

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

Tool 8: Guidance for GBV caseworkers: Applying the guiding principles when working with survivors of disabilities

Purpose of this tool

Many of the issues faced by survivors with disabilities are similar to those faced by all GBV survivors, though in the case of persons with disabilities, they may be magnified by the discrimination, misunderstandings and assumptions often associated with disability.

This tool has been developed to support GBV caseworkers to uphold a survivor-centered approach to working with GBV survivors with disabilities. The guidance is consistent with the best practice principles outlined in globally endorsed documents on responding to GBV (e.g., the *Handbook for Coordination of GBV in Humanitarian Settings*¹) and the United Nations Convention on the Rights of Persons with Disabilities.²

Applying the core GBV guiding principles to survivors with disabilities

The core GBV guiding principles described below should always be upheld when working with survivors with disabilities. The two key issues we must consider in our implementation of the guiding principles with survivors with disabilities are:

(i) Communication: *How do we need to adapt our communication methods to convey the same ideas when we cannot rely solely on verbal communication?* In most cases, survivors with disabilities can communicate directly with GBV practitioners with no adaptations, or relatively small adaptations, such as identifying someone who can interpret their form of sign language or by using simplified language in discussions. In other cases, it may be less clear what the best way to communicate with a survivor is, and additional steps may be required to determine this. When working with persons who find it difficult to communicate:

- Take time, watch and listen. This is a process, not a one-time event. Each time you meet the person you will learn something new about them and understand better how they communicate and what they mean.
- Conduct open conversations with caregivers in which the individual can hear what is being said and participate in any way possible. Remember that people who can't speak or move may still understand what is happening around them and what other people are saying about them.
- Pay attention to any way in which the individual wishes to communicate. This could be through gestures and sometimes their emotions. Some persons with intellectual and mental disabilities

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can exhibit a wide range of behaviors. This is sometimes the way they communicate with others. It is OK, however, to say “I don’t understand.”

(ii) Caregiver involvement: *How and when do we involve caregivers in the care and support of the survivor?* For some individuals with disabilities, family members and caregivers may assist with communication and daily care. While we want wherever possible to have direct communication with and participation of survivors with disabilities, in many cases we may also need the advice and support of their caregivers. Family members and caregivers can be critical partners in helping us define and implement strategies for effective communication and participation with persons with disabilities. The relationship between the survivor and the caregiver is sometimes an enduring, central relationship, and we can focus on supporting and strengthening positive features of this relationship throughout the case management process. Working with and establishing trust with caregivers will also create space for more effective direct engagement with the survivor.

The content below summarizes how the guiding principles are implemented in our work with GBV survivors and highlights challenges caseworkers may face with respect to these two key issues.

Respecting the wishes, rights and dignity of survivors

The essence of this guiding principle is that the caseworker should always seek to validate and empower the survivor. Validating the survivor means that we believe her story and we let her know this. It means that we do not judge her actions, opinions and decisions, but rather we affirm that she is not to blame for the violence or abuse she experienced. Empowering the survivor means that we let her know she is brave for sharing her story and for coming for help, and we communicate that we are here to listen and support her. We allow her to make the decision that is best for her, and we trust that she knows what is best for her.

When implement this guiding principle, we have to be mindful of the following:

(i) Communication: If verbal communication is limited, we can validate a survivor’s feelings and convey empowering messages through non-verbal techniques – we can use drawing, pictures or body language, particularly facial expressions. It may take us some time to establish ways of communicating with the survivor that allow us to convey these important messages. We must be thoughtful and creative.

When you understand, acknowledge this with the individual. In the past, they may have been dismissed by others when trying to communicate their feelings and experiences. Reassure them that you believe them, validating any experiences and emotions that they share with you.

(ii) Caregiver involvement: Societal attitudes, stigma and discrimination relating to disability can affect the way service providers approach case management with survivors with disabilities. In many societies, persons with disabilities are perceived as individuals who must be “cared for” or “protected.” This may result in assumptions that the survivor is incapable of making their own decisions, and staff may defer to others, including family members or other service providers, to make decisions on their behalf. These attitudinal barriers often result in a failure to fully investigate the survivor’s capacity to consent, and reinforces their disempowerment by having others make decisions for them.

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In situations where we may have to involve a caregiver in order to better understand the survivor's situation, obtain consent for services, and make decisions about the survivor's care, we can still empower the survivor by: directing our conversation to the survivor first; always asking permission from the survivor to consult with the caregiver from the very beginning and throughout the conversation; and always checking back in with the survivor throughout the process. More information is provided below regarding the informed consent process for survivors with disabilities.

Ensuring the physical and emotional safety and security of the survivor

All case actions taken on behalf of the survivor must safeguard the survivor's physical and emotional well-being in the short and long term. This means that we must ensure that the space in which we speak to the survivor feels safe to her. In our assessment of the survivor's needs and in our case action planning with the survivor, we must prioritize discussions and actions that will minimize the survivor's risk for further harm. Care and treatment provided by the caseworker and others must be carried out in a space and in such a manner that the survivor can trust that she will not be physically or emotionally harmed by the caseworker or the caseworker's actions.

(i) Communication: Getting to know the individual with disabilities - the things they like and dislike, and the ways they behave and communicate - may help us understand when a survivor does not feel safe talking to us and why. It may also help us to understand when they are assenting to certain activities in the case management process. Watch for signs of agitation, anger or distress that may indicate the individual is not happy to proceed at this time, and respect this, especially if you are talking with the caregiver.

(ii) Caregiver involvement: While many caregivers play a supportive role in the survivor's disclosure of abuse and healing, there may also be cases when the caregiver is the perpetrator of abuse, or we have concerns that the survivor will be harmed if the caregiver finds out about the abuse and/or the survivor's disclosure. It is important to remember that in many GBV cases, a survivor seeking help can significantly increase their risk of further harm if the perpetrator or perpetrator's family and friends find out. In such cases, safety is paramount, and we need to support the survivor in telling us who and where is not safe for her and with whom and where she feels safe. It may be possible, then, with the survivor's consent, to involve this person/people in the survivor's care and to make sure the survivor has a safety plan in place.

Maintaining confidentiality and only sharing necessary information with permission from the survivor

This principle requires that caseworkers and others involved in the care and treatment of the survivor protect information gathered about survivors and agree to only share information about a client's case with their explicit permission. This means ensuring 1) the confidential collection of information during interviews; 2) that sharing information happens on a need-to-know basis or in line with laws and policies, and that permission is obtained from the survivor before information is shared; 3) in the case of referrals, only the details relevant to the referral are shared with the other service provider, and survivor and caseworker reach a decision together about what information should be shared; and 4) case information is stored securely.

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All standard rules of confidentiality apply when working with adult survivors with disabilities. Caseworkers and service providers should only share information about a survivor with the survivor's explicit permission.³ They should never discuss case details with family and friends, nor with colleagues unless knowledge of the abuse is necessary for service provision.⁴ Caseworkers should, however, consult with their supervisors when a survivor does not have capacity to consent and in making decisions that are in their best interests.

Caseworkers and service providers should only share information without the permission of an adult survivor if they believe that the individual may hurt themselves or others, or if there are mandatory reporting requirements in the local setting.⁵ For example, if the person has a legal guardian, they may be required by law to provide information to that guardian, but this will vary across settings.⁶

(i) Communication: Any support persons engaged in the case management process, be they family members, caregivers and/or interpreters, should be briefed on the principles of confidentiality. Participatory activities may also be useful to assist persons with intellectual disabilities to better understand the principles of confidentiality and who they may want to share information with, and to explore different strategies or ways to respond to questions from others.

(ii) Caregiver involvement: Caseworkers should consider strategies to appropriately manage confidentiality if seeking further advice from family members and caregivers on communication methods and/or in decision-making processes. Wherever possible, the decision about who to involve and when should be made in partnership with the survivor, and include an analysis of risks to the survivor's safety if she chooses to involve another person. The caseworker must think through what additional steps need to be taken with the caregiver in order to ensure that they are a supportive person in the survivor's life. For example, do you need to set up a different meeting with the caregiver in order to explain what happened and provide information about how they can be supportive in the survivor's healing process (e.g., by maintaining confidentiality, by not judging or blaming the survivor, by reinforcing their strength and courage to tell someone and seek help, and by not pushing a particular action or service in response to the incident)?

Ensuring non-discrimination

This guiding principle means that we provide the same quality of service to every survivor regardless of their sex, age, ethnicity or disability. By learning the best practices for how to adapt our communication and informed consent processes to survivors with varying disabilities, we can maintain a survivor-centered approach and deliver quality services to this population.

(i) Communication: Societal attitudes, stigma and discrimination relating to disability can affect the way caseworkers and service providers undertake the case management process. Be careful not to make assumptions about the capacity of a survivor with disabilities. This may result in a failure to fully present the different options to a survivor with disabilities, resulting in discrimination in service provision and reinforcing disempowerment as others make decisions for the survivor. It is important to present all available options to a survivor with disabilities, even if you are not yet sure how they will participate in these activities. Present all the options in a way that you think the survivor will understand. Be prepared to try several different ways of communicating these options (e.g., if there is an English class in your women's center, you may want to support the survivor to visit the class to show her what it involves). Give the survivor time to think

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about these options and to ask questions.

(ii) Involving caregivers: Women and girls in the household often assume caregiving of persons with disabilities, in addition to the other roles expected of them in society. They are isolated and at risk of violence inside the home. Hence, it is important to also consider the support that caregivers may need when providing case management to a survivor with disabilities. Thinking through the perspectives and needs of both the survivor and the caregiver, and the intersections and relationships between each individual and the caseworker, can help to shape the process of case management in a way that ensures that the needs of both individuals are met, and that their relationship is strengthened.

Promote the best interests of the survivor

This principle is particularly important for survivors who may not have the capacity to consent to services. If an adult lacks capacity to consent to interventions, caseworkers and service providers have a duty to provide care in the best interests of the survivor. Such decisions should be made, however, in consultation with his/her supervisor. Decisions or actions considered to be in the best interest of a survivor are those that:

- protect the survivor from potential or further emotional, psychological and/or physical harm;
- reflect the survivor's wants and needs;
- examine and balance benefits and potential harmful consequences; and
- promote healing and recovery.⁷

(i) Communication: Even people who lack capacity to consent have a right to information and can play a role in decision-making.⁸ Share information, listen to their ideas and opinions, and explain how and why decisions have been made. Always seek informed assent from the survivor, which is the survivor's expressed willingness to participate in the services or activities proposed. Use pictures, hand gestures or symbols to ask if someone is willing to participate in an activity or to access a service.

(ii) Caregiver involvement: The best interests of the individual are the priority for decision-making, and it is important to note that sometimes the decisions of caregivers may not be linked to the best interests of the individual.⁹ For example, caregivers may want to pursue justice options. If the survivor does not understand the legal processes involved, then it is unlikely to promote healing and recovery, and may even expose them to further emotional harm, as they will have to recount their experiences to others. This referral may not be in the best interest of the survivor, but rather in the best interests of the caregiver, who may be seeking their own form of healing and recovery. Exploring the reasons why caregivers think certain actions are in the best interest of the survivor can help to come to decisions that reflect the wider needs and interests of the individual.

Notes:

1. <http://gbvaor.net/wp-content/uploads/sites/3/2012/10/Handbook-for-Coordinating-Gender-based-Violence-in-Humanitarian-Settings-GBV-AoR-2010-ENGLISH.pdf>
2. <http://www.un.org/disabilities/default.asp?navid=15&pid=150>
3. *Supporting sexual assault survivors with disabilities: A chapter update to the "Support for Survivors" training manual*, p. 12. <http://>

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- www.calcasa.org/wp-content/uploads/2010/12/Survivors-with-Disabilities.pdf
4. Ibid. IRC WPE Program Case Management Guidelines – July 2013 (DRAFT), p. 12.
 5. IRC WPE Program Case Management Guidelines – July 2013 (DRAFT), p. 76.
 6. *Supporting sexual assault survivors with disabilities: A chapter update to the “Support for Survivors” training manual*, p. 12. <http://www.calcasa.org/wp-content/uploads/2010/12/Survivors-with-Disabilities.pdf>
 7. Adapted from the following publications:
<http://gbvaor.net/wp-content/uploads/sites/3/2012/10/Caring-for-Child-Survivors-of-Sexual-Abuse-Guidelines-for-Health-and-psychosocial-service-providers-in-Humanitarian-settings-IRC-UNICEF-2012-ENGLISH2.pdf>
<http://www.dhsspsni.gov.uk/consent-guidepart4.pdf>
http://www.briscomhealth.org.uk/files/Best_Interests_Guidance.pdf
 8. *Consent and people with intellectual disabilities: The basics*. <http://www.intellectualdisability.info/how-to../consent-and-people-with-intellectual-disabilities-the-basics>
 9. *Seeking consent: Working with people with learning disabilities*. <http://www.dhsspsni.gov.uk/consent-guidepart4.pdf>

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