Creating Inclusive Boards And Committees
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By Mary Kay Rizzolo | CQL President and CEO

Who is on your board of directors? What are the different perspectives you have on your committees? How do you ensure everyone is playing a purposeful role? The well-known mantra across the disability rights movement is “nothing about us without us,” so when it comes to leadership entities in your organization and around your communities, it’s critical that people receiving services not only have a seat at the table but especially are active members with meaningful involvement.

To learn more about how our partners can increase the participation of people receiving supports in organizational committees, boards, and other groups, we turned to two of our CQL Board Members, Tia Nelis and Chester Finn.

Insight From The Experts

Tia Nelis is the Self-Advocate Engagement Consultant at TASH. Previously she was a Self-Advocacy Specialist at the Rehabilitation Research and Training Center at the Institute on Disability and Human Development, University of IL at Chicago. Ms. Nelis also is a past chairperson of Self Advocates Becoming Empowered (SABE), the largest self-advocacy organization in the US.

Chester Finn works for the NY State Office for People with Developmental Disabilities (OPWDD) and serves as Vice Chair for the National Alliance for Direct Support Professionals (NADSP) Board of Directors. He is a nationally known disability rights activist who served as National President of SABE and is a past president of The Self-Advocacy Association of NYS (SANYS).
In conversations with Tia and Chester, they shared their recommendations and strategies about how organizations can increase the participation of the people they support on various committees. Here are some of the takeaways that offer guidance and information that you can apply at your agency.

**Before the person joins the committee**

- It is helpful to **identify a mentor** from that board/committee to help the person prepare for the meeting. The mentor may talk with them about the materials, budget, etc., and answer any questions they may have.
- It may be helpful to provide **opportunities for a trial run** to see what the committee or group is all about before they decide whether or not they want to join. People may benefit from seeing how meetings are run in-person before they decide to join or not.

**Facilitating active participation**

- It is important to make sure **materials are accessible**. This may include large print, picture-based materials, audio clips, or other modes of sharing the information. It is important also to not give too much information, as the ‘information-overload’ could be overwhelming.
- Organizations should figure out what’s the **best way to communicate** with the person. Do they prefer email, or would they rather discuss committee work over the phone or in person? “Most of the times we find out the problem is communication,” shared Tia Nelis, when talking about barriers to meaningful participation on committees and boards. “They might be emailing them when they don’t get email or can’t understand email.”
- It is best practice to support the person to **choose their own support** if it is needed to participate. Some committees choose a person that is already on the committee to fill this role, but this may not always work out for the new member.

**Responsibilities of board and committee members**

- Explain what their **responsibilities** are as a member. This includes any fiduciary (fiscal) responsibilities they may have – what do they need to know, and what risk (if any) are they taking on?
- Chester suggested not keeping the same people on committees year after year. There are benefits to **rotating committee members**, including giving more people receiving supports the opportunity to be a contributing member.
- When selecting board or committee members, Chester challenges organizations to select “someone that will hold them accountable... People who will challenge things.”
- Responsibilities should be laid out prior to the person joining the committee so they can make an **informed choice about participating** or their level of involvement.

**During committee or board meetings**

- It is important to acknowledge that how the chairperson or president (or whoever is in charge) includes the person with a disability will set the stage for the other members. If the chairperson role models how to include the person receiving support, the rest of the board will follow. Tia shared “the board takes their cues from the chair or the president and follows how they interact with people.”
- Try to **think proactively** of situations that the person may need to know about before the meeting. For example, if the committee time is during lunch or dinner, the person needs to know ahead of time if they need to bring their own food or bring money to pay for it. Tia shared that “sometimes they don’t tell you things you need to know.” Treating people with dignity and respect can help avoid uncomfortable situations.
Personal Experiences On Boards/Committees

We also asked Tia and Chester to share what their best and worst experiences have been on a board or committee. Hopefully, this provides some ideas for best practices for increasing participation of people receiving services on your boards and committees, as well as some potential pitfalls to avoid.

Tia’s Best Experience
“The best experiences are ones where you really feel included and where you are not just given smaller, unimportant things to be part of. Not just the token person. When I was on the DD Council when John Porter was chairperson and Cathy Ficker Terrill was director, they went out of their way to make sure people were included in all parts of the board, including the bigger roles and responsibilities. I was chosen to be the representative for the council to the Consortium for Citizens with Disabilities (CCD) meeting. The chair of the board was clear that he wanted the board to be inclusive and he led by example. He role modeled. And he really believed people with disabilities can be on the council. So, I had a good experience because he gave me many opportunities to have experiences on the council and play important roles.”

Chester’s Best Experience
“By far the National Council on Disability (under President Barack Obama). We went over legislation – proposed things to send to Congress and the President. We started on 14(c) work and went around the country and talked about closing workshops. We had hearings on housing... on supporting people with disabilities that had kids with disabilities to keep their children at home. They treated us well. Now I enjoy CQL. You get to see what agencies are doing.”

Tia’s Worst Experience
“I was part of one organization where our committee made a recommendation to their board (but board would have final say on the decision). We found out the board didn’t take our recommendation because they had already decided before our committee met, and the recommendation we made didn’t match what they had already decided. If you aren’t going to listen, don’t ask in the first place.”

- Lesson learned: Respect people’s time and expertise. Don’t ask people to be on boards just to say you did so. Value their input!

“Another organization I worked with didn’t believe I had written some things (didn’t think I was capable of writing these letters). They also questioned if what the self-advocates were suggesting was what they truly wanted or what the advisors were instructing them to say.”

- Lesson learned: Don’t underestimate the abilities of people with disabilities. Expect meaningful contributions and value their perspectives and contributions.

Chester’s Worst Experience
“Some agencies don’t want to do it [have people with disabilities on their committees or boards]. They wind up having “tokens” instead. You got to have people on there that are going to tell them the right stuff.”

Lesson learned: Challenge yourself to include people with disabilities on your boards/committees and let them push you a little outside your comfort zone. After all, listening to and responding to the people you support is the best path to person-centered excellence!

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Improving Participation At Your Organization

From introducing mentorship programs, to increasing the accessibility of materials, and providing someone their desired supports for participation, there are numerous ways that human services organizations and other groups can ensure people receiving services are both included and active contributors to boards and committees. Hopefully, you can introduce some of these strategies at your agency to help people with disabilities take on a leadership role – beyond mere tokenism. As Tia stated, “The best experiences are ones where you really feel included and where you are not just given smaller, unimportant things to be part of.”