GRANTEE SPOTLIGHT

Key Lessons on Meaningful Consumer and Family Engagement from North Carolina

the
DELTA CENTER
for a thriving safety net

As part of their Delta Center alumni grant, the [i2i Center for Integrative Health]() (i2i) and the [North Carolina Community Health Center Association]() (NCCHCA) partnered to convene a group of diverse stakeholders to help guide the state's new Medicaid care management program. The group included 15 consumers, family members, and health care providers who met regularly for 9 months. The goal of this consumer advisory group, which i2i and NCCHCA refer to as a collaborative, was to develop recommendations for North Carolina Medicaid (NC Medicaid) about how to design and implement the new care management program to equitably meet the needs of patients and families. Here are four key lessons the i2i and NCCHCA facilitators learned about consumer and family engagement through this project.

Key Lesson #1: Meaningful consumer and family engagement should include intentional pre-work to establish a common purpose and make sure everyone has foundational knowledge.

In organizing the collaborative, the project facilitators invested significant time and effort into pre-work. Key activities included having individual meetings with each consumer and family representative, and creating written materials so members could learn more about the policy topics. The 1:1 meetings helped the facilitators understand more about members' priorities, build trust, set expectations, and identify potential challenges that needed to be addressed up front (e.g., different understandings of key terms).

Before launching the collaborative, i2i and NCCHCA also organized a meeting to introduce NC Medicaid and current and prospective group members. NC Medicaid staff gave a presentation about the new care management program, which generated a lot of questions and engagement from collaborative members. Having NC Medicaid meet with the group demonstrated that the department was supportive of the project and interested in hearing members' perspectives and priorities.

The Delta Center for a Thriving Safety Net is a national initiative launched in May of 2018 that brings together primary care associations (PCAs) and behavioral health state associations (BHSAs) to advance policy and practice change. The ultimate goal of the Delta Center is to cultivate health policy and a care system that is more equitable and better meets the needs of individuals and families.

The Delta Center is led by JSI Research & Training Institute, Inc., bringing together strategic partners including The Center for Accelerating Care Transformation at Kaiser Permanente Washington Health Research Institute, Families USA, the National Association for Community Health Centers, and the National Council for Mental Wellbeing.

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As a result of these level-setting efforts, collaborative members came to the first meeting with a shared understanding of the project, its goals, and their roles, which allowed them to dive into the work more quickly and smoothly.

Key Lesson #2: Compensating consumers and family members for their participation in planning groups is important but comes with challenges.

i2i and NCCHCA shared a commitment to compensating consumers and family members for their participation from both an equity perspective and in recognition of the value they brought to the conversation. One project facilitator remarked, “Too often, consumers are considered volunteers. There’s nothing in it for them other than the ‘feel good’ part. We worked out an opportunity for folks to get paid for their time to make sure we were all sitting around the table, and we were all getting paid for it, which is important and meaningful.”

As important as it is, compensation can be challenging not just in terms of finding the funding to support it, but also in figuring out the appropriate organizational processes for payment. Contracting with government agencies or large companies often means people must go through background checks or other invasive processes to be deemed eligible for payment. This can be a major barrier for people with lived experience. To address this challenge, i2i and NCCHCA requested donations from Medicaid managed care organizations and companies, which eliminated the need for contracts. They also agreed to manage all funds through one partner (i2i) to simplify accounting requirements and streamline payment processing.

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> *—Facilitator*

Key Lesson #3: Consumer group facilitators need strong relationship building skills, humility, and a willingness to listen in order to successfully engage consumers and family members.

Managing a collaborative well takes multiple people, strong facilitation skills, and thoughtful preparation. When a 15-member group of consumers, family members, and health care providers discusses a complex policy initiative, conversations can quickly get sidetracked or heated. Building a strong working relationship with each collaborative member allowed the i2i and NCCHCA facilitators to keep the conversation on track without causing offense. They were also purposeful about giving people time to share and using active listening skills to build trust.

Additionally, the facilitators realized that sometimes they needed to bring in partners with particular expertise to lead conversations. For example, the facilitators invited the NC Medicaid chief of staff to lead a meeting focused on health and racial equity, given her relevant experience in this work. One project facilitator noted, "We were worried collaborative members would think we didn't know as much as we do, but we realized our skill was in facilitation rather than racial equity. We needed to have the humility to bring in people who are the subject matter experts."

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Because the facilitators had invested in building relationships with their collaborative members, people were comfortable having a candid conversation about health and racial equity even with an external facilitator. One collaborative member said, "One of the things that was very, very important to me is my interest in addressing issues around racial disparities. When I mentioned racial equity and disparities, I really felt like I was heard, and knew it was part of the priorities."

Key Lesson #4: When asking consumers and family members to bring their personal experiences to a collaborative group, allow time for people to speak their truths and understand that it may make other stakeholders uncomfortable.

There can be a tension between sharing personal experiences and taking a systems perspective to policy work. It was sometimes challenging for the project facilitators to build in sufficient time for collaborative members to share their specific, individual experiences while also making progress on their state policy recommendations. However, as a project facilitator remarked, "You have to allow people to speak. Some collaborative members were new to us and very passionate about these issues. That's a good thing, but it's something we had to learn about and manage. Some people had never done this kind of work before, and at times it was hard for them to hear there are good parts of the system since they've always been shunned, not heard, and misrepresented."

Additionally, engaging consumers and family members can be challenging for people who work professionally in health care practice and policy. People with lived experience may have strong opinions based on what's happened to them, and health professionals may not be able to relate to this experience. There may also be significant differences between these two groups in the language they use and their understanding of how systems work. Understanding and planning for these dynamics allowed the project facilitators to navigate the complexities and create a shared understanding of the issues across consumers and family members and other health care stakeholders.

Conclusion

Through this project, i2i and NCCHCA demonstrated the tremendous value that consumers and family members bring to state policy conversations. They also created a model that other organizations and states can use to replicate this essential work. By investing the time and resources to understand what's important to consumers and family members and combine those priorities with the goals of the state, health care providers, and other stakeholders, they are working to transform the health care system to work better and more equitably for everyone.

*Funding stipulations from the Robert Wood Johnson Foundation prohibited the use of Delta Center funds for engaging in direct or grassroots lobbying. Grantees used their Delta Center funding to support a broad array of policy activities, including background research, education and training, stakeholder engagement and convening, and building shared policy agendas. As state associations, Delta Center grantees used other non-Delta Center funding sources when they engaged in lobbying and legislative advocacy to advance policy.

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