

## **Charlotte-Mecklenburg Domestic Violence Research Collaborative**

### **Guidelines for Conducting a Trauma-Informed Consent Process**

#### **Background: Why does obtaining consent – and how we do it – matter?**

The Violence Against Women Act (VAWA) is the cornerstone policy for victim services. VAWA sets high standards for the collection, storage, and sharing of victims' personal information and data. With VAWA, concepts such as release-of-information and consent-for-services go beyond simply signing a form. VAWA promotes conversations between victim service providers and clients to empower the client with knowledge of the benefits and risks of signing a release-of-information form or consent for services. Under VAWA, the client has the right to know where their information will be stored, how long it will be stored for, who will have access to it, how it will be protected and secured, and how it can be removed. The client has the right to obtain all of the information needed to feel empowered to make a truly informed decision about whether to consent to services or to release information. And the provider has the responsibility to have a conversation with the client to provide this information.

VAWA's empowerment approach brings a trauma-informed lens to data collection and data sharing practices. Every interaction with a victim/survivor, including completion of mundane paperwork, presents an opportunity to give power back through information and choice. When obtaining consent and when creating consent forms, service providers and researchers can take steps to make these processes trauma-informed.

The Domestic Violence Research Collaborative (DVRC) is a group of self-identified domestic violence survivors, service providers, and researchers in the Charlotte-Mecklenburg area who have convened to examine issues related to domestic violence, data, and research. With respect to trauma informed consent, the DVRC has developed guidelines to encourage critical examination of how service providers, researchers, and organizations can improve their consent process.

#### **When obtaining consent**

Service providers and researchers obtaining consent should think of consent as a process that can evolve over time, as well as a conversation between the person seeking consent and the person deciding whether to give consent. Survivors may change their mind about consent, and it is the responsibility of the person obtaining consent to ensure that survivors have the tools, time, and space to fully consider and understand the consent process and change their mind about their decision to (not) consent.

#### **Recommendation #1: Emphasize the person's rights**

- Right to withdraw consent or modify consent at any point
- Right to refuse to release information and still receive services
- Person's right to refuse to consent and still receive services
  - Can the person still receive services without filling out any of the consent forms? If so make, that clear. If not, make that clear.
- Ensure they know the process through which they can act on their rights

**Recommendation #2: Consent should be a process. (Re)Review consent forms at multiple time points.**

Clients may be coming to access life-saving services, making “consent” hard to obtain.

- Reviewing these forms multiple times allows the survivor to:
  - Engage with the information at different points of time, when they may be out of or further from an immediate crisis
  - Change their mind
- Reviewing these forms multiple times allows the provider/researcher to:
  - Support the client taking power and control back
  - Provide new information as it becomes available
  - Clarify parts of the consent form that may be unclear

**Recommendation #3: Clearly state when you don’t know something or can’t guarantee something.**

- Use this uncertainty as an opportunity to talk through the different possibilities and build trust between yourself and the survivor
  - Viewing consent as an iterative and fluid process will make it easier to come back to these uncertain points if/when they become clearer, as well as to revisit these decision points at different points in the survivor’s experience
- Be clear when you don’t know something or can’t guarantee something. Being transparent helps to build trust.

During our group discussion, several participants described how immediately following an experience of domestic violence, they would not be willing to share any information about themselves. However, many years later, they are willing and eager to share information about their experiences, to prevent and reduce domestic violence. Service providers and researchers should be respectful of this process and consider whether/how the information they are seeking can be collected at a time when the survivor is ready to share.

**When creating consent forms**

In reviewing consent forms across three organizations, the DVRC noted that all three forms looked very different. Each form had its own set of strengths and areas for improvement. In comparing these forms, the following recommendations arose for organizations and individuals writing consent forms:

**Recommendation #1: Provide a summary at the beginning of the form and at the beginning of the consent process**

- Many people may not read the entire document.
- By giving as much information and clarity as possible, consent forms run the risk of becoming too long, at which point people stop reading them
- Summaries at the start of the document provide a balance between ensuring someone understands what they are agreeing to do, and providing additional detail if desired
- Include page numbers next to any summaries in case someone wants to read more about a certain bullet point

**Recommendation #2: Follow best practices suggested by the DVRC to improve document comprehension**

- Use bullet points - People can read lists more quickly and easily than they read paragraphs
- Emphasize the most important points in larger fonts, bold, and/or with clear headings
- Do not use colors that would make the document inaccessible (i.e., to people who are color blind)
- Avoid using additional lines when possible – white space is easier for the brain to digest (e.g., get rid of unnecessary lines in tables)

**Recommendation #3: Only ask for information you absolutely need**

- Be as specific as possible about what data you are collecting when asking survivors to agree to sharing information.

**Recommendation #4: Be mindful of literacy and tone.**

- Use clear language that is easy to understand. Provide definitions when possible or consider whether you can use a different word
  - Consider including definitions throughout the document or a glossary at the end of the document.
- Look for words or terms that are organization or service specific e.g., quality assurance, imminent risk case staffing, and provide a lay person’s definition or use a different word or phrase

A survivor-centered informed consent and release of information form would not read like it’s written by a lawyer and like the purpose of the form is organizational liability. It would read like it’s written for the survivor and the purpose is to empower that person with information so that they can make an informed decision.

In reviewing consent forms across three organizations, the DVRC agreed that ALL the reviewed consent forms felt like they were written to protect the organization. NONE of the reviewed consent forms felt survivor centered.

**Recommendation #5: Explain the individual’s agency over their data. Be clear about how their data will be stored, saved, managed, or used**

- Clarify whether information will be shared:
  - As part of an aggregate number. In this instance, the information would be de-identified and not be able to be traced back to the individual. For example, the total number of people who signed into the shelter this month
  - Without identifying information, but as individual number and therefore potentially identifying. For example, we served one client who has 4 children with her.
  - With identifying information, to be used by someone else, at which point the information will also become de-identified. For example, if data are shared at the individual level, with identifying information (e.g., birthday), for research purposes. However, in the process of research, this information becomes aggregated and de-identified.
- Be clear at what frequency any data will be shared, for how long data will be stored and maintained, and through what process the survivor can retract their information

- Consider what happens after the survivor retracts their information. Are existing reports changed? Who needs to be notified?
- Consider if other people’s data are being collected as part of this process (e.g., children of parent who is domestic violence survivor). How will those children – once adults – have agency over their data, what are the processes your organization has in place to support that agency?

**Organizations and individuals should consider how the organization can support an iterative consent process, where the service provider or researcher can revisit consent with the survivor/client at multiple timepoints.**

- If providing a service:
  - What intake processes need to be adapted?
  - What outtake processes need to be adapted?
  - What happens if the person is no longer available to reauthorize?
- If conducting research:
  - How does the research study timeline need to be adapted?
  - How will confidential information be stored to enable reauthorizing?
  - What happens if the person is no longer available to reauthorize?
- How much time will that take for the provider/researcher and how will that time be reserved for this process?