

Moving Forward, Together:

Create a Range of Opportunities for Consumer Integration

Step 1—The Strategic Plan

Many organizations attempting to integrate people with experiences of homelessness into their service development, design, and evaluation begin with the creation of definitions by which they can measure their own success. Some of the critical questions to consider when forming definitions are in the accompanying box. These definitions are integral to developing a strategic plan allowing agencies to measure their success over time and to keep efforts sustainable.

A. Define the Term "Consumer"

Some Critical Questions to Consider

- Who are consumers?
- How does the agency define involvement?
- How does the agency know it is meaningful?
- How does the agency know there is consumer involvement?
- Is there a numerical goal?
- Is involvement different from integration?
- How does the agency define tokenism?
- Is there a range of opportunities for people?
- Are these positions specifically set aside for consumers?
- Is there reflection of the agency's commitment to integration in the budget?

Many agencies struggle with the definition of consumer, and with good reason. It can create confusion, especially when the voices of consumers are absent and advocates act or speak on their behalf. In the mental health field, it is particularly so when parents and relatives of people diagnosed with mental illness refer to themselves as

"secondary consumers." This substitution of voice is often mistaken for the opinions, experiences, and insights of consumers themselves, producing tension and distrust. In these circumstances, it is critical that agencies specifically define and clarify whom they want to recruit in their capacity-building efforts. To that end, the most consistent definition of "consumer" is "people who are or have in the past received the kinds of services being provided."

B. Define "Significant Involvement"

In a recent paper devoted to the topic of consumer integration in homelessness research, service delivery, policy, and planning, the writers identified a way to think about consumer involvement along a spectrum or a continuum (Barrows et al., 2007). The authors provide a chart, developed by McMullin et al., outlining three discrete stages in the process: tokenism, involvement, and integration. They also suggest using four dimensions to measure the degree of integration: (1) number of consumers involved; (2) the number of roles they occupy; (3) their positional/decision-making authority; and (4) compensation. Additional factors to assess/measure where agencies fall along this continuum might include: (5) the degree of safety/comfort people feel if they choose to disclose their experiences of homelessness in policy or decision-making arenas; (6) environmental factors (e.g., does the agency take into consideration adapting to/accommodating consumers or is the onus on

consumers to adapt to the environment?); and (7) the degree of impact consumers have on the organizational environment, project, or meeting.

Consumer Tokenism, Consumer Involvement, and Consumer Integration in Research

Tokenism	Involvement	Integration
1–2 consumers invited to participate in limited or superficial roles	Small number of consumers invited	Significant number of consumers from diverse populations studied
1–2 consumers expected to represent all consumer perspectives	Limited roles	Key positions including management, research staff, serving on Steering Committees and oversight boards
No concrete decision-making authority	Limited decision-making authority	Decision-making authority
Mostly volunteer time	Some compensation for time and expertise	Competitive compensation for time and expertise

The President’s New Freedom Commission Report called for “involving consumers and families fully in orienting the mental health system toward recovery” (2003, p. 37). In an age when measurement often drives funding, the question of how to measure “meaningful or significant involvement” accurately is fundamental for agencies committed to working toward that end.¹ In addition to the seven dimensions above, Dan Fisher, M.D., Ph.D., offered an eighth that is more subjective. It pertains to the impact consumers have on an environment, meeting, project, or conversation. Consumers might ask themselves, “Did my presence make a difference in the outcome of a meeting or would the outcome be the same if I were not there?” To measure the impact consumers have, non-consumer providers might ask, “Did the presence of people with experiences of homelessness *change* how I thought about and made plans regarding the subject at hand? Did their presence make me uncomfortable enough to reconsider what I thought I knew?” (D. Fisher, personal communication, 2007). Ultimately, each organization will need to decide what significance means to them, commit to that goal over time, and find ways to measure success to sustain those efforts.

¹ The public health field perhaps led the way in generating a numeric standard for their boards and planning councils. However, agencies can apply for waivers if they can show hardship in meeting the standard. Nevertheless, the Bureau of Primary Health Care supports a numeric standard of 51 percent membership on its advisory boards to indicate “significant” consumer involvement. Other agencies required grantees to increase consumer participation on their planning councils to at least 33 percent of people living with HIV (HRSA, HIV/AIDS Bureau, 2004–2005). The intent is to ensure that “the needs of the people most affected by the epidemic are heard and that resources are allocated to meet their needs” (“Implementing the CARE Act,” 2002, p. 6).

C. Use Definitions to Develop a Strategic Plan

Below are some tips on developing a strategic plan for moving along the continuum of consumer integration:

- Set goals and make a plan to work toward integration over time.
- Recognize that it may be difficult for a consumer to feel confident and participate fully without natural allies. Ongoing efforts should focus on increasing consumer involvement over time.
- Identify a pool of consumers who can provide support to those with experiences of homelessness involved in the agency.
- Bring together a committee of people (the majority of whom are people with experiences of homelessness) willing to be a *temporary* workgroup to launch the agency consumer integration efforts. This group can become a permanent advisory committee to work with the peer integration coordinator or it can reconfigure once those efforts are well underway, based on the needs and desires of the group and the agency.
- Increase the number of consumers over time and strive to stratify them in a variety of roles throughout the organization.
- Use advisory boards as training grounds for skill development in areas of policy, planning, financial management, and evaluation to provide stepping-stones to workplace opportunities.

D. Anticipate Costs

One of the greatest challenges for organizations operating within resource-scarce environments is the identification of human and financial resources to support consumer integration efforts. When developing a plan, it might be helpful to anticipate expenses in the following areas:

- Recruiting consumers who are formerly and currently homeless.
- Supporting people who are new in their roles as they transition into the agency.
- Miscellaneous reimbursements such as pre-paid phone cards, childcare, transportation, storage, food, and meeting expenses.
- Office equipment, including access to computers, printers, communication devices, and other office supplies.
- Costs related to communication, outreach, and travel.
- Workforce development and training.
- Fees associated with: (a) hiring consumers to provide staff training in recovery approaches and principles; (b) developing curricula; (c) producing documents; (d) using multi-media (video, photographic history) to collect qualitative information/stories from consumer-providers and non-consumer staff about agency efforts; (e) delivering training in the community and at national conferences; and (f)

reviewing policies and practices as the agency receives feedback about how to tailor the environment in ways that improve access.

Check out the “Related Items” to the Right of the screen.

References

Barrow, S., Tsemberis, S., McMullin, L., & Tripp, J. (2007, March). Consumer integration and self-determination in homelessness research, policy, planning and services. Paper presented at 2007 National Symposium on Homelessness Research, Washington, DC.

McMullin, L., Grassetto, A., Pennington, L. H., Birckett, S., Cole, L., Heller, L., et al. (2006). *Establishing consumer integration in the evaluation of the SAMHSA Homeless Families Program*. Manuscript in progress.

New Freedom Commission on Mental Health. (2003). *Achieving the promise: Transforming mental health care in America: Final Report* (DHHS Publication No. SMA-03-3832).

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