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# ENHANCING PERSONAL EMPOWERMENT

## PEOPLE WITH PSYCHIATRIC DISABILITIES

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For most of recorded history, people with psychiatric disabilities have struggled with maintaining personal power over their lives. The centuries-old battle against stigma is the best example of this struggle. The ancient Greeks first gave voice to the concept of stigma noting that those who were marked with mental illness were often shunned, locked up or, on rare occasions, put to death (Simon, 1992). During the Middle Ages, people with mental illness were viewed as living examples of the weakness of humankind, what goes wrong when people are unable to remain morally strong (Mora, 1992). This kind of attitude led families to hide away those with psychiatric disabilities from public view. Not until the 18th century did asylums and treatment centers emerge for mental illness. Before that time, those with serious and persistent mental illness were often locked up with criminals. Although the struggle for personal power has vastly improved during the last century, people with mental illness still encounter stigma and disempowerment. The recently released report by President George W. Bush's New Freedom Commission for Mental Health (2003) issues a clarion call for practices that facilitate consumer empowerment.

The goals of this paper are threefold:

- Provide a working definition of empowerment as applied to the lives of people with psychiatric disabilities.
- 2. Identify community and service systems barriers to empowerment.
- 3. Describe guidelines and other system enhancements that facilitate personal empowerment.

E H A B I L I T A T I O N

# "There is no medicine like hope, no incentive so great, and no tonic so powerful as expectation of

### Understanding Personal Empowerment

Empowerment has been defined as personal control over all domains of life, not just mental health care but also decisions related to such important areas as vocation, residence and relationships (McLean, 1995; Rappaport, 1987; Segal, Silverman & Temkin, 1995). This is especially important in societies that stigmatize persons with psychiatric disabilities. Western cultures, for example, seem to rob these persons of authority over treatment plans and life decisions (Brockington, Hall, Levings & Murphy, 1993; Link, Cullen, Frank & Wozniak, 1987). Research on the construct of empowerment leads to a better understanding of effective services and their impact on quality of life (Corrigan & Garman, 1997). Rosenfield (1992), for example, found a measure of consumer empowerment correlated with quality of life. Rogers, Chamberlin, Ellison and Crean (1997) completed a more comprehensive series of studies on mental health consumer empowerment with their Empowerment Scale. Items for the Empowerment Scale were first identified by a panel of 10 leaders in the consumer movement and then validated by participants in six self-help programs. An unpublished analysis of 261 responses to the scale, conducted by Rogers et al. (1997), yielded seven factors that describe the construct:

- self-efficacy,
- powerlessness,
- self-esteem,
- effecting change,
- optimism/control over future,
- righteous anger and
- group/community action.

These factors are intercorrelated and seem to correspond with two superordinate factors that describe the impact of empowerment on persons with schizophrenia and on their community (Corrigan, Faber, Rashid & Leary, 1999). These are:

something tomorrow."

### O.S. Marden 1850-1924

- The impact of empowerment on the self is such that, despite societal stigma, empowered consumers endorse positive attitudes about themselves. They have good self-esteem, believe themselves to be self-efficacious and are optimistic about the future.
- The impact of empowerment on the community is manifested by the consumer's desire to affect his or her stigmatizing community. Consumers believe they have some power within society, are interested in affecting change and wish to promote community action.

Readers may note that terms like empowerment and disempowerment are frequently interchanged in the remainder of this article. In part, this interchange represents empowerment as a continuum (Corrigan, Faber et al., 1999; Rogers et al., 1997). At the positive end of the continuum are people with psychiatric disability who, despite their disability, have positive self-esteem and are not significantly encumbered by a stigmatizing community. At the negative end are people who report being unable to overcome all the pessimistic expectations about mental illness. One might think that a paper about empowerment would be presented in the affirmative voice (e.g., What might people with mental illness, service providers and the community at large do to promote personal power?). Unfortunately, much of the research and literature on empowerment looks at the negative impact of its absence (What happens when a person with mental illness is disempowered?) (Corrigan & Garman, 1997; Rapp, Shera & Kisthardt, 1993). Hence, I have chosen to intertwine what is known about disempowerment with what is the vision of empowerment to address the themes of this article.

### BARRIERS TO EMPOWERMENT

Stigma is the societal embodiment of disempowerment; it promotes expectations in both the public at large and individual consumers that people with mental illness are incapable of the responsibilities commensurate with living independently. Results of two factor analyses on more than 2,000 English and American participants revealed three common themes to stereotypic attitudes about mental illness that endorse this assertion (Brockington et al., 1993; Taylor & Dear, 1981):

- Fear and Exclusion. Persons with severe mental illness should be feared because they are dangerous. As a result, they should be kept out of the community and housed in institutions.
- Authoritarianism. Persons with severe mental illness are irresponsible; life decisions should be made for them by others
- Benevolence. Persons with severe mental illness are childlike and need to be cared for.

These kinds of widespread attitudes have two effects on the power of persons with mental illness. First, they rob people of the opportunities that are central to recovery and a quality life (e.g., good jobs, comfortable income, nice housing and good friends). Perhaps of equal concern are the effects that stigma has on some people with

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**NOTE:** These are arrayed from those that minimally foster empowerment to those that more fully enhance personal empowerment.

### 1. From Noncompliance to Collaboration

A change in perspective from expecting consumers to passively comply with treatment to making careplans that are user-friendly.

### 2. Consumer Satisfaction and Other Input on Services

At the absolute minimum, programs that empower participants need to be satisfactory to those participants. Moreover, these programs need to obtain input from consumers to ensure that program design reflects their interests.

### 3. Lodges and Clubhouses

For more than three decades, the mental health system has supported treatment programs that were largely operated by persons with mental illness. Lodges are residential programs in this mold; clubhouses are social and work programs.

### 4. Supported Housing and Employment

Instead of the consumer going to the professional, the best treatment occurs when the professional travels to the consumer and all the places in which consumers need assistance. Provision of services in the person's home or community is the hallmark of Assertive Community Treatment (or ACT). Services in real-world job sites is supported employment.

#### 5. Consumers as Providers

Many persons with mental illness are deciding to return to school, obtain necessary credentials, and assume jobs in the mental health system as providers. In this way, they can change the system from the inside.

### 6. Self-Help, Mutual Assistance and Other Consumer-Operated Services

There is almost a 50-year history of programs developed by persons with mental illness to help peers. These programs provide places where people can provide and receive help from individuals with similar concerns.

### 7. Participatory Action Research

Much of the current research on psychiatric disability and rehabilitation reflects the perspective of the existing mental health system. Persons with mental illness must be equal partners in the research enterprise for future studies to represent the differing interests of consumers.

mental illness. People living with serious mental illness who are immersed in a culture that endorses psychiatric stigma begin to believe this stigma and question their own capabilities for independent living (Wahl, 1995). Because self-stigma has such an insidious impact, its effects on empowerment are examined first.

Some people experience stigma as a private shame that diminishes the person's self-esteem (Corrigan, 1998; Corrigan & Watson, 2002). This kind of shame leads to self-doubt about

whether the person is able to live independently, hold a job, earn a livelihood or find a life mate. Even though they may have mastered their symptoms and disabilities, people with mental illness must also overcome stigmatizing reminders that they still have a disability or are not useful members of society. One recent study showed the breadth of discrimination experienced by mental health consumers (Wahl, 1999). The majority of 1,300 respondents reported discouragement, hurt, anger and lowered self-esteem as a result of their experiences. An earlier study by Link (1982) showed the loss of self-esteem that results from stigma also has practical consequences. Participants in their study reported that being publicly labeled with a psychiatric illness had a negative impact on work and income.

### ACTIVITIES THAT FACILITATE EMPOWERMENT

Research has yet to examine strategies for overcoming self-stigma, but several candidates show promise

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(Corrigan & Watson, in press). Internalizing the kind of messages embodied in recovery may help to diminish self-stigma. Cognitive restructuring may also prove useful in helping people learn to challenge stigmatizing views they may hold of themselves (Corrigan, 1998; Haaga & Davison, 1991). Alternatively, selfstigma will diminish as a person's sense of empowerment improves. Seven sets of strategies have some empirical support for facilitating empowerment of people with mental illness (Corrigan & Lundin, 2001). Each of these is discussed more fully in the remainder of this article.

Empowerment may be construed narrowly in terms of control over the services that help people deal with their disabilities (e.g., problems related to mental illness). It may also be understood more broadly in terms of command over all spheres of one's life, such as succeeding at work, in relationships, during play, spiritually and in as many other domains as possible. Table 1 lists seven strategies that facilitate empowerment. These are loosely ordered from those that should now be obviously accepted by the mental health system — they represent the base of empowerment approaches (like issues about collaboration and consumer satisfaction) - to those that are visionary and need to be more widely accepted and disseminated, such as consumer operated services and participatory action research.

### 1. From Noncompliance to Collaboration

Many mental health providers must drastically reconceive their viewpoint about the consumer's relationship with treatment for empowerment to occur (Fenton, Blyler & Heinssen, 1997; Ruesch & Corrigan, 2002). The old notion was that persons with mental illness should comply with all aspects of treatment: Professionals knew best; anything that strayed from the prescribed treatment program represented unclear thinking due to the illness. Failure to comply was in-

dicative of unconscious motivations to resist health. Mandatory treatments and a coercive system rested on these assumptions. Research evidence seemed to clearly support these conclusions. Depending on the study, anywhere between two-thirds and three-quarters of persons did not take their psychiatric medications as prescribed. More than half of all participants in rehabilitation and similar psychosocial programs did not complete the treatment plan as agreed (Cramer & Rosenbeck, 1998). These data suggest resistance is rampant and significantly undermines treatment of serious psychiatric illness.

Considered another way, however, these data might be perceived to yield completely different conclusions. Rather than 66 to 75 percent of persons taking their medication incorrectly, perhaps two-thirds to three-quarters of all mental health providers are prescribing drugs poorly. Lack of compliance may not represent resistance by a person with psychosis as much as meager treatment by the mental health team. Equally sobering statistics suggest that more than 70 percent of all persons who are prescribed any kind of medicine (not just psychoactive drugs) do not take it the way the doctor ordered (Rogers & Bullman, 1995). Clearly, incorrect use of medication is not solely a problem of persons with mental illness.

Rather than expecting persons to passively comply with care — be it psychiatric care or general medical treatment - what is needed is more enlightened practice that calls for collaboration between providers and consumers. An equal partnership occurs when each party learns from the other: Providers learn about the nature of specific symptoms and corresponding disabilities from the person challenged by these problems; consumers learn the range of treatments and services that address these problems. How do providers and consumers foster a collaborative working relationship? More than a decade ago, we wrote a paper that outlined

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Table 2: Barriers to Collaboration and Ways to Overcome Them

### **BARRIERS** WAYS TO OVERCOME BARRIERS TREATMENT TECHNIQUES NASTY SIDE EFFECTS OF Use new generation of medications that reduce side effects. MEDICATION. Use low-dose medication strategies. Educate consumer to side effects and teach self-tracking strategies. COMPLEX TREATMENT PLANS. Engage consumers in central role in designing treatment plan. Use simple language. Clearly explain steps of treatment Begin simply and slowly; add more complex steps gradually. LONG-TERM TREATMENT. • Regularly assess goals and relevance of treatments to these goals. Provide treatment holidays. Consider place-train options.

#### TREATMENT DELIVERY SYSTEM

**DEPRESSING AND DINGY** ATMOSPHERE OF CLINICS.

- Improve clinic decor and ambience.
- Offer coffee and refreshments.
- Require all staff (including clerks) to be courteous and respectful. Move most services to the consumer's home or other setting.
- LONG WAITS AT CLINICS.
- Maintain realistic schedules.
- Send reminders to consumers.

#### PROVIDER-CONSUMER RELATIONSHIPS

STYLE AND LACK OF INTEREST IN CONSUMER FFFDBACK.

- **PROVIDER'S POOR INTERPERSONAL** Alert administrators about poor provider style.
  - Educate providers about the importance of "collaborative" roles.
  - Educate providers about the need for consumer satisfaction.
  - Pair provider with mentor for remediation.

### **FAMILY-CONSUMER CHARACTERISTICS**

LACK OF KNOWLEDGE OF OR TREATMENT.

- Educate consumers and family members to treatment options.
- **UNREALISTIC EXPECTATIONS ABOUT** Provide opportunities for consumers and family members to share concerns.

Adapted from Corrigan, Liberman & Engel (1990).

strategies for answering this question (Corrigan, Liberman & Engel, 1990), which are summarized in Table 2. As outlined in our earlier paper, these strategies have some empirical support for fostering the collaboration among providers and consumers.

### 2. Consumer Satisfaction and **Other Input on Services**

One of the assumptions of empowerment and collaboration is that treatment teams will design interventions and programs that are pleasing to participants. Hence, assessing consumer satisfaction is a minimal requirement for establishing programs that empower consumers (Corrigan, 1990;

Dickey & Sederer, 2001). Although one might think this to be a straightforward process, assessing consumer satisfaction is more difficult in actuality. Hence, some rules for developing a useful consumer satisfaction scale are provided. Unfortunately, concern with consumer empowerment frequently ends with the assessment phase. Programs collect data on satisfaction but subsequently fail to use it in improving services. A second important part of this process is to consider ways to use information from satisfaction evaluations to further improve the setting.

What goes into a consumer satisfaction scale? When evaluating consumer satisfaction, satisfaction

scales should consider four categories or domains: the service environment, the service providers, specific interventions and preparation for autonomy (Corrigan, 1990; LeBow, 1982). What is the quality of the service environment? Are the rooms pleasant, including the decor, lighting, furniture and temperature? If food is provided, is it tasty and plentiful? How are the service providers? Are they knowledgeable and competent in their specific jobs? Are they approachable, respectful and friendly? Can the consumer interact with them informally? How useful are specific interventions themselves? Do they provide the consumer with the

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needed skills? Do they help the consumer better understand his or her goals? Do they provide the resources and support needed for goals? Is the service preparing the consumer for autonomy? After finishing the program, is the consumer better able to live independently? Is he or she more hopeful about the future?

Unfortunately, this approach to assessing satisfaction can lead to "halo" or "devil" effects (Corrigan & Jakus, 1993a,b). Halo effects occur when the consumer rates everything as satisfactory: The program was great, the staff were great, the food was great, the building was great, everything was great. Research has shown that halo effects are very common in consumer satisfaction studies. Although some services may indeed be satisfactory, rating everything highly does not help to identify those components that need to be changed. Service providers would not know where to put their efforts in improving services. Devil effects are provided by people who are angry with the program. They rate all components as highly dissatisfactory. The program was poor, the staff was lousy, the food was rotten, the building was dingy, everything really stunk. Like the halo effect, rating everything alike (in this case, poorly) does not help providers focus on specific aspects of the program.

To avoid this problem, consumers may be encouraged to compare a specific program to another similar service in which the person has been involved in the past (Corrigan & Jakus, 1993b). For example a counselor might request the following from a client:

"Currently, you are participating in the Opportunities Program on Supported Employment. Tell me another similar program you have participated in the past. Write it here

Now answer the following questions by comparing your experience in Opportunities with this other program."

Research has shown this kind of comparative approach yields to better dif-

ferentiation among components of a program (Corrigan & Jakus, 1993a,b).

Having input on services. The full benefit of evaluating consumer satisfaction will only be realized when providers use the results from these evaluations to actually change services. Unfortunately, this kind of program improvement is frequently done without consumer input. Instead, treatment providers take the findings and decide how to improve program aspects on their own. This kind of approach fails to promote empowerment. The preferred way to handle findings from satisfaction evaluations would be to involve participants in focus groups where they discuss their concerns about aspects of the program and, more importantly, provide recommendations for ways that the program might improve (Rogers & Palmer-Erbs, 1994).

There are two essential roles to fill in these kinds of focus groups: the leader and participating members (Morgan, Krueger & King, 1998). The best leaders for these groups are other consumers who are trained to facilitate these kinds of groups. Although traditional service providers may have skills for running discussion groups like these, members might be hesitant to speak freely because they believe the provider will be biased in favor of the established program. Many consumers are able to lead these groups after one hour of training. We do not have the space here to consider the skills for a focus group leader; the interested reader should consider such resources as Bernard Bass's and R.M Stogdill's Handbook of Leadership (1990).

Focus groups should comprise six to eight members. A good mix of people with different opinions should be invited to the focus group. Include consumers at both ends of the scale — persons who are fully satisfied with the program and those who are highly critical — as well as individuals in the middle. In this way, a polite contrast of opinions is possible. Prior to the meeting, leaders should develop a series of questions to guide the discussion. These questions should be

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based on the results of the consumer satisfaction evaluation.

### 3. Lodges and Clubhouses

Consumers have obtained further control of the mental health system and their world in two kinds of programs: lodges and clubhouses. In both settings, people with mental illness have equal authority to that of the professional staff in operating the program. Lodges were started in the 1960s by George Fairweather as residential and work communities for persons recently transferred from long-term hospitals. Clubhouses spontaneously emerged in New York City as a meeting place for people recently discharged from the state hospital. Both of these models represent consumer dissatisfaction with the way mental health providers acted towards persons with mental illness. This dissatisfaction led to a philosophy that clearly echoes the importance of empowerment.

The Fairweather Lodge: Living and working together. The lodge is made up of persons with psychiatric disabilities who live and work together (Fairweather, 1969). Typically, lodges form real-world businesses to maintain themselves (e.g., janitorial services, bulk mailing, copy centers, or temp agencies). Sometimes, lodges hire non-disabled people who demonstrate expertise in areas needed to maintain the business. They may also seek professional help to serve as "consultants" to lodge members, to provide assistance in those psychiatric and rehabilitation strategies needed to help members manage their symptoms and disabilities.

The lodge program is built on several principles that clearly reflect the spirit of personal empowerment (Fairweather, 1969). These principles have been divided into two sets:

- those that help the consumer fill the role of lodge member (living and working with peers); and
- those that help the lodge develop norms which make it a thriving community (or what Fairweather called "a social subsystem").

People are more willing to embrace a role when they have a stake in it. In other words, living and working with others has to satisfy what the person wants and needs in his or her life now. This means the person needs to have autonomy in his or her role within the lodge. At the minimum, a person's role needs to be voluntary. People cannot be court-ordered to a lodge or sent against their will. In addition, people need the right to self-determination: namely, the opportunity to decide for one's self how to meet his or her responsibilities in the lodge community.

It is the nature of interaction that there be some hierarchy among social roles. Some people need to be supervising others to make sure all needs of the lodge are met. Another principle of lodge programs is that all members have the opportunity to be promoted to leadership jobs and thereby experience the benefits, as well as the demands, of different roles throughout the hierarchy. At the same time, all roles within the lodge must be filled. In this way, the community is assured that all tasks of the lodge are covered.

There is an interesting contradiction between the goals of autonomy and the demands of operating a residential and work community. How does the lodge balance each person's right to self-determination with the community's need to get all its work done? The second set of principles suggests development of community norms that seek this balance. One of the major rules of the Fairweather Lodge is "Members are encouraged to do things as a group" (Fairweather, 1969). Proponents of the lodge program believe that its strength lies in sharing both good times and tough decisions among all members. Group discussion is central to the empowerment and personal growth experienced in this setting. Unfortunately, a second principle of the lodge recognizes that this group must be limited in size. The community can only serve a small number of people in order to meet their work and home needs satisfactorily. This

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can be a sobering thought for some lodge members; namely, that their community is closed to many others like themselves who are also in need (Corrigan & Garman, 1997).

The success of the community occurs in a complicated balance between norms. On one hand, the norms of the program must correspond with those of the larger society in which the lodge finds itself. Basing lodge rules on those in the larger society makes sense because these are the rules with which community members are likely to already be familiar. For example, "respect privacy" and "do not steal" should be two familiar rules to most Americans and therefore be incorporated into the norms of lodges in the United States. The lodge also needs to develop norms that reflect the unique character of its community. For example, the prime rule, "Members are encouraged to do things as a group," is not reflected in Western society as a whole. However, proponents of the lodge program believe this kind of norm is essential for the unique atmosphere needed to develop a community of living and working peers. In like manner, each community needs to consider as a group what other particular rules it will adopt to meet the individual needs of its members.

The Fountain House: A clubhouse for persons with mental illness. During the years after the end of World War II, many people were released from Rockland State Hospital, located outside of New York City, with no community connections. In order to survive, they would meet on the steps of the New York Public Library to provide one another with resources and support. Soon, the group gained notoriety and other persons released from Rockland joined them in this makeshift society they called WANA: We Are Not Alone. In 1948, the group bought a building through the generous donations of a Jewish women's philanthropic group. The building had a fountain in the back yard; hence its name, Fountain House. It was built around a fundamental philosophy:

"Men and women with mental illness have the right to a life which includes access to meaningful, gainful employment; a decent place to live; a community of support; the opportunities for education and recreation offered by the communities in which they live; and the chance to be needed, wanted and expected somewhere everyday" (International Center for

Clubhouse Development, 1948). Several values characterize the clubhouse. In some ways, these principles overlap with the lodge model; in other ways, they reflect the special charm of social clubhouses (Macias, Barreira, Alden & Boyd, 2001). Persons belonging to the clubhouse are members rather than consumers. They have equal power with the professional staff hired to support clubhouse activities, not only in daily operations but also in decisions about budgetary issues. With membership comes responsibility. All members are expected to contribute to some aspect of the clubhouse's operations. Clubhouses are designed so that each member is essential for efficient operation. The fully collaborative nature of staff and consumer leads to all members being considered co-providers.

Clubhouses are open every day of the year. Unlike mental health centers, which typically close for holidays, clubhouses are open for their members to celebrate. Clubhouses also provide a wide variety of opportunities, including housing, education, social support, recreation and vocational training and placement. Services are never pressed upon members. Rather, they are used as the individual sees fit. Clubhouses operate according to a work-ordered day with normal 9 to 5 schedules (Besancon & Zipple, 1995). Each day, members (consumers and staff alike) decide among a variety of work units that comprise the necessary tasks to keep the clubhouse running effectively. Work activities at Fountain House have included horticulture, thrift shop, snack bar and dining room, clerical work, education, and research. Participation in this kind of activity reacquaints members with the demands of the work world as well as its many benefits.

### 4. Supported Housing and Employment

Even though lodge and clubhouse programs have many values that promote empowerment, they still require consumers to go outside their home "turf" to receive services. Programs of Assertive Community Treatment (PACT) turned the service world upside down (Bond, McGrew & Fekette, 1995; Mueser, Bond, Drake & Resnick, 1998; Stein & Test, 1980). Instead of demanding that consumers go out of their way to the offices of providers, why not bring services to the consumers where they need it, such as in their homes or anywhere that the consumers might deem necessary for resources and support? PACT proponents believe the entire range of services — medications, psychotherapy, skills training, money management and the rest can be and should be provided in the person's home or community. A variation of this idea is supported employment, where a job coach provides services alongside the consumer at his or her place of work (Bond, Drake, Mueser & Becker, 1997; Drake et al., 1999).

PACT and supported employment facilitate empowerment in several ways. First, these programs are consumer-centered. Services are defined by the needs of the consumer, not by the provider. Although this may seem obvious now, this value was revolutionary when first proposed. In the past, treatment plans reflected what was best for the consumer AND the provider. Hence, a person would not be referred to an independent housing program if it were outside the case manager's district. A consumer would not begin competitive work until the agency had an available job coach. Consumer-centered services remind the provider that it is up to the agency to A M E R I C A

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find the necessary resources and supports to help consumers achieve their goals on their timeline.

PACT and supported employment are also strengths-oriented (Rapp, 1998). This view differs from the disease model that dominates traditional services. Proponents of the disease viewpoint believe that people are defined by their symptoms and other weaknesses that need to be fixed through treatment. The strengths model recognizes that people are described by their skills, not their shortcomings. Awareness of these skills is essential; these are the tools that people use to accomplish their goals. Providers who are consumercentered make interventions as convenient and efficient as possible. Hence, PACT is comprehensive and cross-sectional. That is to say, it provides services across all domains of need: housing, finances, family, health care, spiritual matters and recreation.

PACT and supported employment are also longitudinal. By this we mean that the needed service is provided by a single team as long as the person needs it. In the past, mental health providers used to have the bad habit of ending services at times not convenient for the consumer. Today, PACT and supported employment continue as the person changes homes or moves in and out of institutions. Sometimes, services are provided indefinitely. Mental health systems of the past had the unwise practice of discontinuing community services for those individuals who had to be hospitalized because of short-term psychiatric emergencies. Unfortunately, these people had to start over with a new team when released a few weeks later. The PACT and supported employment team continue to offer support and resources even while the person is hospitalized or involved in the criminal justice system (Bond, Drake, Mueser & Becker, 1997; Mueser, Bond, Drake & Resnick, 1998).

Effective PACT and supported employment is accessible and available.

This means services are provided in places that are convenient to the consumer, typically in his or her home or place of work. Moreover, service is provided at times that make sense to the consumer. The provider does not ask the person to stay home from work so that the provider may come to the consumer's apartment to discuss shopping. Instead, the provider comes in the evening when the person is home from work and has eaten dinner.

### 5. Consumers as Providers

What better way to influence the system that provides services than for people with mental illness to assume jobs as providers in these services? In this spirit, consumers have filled almost every conceivable position in the mental health system (Mowbray, Moxley, Jasper & Howell, 1997; Solomon & Draine, 2001). Consumers have become job coaches, they have worked on assertive community treatment teams and they have run support groups. Consumers have also worked at all the professional levels that comprise the treatment team, as psychiatrists, psychologists, social workers and psychiatric nurses. Several well-known consumer advocates have cut their teeth as mental health professionals. Daniel Fisher is a psychiatrist; Fred Frese is a psychologist. Each of these gentlemen has gone through more than 20 years of struggling with the psychiatric disabilities resulting from schizophrenia.

Having consumers as mental health providers yields several significant benefits for the individual consumer as well as for people with mental illness in general. At the broadest level, consumers as providers challenge stigmatizing notions about people with mental illness. Public understanding of consumers reaches beyond the simple idea that they are psychiatric diagnoses. Despite their disabilities — or perhaps because of them — people with mental illness are able to support peers with mental illness by providing them with knowledge about psychi-

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atric symptoms, skills to deal with these symptoms and resources to meet their goals. These abilities challenge the notion that people with mental illness are incompetent.

Consumers assume roles that traditional providers frequently will not do or are not able to do well. Many jobs related to supported employment and programs of assertive community treatment require long hours and travel into places that are less than desirable. Most people are not willing to meet these challenges unless they have experienced the same struggles. There are some tasks that only consumers can provide. One of these is the "I've been there too" kind of support. Those in the throes of depression or anxiety receive immeasurable benefits by hearing from a peer who has been in the same situation, survived the challenge and thrived to become a mental health provider. There is one last aspect to consumers becoming providers which must be highlighted: Providing help to others reaps significant benefits for the helper. This is the principle of mutual help that is discussed more in the next section.

### 6. Self-Help, Mutual Assistance and Other Consumer-Operated Services

Consumer-operated services differ from the earlier service model in that they are entirely developed, operated and provided by and for people with mental illness (Davidson et al., 1999; Solomon & Draine, 2001). Consumer-operated services are not just another form of clinical treatment (Luke, Roberts & Rappaport, 1994). Clinical treatment reflects a medical model: People seek out services to resolve symptoms (Corrigan & Penn, 1997). Clinical treatment features a hierarchy between healer and person in clinical settings; healers have some special power that they use to help patients resolve problems. The relationship between healer and patient is expected to end when symptoms remit. Consumer-operated programs

have been likened more to communities with life-long histories (Maton, Leventhal, Madara & Julien, 1989) or to grassroots information and support systems (Meisen, Gleason & Embree, 1991). Mental illness may be the common experience that draws people to consumer-operated services. But unlike traditional clinical treatment, this is not where the impact of consumer-operated services ends. Consumer-operated services place an extraordinary value on peer support, hope and recovery (Van Tosh & Del Vecchio, 2000). Consumer-operated services seek to provide safe settings where a person can find the necessary understanding and recognition that society at large is not able to give. In the ideal, there is no hierarchy of roles in consumer-operated programs; members are peers benefiting from interactions with equals. There are no limits placed on the amount of time a person can be involved in a program. Depending on personal needs, some members come and go from consumer-operated programs, while others may stay connected for years (Durman, 1976; Luke et al., 1994).

#### Types of Consumer-Operated Services.

Three kinds of programs comprise the consumer-operated services: consumer-run drop-in centers; peer support programs; and education and advocacy programs.

Consumer-run drop-in programs provide an open venue for consumers to receive a variety of services as needed in a specific location that is open at set times during the day and week. Individuals participate in drop-in activities on a voluntary, at-will and non-coercive basis. Service components parallel the gamut of traditional mental health activities and may include assistance with entitlements, medication education, clothing, bus or transportation passes and moving. Peer support programs are typically

Peer support programs are typically individual or group-based assistance and encouragement

organized around a worldview or 12-step approach that is consistent with empowerment and recovery. Peer support programs, like dropin centers, may tackle a broad range of work, housing, health and relationship goals that are needed by participating consumers.

Education and advocacy programs operate under the belief that consumers with knowledge about mental illness and psychiatric services are best able to address their own disabilities as well as to fix what is wrong with the mental health system. Education and advocacy programs use welldefined curricula to teach consumers this kind of information, usually in short-term classroom settings. The education and advocacy program model also relies on peer support to accomplish its goals (Corrigan & Lundin, 2001).

### 7. Participatory Action Research

The purpose of research is to discover what kind of outcomes result from providing a specific intervention program (for example, Programs of Assertive Community Treatment) in a certain way (e.g., using a team of providers instead of individual case managers) with a specific group of consumers (e.g., persons with mental illness recently released from prison). Research is meant to answer questions about programs. Traditionally, this kind of research is completed by academic experts, people with many years of education leading up to a doctorate in social science or medicine and working as a professor in a university. There is widespread belief that social science requires many years of study in statistics and research methodology and can, hence, only be completed by these kinds of experts.

Many consumers believe that this kind of "scientist as expert" view actually causes problems of its own and diminishes empowerment (Rogers & Palmer-Erbs, 1994). They A M E R I C A

describe a "blame the victim" mentality that permeates much research. According to this mentality, traditional research shows how persons with serious mental illness lack skills, lack work histories, lack motivation, lack family ties, and so on (Rapp et al., 1993). It is these person-centered deficits that account for all the individual's problems and hence should be the focus of research and services.

This point may be better understood if we consider how research in other disabilities — blindness for example - has developed over time (Whyte, 1991). As the result of forceful input from persons who are blind, researchers realized that teaching people how to live with their impairment is not enough. We also need to change the environment so that those who are blind can get around more easily. Research in this area led to Braille in elevators, crosswalks that beep, and better use of dog guides. This kind of research is only going to be accomplished when people with disabilities are full partners.

Participatory Action Research (PAR) describes how researchers and consumers become partners in studying mental illness and appropriate treatment (Rogers & Palmer-Erbs, 1994). PAR calls for a significant change in the roles of consumers and professionals, calling for consumers to actively investigate research hypotheses themselves and enlist trained researchers as consultants to their projects. The goal of PAR is to advance research that supports the fundamental assertions of consumer empowerment. Instead of asking typical research questions (e.g., How does the consumer fit into society?), PAR examines questions such as: What must society provide in terms of resources and accommodations in order to enable the consumer to also be one of society's resources?

Participatory Action Research is no longer a pipe dream. Many federally funded research efforts have incorporated the priorities of PAR into their

guidelines. For example, several largescale projects funded by the U.S. Substance Abuse and Mental Health Services Administration (SAMHSA) require a consumer advisory panel to have an active partnership in planning and implementing its research projects. As a result, most decisions that govern the projects are made through a sometimes tortuous exchange between the consumers on the project and the science investigators. The result is a research project that represents the best interests and insights of consumer empowerment.

### **SUMMARY**

When President George W. Bush released the final report of the New Freedom Commission on Mental Health in 2003, the commission's charge was to evaluate the state of the American mental health system and propose a guiding vision for the years to come. Central to its message was the idea of empowerment; that a successful service system must rest on personal decision making by the individual who is to benefit from services. The commissioners also noted that evidence-based practices are essential for America to enjoy a highquality care system. This article contains a review of seven evidencebased approaches promoting individual empowerment for consumers of mental health services. With the charge of the president's commission and the continuing research and development that its report will hopefully generate, empowerment and the greater achievement of life goals for people with mental illness will only blossom.

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A U T U M N

R E H A B I L I T A T I O N

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