

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

Tool 10: Working with caregivers of survivors with disabilities

Purpose of this tool

Working with caregivers of survivors with disabilities is critical to ensuring the safety and opportunities of both the survivor and the caregiver. This tool provides information and guidance to support service providers in developing positive, useful and balanced relationships with caregivers of survivors with disabilities.

Key issues for us to consider in our work with caregivers include:

Caregivers are people first and foremost (most often women and girls) with their own perspective, needs and feelings. Caregiving is a complex role, and caregivers may have conflicting feelings – they may feel guilty, resentful, angry, afraid, concerned and as though they have failed. They may prioritize the person they are caring for above everything else, including themselves, and they may focus all their attention and love in one direction, which can be difficult for others in the household. They may also have unmet needs of their own, particularly if they carry the full responsibility for care with no one to support them. For female caregivers, caring for a person with disabilities comes in addition to the many other responsibilities and duties expected of them at home.

The relationship between the survivor and the caregiver is the enduring, central relationship, and focusing on supporting and strengthening this is important to the survivor's healing. It is important to pay attention to the dynamic between the survivor and their caregiver. What are the strengths of this relationship? What do both people have confidence in and what is this relationship built on? What are the mutual expectations and assumptions? How do these interact? What tensions can you see? What do you think is contributing to these tensions?

Caregivers are also exposed to the threat and reality of GBV, and we have to pay attention to their safety concerns and their opportunities to have more control over their lives. Caregivers are most often women and adolescent girls, meaning they already experience disadvantage within the household and community, and are likely over-burdened with domestic responsibilities, including the care of children and the elderly, and household chores. Caregiving can be a very isolating experience, and more so for women who are already less likely to have access to opportunities outside the home. This is also an opportunity to talk about female caregivers' own exposure to and risk of violence, including violence from the people they care for or domestic violence, and work with them to plan for safety and access to services.

Caregiving is a demanding role that can impact caregivers' own well-being, their other responsibilities and household and family dynamics. We may have expectations and assumptions about how people should behave in different roles, and it is important to make sure that these are not clouding our assessments when it comes to working with caregivers. We should be mindful about not reinforcing norms and values that hold women responsible for the care of others and judge them harshly on how they provide it. For example, if a woman responsible for the care of an adolescent girl with disabilities locks the girl in a room while she goes to the market, it may be that she feels this is her only option to keep the girl safe while she is not there. Within their responsibilities as caregivers, women may have very limited options and few people that help them. It is

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essential to talk with caregivers about their context, environment and constraints before helping them to explore alternatives, and to understand the rationale for their actions and decisions, rather than working from our own assumptions and judgements.

Providing good support for caregivers is one of the most effective ways to improve the safety and well-being of those they care for. It may be useful to work separately with caregivers (in addition to working with survivors and caregivers together). This can serve a psychosocial intervention in and of itself by creating a safe space for caregivers to talk about the issues that affect them, their own emotions – positive and negative – without feeling that they are being demanding or selfish, or that they are not properly heard. It is also important to recognize that feelings about being a caregiver are complex, and it is normal to feel frustration, resentment and anger, along with love and concern. Helping women to develop ways to understand and manage these feelings can be very helpful in strengthening the core relationship between the caregiver and the person being cared for, and developing strategies for ensuring that a caregiver's needs are met.

In providing such support to the caregiver, it is important for the caseworker to think about: *What is the caregiver looking for from you? What kind of alliance do you want to build with them, and what kinds of boundaries will you need to pay attention to? How realistic/possible are their expectations? What elements of this relationship might be difficult, and what can you build on?*

Practical tips to support caregivers

- Discuss the social networks and support available to caregivers. Strategizing ways to find respite, identify opportunities to meet other women and strengthen supportive relationships can be very valuable, including to break through the isolation caregivers often experience. Peer support groups can provide an opportunity for caregivers to meet others and to share experiences, challenges and successes with each other.
- 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 and when they are different from the messages women get about how they are supposed to feel.
- 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 attend community activities they enjoy);
 - » identifying people that they trust to ask for help or additional support.
- Breathing and visualization exercises can sometimes be useful when feeling overwhelmed and/or anxious.
- Support caregivers to have access to the different services and programs that they can attend, such as skills training or economic empowerment and women's groups, which will support their empowerment.

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