

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

## Tool 9: Guidance for GBV service providers: Informed consent process with adult survivors with disabilities

### Purpose of this tool

The Convention on the Rights of Persons with Disabilities (CRPD) highlights that persons with disabilities have the same rights to make their own decisions as everyone else, and that appropriate measures must be taken to support them to exercise their legal capacity. **An individual cannot lose their legal capacity to make decisions simply because they have a disability.**<sup>1</sup> Where a person does not have capacity to make their own decisions, and someone else will be speaking for them, we need to take measures to ensure that decisions are made in a way that reflects the rights, will and preferences of the individual, are tailored and appropriate to the person's circumstances and are reviewed on a regular basis to ensure that all opportunities to exercise capacity are optimized.<sup>2</sup> As highlighted in Tool 8 (*Guidance for GBV caseworkers: Applying the guiding principles when working with survivors of disabilities*), a critical element to the survivor-centered approach is that the survivor makes decisions about their care and treatment, and such decisions are respected and followed by service providers.

This document is intended to help service providers navigate informed consent processes with **adult** survivors with disabilities.

### Understanding informed consent

Informed consent is defined as “the voluntary agreement of an individual who has legal capacity to give consent.” To provide “informed consent,” the individual must have the capacity and maturity to know about and understand the services being offered and be legally able to give their consent. Determining who is “legally” able to give consent for certain types of services will depend on the context that you work in—however, usually children under age 15 are not legally able to provide consent on their own.

The informed consent process has three key components:

- i. providing all possible information and options to a survivor in a way they can understand;
- ii. determining if they can understand this information and/or their decisions (also referred to as “capacity to consent”); and
- iii. ensuring that the decisions of the survivor are voluntary and not coerced by others (e.g., family members, caregivers or even service providers).



*1. When conducting the informed consent process, it is important for service providers to remember the following:*

- **Assume capacity to consent.** All adults have capacity to make their own decisions unless demonstrated otherwise. This applies to people with all types of impairments, including those with intellectual impairments. While family members and caregivers play a significant role in the lives of many persons with disabilities, and are a valuable resource in facilitating understanding and communication, they do not necessarily have the legal authority to make decisions for an adult with disabilities.<sup>4</sup>
- **Capacity to consent refers to the ability to make a particular decision at a particular time.** Capacity can change over time, but also according to the nature and complexity of the decision. For example, Maria has an intellectual disability. She may have the capacity to understand and consent to HIV post-exposure prophylaxis, because she understands the concept of taking medicine as a treatment and has taken medicines before to prevent other illnesses. She may, however, find it more difficult to understand what legal assistance means and therefore would not be able to consent to a referral to legal assistance. Consent is an ongoing process and not a one-time event. It is important that we never assume that a survivor's consent to one service means that she consents to everything.
- **Capacity to consent depends on understanding, and understanding can vary according to how we communicate information.** For example, Maria may initially decline or accept referral to an economic empowerment activity. But have we conveyed the information in a way that she can understand it and use it in making her decision? If we discuss her goals, describe the activities to her, explore what she likes and doesn't like about these activities and support her to visit the class without having to make any commitment to participating, then Maria will understand better the activity, and the possible positive and negative outcomes for her, enabling her make a more informed decision, and enhancing her capacity to consent. Hence, in some circumstances, it can be more helpful to seek consent for smaller steps in a longer process, so that survivors are in control of every part of a process and can stop it at any time.

*2. If you determine that a survivor does not have the capacity to consent, it is important for you to consult a supervisor to determine the best way to proceed, using the best-interest principle.*

- **The initial informed consent process: consent to receive your organization's services.** When working with a survivor who you are not sure has the capacity to consent, it may be necessary in the initial informed consent process to involve another trusted individual who can help facilitate the communication and understanding regarding the services you are offering. To the extent possible, the decision about whom to involve should be made in partnership with the survivor. If there is no one accompanying the survivor, consult your supervisor as to how to proceed, using the best-interest principle. For example, you may decide that it is in the best interest of the survivor to approach the caregiver and get their consent for services on behalf of the survivor. A staff member should never make such a decision on their own. Such a decision must always be reached by analyzing the survivor's situation with respect to safety. Remember that getting the caregiver's consent for your organization's services does not mean that you have the survivor's or the caregiver's consent for any other interventions.
- **Consent for referrals and other services.** If caregivers or others are involved, it is important that you continue to use the best-interest principle to ensure that the survivor's wishes and needs

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remain the focus, and the survivor feels safe. **Be sure to observe the survivor's interactions with the caregiver.** If you feel the power dynamic and relationship between the caregiver and the survivor is affecting the right of the survivor to participate in decision-making and/or if decisions are not aligned with their wishes and desires, consult your supervisor in order to determine how to proceed. Remember that the **interests of family members and caregivers may not be linked to the best interests of the individual.**<sup>5</sup> For example, in the case of Maria, a GBV survivor with a disability, her mother and father may want to pursue justice options for the case. If Maria does not have the capacity to consent to this referral, then caseworkers must ask, "Is this in Maria's best interest?" As she does not understand the legal process, it is unlikely to promote healing and recovery, and may even expose her to further emotional harm, as she will have to recount her experiences to others. This referral may not be in her best interests, but rather something the mother and father want to do for their own reasons. Exploring the reasons they want to seek legal assistance and whether it would be in Maria's best interest to do so can help Maria's parents better understand that such an action does not reflect Maria's needs and interests. If the parents' refuse to reconsider, you should bring such a case to the attention of your supervisor so that options for intervening on behalf of the survivor can be discussed.

### 3. When involving others in the informed consent and decision-making process, remember:

- **Even people who lack capacity to consent have a right to information and can play a role in decision-making.**<sup>6</sup> Share information, listen to their ideas and opinions, and explain how and why decisions have been made. This interaction will also assist in the monitoring of changes in capacity to consent over time and with different types of decisions.
- **Always seek informed assent from the survivor.** If you deem that a survivor is not able to provide "legal consent," you must seek to obtain informed assent, 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. Also watch for signs of agitation, anger or distress that may indicate that the individual is not happy with something that is being discussed or an activity that is being undertaken.

### Notes:

1. *Handbook for parliamentarians on the Convention on the Rights of Persons with Disabilities.* <http://www.un.org/disabilities/default.asp?id=212>
2. Article 12 of the CRPD relates to equal recognition before the law. <http://www.un.org/disabilities/documents/convention/convopt-prot-e.pdf>
3. Adapted from: *Consent and people with intellectual disabilities: The basics.* <http://www.intellectualdisability.info/how-to../consent-and-people-with-intellectual-disabilities-the-basics>. See also, *Informed consent in adults with developmental disabilities.* <http://www.surreyplace.on.ca/Documents/Informed%20Consent%20in%20Adults%20with%20DD.pdf>
4. This is sometimes referred to as "substituted decision-making" – when the guardian or caregiver has court-authorized power to make decisions on behalf of the individual without necessarily having to demonstrate that those decisions are in the individual's best interest or according to his/her wishes. Even where an individual has legal authority, the Convention on the Rights of Persons with Disabilities calls for safeguards to be put in place to protect against abuse of these mechanisms. <http://www.un.org/disabilities/default.asp?id=242>
5. *Seeking consent: Working with people with learning disabilities.* <http://www.dhsspsni.gov.uk/consent-guidepart4.pdf>
6. *Consent and people with intellectual disabilities: The basics.* <http://www.intellectualdisability.info/how-to../consent-and-people-with-intellectual-disabilities-the-basics>

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](http://wrc.ms/disability_GBv)