

What is the Focus?

The Focus newsletter highlights important issues in mental health, providing timely information on a range of topics, including workforce development, supported education, organizational development and sustainability, peer-to-peer services, youth transition and system transformation. Have a suggestion for a topic? Let us know!



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People with Lived Experience Serving on Boards, Committees and Councils

Nothing About Us, Without Us!

Everyone wants to have their voice heard, especially in forums where decisions that impact them directly are being made. It simply makes sense that if a policy is going to be created, a program enacted or an effort made to improve circumstances for a given population, representatives of that population that have real lived experience should be a central part of that process. It's this realization that has given rise to the adage, "Nothing about us, without us!" as a principle that should guide any efforts at social change for a particular group of people.

The importance of having people that have "been there and done that" at the table when their issues are discussed has certainly been recognized in the world of behavioral health. For many years, the realm of behavioral health policy belonged exclusively to "experts" that made policy decisions without consulting the people that their policies were designed to help. In recent decades, mental health consumers have finally begun to take a place at the table, and opportunities for meaningful participation have gradually opened up. Thanks to the work of a generation of advocates that called for change from outside the behavioral health system, there are now opportunities to create systems change by engaging the system from the in-











Where Do We Engage?

There are many ways that mental health consumers can engage the system, including advocacy and communication with legislators, professionals and policy makers. Sharing personal stories of recovery can impact people on a personal level, and humanize mental health issues.

Beyond advocacy on an individual level, people can also engage in systems change work by participating in boards, committees, councils or advisory groups that are connected to the mental health system of care. Many states have Mental Health Planning Councils or similar bodies that exist to facilitate consumer input in their states' planning process. These Planning Councils may also have a role in making recommendations on how federal block grant funds are budgeted. Protection and Advocacy agencies, which exist in each state to protect the rights of people with disabilities, operate Boards of Directors and advisory groups. Community Mental Health Centers also rely on Boards and other committees for consumer input. Even provider agencies have been known to accept input from consumers through advisory bodies.

Tips for Getting Involved

There are definitely opportunities for consumers to engage the system, but how can somebody go about it? Maybe there is a board, committee, or planning council in your area that you would love to be a part of. How do you go from being an outside observer to being an active participant? Here are a few ideas:

- Observe Many meetings of boards, committees and planning councils are open to the public. You can
 learn a lot by just attending meetings, and listening to the proceedings. By observing, it will become clear
 what issues are most important to the group. You can learn how they run their meetings and make decisions. It will also become apparent as to which members are most vocal, and you will be able to get a
 sense of the tone that is set within a group. Most importantly, you should be able to learn whether or not
 a group is familiar with recovery principles, and friendly to including the perspectives of people with lived
 experience.
- Learn the culture Every board, committee or council has its own unique culture. It's worth taking the time to learn as much as possible about that culture before becoming a vocal member. Some pieces of this culture will be laid out in black and white. The name of the group will give you the first indicator of its purpose, because it will show how the group identifies itself. Some groups will have a mission or purpose that is clearly stated. In some instances, when a body has been created by law, the group's purpose may even be described in statute. Whatever the nature of the group you would like to join, or however it was created, try to learn as much as you can before getting involved.
- Follow the process Is there time for public comment at meetings? Is there an application process? Are there requirements in terms of place or residence, professional experience, etc.? The more you know about the mechanics of how a given group works, the better prepared you will be to engage that group

on its own terms, and the more likely that engagement is to be successful.

- Develop relationships One good way to become an effective member of a board, committee or council is to begin by developing individual relationships with particular members. You may notice that there are people in a group that are friendly and approachable. You may notice that certain participants in meetings seem more receptive to input from outside voices, or even from people with lived experience specifically. Try to seek out those people, and develop a rapport with them as individuals before you become a full-fledged member of the group. Take the time to develop a personal relationship with one or two members that is based in common interest. Consider sharing your story, or at least talking openly about why the work of the group in question is important to you, and why you feel your input as a person with lived experience would be valuable. If you make the effort to develop personal relationships with select members before you become part of a group, you will feel more comfortable once you become a full-fledged member, and you will have ready-made allies to support you in speaking out when the time comes.
- Don't go it alone Trying to become active in a board, committee or planning council can be intimidating. You know that you are the expert, because you have lived experience. At the same time, the culture of the group you want to become part of may be hard to understand. Additionally, the group may include professionals, government officials, or others that play roles of authority in traditional power dynamics. One way to overcome the intimidation factor in a group setting is to bring a like-minded peer. One person in a new setting may be afraid to speak up. Two people working together can rely on each other for support, courage and affirmation.
- Be open-minded Most boards, committees and planning councils bring together people with diverse backgrounds. Some may be healthcare professionals, some may represent provider agencies, and some may represent diverse social, personal and professional backgrounds. You may encounter family members, or other advocates with varied perspectives. Remember, committees, boards and planning councils work by consensus. It's very unlikely that every member will agree on a given topic. Even when disagreement occurs, it's essential to listen to other members openly. Disagreement and debate are a normal part of the process, so don't let them prevent you from making your voice part of the conversation.
- Don't give up It can definitely be intimidating to try to engage with a board, committee or council that has its own history and power dynamics. You may worry that you are just a token self-advocate, and that your experiences and opinions aren't being valued. Try to remember that change happens over a long period of time, through the work of countless individuals like you. It might be difficult to see on a day-to-day basis, but by making an effort to have the voice of lived experience represented in your community, you are making a difference. If you can stay engaged, even when it becomes frustrating or difficult, you will eventually be able to look back and recognize the difference your advocacy has made.



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