Nothing About Us Without Us

Engagement of the Consumer in the Core Implementation Team

An essential component of becoming a Trauma-Informed (TI) organization is the incorporation of the voice of lived experience in shaping all elements of practice. Following her involuntary confinement in the 1960s in a psychiatric facility, Judi Chamberlin authored *On Our Own: Patient-Controlled Alternatives to the Mental Health System.* Judi was an inspirational American activist, leader, organizer, public speaker and educator in the psychiatric survivor's movement. The term "Nothing About Us Without Us" is a direct result of her activism, along with the incorporation of peer support specialists as an integral part of the mental health system. Her work has also resulted in person-centered, self-directed and recovery-oriented treatment and planning. We can not do this work without completely embracing the voice of trauma survivors into every aspect of our organizations.

Countless benefits result from embracing the voice of lived experience, as it offers the most accurate perception of what it feels like to receive services in an organization or system. Including this voice throughout our process provides the opportunity to shed light on blind spots, creating opportunities for organizational change. However, this process is typically the most challenging for many organizations embarking on TI transformation due to many layers of complexity.

Two primary stumbling blocks to incorporating persons of lived experience into the process are the discomfort of allowing those we serve full membership on the Core Implementation Team (CIT) and navigating dual relationships. The following information has been developed by the National Council for Behavioral Health (The National Council) to assist organizations through these complexities.

First, it is important to note that when possible, the National Council recommends that organizations invite at least two persons of lived experience to be part of their CIT. This invitation should be made at the very beginning stages of the work rather than after the team is established and already through the initial team development phase. Inviting at least two people allows for natural peer support and increased psychological safety within the CIT for the participating individuals.

Prior to having persons of lived experience join the team, it is vital that team members have the difficult conversation about their attitudes and beliefs about recovery and their reactions to adding an individual with lived experience as a prominent decision maker. Discussing fears and reservations openly about this process decreases the possibility of conscious or unconscious microaggressions within the group dynamics.

The CIT should explore how it will feel to discuss sensitive issues such as countertransference, financials, and staff turnover with consumers/patients/students present. Once the members

who represent the voice of lived experience are integrated into the CIT, an outside observer attending meetings should not be able to distinguish who is or is not an employee.

The discomfort of dual relationships is the most frequently sighted reason for not fully engaging consumers in the CIT. It is important to understand that dual relationships are not inherently unethical. A second relationship becomes unethical if it is likely that one relationship will hinder the second. Two essential components of this determination are consultation with professionals and informed consent with the consumers.

The National Council recommends the following steps to fully incorporate persons of lived experience into your CIT:

Step 1: Recognize that the individual could be someone actively using your services or a former service recipient. Peer support specialists can also bring this voice and support other members you might invite. The CIT lead should discuss the opportunity to participate on a CIT with the individual, including roles, responsibilities and expectations.

Note: if the individual is actively receiving services, it is important to include the individual's treatment team lead in the conversation and process to ensure ongoing treatment is not compromised. It is also important to recognize that in order to support the individual or family member in this ongoing process, a mechanism must be put into place to openly address any CIT work that may directly impact their treatment, services or education.

Step 2: Provide the following psychoeducation to the person with lived experience (Note: this time is not billable):

1. Psychoeducational information on dual relationships and document this conversation in the course of a therapy session or treatment engagement
2. Trauma, it's impact and the limitless possibilities of recovery
3. HIPAA and agreement to uphold the organization's policies surrounding compliance
4. Background information on trauma-informed care (TIC), why the organization is pursuing TIC, why the team is looking to add persons with lived experience to the CIT, purpose of meetings, frequency of meeting and expectations

Step 3: Encourage the person with lived experience to conduct independent research on dual relationships and discuss with trusted friends or family. The provider will request permission to consult with another professional regarding how participating on the CIT could potentially impact the therapeutic relationship.

Step 4: Discuss and document issues related to HIPAA, if this will hinder relationships and what steps will be taken if it does later.

Step 5: Discuss the best title for the person with lived experience and how they would like to be introduced to the team.

Step 6: Recognize the person with lived experience is most likely a volunteer and everyone else on the team is a paid employee. In order to create some level of mutuality, the National Council recommends making certain the person has transportation or transportation tokens in order to attend the meetings. It is vital that to find a meaningful way to acknowledge their participation and the value of their time.

Step 7: Maintain an open and transparent dialogue with the individual about their comfort in inclusion in the team and what they need to feel safe and open in the process.

Ongoing Considerations:

1. Think creatively about what the individual can add to the team. Which domains would they be most interested in? Assign them to this team or subcommittee.

2. Create opportunities for other people with lived experience receiving services within the agency to participate. Use clients to participate as respondents to surveys wherever possible or to review new staff trainings. Before implementing any changes use a focus group format to determine the impact it would have on those receiving services.

3. The person with lived experience may have other responsibilities, i.e. work, etc. How will you ensure that they can participate in the meetings? Will meetings be at convenient times for them? Can they participate by phone or video conference?

As you follow this process, enjoy the growth and endless opportunities you will start to experience when we partner with those who experience our services to improve care for all.