Engaging Patients and Community Members in Trauma-Informed Care Implementation Planning

Meaningfully engaging the perspectives of patients and community members, including those with lived experience, is a critical step for health care organizations seeking to adopt a trauma-informed approach to care that is truly responsive to the needs of the people it serves. This type of feedback can provide invaluable guidance at both the program planning stage and throughout implementation. Patients and community members can provide first-hand insights into how care is experienced, and what changes an organization can make to improve the care delivery experience. Furthermore, including patients and community members in decision-making processes and the design of services can be empowering and help break down hierarchies that exist between the community and the provider organization, all of which further strengthens trauma-informed care efforts.

Following are considerations to guide health care organizations in meaningfully engaging patients and community members around designing and implementing a trauma-informed approach to care. These considerations were informed by the work of the health care organizations (see acknowledgements) that participated in Advancing Trauma-Informed Care, a national initiative led by the Center for Health Care Strategies (CHCS) through support from the Robert Wood Johnson Foundation.

Incorporate patient and community member feedback early in the process.

Many health care leaders agree it is important to incorporate patient and community voice early in the process of becoming trauma-informed to ensure that adoption efforts focus on areas that meaningfully support patients. For example, when working with patients to re-evaluate its screening processes both for trauma and other health conditions, the Women’s HIV Program at the University of California, San Francisco (UCSF-WHP) learned that the women they serve did not want to be screened for substance use disorder as they had concerns about privacy, being judged by staff, and potential legal repercussions. Clinic providers clarified that knowing a patient’s substance use history is important in order to protect their health. The patients and clinic staff came up with a compromise: physicians could screen for substance use, but would first provide a clear rationale for asking such a private question, should not disclose a patient’s status unless absolutely necessary, and should screen everyone equally.

Create a variety of outlets to solicit feedback.

People will be comfortable sharing information in different ways, and some will prefer to do so anonymously. Potential mechanisms for soliciting feedback include: community advisory boards; human-centered design; community-based participatory research; focus groups; and surveys. UCSF-WHP solicits patient feedback through both

Additional Resources

- **Engaging Consumers in their Health** includes tools and advice for developing a patient engagement strategy from participants in the Robert Wood Johnson Foundation’s Aligning Forces for Quality initiative.
- **Institute for Patient- and Family-Centered Care** provides resources to help integrate patient- and family-centered care into all aspects of health care.
- **Tamarack Institute** offers training, consultation, and resources to help organizations facilitate community change through a variety of interconnected practices, including community engagement.
focus groups and monthly stakeholder meetings. Focus groups were used at the start of the clinic’s transformation process to trauma-informed primary care to better understand: (1) how, when, and by whom women want to be screened for trauma; (2) the types of trauma-specific services that patients want, and how these should be implemented; (3) ways to ensure more meaningful involvement of patients in the ongoing implementation of trauma-informed primary care; and (4) other issues affecting women’s ability to heal from trauma. The monthly stakeholder meetings offer an opportunity for patients and staff members to discuss how to improve the clinic experience on an ongoing basis. Four patient representatives and a staff member from each discipline (e.g., nursing, social work, medicine, etc.) participate in the meetings, and patients take turns participating each month in order to provide broader feedback.

**Be transparent about expectations.**

Health care organizations should provide clear information about patients’ roles and responsibilities, time commitment, compensation, and training required for participating in organizational planning for trauma-informed care. **Stephen and Sandra Sheller 11th Street Family Health Services** (11th Street) has a robust community advisory committee (CAC) that includes patients, community members who are not currently receiving care at 11th Street, and representatives from community-based organizations. Prior to engaging new committee members, 11th Street staff provide clear guidance that the advisory group meets monthly and all new members are required to participate in a multi-layered training that includes a session on the basics of trauma and its impact on health. Patient Ambassadors, a sub-group of members from the CAC, receive additional trauma-informed care training to help guide their conversations with patients in the clinic and in the community.

**Provide appropriate compensation and supports.**

Patients and community members should be compensated for their time and input, as would any other highly valued consultants. Health care organizations should speak with patients and community members directly about the most appropriate way to provide compensation, and think through strategies to facilitate patient and community member participation in organizational planning, including offering transportation, child care, easy to access meeting locations (e.g., in the community) and culturally sensitive food options. At 11th Street, Patient Ambassadors collectively opted to receive a gift card for every 20 hours of volunteer time at the health center.

**Acknowledgements**

Development of this fact sheet was informed by the work of Advancing Trauma-Informed Care pilot sites, including: Center for Youth Wellness; Greater Newark Healthcare Coalition; Montefiore Medical Group; San Francisco Department of Public Health; Stephen and Sandra Sheller 11th Street Family Health Services; and Women’s HIV Program at the University of California, San Francisco.

**Learn More**

This fact sheet is a product of Advancing Trauma-Informed Care, a national initiative made possible by the Robert Wood Johnson Foundation that aimed to better understand how trauma-informed approaches can be practically implemented across the health care sector. To learn more, visit CHCS’ Trauma-Informed Care Implementation Resource Center at TraumaInformedCare.chcs.org.
Endnotes


2 Ibid.


4 Email from Katherine Brown, Principal, Constellation Consulting to Anna Spencer, July 2, 2019.