

Building Capacity for Disability Inclusion in Gender-Based Violence Programming in Humanitarian Settings

Tool 1: Guidance on including persons with disabilities and caregivers in GBV assessments

Purpose of this guidance note

This document provides an overview of the process and tools to use when conducting an assessment with persons with disabilities, particularly women and girls with disabilities, and their caregivers about the risks of GBV in their communities, potential barriers to accessing response services and participating in programs and activities, and their suggestions for improving GBV programs. The guidance note should be read before implementing *Tool 2: Group Discussion Guide* and *Tool 3: Individual interview guide*. This assessment process and tools are designed to complement other GBV assessments conducted in humanitarian contexts. Examples of standard tools for GBV emergency assessments in crisis-affected communities are available from the GBV Responders' Network at: <http://gbvresponders.org/>

Who do we want to consult?

We are interested in the perspectives of women, girls, boys and men with different types of disabilities, including:

- those with difficulty moving and walking (since birth or due to an impairment acquired later in life);
- those with difficulty seeing, even when wearing glasses;
- those with difficulty hearing, even when using hearing aids;
- those with intellectual disabilities who may have difficulty understanding, learning and remembering new things;
- those with mental disabilities and mental health conditions;
- those with multiple disabilities, who are often confined to their homes and who may need assistance with personal care.¹

In GBV program assessments, it is particularly important to consult with women and girls, including those with disabilities and those who are caregivers, to understand their needs, perspectives and priorities. Women and girls often take on the role of caregiver for family members with disabilities, in addition to their other roles and responsibilities. Women and girls may have been caregivers prior to becoming displaced, or could find themselves in this new role when a family member acquires a new disability during a humanitarian emergency. Caregivers may be isolated and at greater risk of violence, both inside and outside the home. They are important to include in consultations so that their perspective and needs are taken into account.

How can we best facilitate the participation of people with disabilities and caregivers?

We all have experiences and skills we can draw upon when consulting with persons with disabilities. Every day we use speech, writing, gestures, pictures and posters, and activities to convey and understand information. These basic approaches can also work with people with disabilities. It is important to find the approach that works best for the particular individual or group with whom you are consulting. You can ask persons with disabilities or their caregivers for their preferred communication method, and you should always be prepared to try an alternative approach if one method does not work. Persons with disabilities have many different skills and capacities that you can use in communication and consultation.

Wherever possible, persons with disabilities should participate directly in the discussions. If an individual does not feel comfortable communicating with you on their own, or you cannot find an appropriate method of communication, you can also collect information from the caregiver. It key, however, to try to communicate with the person with disabilities first. Some individuals can communicate directly with you, but may not want to be separated from their caregivers, or may want support from someone they trust, particularly during the consent process. In these cases, allow the individual to make their own decision about what type of support they need, and who they trust to provide that support.

Before carrying out your assessment:

- Read and become familiar with the WHO Guidelines on Ethical and Safety Recommendations for Researching, Documenting and Monitoring Sexual Violence in Emergencies. Ensure that all staff understand the principles of this document and are able to incorporate them into the assessment process.
- Identify and mitigate risks that may arise from your consultations. Before recruiting participants, meet with community leaders and/or local government representatives to explain the purpose of the assessment. Where possible, link with leaders of local women's groups and leaders of groups for persons with disabilities – both formal and informal – during participant mobilization. Careful consideration should be taken when talking with caregivers, as they may be perpetrators of violence, which will limit the participation of survivors being consulted while their caregiver is present, or may expose survivors to further risk.
- Emphasize that participation is voluntary. Persons with disabilities and caregivers can choose not to participate or can withdraw at any point during the consultations. Watch for signs that persons with communication difficulties are not comfortable participating in an activity (e.g., becoming distressed or agitated or start crying), particularly when you are talking with their caregiver.
- Get consent for participation. As with all activities, GBV staff should obtain consent from individuals before they participate in the assessment. Persons with disabilities and caregivers should be briefed on why you are undertaking these consultations. They should also know how you will use or share the information they provide. If participants do not wish to participate or to continue with the consultation once it has started, it should not affect the services they are already receiving or their opportunity to seek GBV services in the future. For interested participants under the

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age of 18 years (e.g., adolescents with disabilities and their siblings), consent should also be sought from their parent or guardians. Processes of seeking consent should follow the principles and guidance in the WHO Guidelines, in accordance with age and developmental levels. Some adults with intellectual disabilities may choose to have a trusted caregiver, family member or friend participate with them in the consent process and/or the consultation. They should be asked in private and in advance if this is the case.

- Be clear and up front with participants about the purpose of the consultation and what services your organization can and cannot provide. Participants should understand that the purpose of the consultation is to better understand how persons with disabilities and their caregivers can be included in *existing* GBV activities and how survivors can access *existing* services. The consultation not will lead to the creation of *new* services.
- It may take time for persons with disabilities, particularly women and girls, to share their perspectives with you. They may have never participated in an activity like this before, and may not be used to people asking for their opinions. It also may take them time to feel safe and comfortable. If this is the case, try talking with them through a series of meetings, using different approaches, such as participatory activities, group discussions or more private interviews (see Tools 2 and 3 for related guidance). Start discussions with general topics and move towards more sensitive topics as the participants become more comfortable. Guide group discussions towards general, rather than personal conversation, so people do not feel pressure to disclose their own experiences of violence.
- Be sure another trained staff member is available to speak privately with participants who require additional psychosocial/emotional support and or referrals to other services. The staff member should have experience working with survivors of GBV.
- Be flexible about when and where consultations take place. The assessment team should try as much as possible to accommodate persons with disabilities by holding consultations as near to their homes as possible – always prioritizing the safety of the participants.
- Make sure that caregivers are included in the assessment. They should be consulted separately about their own experiences and needs.

Group discussions

Group discussions are best conducted with 8-10 participants and should not be longer than 90 minutes. If groups take longer than this to complete all activities in the Group Discussion Guide (see Tool 2), you may wish to conduct Parts A and B on one day, and Parts C and D another day, if participants are willing and able to return.

Group discussions should be conducted separately with men and women to gather in-depth information about their specific and varied needs. Women should lead the discussions with other women to ensure the space is comfortable and safe and that participants feel free to express themselves, including to talk about the violence they are exposed to, in line with WHO Guidelines on assessments related to violence.

Persons with different types of disabilities can participate in the same group discussion, according

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to their communication skills and abilities. Separate and/or specific groups may be necessary to facilitate effective participation of the following groups:

- adolescent girls and young women with disabilities;
- people who are deaf and use sign language to communicate;
- persons with intellectual disabilities who might prefer to use drawing, stories or photos to stimulate discussion. In such cases, smaller groups (4-6 participants) may be necessary.

In some settings, it might be most effective to have a separate group for people with new disabilities (e.g., acquired through war injuries) to explore their specific concerns. It may also be helpful to run separate, parallel discussions or activities with caregivers and persons with disabilities, in the same or a nearby venue. This can create a safe space for each group to explore their different concerns, may decrease the demands on caregivers who now would not need to come on multiple days, and increase the participation of people who are not used to being separated from their caregivers.

See *Tool 2: Group discussion guide*

One-on-one semi-structured interviews

One-on-one semi-structured interviews may be used for persons with disabilities and their caregivers who are isolated in their homes, and those with mental disabilities who prefer one-on-one communication in a familiar environment. Wherever possible, interviews should be conducted directly with individuals with disabilities, but they can also choose to have others present to support their participation. In some cases, where no method of communication can be established, information can be collected from caregivers. Risks need to be weighed according to the principles laid out in the WHO Guidelines, and the interview may need to be reconsidered. The *Individual interview guide* (see Tool 3) will help you to identify other information that might be helpful in program design and implementation.

See *Tool 3: Individual interview guide*

Notes:

1. Adapted from the Washington Group Questions on Disability. http://www.cdc.gov/nchs/washington_group/wg_questions.htm

To download the report *"I See That It Is Possible": Building Capacity for Disability Inclusion in Gender-based Violence Programming in Humanitarian Settings*, the complete *Toolkit for GBV Practitioners* and *Stories of Change*, visit http://wrc.ms/disability_GBV