



The Key

ASSISTANCE REPORT

Focus on **SUSTAINABILITY**

National Mental Health Consumers' Self-Help Clearinghouse

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What are the differences between peer-run programs that succeed and those that fail? Mark Salzer, Ph.D., director of the UPenn Collaborative on Community Integration and a leading expert on this topic, says: "Programs have to establish realistic goals, stay attuned to changing funding environments, and be mindful of the changing needs of the people they support."

Salzer asks tough questions: Are the goals realistic? Do the programs meet the needs of the people being served? Are the resources there? "Any program should have people sitting down [and] being self-critical about what they are doing," he says. Programs that succeed, Salzer notes, plan and adapt while maintaining fidelity to their core missions.

Organizations develop such *sustainability* only through rigorous outreach and internal vigilance. But for even the smallest storefront project, the payoff is enormous: the potential to carry a transformative vision from neighborhood to nation.



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STARTING SMALL

In 1981, a small group of people who shared the experience of being locked up in state psychiatric hospitals, or receiving services in the inadequate community mental health system, started meeting in a church basement in Catonsville, Md. They talked about how to help themselves and each other recover through the power of self-help and mutual support.

This idea was shared by some others – many calling themselves ex-mental patients or psychiatric inmates – who were scattered around the country. A nascent movement emerged, asking: Why shouldn't we provide services for ourselves, supplementing or bypassing broken community mental health services?

Back in Maryland, the Catonsville group settled on a goal: create a

drop-in center where people who had mental illnesses, or who identified as psychiatric survivors, could support

TIPS FOR CREATING SUSTAINABILITY

- Make sure that your organization is responsive to the needs of the people who use it. Get feedback, adapt as needed, and don't let the need for new funding divert your attention from what matters.
- Create an organizational culture where leadership and vision are shared, so that continuity does not depend on one person.
- Find methods to evaluate your program to show how it makes a difference in people's lives: providing measurable results to funders creates a powerful case for continuing the program.
- Get the program known in the community. Better yet, involve the community.
- Your stakeholders' needs may change, your community may change, funding systems may change. Nurture an organizational culture that readily adapts to change.
- Organizations that depend on a single funding source are vulnerable. Work on finding other sources of funding – even small amounts for special projects – so that if the major funder pulls its support, you still have something to build on. In addition, the process of obtaining funding from other sources will create an organizational culture of adaptation and resilience.
- Engage in strategic planning: involve key stakeholders in an ongoing discussion of where the organization should go in the future.

their own and their peers' recovery through shared experience. A year later, the group incorporated as On Our Own, Inc., taking its name from Judi Chamberlin's seminal book of that title. In 1983, On Our Own received a small federal grant and opened a drop-in center in Baltimore.

Fast forward to 2009: On Our Own, now a statewide Maryland advocacy organization that spun off from the drop-in center in 1993, provides technical assistance to individuals and consumer organizations, an anti-stigma program, a housing program, and a peer-support program that helps consumers transition from state psychiatric institutions to the community. The programs have become national models.

TOUGH QUESTIONS

The history of On Our Own of Maryland, a story of sustainability, is about simple practices that keep an organization true to a path that starts at the grassroots and moves forward, through planned growth, to a realized vision – then back to the grassroots and toward a refined vision.

Supporting sustainability means facing tough questions, airing unspoken disagreements and resolving them – sometimes painfully. Sustainability requires periodic review of policies, practices, and programs to ensure that they continue to reflect peer values and to keep up with evolving stakeholder needs.

Failure to plan is an invitation for disaster. Notes Salzer, "I've worked with many traditional providers and self-help programs, and few engage in strategic planning – not for five years ahead or even one year ahead."

VALUES AND ROOTS

Don't let the temptation to pursue ill-fitting funding opportunities distract your organization from its mission, experts say. Remember, peer-run services have a proven track record that can be attractive to funding sources. Deborah Delman, director of The Transformation Center of Roxbury, Mass., says, "Our lived experience translates into programs that are uniquely effective, and our payers have

learned they need what [peer-operated programs] have to offer."

Two decades ago, Delman helped incorporate M-Power, a Massachusetts-based self-help and advocacy organization. The Transformation Center was spun off in 2008 to provide training, peer support, advocacy, and systems change activities, while M-Power focuses on legislative action and systems advocacy using grassroots tactics.

Delman notes that both organizations adapt while remaining true to core values. "The goal is to demonstrate to payers that there is something truly important here and that they have to come to us, whether the issue is seclusion and restraints, early death in our population, or managed care [organizations] not listening [to consumers]."

TUNE IN AND ADAPT

Adapting is critical. Ellen Healion, executive director of Hands Across Long Island (HALI), says her colleagues noticed in the 1990s that the numbers of people with mental illnesses in jails and prisons were growing – as the numbers in psychiatric institutions plummeted. "So we went where the people were: we went to Sing Sing [a New York State penitentiary] and to the [Suffolk] County Jail." (HALI's forensic programs include a weekly anger management program at a local jail, criminal justice advocacy, and a community orientation and re-entry program.)

Mike Finkle, director of On Our Own of Maryland, says the organization performs a needs assessment annually. "We ask our affiliated consumer groups, 'What are your most pressing needs?' " says Finkle. "Our board is pretty much composed of [leaders from] consumer groups around the state, so we have local input on how we can help them and how they can help us." Adds Delman, "A deep connection to our grassroots voice is critical to how we adapt and maintain sustainability."

SHOW OUTCOMES

A 1997 survey of community-based peer-support programs found that

almost 40 percent of the people interviewed nationwide thought that collecting data on members would discourage people from using services, and 43 percent felt that data collection and evaluation would be a burden to the organization. (See *Resources* sidebar.)

"I appreciate the concerns people have," says Salzer of the UPenn Collaborative, a national rehabilitation research and training center funded by the National Institute on Disability and Rehabilitation Research. "However, they may reflect unwarranted fears about anonymity, and lack of knowledge about what resources are necessary for conducting evaluations that enable them to most effectively operate their programs and market their benefits. Such data are especially important these days."

A peer-support program can easily collect information to show outcomes with minimal intrusion. "People can sign in with whatever anonymous ID they prefer: Mickey Mouse, Richard Nixon, whatever," Salzer says. "Just encourage folks to use that same ID each time they visit. And, yes, some staff time and energy are needed, but not as much as people might think."

Finkle and Healion report that their organizations each found an academic partner eager to develop appropriate training curricula and evaluation tools. Some universities provide technical assistance tools for peer-run services online. (See *Resources* sidebar.)

NURTURE LEADERSHIP

Looking to build capacity for peer-run services in the early 1990s, On Our Own recognized a need to develop leaders to run them. With input from On Our Own, the Maryland Association of Psychiatric Support Services, with the state Mental Hygiene Administration, created the Leadership Empowerment Advocacy Project (LEAP), which identifies and recruits potential consumer leaders. LEAP alumni have established new peer-run services across Maryland, and several currently serve on On Our Own's board of directors.

Healion warns that peer-run organizations can easily slip into bad habits that squash new leadership. "I've learned that my job is not to be in charge and make the decisions; it's to support people so they can do the work," she says. "When you're a leader, you have to give away the ownership." This provides room for colleagues to develop leadership skills that sustain the organization, Healion notes.

Finkle, Delman, and founders of other organizations that adapt to changing environments and constituent needs also share ownership and leadership. "You need other people in that organization to help you," Healion explains. "Not a coffee-getter, or someone to get your mail; you need someone to whom you can sit down and say, 'I don't know where to go.'"

MISSION, VISION

Unresponsive programs that have seemingly irrelevant mission and vision statements posted on the walls are all too common. But, done right, these statements represent the aspirations of stakeholders and remind everyone of the purpose of the work. Without them, organizations drift and sustainability is compromised.

The Transformation Center in Roxbury, Mass., is in the pilot phase of its current round of planning; later, new vision and mission statements will guide a new strategic plan. The Center has adapted its planning process, last performed eight years ago, to represent the growing diversity of today's mental health consumer/survivor population in Massachusetts. "We're talking to people who speak Spanish, Portuguese Creole, ASL [American Sign Language]. We are going into homeless shelters and wherever we find people with mental health conditions," Delman says. Comments will go up on the Web – accessible to speakers of these languages as well as English, she adds.

Delman explains: "We take whatever arises from our diverse constituencies, identify themes that come up from the communities, and make sure they are reflected as we look at what our programs will look like going forward."

RESOURCES

If the links don't work, please type them into your Web browser.

Peer Outcomes Protocol Project. Center on Mental Health Services Research and Policy, University of Illinois at Chicago <http://www.cmhsrp.uic.edu/nrtc/pophome.htm>

The Data Needs of Community-Based Peer Support Programs. Campbell, J., Missouri Institute of Mental Health (1997) <http://www.cmhsrp.uic.edu/download/POP.Report.pdf>

Program Sustainability: Developing Strategies for Maintaining Programs Over the Long Term. American Indian Development Associates <http://www.aidainc.net/Publications/Sustainability.pdf>

Keeping the Work of Social Entrepreneurs Alive: The Importance of Being Sustainable. Changemakers.net <http://proxied.changemakers.net/journal/01april/cannon.cfm>

Building Adaptive Capacity: The Quest for Improved Organizational Performance. Sussman Associates, prepared for Management Consulting Services, Boston http://www.barrfoundation.org/usr_doc/Building_Adaptive_Capacity.pdf

Publicize your program: *Working with the Media.* National Consumer Supporter Technical Assistance Center of Mental Health America <http://www.ncstac.org/content/materials/WorkingWiththeMedia.pdf>

UPenn Collaborative on Community Integration <http://www.upennrrtc.org>

Hands Across Long Island <http://www.hali88.org/>

On Our Own of Maryland <http://www.onourownmd.org>

The Transformation Center <http://www.transformation-center.org>



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 www.cdsdirectory.org, is searchable 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, 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 or NMHCSH Clearinghouse, 1211 Chestnut Street, Suite 1100, Philadelphia, PA 19107.

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