



# The Key

## ASSISTANCE REPORT

Focus on **EMPOWERMENT IN THE BOARDROOM**

### National Mental Health Consumers' Self-Help Clearinghouse

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#### A COMMITTEE MEMBER IS BORN

About 14 years ago, Jimmy Burke was in a homeless shelter in Nebraska. He had just been discharged from a psychiatric hospital in his home state of Texas, where he received treatment for schizoaffective disorder, Tourette syndrome, and other disorders. Someone there recommended that Burke transfer to the Omaha shelter, which took a Christian-centered approach to helping people get on their feet. Depressed, desperate and almost 21 with nowhere to go, Burke, who is a devout Christian, went. But the trip did little to change his situation, except that now he was far from the people and places he knew.

In the years that followed, however, Burke's situation changed substantially. His experience led him through the circuitry of the mental health system in Nebraska, and to a volunteer job at a Lincoln rehabilitation center in 1997. Burke took on more and more responsibility there and impressed his supervisor so much that she approached him about serving on a local mental health council.



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"She really championed me," Burke explained. "She helped me apply and get together letters of recommendation because they needed some seats filled."

The former homeless man, who works part time as stigma and wellness coordinator for the Mental Health Association of Nebraska, estimates he now spends about 10 to 15 hours a month serving on boards and committees. Burke's journey to the boardroom may

have seemed unlikely 14 years ago, but his experience is part of what many people who have been diagnosed with mental illness have fought for in the past 30 years. Thanks largely to the mental health consumer/survivor movement, people who once had little if any power over their own treatment are taking "a seat at the table," where their experiences with the behavioral health system—good and bad—constitute valuable expertise.

## TOKENS AND REAL POWER

Individuals very rarely make policy decisions in bureaucracies such as the behavioral health system. Instead, groups like boards of directors, commissions and councils wield the power. Every corporation, both for-profit and nonprofit, has a board of directors, and almost every board has committees that focus on specific issues. Also, government boards at all levels form advisory bodies to help make policy decisions. Members very rarely receive pay aside from reimbursement for expenses, so consumers who rely on aid programs for income and healthcare can participate without fear of losing benefits.

As the consumer/survivor movement has led more people to advocate for themselves, an increasing number of boards and advisory bodies are being required to set aside seats for consumers and relatives of consumers. However, some people report that they feel like “token” members. The term is typically used to describe a situation where a board or advisory body includes one or two consumers to create an appearance of consumer involvement, but fails to value consumer members’ input as much as that of other members.

Burke, who serves on his state’s mental health advisory committee, said he felt at first as if he had to earn the respect of the “professionals” who served with him.

“Whether they’re doing it intentionally or not, they have this idea of what consumers are supposed to be like: that they don’t know well enough to know what’s best for them,” he said. But he stressed that people shouldn’t let this attitude scare them away. “Consumers that are trying to be on boards with professionals shouldn’t be intimidated. Understand that we’re not trying to replace professionals in the field of mental health care; we’re trying to work with them.”

Many consumers have reported overcoming tokenism, but many have also taken reserved seats on advisory bodies that ultimately had little influence.

Judi Chamberlin, veteran activist and author of “On Our Own: Patient-Controlled Alternatives to

the Mental Health System,” has served on many boards and advisory bodies since she took her first such position more than 20 years ago. She sat on a protection and advocacy council for Massachusetts that was required by federal law to be made up of at least half consumers and family members of consumers. Her particular group worked very well with her state mental health authority, she said, but this is not always the case.

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“For a lot of people, it’s an exercise in frustration to be on an advisory council when you do all this work and then people can just ignore you,” Chamberlin said. However, she added that committees and other entities such as task forces, which may be established to accomplish short-term goals, sometimes have “real power.”

“It depends on the law or executive order that brings them into existence,” she said. “You have to look at the documents and see if they have power.”

## SETTLING IN

Some boards, committees and other entities offer orientation sessions or materials to help new members assimilate. Some even provide mentors. This is the ideal situation, but the fact is that many of these bodies don’t formally orient new members, instead leaving them to learn through observation and their own homework. Consumers who’ve done due diligence before joining the group may feel well-prepared to take their seats when their terms begin. Still, some aspects of the job may take getting used to.

### Find a Seat

Opportunities for consumer involvement vary by location. Local chapters of large mental health organizations may not only include consumers on their own boards and committees, but offer leads to other organizations in your community that do as well.

Here are the two most prominent:

**The National Mental Health Association (NMHA)** is the oldest and largest nonprofit organization addressing all aspects of mental health and mental illness. Visit [www.nmha.org](http://www.nmha.org), go to Affiliate Network at the top and click on Affiliate Directory to find the organization for your region. You can also call 1-800-969-NMHA (6642) for information. The line is staffed between 9 a.m. and 5 p.m. Eastern Time Monday through Friday.

**The National Alliance on Mental Illness (NAMI)** is the nation’s largest grassroots organization dedicated to improving the lives of people with serious mental illness and their families. It has organizations in every state and in more than 1,100 local communities. To find the affiliate nearest you, visit [www.nami.org](http://www.nami.org), go to the Find Support menu and choose State & Local NAMIs. The information is also available by phone between 10 a.m. and 5 p.m. Eastern Time Monday through Friday at 1-800-950-NAMI (6264).

Burke said he had trouble sitting through long meetings at first, but that this is no longer a problem.

"The meetings run from like 8 a.m. to noon, then from like 1 to 5," said Burke. "It does make for a long day, but I'm more used to that now... because I'm able to participate and I'm not just sitting there just being a sponge; I'm able to offer things."

Some consumers also said they struggled to learn parliamentary procedure. Many groups use the strict "Robert's Rules of Order," which provides very specific guidelines for running a meeting. Other groups follow rules that echo Robert's but are much less stringent.

Sylvia Caldwell, who took a seat in early 2006 on the board of directors of the Alaska Mental Health Consumer Web, a drop-in center in Anchorage, said that, long meetings aside, she's excited about the opportunity to understand more about the board's business. For instance, she's eager to learn about the grant-writing process and how non-profits work in general. For now, her duties include planning a fundraising car wash and working one-on-one with the people who visit the drop-in center.

Before she took her place on the Web's board, Caldwell, who is African-American and has been diagnosed with bipolar disorder, served on the boards of several civic organizations, including Blacks in Government, but didn't stay on those long. She credits this enthusiasm for the Web's work with fueling her interest in learning about the nuts and bolts of the board's business.

"I decided that, because of my mental illness, this was an area where I would be much more able to give something back..." she stated. "It's been very important to me to have minorities have a face out there."

Burke said he was grateful for some of the knowledge he's gained so far, too. For example, he came to the table as one person on a mission to serve people who have been diagnosed with mental illnesses, and he's learned to increase his power through networking.

"When you advocate," he said, "never go alone. Go with somebody."

Asked what she would tell consumers new to the world of boards and committees, Chamberlin offered some words of inspiration.

"It can be a lot of work," she said, "but it can also be very rewarding. Certainly, people need better services... We've really got to push those changes along. Who cares more about recovery than us? It's our lives. Otherwise it's just going to be so much more talk."

If you're the only consumer, or one of the only consumers, on a board or advisory body, you're likely to have opinions that differ from other members'. Some advocates recommend thinking like an educator rather than an adversary. Offer personal accounts, introduce other consumers to the board, and present information from additional sources to bolster your position. By not focusing on attacking other members' proposals but pointing out positive alternatives, you're more likely to accomplish your goals.

## RESPECT AND RESPONSIBILITY

The lure of serving on boards can be strong for people who have traditionally been defined mainly by their disabilities. For example, someone who has been labeled "schizophrenic" for 20 years might welcome the prestige of sitting on the board of directors for a state mental health agency.

This can lead to a situation some experts call "co-optation," in which consumers begin to identify less with the consumers they represent and more with a board or committee on which they serve.

Chamberlin, who became an advocate after she was forcibly committed to a psychiatric hospital in the 1970s, said this seems natural.

"That's kind of easy to understand when we live in a world where if you say that you're an ex-mental-patient people say,

## Free Guide to Serving on Boards and Committees

The National Mental Health Consumers' Self-Help Clearinghouse offers a free in-depth technical assistance guide to "Serving on Boards and Committees." The file is available for download directly from the Clearinghouse Web site at [www.mhselfhelp.org](http://www.mhselfhelp.org), or by request via phone, e-mail and, with an order form printed from the Web site, via fax and mail.

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"Ooh, is this person going to attack me?" she explained. "It's kind of easy to start identifying with the more powerful people. Certainly, there are people who get into a position where they can be seen as something other than a consumer and they will do anything not to be seen as a consumer."

Still, she stressed that representatives should remember to serve consumers first and foremost.

"That gives you a responsibility not just to make yourself important, but to make things better for all consumers."

And that, she said, includes fighting the stigma and discrimination that make consumers so vulnerable to co-optation in the first place.

Search the Clearinghouse Directory of Consumer-Driven Services at [www.cdsdirectory.org](http://www.cdsdirectory.org) for organizations near you that may need representatives.



The Clearinghouse welcomes all programs in which consumers play a significant role in leadership and operation to apply for inclusion in its Directory of Consumer-Driven Services. The directory, accessible at <http://www.cdsdirectory.org>, is search-

able by location, type of organization, and targeted clientele, and serves as a free resource for consumers, program administrators and researchers.

Apply online at [www.cdsdirectory.org/contact](http://www.cdsdirectory.org/contact), via fax at 215-636-6312, or by phone at 800-553-4KEY (4539). To receive an application by mail, write to [info@cdsdirectory.org](mailto:info@cdsdirectory.org) or NMHCSH Clearinghouse 1211 Chestnut Street, Suite 1100, Philadelphia, PA 19107.

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