It is useful to have a framework for involving consumer/survivors of mental health services. Through practical examples, barriers to consumer/survivor involvement and strategies for increasing involvement are identified and discussed.

Changing Roles of Consumer/ Survivors in Mature Mental Health Systems

Sinikka McCabe, Rae E. Unzicker

When mental health systems are examined from the perspective of consumer/survivor involvement, most of them, including those often considered to be mature, are still in their infancy. A truly mature mental health system would be one in which it is taken for granted that consumer/survivors are included and actively involved at all levels of mental health service delivery system, including uppermost levels of management and policy making.

As mental health systems mature and as they develop services based on the concepts of community treatment, psychiatric rehabilitation, and recovery, they also change their views of the abilities of people with psychiatric disabilities. Increasingly, the service recipient is being viewed as an equal partner in the treatment process, not a passive service user. Mature mental health systems recognize that there is virtually no difference in intelligence, ability, and talents between people who have experienced treatment in the mental health system and those who have not. The difference is in perspective, and this different point of view is viewed as valuable, worthwhile, and important.

Mature mental health systems also recognize that the opinions of people who have experienced mental health services vary greatly: the point of view of someone using short-term counseling is vastly different from that of a person who has been institutionalized for several years. In fact, the experiences are so

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different that Everett (1994) describes "consumers" and "survivors" with differing agendas and goals. Consumers are seen as reformists willing to work for incremental improvement, while survivors are freedom fighters who want liberation from the mental health system and to create alternative and holistic ways to alleviate human suffering. The interactions of the two groups are also different: consumers interact more with the mental health systems and less with each other, while survivors have more interaction with each other and less with the professionals.

Family members of persons with psychiatric disabilities also approach mental health service and policy issues from a different perspective. While mature mental health systems recognize that the viewpoint and opinions of family members are important, they also realize that family members should speak for themselves and not on behalf of the recipients of mental health services.

For the purposes of this chapter, we use the term *consumer/survivor* to describe the recipient of mental health services. We also define consumer/survivor as an individual who has experienced at least one night in a mental health facility or who has received services from the traditional mental health system.

Challenges of Consumer/Survivor Involvement

Mental health administrators who wish to involve consumer/survivors in meaningful ways face many challenges. One is the question of who represents the consumer/survivors. It is relatively easy for the mental health system to identify and involve those consumer/survivors who are willing to speak out and be identified. It is more problematic to define what is fair representation of the much larger number of individuals who do not speak out. This is a serious concern for administrators, as well as for organized and emerging consumer/survivor voices. It is clear that most people who utilize the mental health system do not speak out. It is less clear why they do not. Is it because they are fairly satisfied with the services they receive? Is it because they are afraid to speak out due to perceived or real threats of retribution? Is it because they are unable, due to their condition or the effects of medications? Is it because they are dealing with internalized oppression? Is it because they are concerned about further stigma? These are critical questions, and it is incumbent on both administrators and established consumer/survivors to consider them. One possible way to deal with this issue is through random customer-satisfaction surveys; another is a more proactive outreach to service recipients of existing service programs and facilities, with specific attention paid to people who are quiet.

The fact that many consumer/survivors do not speak out is sometimes used as a rationale to discount the opinions of those who do. Consumer/survivors find this attitude not only condescending to those who have chosen to speak, but also insulting to those who choose, for their own reasons, to keep quiet about their experiences. It is as easy to believe that outspoken people represent the broader experience, by extrapolation, as it is to believe that they do not. This is one area in which it is important for mature mental health system administrators to recognize that speaking out is often a difficult and painful process for consumer/survivors. For many, it means reliving experiences they might prefer to forget. For others, it means facing stigma and discrimination on a daily basis. To speak out should be seen as a strength, a task undertaken by those who are passionate about their experiences and about system change.

Mature mental health systems are also challenged to acknowledge the power imbalance and authoritarian culture in which the services have flourished. The long-held perception that people with psychiatric disabilities are unable to make decisions in their own best interest has resulted in professionals assuming power and control over decision making both for treatment planning and for policy making. Ridgeway (1988) reports that this contributes to consumer/survivors' feelings of internal chaos, self-doubt, powerlessness, and worthlessness. The mental health administrators are challenged to recognize that consumer/survivor attitudes of distrust, anger, or apathy are signs of internalized oppression created by these environments.

Many consumer/survivors speak about their experience as a service recipient in these environments and describe the process of internalizing oppression. Deegan (1990a, 1990b) calls this process "spirit breaking" and suggests that it results from the cumulative experiences of humiliation, being made to feel less than human, and receiving services in environments in which hopes are shattered. In these service systems, Deegan argues, apathy and indifference become a way of surviving. Blaska (1991) similarly describes the process of having one's dreams, hopes, and identity reduced to a three letter acronym, CMI, chronically mentally ill. Chamberlin (1978) and Unzicker (1989) describe the devaluation process they experienced in the mental health system and discuss the anger that was generated by that process.

Mental health administrators who are committed to designing systems that are more inclusive of consumer/survivors also face the process of raising their own consciousness without defensiveness, and with the intent to listen and validate the anger and frustration that many consumer/survivors exhibit. Many mental health administrators, policy makers, and researchers, including the coauthor of this article, report that their first step toward understanding the consumer/survivor viewpoint was to stop assessing and trying to diagnose the consumer/survivor and to start actively listening to what the person was saying.

Mental health systems are also challenged by the participatory demands of their clients and former clients and the reactions of their staff. It is difficult for professionals, who are trained to separate themselves from clients and who view interaction with clients in terms of transference issues, to welcome these same people into process-oriented activities like advisory committees and governing boards. It is even more difficult for some of them to consider hiring or integrating clients and ex-clients as equal staff members. As a result of this challenge, some systems are beginning to redefine the traditional boundaries in mental health. This issue is discussed in depth in Chapter Four.

Yet one more challenge faced by mental health systems as well as by consumer/survivors active in the mental health policy making arena is the fact that consumer/survivors are often discounted or marginalized for their status as recovered or recovering individuals. They often hear statements like: "You must have been misdiagnosed" or "You must have received some help, otherwise how could you function so well?" or "Well, you do not represent people in this system because you are no longer receiving services in this system" or "You are so much higher functioning than the clients in our system that you really can't tell us what kinds of services our clients need." The double bind that this places the consumer/survivor in is obvious: if you get well, you are really not representative; if you remain sick, you are too sick to be of any significant use or importance!

Framework of Collaborative Models

The concept of mental health consumer involvement, be it at the federal, state, or local level, is easier to conceptualize than to define and implement in concrete, measurable ways. The former Community Support Branch of the National Institute of Mental Health (now in the Center for Mental Health Services) has provided strong leadership in defining various methods of consumer involvement and empowerment. In the mid eighties, this branch begun funding consumer Alternatives Conferences as well as consumer service demonstration grants to states, and these initiatives continue today. Many of the ideas presented to this article have grown directly or indirectly from these efforts. Congress has also recognized the importance of the consumer/survivor perspective; the federal Mental Health Planning Act, PL 99–660 of 1986, required the state-level mental health planning councils established under this act to draw at least half of their membership from people who are neither state employees nor providers of mental health services. The guidelines to the states further require that the planning boards include adults who are receiving or have received mental health services. In 1989, the National Association of State Mental Health Program Directors approved a position paper on consumer contributions to the mental health delivery systems.

One approach to defining consumer/survivor involvement and collaboration in a mental health system is to focus on the involvement of consumer/survivors at four levels. These levels are policy and planning, service delivery, training and education, and consumer/survivor-operated programs (Curtis and others 1991; Human Resource Association, 1989; National Association of State Mental Health Program Directors, 1989). We feel that this framework can be applied at any level of the mental health service system from an individual program to a national system.

Consumer/Survivor Involvement in Policy Making and Planning. Many mature systems recognize that consumer/survivors are really not equal partners in the mental health system until they sit at the tables where policy and funding decisions are made. Several state mental health laws require consumer/survivor participation, often combined with family participation. In Wisconsin, for example, the state Mental Health Act requires that a family member or service recipient be appointed to the county mental health, substance, and developmental disability service governing boards. In New York State, the outpatient standards require that consumer/survivors participate in each program's governing body.

In the federally funded Protection for Individuals with Mental Illness programs that operate in every state, at least half of the membership of their advisory bodies must be consumer/survivors or family members. In addition, the chair of the council must be a consumer/survivor or a family member. However, advisory councils, while often useful, can only advise; they do not have the power of a governing board to make programmatic, policy, or fiscal decisions.

Tokenism is often prevalent on policy-making bodies, where there is representation of one or two carefully selected consumers who are passive or who agree with the agency agenda. These consumer/survivors are appointed to the decision-making bodies to meet the requirement for consumer/survivor participation or to demonstrate the progressiveness of the agency. In order to combat this kind of tokenism, it is suggested that a substantial number of members of the governing bodies be consumer/survivors. Curtis and others recommend a target figure of 50 percent consumer/survivors and family members, while the Human Resource Association recommends that at least one-third of members should be consumer/survivors. Mature mental health systems are also acknowledging the importance of the insights of those consumer/survivors who are perceived by the mental health system as being highly critical of the system or who are viewed as trouble makers. While their criticism is challenging for the mental health systems to seek out and hear, their ideas can and will improve the services available.

Leadership training for consumer/survivors is critical to combat another barrier to full participation: the tendency of nonconsumers to ignore the consumer point of view, or condescend, insult, or further stigmatize the consumer/survivor. The National Empowerment Center (Anderson and Deegan, 1992), the World Health Organization British Columbia Project (1993), and the National Mental Health Consumer Self-Help Clearinghouse (1988), along with several states, have developed resources that provide practical advice to consumers on how to be assertive and effective board members.

Financial considerations also lead to internal and external debates about the value consumer/survivors bring to policy discussions and how to compensate this value. Although consumer/survivors have places at the table, they may not be equal: while other policy makers attend as part of their jobs, consumer/survivors often miss meetings due to simple, practical matters like lack of funding for transportation, timing of the meeting during work hours, or lack of money for lunch. In order to overcome this practical barrier to consumer/survivor participation, mental health agencies are beginning to compensate consumer/survivors for travel expenses as well as for their expertise and input. We have seen this work quite well in Wisconsin, where consumer/survivor members of a statewide consumer policy making council are paid, in addition to their expenses, an honorarium of $150 per two-day meeting. The Wisconsin Bureau of Community Mental Health also pays consumer/survivors $10 per hour for participating in meetings of work groups and task forces established by the State Bureau of Community Mental Health. The level of commitment, input, and participation in these meetings has risen and stayed consistent. Moreover, the participants feel valued, though it is clearly stated that money is not and should not be the primary motivating factor for their involvement.

Another way to bring the voice of consumers into the decision-making processes of mental health agencies is the use of consumer preference studies and service satisfaction studies. In an effort to include Total Quality Management principles in mental health service delivery, the use of consumer satisfaction and preference studies has virtually exploded during the past few years. Tanzman (1993) identified forty-three studies in the United States and Canada that researched the preferences of mental health consumer/survivors regarding housing and support services. The New York Office of Mental Health reported in 1993 that it will conduct a consumer satisfaction survey of licensed outpatient programs throughout the state. In 1994, Wisconsin's mental health act was amended to require that during certification visits of mental health programs, the certifiers are to interview current service recipients to get their input. The City of Philadelphia Office of Mental Health has established a satisfaction survey team of consumer/survivors and family members that interviews recipients of mental health services and reports these results directly to the City Office of Mental Health (Mid Atlantic Regional Information Exchange, n.d.).

The involvement and input of consumers as evaluators and researchers is another significant aspect of note. In the examples mentioned earlier, both New York State and the City of Philadelphia employ consumer/survivors to conduct their studies ("What Makes a Mental Health Program 'User-Friendly'?," 1993). Tanzman (1993) reports on eighteen studies that used consumers or former patients to collect data on consumer preferences. Anagnos, McConnell, Chafetz, and Barto (1993) describe a program in San Francisco that uses community members as well as mental health service consumers to collect data to evaluate clinical services. Also, several qualified consumer-researchers on both coasts have begun to influence the research methods and the research agenda of many agencies. The Center for Mental Health Services has involved consumer/survivor-researchers in the Mental Health Systems Improvement project, an effort to improve state level mental health management information systems.

Some state mental health agencies have integrated recipients of mental health services into their top level management teams. People with firsthand experience in mental health services bring a unique perspective to the day-to-day decisions of a state mental health authority. Many state agencies have also found that a consumer/survivor on the staff of a mental health authority can function as a liaison and advocate between local consumer self-help programs and the state bureaucracy. An increased focus on Total Quality Management also underscores the value of consumer focus and input into the management decisions of a state-level mental health agency (Human Resource Association, 1993). While many states have consumer affairs offices, these offices are functioning at varying levels of success (Rogers, 1994), primarily depending on the commitment of the state mental health agency to make their efforts meaningful. There can be conflicts, ambiguities, and turf battles between a statewide consumer organization that advocates outside the state mental health agency and the consumer office that functions inside the state mental health agency. To address or avoid this problem, clearly defined roles are critical for the state mental health agency consumer offices, which should not presume to supplant grassroots consumer/survivor organizations at the state or local level.

Finally, we suggest one simple policy change that could revolutionize the mental health service system: no policy meetings should be held, at any level, without significant input from service recipients. We know of beginnings of this practice at least in the Philadelphia mental health system, where meetings have been rescheduled due to the lack of consumer participation (Richman, 1994). The Wisconsin Bureau of Community Mental Health (1993) biennial work plan for 1993–1995 states that no work groups or task forces may be established without including consumer/survivors on them. While this policy can be at first threatening to the existing power structure and cumbersome to implement, it can be an important first step toward true inclusion and empowerment of consumer/survivors.

Consumer/Survivor Involvement in Service Delivery. The involvement of consumer/survivors in service delivery takes place through several avenues: developing consumer-centered or consumer-directed treatment plans, involving consumer/survivors in protecting the rights of other consumers and survivors, and employing consumer/survivors in mental health agencies.

Consumer-centered services have been the central concept of the national community support program movement. Turner and TenHoor wrote in 1978 about the critical importance of consumer-centered services. Mature mental health systems continue to face the challenges of the embedded attitudes of both service recipients and professionals in an effort to equalize the power relationship and mitigate tokenism. One possible option is to hold ongoing dialogues between professionals and service recipients with the assistance of a good facilitator. This process allows for both to express their divergent points of view and to appreciate differences in perception and perspective. One example of this approach is Pioneer Dialogue conducted in 1992 in Fort Lauderdale, Florida (Florida Department of Health and Rehabilitation Services, 1992).

Mature mental health systems strive to develop a service delivery system that incorporates a belief in recovery, practices that underscore this belief, and programs that operate from this belief. Moser and Burti (1989, p. 108) outline a set of values that are consistent with this goal:

1. Do no harm.

2. Do unto others as you would have done to you (e.g., the same principles apply to client and staff; everyone should treat each other with dignity and respect).
3. Be flexible and responsive.
4. In general, the user knows best.
5. Choice, the right to refuse, informed consent, and voluntarism are essential to program functioning.
6. Anger, dependency, sexuality and development potential are acceptable and expected.
7. Whenever possible, legitimate needs should be filled.
8. Take risks; if you don't take chances nothing ever happens.
9. Make power relationships explicit.

A practical example of involving consumer/survivors in service delivery is using peer support in informed consent, especially to procedures that may be controversial, such as the administration of electroconvulsive therapy (ECT) or of medications with significant and problematic side effects like Clozapine. Many consumer/survivors are interested in the "other side of the story" in order to make a truly informed decision. It therefore seems practicable that this information could be provided by a peer who either has firsthand experience or who is well informed of the benefits and negative consequences of the proposed treatment.

There is a good deal of discussion about employing consumer/survivors as mental health service providers. Besio and Mahler (1993) discuss a number of benefits of hiring consumer/survivors as service providers, including their empathy and understanding, tolerance of unusual behaviors, ease of relating to the service recipients, knowledge of available resources, positive role modeling, and strong sense of responsibility for clients. The employing agencies also indicated increased insight about mental illness and increased level of sensitivity toward the experiences of consumer/survivors and reduction in community stereotyping of mental health consumers.

However, Besio and Mahler also report barriers to consumer/survivor employment, including issues of confidentiality, role confusion, employment stresses, reasonable accommodation, and stigmatization and distrust by nonconsumer staff. Furthermore, some systems have developed a separate-but-equal system with specific positions for consumers, such as "consumer case manager" and "consumer advocate." People holding these positions sometimes report having limited access to the files of the individuals on their case load, being specifically excluded from regular staff meetings, and perhaps more importantly, from the informal camaraderie and after-work gatherings of the nonconsumer staff.

Howie the Harp (1991), Shepherd (1992), and Stoneking (1992) have identified numerous ways to help consumer/survivors succeed in employment in mental health agencies. They recommend that agencies discuss employee performance in a timely manner, respecting and validating employee feelings and opinions, and develop accommodations that are mutually discussed and agreed upon by the employee and the employer. Necessary accommodations include things like providing flexible time off to deal with emotional upsets, and flexible work hours to accommodate the sleeping problems often associated with psychiatric disabilities. In addition, the agency should educate other staff members, and should pay special attention to the consumer employee's ability to retain benefits, especially medical coverage.

Another group of consumer/survivors who must be recognized are the professionals who have experienced psychiatric services firsthand. Many still remain in the closet due to stigma of mental illness and fear of the response of the colleagues and superiors to the staff person's disclosure of the psychiatric history. Fisher writes: "The concept and practice of people with psychiatric disabilities working in the mental health field is not new. What is new is that we are now openly describing our experiences so that others can learn what we have found valuable to our recovery" (1994, p. 67).

Mature mental health systems should be striving toward an environment where consumer/survivors are employed as staff and where staff who have firsthand experiences with the mental health system feel free and empowered to bring that experience forth to enrich and improve the services of the system.

Training and Education. Mature mental health systems value the expertise and insight of consumer/survivors, and involve them in systemwide training and education activities. They involve consumer/survivors as presenters and participants at preservice as well as inservice education of mental health staff. These systems enable and empower consumer/survivors to coordinate their own educational programs as well as to attend consumer/survivor conferences. Curtis and others (1991) describe setting a goal that no training is planned or provided by a mental health system without significant participation of consumer/survivors on the planning committee, as presenters and participants. In order to provide financial support to assist consumer/survivors attend the training, many mental health organizations provide for reduced fees or scholarships. A very practical way to assist consumers take advantage of available training is for agency staff to invite at least one consumer to attend each training event with them.

Mental health governing bodies are increasingly interested in hearing firsthand accounts, positive and negative, of persons who have used their services. This enables board members have a clearer sense of mission, purpose, and responsibility for developing and overseeing programs and services that are mandated by real needs. In Wisconsin, the state Council on Mental Health has set aside funds to enable consumer members of the Council make presentations to local civic groups and county mental health boards about their experiences in the mental health system.

Increasingly, consumer/survivors have also been able to get access to the classrooms of academic institutions as guest lecturers and sometimes co-lecturers with the faculty. The new generation of mental health professionals will truly have a very different view of the abilities of mental health service recipients when they have been taught by them in the classroom!

Consumer/survivors often find it difficult to take part in statewide or national consumer activities and conferences. To combat this problem, some mental health systems have set funds aside to help consumer/survivors attend these conferences. For example, attending the national Alternatives conference with several hundred other consumer/survivors can be a life-changing, empowering experience for a person who has struggled with psychiatric disability in isolation.

Consumer/Survivor-Operated Programs. The opportunities for peer support programs are virtually endless, from assisting patients entering a facility to community support of individuals with psychiatric labels. Consumer/survivors operate crisis safe houses in California, a crisis hostel in New York, drop-in centers in Vermont and Massachusetts, peer support telephone lines in Wisconsin, housing referral services in Ohio, homeless outreach services in Pennsylvania, cooperative educational programs for professionals in New York and case management programs in Oregon . . . the possibilities are literally limitless! Some consumer/survivor-operated self-help programs provide an alternative to formal mental health system services, while other self-help programs provide supports to the consumer/survivor in addition to those provided by the formal mental health system.

Chamberlin (1990, p. 331) writes in "The Ex-Patient Movement": "self-help is a concept, not a single program model. The concept is a means by which people become empowered and begin to think of themselves as competent individuals as they present themselves in new ways to the world. By its very nature, self-help combats stigma. . . . Self-help is not a miracle nor a cure-all, but it is a powerful confirmation that people, despite problems and disabilities, can achieve more than others (or they themselves) may have ever thought possible." Excellent manuals and reports have been written by consumer/survivors for consumer/survivors on how to start and maintain a self-help organization, including *On Our Own: Patient-Controlled Alternatives to the Mental Health System* (Chamberlin, 1978) and *Reaching Across: Mental Health Clients Helping Each Other* (Zinman, Harp, and Budd, 1987).

One of the major barriers to the development of a strong network of consumer-operated programs is the lack of solid, ongoing funding for such services. Often these programs are funded through time-limited special-project grants, and consumer/survivors rarely have the energy or financial resources to seek permanent funding. While there are pitfalls in accepting and using money from a government mental health agency, the availability of specific, ongoing funding is certainly a crucial issue if the consumer/survivor self-help movement is to be assured. Curtis and others (1991) suggest that mental health systems should set a target percentage, say 10 percent, of total system service funding for consumer-operated programs and then annually measure progress toward the designated goal. In Wisconsin, a portion of the federal Community Mental Health block grant has been permanently earmarked for consumer and family peer support and self-help activities. Several Wisconsin counties have further earmarked their own funds for consumer-operated programs.

Beyond First Steps

Most people with psychiatric disabilities simply want what other people want: a sense of belonging, an adequate income, a way to get around, and decent place to live (Ridgeway, 1988). It is also interesting to note that in the client preference studies, the majority of respondents rank "mental health services" low, but put a high value on the ability to reach a staff person any time day or night for help in dealing with emotional upsets (Tanzman, 1993). Ridgeway (1988, p. 22) goes on to state that: "The belief that clients cannot define their own need realistically or identify their own self interests is not borne out by studies that find clients to be careful, thoughtful and accurate informants."

Conclusion

Given the current state of mental health policy and practice in the United States, even mature mental health systems have a long way to go before they truly listen and hear what the consumer/survivors are telling them about the services that they need and want. Perhaps a useful definition of a mature mental health system, whether community based, state level, or federal, is a system that not only listens, but actively involves the input of consumer/survivors and promptly responds to the expressed needs and wants of its constituency. This philosophy has worked for thousands of successful businesses, and it seems sensible to think it will work for a mental health system that is committed to developing policies and services that are actually helpful to persons with psychiatric disabilities.

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SINIKKA MCCABE is director of the Bureau of Community Mental Health in the Wisconsin Department of Health and Social Services and is treasurer of the board of directors of the National Association of State Mental Health Program Directors.

RAE E. UNZICKER is an independent advocate and consultant in Sioux Falls, South Dakota, and treasurer of the National Association for Rights Protection and Advocacy. She was recently appointed by President Clinton to the National Council on Disability.