellectual, and psychosocial impairments who are **persons first**: women, girls, men, boys
- are not “special”, but **part of human diversity**; being human has a broad spectrum of possibilities: there are many ways of walking, seeing, thinking, communicating, interacting, etc. and all are respectable
- do not need to be “fixed”, it is instead the environment that needs to be open to all its members
- have skills, **capacities**, **experiences** that can be strengthened and built upon through regular case management
- have the same **rights** and **obligations** as all people

Disability...

- is not equal to impairment and it is not a “medical problem”
- results of the **interaction** between persons with impairments and barriers in society
- can change: a positive interaction (e.g. by removing barriers) results in participation and inclusion; a negative interaction (e.g. with barriers, with gender-based discrimination, with forced displacement) results in disempowerment and marginalization

Interacting with survivors with disabilities is a matter of persons, not of disabilities.

Key Facts

- Persons with disabilities are not more vulnerable to violence because of their impairment, but rather because they are perceived as different, have less power and status, are marginalized and are even directly targeted for violence due to these same factors. (IRC/WRC 2015a)
- Social isolation and loss of protective community networks can compound this situation in displacement settings. (IRC/WRC 2015a)
- Women and girls with psychosocial and intellectual disabilities are perceived to be most at risk of sexual violence, and family and service providers may only become aware of sexual violence against them when they become pregnant. (IRC/WRC 2015a)
- There are reported cases of child marriage among girls with “minor” disabilities who may be pressured to an early marriage before they are perceived as “less desirable” due to both their age and disability. (WRC 2018)
- There are reported cases where family members have forced girls with disabilities to beg in the street, which exposes them to the risk of sexual abuse. (WRC 2018)
- Girls with disabilities may be considered as “easy targets,” assuming that they will be less credible or not having husbands or males to protect them and that “there would be fewer repercussions.” (WRC 2018)
- Girls with disabilities may be coerced into sterilization. (UNICEF 2017)
- Children with disabilities are more likely to be institutionalized and face sexual abuse in institutions. (UNICEF 2017)
- Sexual violence against men and boys with intellectual disabilities has also been reported, as well as against caregivers (majority of whom are women and girls) of persons with disabilities. (WRC 2018)
- Survivors with disabilities may wait over one month to report violence, due to the additional barriers they face to disclosure. (IRC/WRC 2015a)

Key Attitudes

- Do not focus on the impairment, **focus on the person**: what does the person need as a survivor of GBV? What prevents these needs from being met?
- **Identify barriers**. There are many things that prevent persons with disabilities from being included in our activities that can be addressed.
 - **Attitudinal Barriers**: Negative stereotyping, social stigma, and discrimination by staff, families and community members all affect a person with disabilities access and inclusion in society. For example, believing that persons with disabilities do not need information on GBV prevention and response services, that they do not have a sexual life and therefore, are not in need of sexual and reproductive health information or services.

- **Communication Barriers:** Information may be presented in formats that are not accessible for persons with disabilities, including those with visual, hearing and intellectual/psychosocial disabilities. For example, GBV prevention materials produced only in one format.
- **Environmental or Physical Barriers:** Buildings, roads and transport may not be accessible for persons with disabilities, for example, GBV facilities and transportation not being accessible.
- **Policy & Administrative Barriers:** Rules, policies, systems and other norms may disadvantage persons with disabilities, particularly women and girls, for example, GBV data collection systems not disaggregating information by disability, not facilitating knowledge about service accessibility.
- **Don't make assumptions:** do not assume that you know what a survivor with a disability wants or feels, or that she/he does not understand, cannot do certain things or would not be interested in participating in certain activities.
- **Assume capacity.** Look at what they can do, not just at what they can't do. Identify strengths and capacities, including in how to interact with them and adapt case management processes to be accessed by them. Assume survivors with disabilities have the capacity to make their own decisions
- **Avoid reinforcing negative power dynamics.** Persons with disabilities often have decisions made for them by other people, including family members, caregivers, partners and even service providers. Support them to develop their own **sense of agency** and power to make their own decisions. At the same time, work also with caregivers and families to support healthy relationships and balanced power dynamics.
- **Be flexible and take time to consult with them.** Identify safe, confidential and calm ways to interact with persons with disabilities. Time is one of the best things we can give to anyone.

Key Actions

Apply the guiding principles for case management to survivors with disabilities:

- **Ensure Safety:** Discuss with survivors with disabilities to determine protective or perpetrating relationships with family members, caregivers and community members.
- **Respect Confidentiality:** Brief all support persons engaged in process – survivors, family members, caregivers and/or sign language interpreters – on the principles of confidentiality.
- **Respect Wishes, Rights & Dignity:** Direct conversation to the survivor first, always asking permission from the survivor to consult with others (including caregivers).
- **Non-Discrimination:** Provide accessible information about the full range services to all survivors, including persons with complex, severe

or multiple disabilities – don't make assumptions about which ones are appropriate for them.

This also includes:

- **Empowerment:** give the power and the control to the survivor.
- **Collaboration:** develop the relationship between the client and the case worker
- **Accountability:** case workers are accountable to the survivor as well as to the ethical principles of their practice, implement the quality, best practice

Support **decision making and respect the process of consent**. Adults with disabilities have the same rights as everyone else to make their own decisions. An individual cannot lose the legal capacity to make decisions simply because she has a disability. All survivors have a right to information and should play a role in decision-making. To aid in this process, adapt the **three key components** of informed consent processes by: 1) **providing all possible information** and options to a survivor in a way they can understand; 2) **determining if they can understand** this information and/or their decisions (also referred to as “capacity to consent”); and 3) ensuring that the decisions of the survivor are **voluntary** and not coerced by others (e.g., family members, caregivers or even service providers). The following actions can be put in place to adapt this process:

- Take time to explain process and concepts.
- Always talk directly to the individual, even when a caregiver is present.
- Use a range of methods to convey information in a way that the survivor can understand: pictures, hand gestures, symbols or adapted material (e.g. communication boards, modeling compound, puppets) to ask if someone is willing to participate in an activity or to access a service.
- Let the survivor choose any support people they wish to include in the decision-making process.
- If a case worker is still establishing communication methods with the survivor and needs to ask for advice from the caregiver, make sure to have these conversations in front of the individual, so they can hear what is being said and participate in any way possible.
- If somebody is accompanying a survivor, the case worker should note the body language of the survivor to know whether he/she is a trusted person

Address barriers. Evidence shows that the following actions have worked before to address the following **barriers**:

- **Attitudinal Barriers:** working directly with survivors with disabilities allows practitioners to see beyond the person's impairment, appreciate their skills, and apply their existing training in using a survivor-centered

approach to working with this group; recruiting women with disabilities as community mobilizers for GBV activities.

- **Communication Barriers:** Adapt informed consent materials and processes to be as accessible as possible; adapting existing GBV prevention community mobilization materials such as SASA! to be accessible (e.g. audio and printed format, easy-to-read versions) and depict diverse persons with disabilities as part of the wider community; arrange tailored case management services with more effective and appropriate communication approaches (e.g. using communication boards or Sign Language Interpreters);
- **Environmental or Physical Barriers:** Making accessibility modifications in GBV facilities; providing allowance for accessible transportations or for a trusted family member to come with the survivor; arranging home visits and home-based activities;
- **Policy & Administrative Barriers:** Collect, analyze and use data disaggregated by sex, age and disability.

Strengthen capacities. Evidence also shows the following actions work to **strengthen the capacities** of survivors with disabilities:

- Develop peer networks through social empowerment activities such as discussion groups, asset-based programming and Village Savings and Loans Associations to foster relationship building and trust among women and girls with disabilities and others in the community.

Refer survivors with disabilities with intention.

- Don't automatically refer survivors with disabilities to "disability-specialist" providers first (e.g. rehabilitation services). Survivors with disabilities have the same needs for protection, health, legal, psychosocial support, and other services as other survivors.
- Get to know local organizations of persons with disabilities (DPOs) and other community-based groups working with persons with disabilities in your community.
- Offer all service options to survivors with disabilities.
- If a survivor accepts or desires to attend certain services, work together to develop a way in which they can attend.
- Provide extra follow-up to ensure that the referrals you make are completed and that the person referred was not denied or refused services based on their disability.
- Work with services providers to address potential barriers in their facilities and services.

Ask the individual with a disability to give you **feedback on their experience** during the referral process.

Engaging Caregivers of Survivors with Disabilities

Key Actions

- Maintain primary communication and participation with the survivor.
- Ask for permission from the survivor to communicate with the caregiver or family member.
- Work with the caregiver and the survivor in supporting progressive independency and autonomy if that is an objective expressed by the latter.
- It is essential to talk with caregivers about their context and environment, and to understand their reasoning, rather than working from our own assumptions and judgements, before helping them to explore alternatives to harmful attitudes or actions.
- Talk with caregivers about the impact of caring on their well-being and their capacity to think about their own needs and the feelings that they have. Make sure you recognize that these are normal feelings to have and that caring is complicated and demanding.
- Help them to identify their own feelings without guilt, particularly when their feelings are difficult.
- Discuss strategies for paying attention to their own feelings and needs such as:
 - Forming relationships with other women and/or caregivers in similar positions.
 - Finding ways to maintain activities that are important to their own self-care and well-being (e.g. taking time to eat well, bathe, sleep, and to attend community activities they enjoy).
 - Identifying people that they trust to ask for help or additional support.
 - Participating in peer support groups can provide an opportunity for caregivers to meet others and to share experiences, challenges and successes with each other.
- Support caregivers to have access to the different services and programs available, such as skills training or economic empowerment, women's groups and so on, while also ensuring that the survivor with disabilities has alternative support.

Collecting Data on Persons with Disabilities

To make people count, we have to count people right: collecting safe and ethical information on survivors with disabilities can support you and the humanitarian community to follow trends in service provision, referral pathways and experiences of GBV.

Asking one question as “Do you have a disability?” is proven to underreport prevalence of disability and may result in stigmatization for many people. Instead, registration and case management systems can use two sets of questions to identify adults and children with disabilities and to disaggregate data by disability:

- The Washington Group Short Set of Questions - identifies adults with disabilities through questions related to difficulties performing six activities: walking, seeing, hearing, cognition, self-care and communication.
- The Washington Group/UNICEF Survey Module on Child Functioning - a set of questions to identify children aged 2 to 17 years old who have difficulties across 14 domains, including seeing, hearing, mobility, communication and comprehension, learning, relationships and playing.

Persons with disabilities are a very heterogeneous group of persons; these sets of questions have been designed and tested for years to ensure they capture statistically relevant information in a non-stigmatizing way. In each group of questions there are multiple choices, this is to best reflect that disability is identified through a continuum of difficulties. A person with a disability will identify if answering “a lot of difficulties” or “cannot do at all” in at least one question.

What can the questions do?

The resulting data these questions can contribute to helps service providers monitor the numbers of survivors with disabilities that participate (or not) in GBV activities and services. When not used in a potentially identifying way (preferred to use percentages), disaggregate of GBV data by sex, age and disability can provide useful demographic information for analysis.

However, the questions should not be used to identify impairments. They only identify barriers. Additional questions may have to be asked for that purpose, but no standard set of questions have been developed yet. Evidence shows that placing these with other demographics (like sex and age) decreases the expectations of receiving disability-specific services.

References and Resources

- IRC/WRC (2015a) [*“I see that it is possible” Building capacity for disability inclusion in Gender-Based Violence Programming in Humanitarian Settings.*](#)
- **Toolkits/Guidance**
- IRC/WRC (2015b) [*Building capacity for disability inclusion Gender-Based Violence Programming in Humanitarian Settings - A Toolkit for GBV Practitioners.*](#)
- WRC (2018) [*Guidance on Disability Inclusion for GBV Partners in Lebanon: Case Management of Survivors & At-risk Women, Children and Youth with Disabilities.*](#)
- UNICEF (2017) [*Including children with disabilities in humanitarian action - Child Protection.*](#)
- Age and Disability Consortium (2018). [*Humanitarian inclusion standards for older people and people with disabilities.*](#)

