Building Consumer Partnerships to Advance Racial Equity

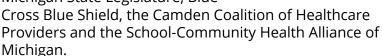
Ask the Expert: Q&A with Deborah Riddick



During the Delta Center for a Thriving Safety Net's May 2021 convening, Deborah Riddick, Director of Government Relations at the Oregon Nurses Association, presented a practical framework for state primary care (PCAs) and behavioral health associations (BHSAs) to center people with lived experience in the associations' work to advance racially equitable health policy and practice. Participating state associations appreciated Deborah's expertise, and were eager for additional guidance on how to integrate Deborah's lessons into their own work. State associations vary widely in terms of capacity, existing and potential partnerships, and political contexts, which shape their opportunities and challenges in incorporating consumer voice and advancing racial equity. Building on her presentation, the Delta Center team posed follow-up questions to Deborah.

About Deborah Riddick, JD, RN

Deborah Riddick has spent her career expanding patients' access to health care and bringing stakeholders together to raise communities' health standards. She has extensive experience practicing as a direct-care registered nurse and as a nurse educator. She has also shaped public health policy as an analyst and director of health policy for state and local organizations including the Michigan State Legislature, Blue



Deborah is a licensed registered nurse in multiple states and a founding member of the HHS/OMH Great Lakes Regional Health Equity Council. 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. (JSI) with the National Association of Community Health Centers (NACHC) and the National Council for Mental Wellbeing (National Council) as strategic partners, and support from the Robert Wood Johnson Foundation.

Email: deltacenter@jsi.com **Web:** <u>deltacenter.jsi.com</u>

Support provided by



Robert Wood Johnson Foundation

Finding consumers and consumer advocates

Delta Center Team: Many provider organizations hear from their patients on a daily basis and through their boards, but incorporating consumer voice in a consistent, systematic way is newer for state associations, which typically focus on policy and supporting practice change among members.

What guidance would you offer to state associations that are just starting to reach out to consumers, particularly to inform their state policy work?

Deborah: Consumer input can be provided by consumer advocacy organizations or come directly from consumers with lived experience residing within the community. Keep in mind that the definition of community can look different depending on the perspectives of the definer. An association may define 'community' based on their mission, vision, and primary relationships, whereas it may be defined in other ways by consumers, families, advocates, and local organizations. There will be a disconnect if your association is determining the meaning of community from a perspective of your own privilege with a narrow focus on your own mission. Ultimately, the purpose is to better meet the needs of the patient populations you serve, so when we talk about working with and for the community, we must center this work around those individuals and families.

Consumer advocacy organizations may have more familiarity with the policy advocacy process, and should be selected based on their degree of connectedness to the community. Consider which consumer organizations have a track record of community service that the community members recognize and respect.

As for partnering with consumers with lived experiences, this is often a longer-term endeavor to build a robust community network that is built on trust, mutual respect, and transparency. Your association may need to think about what infrastructure and personnel skills are needed to support engagement goals (e.g., tasking a staff member to monitor the news and who is showing up as the voice of the community).

One thing to remember is: the quality of your engagement can only be as good as the partners you engage. To start identifying partners that represent the community, whether at the individual or organizational level, consider the following questions to guide you and your association:

- 1. Whose voices are out there and how have they successfully garnered the support of their community?
- 2. How can our association shift beyond traditional criteria for identifying valuable collaborators (e.g., beyond education level, board membership, etc.)?
- 3. Where is our industry headed and how can we start identifying partners to begin the foundational network for future projects?

Keep in mind that power is not always "titled" and your association should understand what power means to the community in a local and communal context. Perceptions of who are power brokers are not universal. Understanding this can influence who is brought to the table as decision makers and is empowered to voice their opinions.

Implementing effective advisory groups with consumers

Delta Center Team: Many state associations have or are planning to have an advisory group that includes consumers and/or statewide consumer advocacy groups. Of course there are trade-offs to different approaches to gathering consumer input (see <u>Section 2 of this paper</u>), but **what guidance would you offer to state associations to implement their own advisory group with intentionality?**

Deborah: Advancing equity is not just about the outcome, but the process as well. Associations have the power to push for real change but often fall into the trap of tokenization. They can build a platform for consumers to share their voice, but then bring people into a setting where they feel out of place. When everyday people are brought into a boardroom, the interaction is conducted on the terms of the organizing body. A community setting like the YMCA, or any place where the consumer feels a sense of established identity, can foster more equitable terms for the conversation to take place.

Bi-directional learning can also play a critical role in how effective an advisory group can be. Oftentimes, because it is expedient, consumers play a "consultant" role in an advisory group with no explicit promise that the information they provided will be acted on in whole or in part. This type of relationship is one-directional.

Bi-directional learning comes from a place of saying, "We need you and you have the information we don't have in order to move forward," while also recognizing that the association cannot move the community forward when they themselves are not moving. I suggest starting with clear goals and expectations, as well as some level-setting that can serve as initial introductions and a time-limited open space to just ask questions like, "What is something that I don't know that can help us do this work better together? Where is there room to grow and what has our organization done well and not so well?" By calling this out, your association can be proactive rather than reactive. Share what you hear back, and build this information into the work moving forward to address it.

Cultivating authentic relationships with consumers

Delta Center Team: Organizations can engage consumers in many different ways, and to different degrees. **How can state associations** cultivate authentic relationships with the consumers— particularly, individuals from historically underrepresented communities?

Deborah: Authentic relationships with consumers need to start with the organization's sincere willingness to engage them and work through challenges and discomfort. Community health centers and community mental health centers have a tradition of consumer involvement through structures such as boards and peer workforces. However, these consumer engagement strategies, though valuable, need to be deepened to ensure accurate and genuine representation of the consumers that have been historically underrepresented. Equity work starts with sharing in the discomfort to move through your journey together even if it can feel personal and overwhelming at times. There must be a degree of organizational readiness that also acknowledges that this is not a moral judgement; some people just have different lived experiences and each person must be open to understanding each others' stories.

It may be helpful for your association to begin by defining the scope of activities, resource requirements, and initial "pitch" to consumers when introducing the idea of a potential partnership. Consider what your project- or organization-specific goals are as they relate to the relationship and engagement, and how a racial equity lens will be incorporated across all strategies from beginning to end. Also think about what resources and platforms your association can offer in return—all of it is a negotiation. Support can look like offering community partners subject matter expertise within the policy sphere or simply providing space, food, time, and compensation for community members to have an open and real dialogue about their most pressing needs while you listen in. Historically, the power structure starts with an organization outreaching to the community, but as of late, that's been turned on its head whether the community is making demands, which is why organizations are struggling. Understand where your association is in your journey of incorporating consumer voice and advancing racial equity, how far your association is willing to go, and be honest with yourselves when it gets challenging—that is what authenticity and willingness to change looks like.

Advancing equitable health policies together with consumers

Delta Center Team: In the wake of George Floyd's murder, there has been heightened awareness of and commitment to advancing racial justice in many areas, including health. State associations have the opportunity to provide valuable input into state task forces and policymaking bodies that are seeking to make health equity a priority. **How can state associations partner with consumers effectively on specific state policy recommendations that will advance equity?**

Deborah: The window of opportunity to advance racial equity is now, and that window is closing a little bit every day. Even if you don't fully understand what to do, go back to the relationships in your community. If your association has any capacity to draw upon those lived experiences, or partnerships with organizations who are already doing the work but are not at the table, in my own experience I have found it useful to lend my privilege and lend my space. For example, I was working with a group who was unable to get a meeting with legislators. I made the calls and got the meeting scheduled for them within days. You don't need to be there, but you can help facilitate the connection.

If there are meetings where community folks are feeling nervous, have someone from your association attend as a silent partner. This shows the decision maker that, "This is important to us." I don't interject. Just being in that room sets a different expectation of what will go on in that conversation.

It's also important to let the groups who have been doing the work to lead the effort; I push from behind. Don't take over because you can do things faster or smarter. It's okay to give suggestions and then get out of the way. Even if there are missteps, you can debrief afterwards, and community groups will gain additional skills that they will carry beyond your relationship.

Navigating challenging political environments

Delta Center Team: The political context in which state associations are advocating for racially equitable policies can be very challenging in some states. What advice would you offer to state associations that face resistance or political sensitivities towards discussing or advancing racial equity in their state?

Deborah: I think that level setting expectations is necessary. Not everyone is in a progressive state, but there are things people can still do. We are changing as a nation. Someday you will get to the promised land, and you can't give up before you're there. You have to lay the foundation so you can take advantage of the opportunity when it comes.

With relationships, if your neighbor asks for a cup of sugar, you are more likely to give it if they have already spoken to you before they needed something. When I was in Michigan, one of the closest people I worked with was a Republican legislator, and I got to know him before we needed anything from him. We connected on Michigan's health equity law, and we strengthened our relationship over our mutual interest in school-based health centers and provider status. We had that relationship no matter what pivoted, and it kept us intact. Even if we didn't agree on everything, there was an area where we had common ground or common purpose and we focused on that.

To build relationships with key stakeholders, it is often helpful to bring in consumers who share political affiliations or ideologies to speak to those who might seem opposed to your proposed policies to advance racial equity. People typically change their viewpoints not from objective facts but rather from persuasive stories that many people can identify with from their own experience. Data is good, but stories with data are even better. If you can demonstrate shared values, which help people feel connected to one another, then you open their ears to your heart and then your mind.

Good policy is often the result of compromise where no one gets everything, but everybody gets something, so your association may need to be flexible in order to find different leverage points with decision makers. For example, if the legislature will not pay for audio-only telehealth visits, you may need to look for compromise to address their concern that "you need to see the patient." Maybe it's on the phone, but it's a visual meeting, and flipping on the camera should be doable if that will make the funds flow.

At the end of the day, let the work speak for itself. A lot of people do great work because they know it's not about them. You don't need to wave any flags or have any announcements to move your priorities or strategies in the direction of racial equity. We have a lot of corporations trying to publicly say things, but their work is absent. It's not what you say—it's what you do.