

# MOVING FORWARD TOGETHER

## CHALLENGES TO CONSUMER INTEGRATION

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### INTRODUCTION

The challenges to consumer integration overlap and are complex, affecting individuals and agencies in interrelated ways. These issues are worthy of greater elaboration than allowed here. This section concentrates on the primary shared concerns consumers and agencies identify: stigma and discrimination; boundaries/multiple relationships; stress/burnout; and challenges related to finances and time (“Consumer Practitioners in PATH-Funded Programs,” 2006).

### STIGMA AND DISCRIMINATION

Link and Phelan (2001) define stigma as a series of interrelated processes occurring in the context of power imbalances. They note the persistence of stigma as a result of individual/interpersonal and structural forms of discrimination.

#### CHALLENGES

- Stigma and discrimination
- Boundaries/multiple relationships
- Disclosure
- Confidentiality
- Unlearning established roles
- Stress/burnout
- Lack of time
- Concerns about finances/ budget

people with experiences of homelessness face on a daily basis. After a period of time, people internal-

ize this sense of powerlessness and defeat, making it difficult to feel they have anything worthwhile to contribute to research, policy, or delivery of services (Barrow et al., 2007). When people internalize stigma, it may take time for them to believe that their perspectives and insights really do make a difference. Persistence can be helpful in encouraging people to speak up and share their expertise. At the same time, asking people (covertly or overtly) to reveal private information they do not wish to reveal is a violation of their rights to privacy and confidentiality. When an agency commits to consumer involvement, it is necessary to create spaces at the table for people willing to disclose their experiences openly.

*“Many of our staff are consumers, but we don’t know exactly who they are.”*

Issues relating to disclosure are complex (“Consumer Practitioners in PATH-Funded Programs,” 2006; Carlson et al., 2001; Prescott, 2001; Fisk, Rowe, Brooks, and Gildersleeve, 2000). The degree of disclosure may relate intimately to the

degree of perceived safety or discrimination within environments (Prescott, 2001; Fisher, 1994). Staff attitudes toward consumers may reflect assumptions of incompetence, or may be “negative, fearful, exclusionary, guarded, and distant” (“Consumer Practitioners in PATH-Funded Programs,” 2006). According to one provider, “The challenge is not with our consumers as much as with our own leadership...and our own agency bias. There are a few people who push consumer involvement forward but there’s a lot of struggle.” Another provider said, “We promote consumer involvement in the community, yet we’re leery as to whether they are capable [of working for us].” Some consumer providers report feeling excluded from decision-making processes and assigned fewer responsibilities than colleagues who are not consumers (“Consumer Practitioners in PATH-Funded Programs,” 2006). Adequate supervision and dialogue within workplaces and organizations can minimize this type of stereotyping and discrimination (Carlson et al., 2001; “Consumer Practitioners in PATH-Funded Programs,” 2006).

Subtle discrimination can take place when agency practices overlook the conditions of extreme poverty under which people who are homeless live. Thus, the agency extends an invitation for “involvement,” but in a way that people either do not receive it or are unable to accept it. Poverty can lead to difficulties with regular communication, accessing dependable transportation (especially in rural areas), or regularly attending meetings or jobs. Some providers cite the “digital divide” as a particular problem. As one provider commented, “A lot of agency business is handled by e-mail and we’re not sure how to reach people without computer access.” Commonplace business practices can require credit cards to hold hotel rooms or make flight reservations, or the need to make long-distance conference calls during the workday (Barrow et al., 2007).

## **BOUNDARY/MULTIPLE RELATIONSHIP ISSUES**

Boundary or multiple relationship issues are among the most commonly cited challenges to consumer integration, particularly for people providing direct services. Boundaries, confidentiality, and other ethical issues are the most complex when people work or volunteer in the same agencies where they currently receive services (“Consumer Practitioners in PATH-Funded Programs,” 2006; Carlson and McDiarmid, 1999). On one level, when a consumer becomes a paid provider of services, it can complicate relationships once strictly peer-to-peer. As one

provider observed, “A challenge for new consumer employees is shifting their role and understanding that as staff we have to be careful about personal relationships with people we serve.” Some agencies have standard policies prohibiting providers from having any kind of personal relationship with individuals receiving services. Such a policy may pose a hardship for consumers who rely on their friends and peers as a support system to maintain their own sense of well-being.

Related to boundary issues are the challenges of role conflict and role confusion (Carlson et al., 2001). In the mental health or other service systems, both consumer and non-consumer providers of services learn to play roles that are very specific and continually reinforced. Stepping out of those roles can be difficult. Consumer providers may struggle with negotiating the various and sometimes contradictory expectations of their dual identities. Some people report feeling as if they are in a “no-man’s” land (Shepard, 1992). It can be difficult for consumers and non-consumers to relate to one another as colleagues and collaborators in a field constructed on hierarchies of power. Some mental health treatment and homeless service settings may default to categorizing people as “sick” versus “well” or “client” versus “helper” (Carlson et al., 2001; Mead and McNeil, 2006). For people who received services, unlearning the client role can take time.

For non-consumers, there can be an equally steep learning curve relating to their colleagues who have experiences of homelessness as equals. The “treatment” dynamic can filter into workplace interactions. As one supervisor reported, “My employee’s treatment team would come to ask me how he is doing. I tried very hard to make a clear line between work and treatment, but it wasn’t always easy.” In one study of interactions on Assertive Community Treatment (ACT) teams, non-consumers reported they tended to assume more of a “therapist” role with consumers they supervised, blurring the lines between supervision and therapy (Dixon, Hackman, and Lehman, 1997), presenting problems for supervisors and consumer providers alike. Some providers with experiences of homelessness noted that others pathologized their behavior on the job, viewing their expressions of frustration as “symptoms” (Carlson et al., 2001; Prescott, 2001). Mentoring and supervision is useful in navigating roles and expectations in the workplace.

Confidentiality can be a concern when consumer providers have friends currently receiving services

at the agency where they work or volunteer (“Consumer Practitioners in PATH-Funded Programs,” 2006). However, there is no evidence suggesting people with experience of homelessness providing services are any more likely to breach confidentiality than non-consumer providers (Carlson et al., 2001). Questions still arise regarding what to do when consumer providers obtain information about individuals who are friends through case files or conversations at team meetings. Supervision, training, and establishing role clarity can address some of these issues. Other concerns pertain to feelings of awkwardness if consumers receive services where they work and come into contact with colleagues who have access to highly confidential information about their lives (“Consumer Practitioners in PATH-Funded Programs,” 2006).

## **STRESS AND BURNOUT**

As in other human service environments, stress and burnout are factors that impede consistent consumer participation, whether on boards, committees, or on the job. When agencies or organizations rely on a single person to represent the consumer perspective at every meeting and function, they run the risk of overburdening that person. Like other workers in social service settings, people with experiences of homelessness may be in poorly compensated, low status, and extremely stressful positions—factors that contribute to job burnout (Mowbray and Moxley, 1997). Consumers may have a difficult time leaving their jobs behind when they go home for the day (“Consumer Practitioners in PATH-Funded Programs,” 2006). Stresses compound when consumers in the workplace no longer participate in peer support activities, e.g., participating in groups. They may need additional support to deal with role transition, lack of role clarity, and loss of external support.

## **TIME AND FINANCIAL CHALLENGES**

As noted in the Consumer Practitioners in PATH-Funded Programs: Report of the Consumer Involvement Workgroup (2006), fear of losing benefits is a primary concern for people with experiences of homelessness contemplating a return to the workforce. Some consumers prefer to maintain their income within allowable limits, which affects the number of hours they choose to work. One provider mentioned that he would like to see more people with experiences of homelessness working full-time at his agency, but felt he needed to respect their desire to remain part-time employees. If salaries are low or without benefits, people may feel the risk of letting public assistance and other benefits go is

too high (Shaheen, Mikloucich, and Dennis, 2003; “Consumer Practitioners in PATH-Funded Programs,” 2006).

As with any significant change, there are certain unanticipated costs associated with embarking on a new initiative. Administrators, as well as budget and financial managers, voice concern about meeting the costs associated with integration efforts. While some literature initially reflected the cost-effectiveness of peer support programs in the mental health setting, current research indicates this finding was the result of research based on the use of volunteers or low-paid peer support workers (Barrow et al., 2007). While there can be a tendency for costs to increase, especially in the beginning of the integration process, “other expenses will decrease over time as trust, clarity of roles, and involvement become operationalized” (Prescott, 2001, p. 10). Related to concerns regarding increased costs are those pertaining to the increase in time, attention, training, and staff supervision needed when people with experiences of homelessness just begin to re-enter the workforce. They may need additional support adapting to office environments, understanding basic management skills, and require in-depth explanations of procedures and policies. Team leaders sometimes felt that the time it took to orient and train consumers affected their ability to perform their other job duties.

Ideally, agencies should develop plans for integrating consumers with a variety of backgrounds but financial realities may limit their capacity. Hiring consumers with specific skills (e.g., evaluation, management, or training) in positions that match their expertise can be an easier initial step. Strategic planning can help programs define their own terms of integration and establish realistic goals to involve consumers with differing levels of expertise, skills, and recovery into multiple levels of their organizations.

*How has your agency overcome these challenges? Click “Add Comment” below to share your thoughts.*

## 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.

Carlson, L. & McDiarmid, L. (1999). *Consumers as Providers of Mental Health Services: A Literature Review and Summary of Strategies to Address Barriers*. Lawrence, KS: University of Kansas, School of Social Welfare.

Carlson, L., Rapp, C., & McDiarmid, D. (2001). Hiring consumer-providers: Barriers and alternative solutions. *Community Mental Health Journal*, 37(3), 199–213.

*Consumer Practitioners in PATH-Funded Programs: Report of the Consumer Involvement Workgroup* (2006). Retrieved from <http://pathprogram.samhsa.gov/Resource/Consumer-Practitioners-in-PATH-funded-Programs-Report-of-the-Consumer-Involvement-Workgroup-26194.aspx>

Dixon, L., Hackman, A., & Lehman, A. (1997). *Consumers as staff in Assertive Community Treatment programs*. *Administration and Policy in Mental Health*, 25(2), 199–208.

Fisher, D. B. (1994). A new vision of healing as constructed by people with psychiatric disabilities working as mental health providers. *Psychosocial Rehabilitation Journal*, 17(3), 67–81.

Fisk, D., Rowe, M., Brooks, R., & Gildersleeve, D. (2000). Integrating consumer staff into a homeless outreach project: Critical issues and strategies. *Psychiatric Rehabilitation Journal*, 23(3), 244–252.

Link, B. G., & Phelan, J. C. (2001, September). *On stigma and its public health implications*. Paper presented at the conference Stigma and Global Health: Developing a Research Agenda, Bethesda, MD.

Mead, S. & MacNeil, C. (2006). Peer support: What makes it unique? *International Journal of Psychosocial Rehabilitation*, 10(2), 29–37.

Mowbray, C. T. & Moxley, D. P. (1997). Futures for empowerment of consumer role innovation. In C. T. Mowbray, D. P. Moxley, C. A. Jasper, & L. L. Howell (Eds.), *Consumers as providers in psychiatric rehabilitation* (pp. 518–525). Columbia, MD: International Association of Psychosocial Rehabilitation Services.

Shaheen, G., Miklouchich, F., & Dennis, D. (2003). *Work as a priority: A resource for employing people who have a serious mental illness and who are homeless*. Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration.

Shepard, L. (1992). *So you want to hire a consumer? Employing people with psychiatric disabilities as staff members in mental health agencies*. Burlington, VT: Trinity College, Center for Community Change through Housing and Support.