Illness Self-Management Strategies

A guideline developed for the Behavioral Health Recovery Management project.

Patrick W. Corrigan University of Chicago Center for Psychiatric Rehabilitation

Patrick Corrigan, Psy.D., is Professor of Psychiatry at the University of Chicago and executive director of the University's Center for Psychiatric Rehabilitation. Corrigan is also director of the Chicago Consortium for Stigma Research, an NIMH funded-research center comprising six Chicago area academic institutions. Corrigan is editor of *Psychiatric Rehabilitation Skills* and recently authored *Don't Call Me Nuts! Coping with the Stigma of Mental Illness* published by Recovery Press.

The Behavioral Health Recovery Management project is an initiative of Fayette Companies, Peoria, IL; Chestnut Health Systems, Bloomington, IL; and the University of Chicago Center for Psychiatric Rehabilitation.

The project is funded by the Illinois Department of Humans Services'
Office of Alcoholism and Substance Abuse

Personal empowerment is a key component of the recovery process. People with serious mental illness and psychiatric disability must have a central role in all aspects of assessment and treatment planning for services to best help them accomplish their life goals. This guideline reviews three sets of strategies that facilitate this mission.

- Motivational strategies that help consumers understand their goals and build relationships with service providers;
- Educational approaches that arm consumers with information and skills so they are better able to make decisions about their treatment options; and
- Consumer-operated programs: intervention services that were developed BY consumers
 FOR consumers.

RATIONALE FOR ILLNESS MANAGEMENT STRATEGIES

There is a long history in medicine of teaching persons with medical diseases and their families about illness in order to increase one's control over recommended treatments and to manage the symptoms and disabilities that result from the disease (Hanson, 1986; Mueser, Corrigan et al., in press). Education-based approaches are especially common in the treatment of chronic illnesses such as diabetes, heart disease, and cancer. Within the mental health field, didactic methods for educating consumers have been referred to as *psychoeducation* (Anderson, Reiss, & Hogarty, 1986). *Illness management* strategies help consumers collaborate with professionals in the treatment of their mental illness, to reduce their susceptibility to relapses, and to cope more effectively with their symptoms.

There are a variety of illness management strategies developed by consumers (e.g., Mary Ellen Copeland and Daniel Fischer) and others (e.g., Boston University's Recovery Workbook)

that show great promise but do not have empirical support. The guidelines reviewed here are limited to those with either rigorous qualitative or quantitative support. We briefly review the evidence base for each set of strategies followed by a more comprehensive discussion of practice guidelines that illustrates the principles and mechanics of each approach.

IDENTIFYING GOALS THROUGH MOTIVATIONAL INTERVIEWS

Proponents of psychiatric rehabilitation believe that effective services begin with an assessment of the person's goals (Anthony & Liberman, 1992; Bachrach, 1992; Mosher & Burti, 1992). Goal assessment assures that the focus of treatment is driven by the consumer's perceptions of important needs. Consumer advocates believe the kind of personal power embodied in goal assessment is essential for people with severe mental illness to regain equal status and independent living in their community (Chamberlin, 1984; Deegan, 1992; Fisher, 1994). A variety of methods have evolved to assess goals (Brewin & Wing, 1993; Corrigan, Buican, & McCracken, 1995; Marshall, Hogg, Gath, & Lockwood, 1995; Phelan, Link, Stueve, & Moore, 1995); typically, they combine open–ended questions about the person's needs with Likert scale ratings about the importance of these needs. Unfortunately, these methods frame goal identification as a yes/no determination; e.g., "yes, obtaining supported housing is important to me and I'd like some assistance in this area" or "no, I don't want to change my work experiences now." Rather than viewing a specific goal as a categorical decision, a more comprehensive picture may be obtained by considering the profile of factors that motivate and discourage a specific decision. For example, what are the advantages and disadvantages for a consumer to change his or her current work setting. This kind of assessment helps the person to identify specific barriers to achieving goals as well as the personal benefits related to that pursuit.

Motivational interviews help the consumer consider the various costs and benefits of specific life goals.

Basics of the Motivational Interview

Motivational interviewing combines the fundamentals of behavior analysis with principles from Rogerian therapy (Miller & Rollnick, 1991). Behavior analysis is an assessment strategy in which the clinician identifies rewards (i.e., advantages) and punishers (disadvantages) that affect a specific behavior. The list of rewards describes reasons why the person might take on the effort of a new behavior. For example, Paul Simpson, 43 years old, unmarried, and with an 18-year history of schizophrenia, is considering whether to date. Benefits of dating, identified by Mr. Simpson, are listed in Figure 1. The list of punishers provides reasons why the person might not consider giving up the behavior. These are the barriers to taking on a new behavior like dating.

Figure 1

Figure 1. Motivational interview worksheet. In this exercise, Paul Simpson has listed the costs and benefits of dating.

Name	Paul Simpson	Date	May 21, 1	999	
Write down the disadvantages and advantages of <u>dating</u> .					

DISADVANTAGES	ADVANTAGES		
The girl will make fun of me.	I'll meet someone nice.		
I can't afford it.	I might do something fun.		
I get nervous in public places.	I can double date with friends.		
My parents won't approve.	I might fall in love and marry.		
I don't have dating skills.	I'll stop being shy.		
	I'll get out of the house.		

In motivational interviewing, clinicians help the person identify the profile of rewards and punishers that affect the specific behavioral goal. The clinician might use a form like the one in Figure 1 filled out for Paul. The list of rewards and punishers defines a decisional balance sheet. If the advantages of behavior change outweigh the disadvantages, the person will engage in activities that facilitate and overcome barriers to change; e.g., Mr. Simpson might enroll in a dating group to improve his interpersonal skills. If, however, the disadvantages outweigh the advantages, then the person will not be motivated to change.

The decisional balance also suggests ways in which the person might move towards adopting a behavioral goal. Remember that the disadvantages outlined in a motivational interview are the barriers to adopting that behavior. For example, Mr. Simpson identified five reasons why dating might be a problem for him including the risk that women might make fun of him or that he cannot monetarily afford to take them out. Strategies that diminish these costs will predispose the person to pursue the goal. Hence, Mr. Simpson might be more likely to date if he could learn strategies for identifying women who are friendly and supportive rather than belittling and sarcastic.

Practitioners might mistakenly assume the purpose of motivational interviewing is to use the list of advantages and disadvantages to <u>logically</u> prove that a client's goal is either attainable or unattainable. Clinicians with this perception might unwittingly take a heavy hand, forcefully listing advantages when the person is unable to identify them. "C'mon Paul. You know dating is the only way to get out and meet people. Admit it!" Unfortunately, motivational interviewing has now become confrontational and suffers significant pitfalls as a result. Miller and Rollnick (1991) believed the value of motivational interviewing lies in persons <u>discovering</u> the advantages and disadvantages for themselves. Therefore, they outlined five principles to make sure the

client's perceptions of a goal are obtained. (1) Express empathy. Clinicians use the Rogerian skill of reflective listening to help clarify the person's experience of advantages and disadvantages. This method communicates acceptance of the client that frees him or her from having to rationalize their reluctance to make change.

- (2) Develop discrepancy. Clinicians help clients understand how failing to change behavior blocks important personal goals. An attitude of discovery is encouraged rather than a confrontational approach. Mr. Simpson discovers for himself the disadvantages of dating, especially in terms of life goals. (3) Avoid argumentation. Even when using a nondirective approach like motivational interviewing, clients are going to continue to deny the importance of behavior change. Clinicians need to avoid these traps and not engage the person in an argument about whether something is really a disadvantage.
- (4) Roll with resistance. Resistance is an indication that the clinician is addressing issues that the client does not perceive to be relevant or important. Miller and Rollnick remind the clinician that the client is an excellent resource for determining how to get back to barriers to change. Have the client solve this kind of difficulty using his or her own resources. (5) Support self-efficacy. The client is responsible for deciding to change. Clinicians should have confidence that their clients will decide to change when ready. Only then are persons able to participate in a program to successfully reach their goals.

Barriers to the Motivational Interview

Persons with severe mental illness may have several disabilities that interfere with traditional motivational interviews (Bellack & DiClemente, 1999). First, many persons with schizophrenia have significant cognitive deficits that may interfere with their ability to fully

participate in motivational interviews (Green, 1998). However, research on cognitive rehabilitation has identified several strategies that diminish the impact of attention and memory deficits on decision-making tasks (Corrigan & Yudofsky, 1996; Silverstein, Valone, Jewell, Corry, Nghiêm, Saytes, & Potrude, 1999). In particular, listing costs and benefits to individual actions can be especially helpful to persons with cognitive disabilities.

Second, many persons with severe mental illness do not seem to be motivated by common reinforcers (Bellack & DiClemente, 1999). Some individuals demonstrate significant anergia and disinterest in commonly motivating social events (Andreasen, 1990; Carpenter, Heinrichs, & Alphs, 1985). These persons might show significant difficulty in identifying the costs and benefits of specific goals. Others show marked anhedonia (Blanchard, Mueser, & Bellack, 1998); they might have special difficulty listing benefits, especially those highly loaded with positive affect. The question remains for future research whether these disabilities in motivation irrevocably interfere with the kind of goal assessment embodied in motivational interviews or whether the decisional balance fostered by this process helps circumvent the difficulties caused by negative symptoms.

Motivational Interviews are Only the Beginning

Motivational interviews are effective strategies for helping persons identify benefits and barriers to individual goals. Clinicians would do well to remember, however, that motivational interviews are only the first step to helping people actualize their goals. Just because the individual determines that pursuing a specific goal would yield far more benefits than costs does not mean that the goal will be achieved. The person may suffer several disabilities related to the psychiatric disorder that impede achieving this goal. The person motivated to accomplishing a specific goal may avail several other illness self-management strategies including skills training

and consumer-operated services. The full range of psychosocial therapies like these is most effective, however, when it reflects the goals identified by the persons with psychiatric disability.

FACILITATING PARTNERSHIPS THROUGH EDUCATION

Sometimes consumers need more information or skills so that they can more fully participate in treatment partnerships. A large part of the research in this regard has focused on taking medications but would logically seem to apply to the full range of psychosocial treatment options. *Psychoeducation* about medication teaches information about the benefits and side effects of medication, and strategies for managing side effects, so that consumers can make informed decisions about taking medication. These programs tended to be brief, with most programs lasting only one or two sessions. Most of the studies on education reported that consumers increased their knowledge about medication (Angunawela & Mullee, 1998; Brown, Wright, & Christensen, 1987; Kleinman, Schachter, Jeffries et al, 1993; Kuipers, Bell, Davidhizar, et al 1994; Munetz & Roth, 1985; Seltzer, Roncari, & Garfinkel, 1980). However, research for the most part failed to show that increased knowledge led to actual changes in medication practices. Hence, psychoeducation programs need to include generalization strategies so that increased knowledge leads to change in behavior (Corrigan & Basit, 1997).

The Practice of Psychoeducation

BHRM guidelines written by Robert Liberman and colleagues provide an excellent resource for how to conduct psychoeducation; the interested reader should refer to it for more information. Table 1 briefly reviews some of the key learning activities as a way to orient the reader to this process. We illustrate the learning activities with an example from symptom management where consumers learn to track the warning signs of relapse. With this kind of

information, consumers are better able to determine when aggressive assistance is needed from a health care provider including when adjustments should be made to one's medication.

Table 1: Learning activities that facilitate the acquisition of information and skills.

Introduce learning points

Model skill area

Role-play new skill

Provide feedback

Facilitate generalization

Introducing learning points. In essence, psychoeducation seeks to teach consumers discrete skills and important facts so that they can fully tackle their life goals. The process begins, therefore, with a brief introduction to the to-be-learned information. Learning points should be very short and succinct. Not more than a few key words and a 20 second explanation are needed because the remaining learning activities are oriented towards helping the person acquire the skill. Consider this example of learning points:

"Today, we focus on warning signs.

- Warning signs are symptoms that suggest you are relapsing and may need some special help.
- Warning signs differ from person to person so we are going to review a checklist of possible warning signs that might apply to you.
- By tracking your warning signs, you are better able to make decisions with your psychiatrist about medications and other treatment."

An important point is to check whether consumers are hearing and comprehending correctly the message. One way is to follow-up the introduction with brief questions and answers. "Sean, what is a warning sign?" Research suggests that individual consumers are more likely to remember important learning points if they translate the idea into language that is meaningful to them. For example, Sean said warning signs mean, "I'm getting sick again and need to call the Doctor." The goal is not to encourage participants to parrot back the answer but instead to try to put some personal meaning to it.

Model skill areas. Much of what is being taught are specific behaviors that are best understood when the consumer observes a model demonstrating the skills. Hence, the next step in psychoeducation is to follow-up learning points with a demonstration of the skills that correspond with these points. Several videotaped courses exist that providers might use; these videotapes are presented to a group of consumers and then they discuss what was seen. (See Robert Liberman et al's BHRM discussion on skills training for a list of videotapes.)

Alternatively, skills trainers can demonstrate the skills for themselves. In the example below, two skills trainers model how to identify warning signs. One acts as the therapist and the second as a consumer. The therapist is speaking here.

"There are three steps we must follow to monitor warning signs. First, we must identify warning signs that are relevant to each of us individually. On the worksheet I just handed out, you will note a list of warning signs that other consumers frequently experience.

Let's go through each warning sign, one at a time and ask yourself, 'Does this frequently happen every time my mental illness gets worse?' So Harry, what about 'Can't sleep at night'? Does that often happen to you before your illness gets worse?"

Whether using videotape or live demonstration, the important message is to encourage participants to pay close attention so they can answer some questions about the demonstration.

"Mary, you just saw the two skills trainers demonstrate how to monitor warning signs.

What is the first step?"

Like reviewing learning points, the goal here is not to ascertain whether participants have memorized correct responses but rather whether they understand the gist of the modeled demonstration. In cases where several consumers seem to have missed the point, skills trainers may wish to repeat it again.

Role-play new skills. Research has shown the most important part of psychoeducation is role-playing new skills. Consumers who rehearse a skill are able to experience its benefits as well as learn how the skill might be fine tuned to meet individual needs. Typically, behavioral role-plays involve a couple of consumers who are following a loosely organized script to practice the targeted skill.

"In this role-play I want two consumers to volunteer. Okay Harry, I want you to pretend you are a consumer who is unsure of his warning signs. And Sue, I want you to be a friend who will use the Warning Sign Worksheet and help Harry to identify those warning signs that are relevant and meaningful to him."

As Liberman et al. point out in their BHRM Web page, the secret to effective role-plays is sufficient set-up of the situations so that participants can successfully complete the goal. The mistake that skills trainers often make is to rush through the instructions so that the consumer role players are unsure of their parts. They then make several mistakes and feel embarrassed. They will not want to participate in future role-plays nor will they want to use the behavior that made them look like a fool. At a minimum, skills trainers should check out with participating

consumers whether they are clear about their role in the practice session. What are they supposed to say and do? What is the goal in the situation? With these kinds of preparations, the role-play is more likely to be experienced as an engaging and positive situation.

Provide feedback. Three forms of feedback can be provided after the role-play. Peers can share their opinion about the success of the interaction. Skill trainers can provide feedback. And role-play participants themselves can provide self-analysis. Regardless of who is giving feedback, an essential rule must be reinforced by skill trainers: Be Positive! Role-play participants who are pelted with critiques will not likely find the behavioral rehearsal to be a positive experience. Shaping skills through positive feedback about approximations to the skill always yields better results.

"What I liked in this interaction, Sam, was you were looking at Eileen and speaking in a clear, but respectful manner."

Facilitate generalization. As suggested earlier, many of the skills learned in psychoeducation programs do not readily generalize to the rest of the person's life. For example, people learn warning sign monitoring skills at the skill-training program but do not use them at home. There are several strategies that facilitate the transfer of newly learned skills from the training session to the other settings that are important in the consumer's life. Prominent among these is homework; instruct participants to try out a newly learned skill in settings outside of the psychoeducational program. Once again, setting up homework is the important rule here. Spend some time with the consumer so he or she knows exactly what skill they are going to practice, what will be their goal, who will they try it out on, when, and where.

CONSUMER-OPERATED SERVICE PROGRAMS¹

Consumer-operated services differ markedly from more traditional clinical treatment (Luke, Roberts, & Rappaport, 1994). Clinical treatment reflects a medical model: persons seek out services to resolve symptoms and replace deficits (Corrigan & Penn, 1997). There is a hierarchy between healer and patient in clinical settings; healers have some special power which they use to help patients resolve their 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 grassroots information and support systems (Meisen, Gleason, & Embree, 1991). Mental illness may be the common experience that draws persons to consumer-operated services. But, unlike traditional clinical treatment, this is not where the impact of consumer-operated services ends. They provide a setting where the person can find the necessary understanding and recognition that society at large is not able to give. 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 (Luke, Roberts, & Rappaport, 1994).

Types of Consumer-Operated Services

Researchers have identified several groups of services where consumers have key roles; they include consumer-operated services, consumer partnerships, and consumers as employees (Davidson, Chinman et al., 1999; Solomon & Draine, 2001). The one characteristic that distinguishes consumer-operated services from these other consumer-related programs is control.

¹ For more information on Consumer Operated Services, the interested reader should consult the BHRM web guidelines by Mark Salzer.

All aspects of consumer-operated services -- from basic mission, to program design, to day to day finance and operations -- are controlled by a group of consumers. Three kinds of programs comprise consumer-operated services: consumer run drop-in centers, peer support programs, and education/advocacy programs. Consumer run drop-ins provide an open venue for consumers to receive a variety of services as needed. 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 individual or group-based assistance and encouragement organized around a worldview or 12step approach that is consistent with empowerment and recovery. Peer support programs, like drop-in centers, may tackle a broad range of work, housing, health, and relationship goals that are needed by participating consumers. Education and advocacy programs believe that consumers with knowledge about mental illness and psychiatric services are best able to address their own disabilities AND fix what is wrong with the mental health system. Education and advocacy programs use well-designed curricula to teach consumers this kind of information, usually in short-term classroom settings. Education and advocacy programs also rely on peer support to accomplish their goals.

Previous research on consumer-operated services. There have been a significant number of empirical studies of consumer-operated services which have yielded two recent reviews of the literature (Davidson, Chinman et al., 1999; Solomon & Draine, 2001). Rather than summarize these reviews, key trends are briefly considered. The majority of prior studies on consumer-operated services has been descriptive and/or qualitative largely seeking to identify the characteristics of people who opt to participate in these programs, the processes that lead to

change, and/or the consumer's perspective on benefits of program participation (Chamberlin, Rogers, & Ellison, 1996; Mowbray, Chamberlain, Jennings & Reed, 1988; Kaufman, Schuldberg, & Schooler, 1994; Kennedy, 1989; Luke, Rappaport, & Seidman, 1991; Mowbray & Tan, 1993; Segal, Silverman, & Tempkin, 1995). One interesting example of this ilk was the findings from a Center for Mental Health Services (CMHS) multi-site study on consumer-operated programs. CMHS funded fourteen consumer services in 1988 with the goal of demonstrating and evaluating their efficacy. Results of a qualitative evaluation showed that participants in these programs reported improvements in self-reliance and independence; coping skills and knowledge; and feelings of empowerment (Van Tosh & del Vecchio, 2000).

Additional studies have sought to understand the perceived benefits of consumeroperated services by completing outcomes studies with control conditions. For example,
research on peer support programs, using nonrandomized control groups or pretest scores as
comparisons, has shown participation in these services yields improved psychiatric symptoms
and decreased hospitalization (Galanter, 1988; Kennedy, 1989), larger social support networks
(Carpinello et al., 1991; Rappaport et al., 1985), and enhanced self-esteem and social functioning
(Kaufman et al., 1994; Markowtiz et al., 1996). Based on this research, one might conclude that
substantial preliminary evidence exists supporting consumer-operated services. However, the
standard of internally valid, evidence-based outcomes research -- random-controlled trials -- has
not been completed on consumer-operated services. Without this kind of research, the impact of
history and other variables that might confound interpreting the benefits of consumer-operated
services cannot be ruled out. Moreover, research in this category needs to target a broad list of
outcomes that are likely to improve because of participation in consumer services. In order to
address these research concerns, eight consumer-operated service programs began a randomized

trial in 1998 that is examining the impact of consumer-operated services. (This multi-site study is funded by the U.S. Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration.) Although data collection continues, an important part of the study is definition of the practices that define consumer-operated services. These practices are described here based on an as yet uncompleted analysis of the common ingredients.

Basic Principles and Practices that Comprise Consumer-Operated Services

The basic elements of consumer-operated service programs are summarized in Table 2. These are believed to be the ingredients that give consumer-operated programs their unique influence. The various principles and practices have been grouped into five higher order factors: structure, environment, belief system, peer support, and education/advocacy.

Table 2. The Key Principles and Practices of Consumer-Operated Services.

<u>These principles and practices were gleaned from the list of common ingredients developed by</u> the Consumer-Operated Services Project funded by the U.S. Substance Abuse and Mental Health Services Administration.

STRUCTURE

Consumer controlled and operated Primarily responsive to participant feedback

ENVIRONMENT

Reasonably accommodating in demands Accessible in one's neighborhood A safe and non-coercive environment

BELIEF SYSTEM

Recovery: all participants have the unique capacity to overcome their illness and accomplish their life goals

Diversity: all behaviors are understood in terms of "ordinary" human terms

Helper's principle: helping one's self and others is key

Peer principle: relationships based upon shared experience and values

Creativity: artistic expression is helpful in recovery

Humor: consumer-operated services encourage laughing at one's self and situation

Spiritual growth: spiritual beliefs and subjective experiences are respected

PEER SUPPORT

Interpersonal support: participants are available to each other to lend a listening ear and empathy

Telling one's story: personal accounts of life stories are embedded in all forms of peer support

Peer mentoring and teaching: consumers learn to deal with life through peers

EDUCATION AND ADVOCACY

Self-management and problem solving: participants learn practical skills and solutions to deal with life concerns

Information giving: participants teach and are taught community survival skills Self, peer, and systems advocacy: participants make sure barriers do not prevent them or their peers from achieving life goals

Structure

The organizational structure of consumer-operated programs has two essential characteristics. First, all aspects of the program are controlled by people with mental illness. The program is designed by consumers and implemented by consumers. The physical plant is managed by consumers, as is the budget necessary for the program to be effective. Practically, this means that the leadership is dominated by consumers. Consumer-operated services might include professional providers or others who do not act in key roles. However, the board of directors needs to be at least 50% comprised of consumers and the executive director should be a person with mental illness.

Secondly, the day-to-day structure of the program is responsive to the concerns and feedback of participating consumers. This can be experientially very different from traditional mental health services where participants may have to adapt their needs to the rules of the program. For example, most participants in traditional day treatment typically have to reserve their service needs for a 9 to 5 day. Consumer-operated services are by design responsive to participant concerns. Hence, if a consensus of participants expresses concerns about program or

infrastructure change, then the leadership of consumer-operated services will likely make corresponding changes.

Environment

Three ingredients are important to the environment of consumer-operated services. As suggested above, consumer-operated systems seek to be reasonably accommodating in demands. Hence, not only is the program structure immediately responsive to a consensus of consumer interests (e.g., participants wish to change the hours of a program), the consumer-operated service also seeks to meet the unique needs of specific consumers. Hence, if a consumer expresses his or her ability to only participate in a small component of the program, the consumer-operated service would be open to this exception.

Two other qualities of consumer-operated services are also reflective of more progressive models of traditional mental health services. Consumer services typically seek to be readily accessible in the participants' neighborhood at hours that are convenient to them. Moreover, consumer-operated services seek to be safe places. At a minimum, this overlaps with traditional mental health concerns about making sure that all service participants are safe from the agitation that might result from the symptoms of peers. Moreover, consumer services seek to be free of the kind of treatment coercion that may be experienced in traditional services; e.g., pressure from a treatment provider when their perception of appropriate life goals (like taking medication) does not correspond with the consumer's vision.

Belief System

Consumer-operated systems have been visionary in several conceptions of mental illness and psychiatric service. Consumer-operated services have strongly embraced the recovery process; i.e., that consumers have the potential to accomplish any life goal that they choose to

target despite a serious mental illness and psychiatric disability. The kind of hope and energy of this perspective permeates the programs at consumer-operated services. Moreover, consumer services endorse the idea of diversity. In a psychiatric setting, behaviors are frequently pathologized: "The consumer came late to group because he has an unconscious desire not to get well." In consumer-operated services, all behavior is looked at in terms of ordinary human terms: "He came late to group because he missed his bus." Even behavior that might be viewed as psychotic in some settings is reframed as within the continuum from highly normal to eccentric, but ordinary behavior.

Two additional principles guide the belief system of consumer-operated services: the helper principle and the peer principle. The helper principle reflects the essential wisdom of mutual assistance; namely, program participants benefit not only from being helped by others (e.g., learning ways to deal with problem situations or gaining support to weather life stressors) but also from helping peers (which substantiates the message that they are ordinary competent people and augments feelings of worth). The peer principle takes this idea one step further; participants have shared experiences that lead to similar values. Consumer-operated services provide the setting and power for peers to explore these experiences.

Another interesting part to the consumer program's belief system is the recognition of therapeutic or personally helpful processes not found in traditional mental health services. These include creativity, humor, and spiritual growth. Most consumer-operated programs include opportunities in both visual and performance arts that are helpful in recovery. Consumer-operated programs also promote self-humor; often laughing at one's self and situation can help to overcome a life challenge. Finally, many consumer services promote spiritual growth where

these kinds of subjective beliefs and experiences are not only respected but encouraged and nurtured.

Peer Support

Perhaps the heart of consumer-operated services is peer support. Recovery and empowerment are facilitated through open interactions among people who have experienced the same life challenges. Hence, interpersonal support that fosters a listening ear and unconditional empathy is universally prominent in consumer-operated services. As part of peer support, telling the person's story is a central mechanism. Peers encourage peers to recount both the way up and the way down that defines what brought the individual to the consumer service. Some consumer programs might take peer support to a further step encouraging mentoring and teaching. In this kind of program, some consumers assume more formal roles in helping peers meet specific needs. Despite these kinds of roles, the program still attempts to avoid any kind of hierarchy in the helping relationship.

Education/Advocacy

One way in which consumers acting as teachers may help peers is through education. In fact, many of the psychoeducational practices reviewed earlier apply here. Several consumer-operated service programs have formal education programs where consumer/teachers instruct peers on specific skills -- like problem solving and symptom self-management -- or share information related to practical actions. Community survival focuses on everyday issues like how to get around town on public transportation and how to negotiate government entitlement offices. Consumer programs also endorse personal and peer advocacy. These might include assertiveness lessons so a person might learn how to avoid unnecessary submissiveness or aggression. Alternatively, these efforts may include a focus on political advocacy where

consumers learn, and then implement, strategies that impact local legislators and policy makers about issues of interest to the consumer.

SUMMARY

At the heart of recovery and empowerment is that one's mental illness can be self-managed. Three strategies that foster this kind of self-management were reviewed here: motivational interviewing to establish a person's goals, psychoeducation to learn skills to accomplish these goals, and consumer-operated systems which provide communities where these goals can flourish. People who are able to incorporate illness management approaches like these will be able to accomplish the goals that define a quality life.

References

Anderson, C.M., Reiss, D.J., & Hogarty, G.E. (1986). Schizophrenia and the Family.

New York: Guilford Press.

Andreasen, N.C. (Ed.). (1990). Schizophrenia: Positive and Negative Symptoms and Syndromes. Basel, Switzerland: S. Karger AG.

Anthony, W.A., Liberman, R.P., (1992). Principles and practice of psychiatric rehabilitation. In Liberman, R.P (Ed.), <u>Handbook of Psychiatric Rehabilitation</u>. New York: Macmillan Publishing Company.

Angunawela, I.I., & Mullee, M.A. (1998). Drug information for the mentally ill: A randomized controlled trial. International Journal of Psychiatry in Clinical Practice, 2, 121-127.

Bachrach, L.L (1992). Psychosocial rehabilitation and psychiatry in the care of long-term patients. American Journal of Psychiatry, 149(11), 1455-1463.

Bellack, A.S. & DiClemente, C.C. (1999). Treating substance abuse among patients with schizophrenia. <u>Psychiatric Services</u>, 50(1), 75-80.

Blanchard, J.J., Mueser, K.T. & Bellack, A.S. (1998). Anhedonia, positive and negative affect, and social functioning in schizophrenia. <u>Schizophrenia Bulletin</u>, 24(3), 413-424.

Brewin, C.R. & Wing, J.K. (1993). The MRC needs for care assessment: Progress and controversies. <u>Psychological Medicine</u>, 23(4), 837-841.

Brown, C.S., Wright, R.G., & Christensen, D.B. (1987). Association between type of medication instruction and patients' knowledge, side effects, and compliance. <u>Hospital and Community Psychiatry</u>, 38, 55-60.

Carpenter, W.T., Heinrichs, D.W., & Alphs, L.D. (1985). Treatment of negative symptoms. Schizophrenia Bulletin, 11(3), 440-452.

Carpinello, S. E., Knight, E.L., & Janis, L. (1991). A qualitative study of the perceptions of the meaning of self-help, self-help group processes and outcomes by self-help group leaders, members, and significant others. Unpublished manuscript.

Chamberlin, J. (1984). Speaking for ourselves: An overview of the ex-psychiatric inmates' movement. Psychosocial Rehabilitation Journal, 8(2), 56-63.

Chamberlin, J., Rogers, E.S., & Ellison, M.L. (1996). Self-help programs: A description of their characteristics and their members. Psychiatric Rehabilitation Journal, 19(3), 33-42.

Corrigan, P.W., & Basit, A. (1997). Generalization of social skills training for persons with severe mental illness. Cognitive & Behavioral Practice, 4(1), 191-206.

Corrigan, P.W., Buican, B., & McCracken, S. (1995). The Needs and Resources Assessment interview for severely mentally ill adults. <u>Psychiatric Services</u>, 46(5), 504-505.

Corrigan, P.W., & Penn, D.L. (1997). Disease and Discrimination: Two paradigms that describe severe mental illness. <u>Journal of Mental Health</u>, *6*, 355-366.

Corrigan, P.W., & Yudofsky, S.C. (1996). What is cognitive rehabilitation? In P.W. Corrigan & S.C. Yudofsky (Eds.), <u>Cognitive Rehabilitation for Neuropsychiatric Disorders</u>. Washington, DC: American Psychiatric Press, Inc.

Davidson, L., Chinman, M., Kloos, B., Weingarten, R., Stayner, D., & Tebes, J.K. (1999). Peer support among individuals with severe mental illness: A review of the evidence. Clinical Psychology-Science & Practice, 6(2), 165-187.

Deegan, P.E. (1992). The Independent Living Movement and people with psychiatric disabilities: Taking back control over our own lives. <u>Psychosocial Rehabilitation Journal</u>, 15(3), 3-19.

Fisher, D.B. (1994). Health care reform based on an empowerment model of recovery by people with psychiatric disabilities. Hospital & Community Psychiatry, 45(9), 913-915.

Galanter, M. (1988). Zealous self-help groups as adjuncts to psychiatric treatment: A study of Recovery, Inc. <u>American Journal of Psychiatry</u>, 145(10), 1248-1253.

Green, M.F. (1998). Schizophrenia from a Neurocognitive Perspective: Probing the Impenetrable Darkness. Boston: Allyn and Bacon.

Hanson, R.W. (1986). Physician-patient communication and compliance. In K. E. Gerber & A. M. Nehemkis (Eds.), <u>Compliance: The Dilemma of the Chronically III</u>. New York: Springer Publishing Company.

Kaufmann, C.L., Schulberg, H.C., & Schooler, N.R. (1994). Self help group participation among people with severe mental illness. <u>Prevention in Human Services</u>, 11, 315-331.

Kennedy, M. (1989). Psychiatric hospitalizations of GROWers. Paper presented at the 2nd biennial conference of Community Research and Action, East Lansing, MI.

Kleinman, I., Schachter, D., Jeffries, J., et al. (1993). Effectiveness of two methods for informing schizophrenic patients about neuroleptic medication. <u>Hospital and Community</u>
Psychiatry, 44, 1189-1191.

Kuipers, J., Bell, C., Davidhizar, R., et al (1993). Knowledge and attitudes of chronic mentally ill patients before and after medication education. <u>Journal of Advanced Nursing</u>, 20, 450-456.

Luke, D.A., Rappaport, J., & Seidman, E. (1991). Setting phenotypes in a mutual help organization: Expanding behavior setting theory. <u>American Journal of Community Psychology</u>, 19(1), 147-167.

Luke, D.A., Roberts, L., & Rappaport, J. (1994). Individual, group context, and individual-group fit predictors of self-help group attendance. In T.J. Powell (Ed.), <u>Understanding the self-help organization: Frameworks and findings</u>. (pp. 88-114). Thousand Oaks, CA: Sage Publications.

Markowitz, J.C., Clougherty, K.F., Spielman, L.A., Jacobsberg, L.B., et al. (1996). "Is interpersonal psychotherapy superior to supportive psychotherapy?": Reply. <u>American Journal of Psychiatry</u>, 153(11), 1510.

Marshall, M., Hogg, L.I., Gath, D.H., & Lockwood, A. (1995). The Cardinal Needs Schedule: A modified version of the MRC Needs for Care Assessment Schedule. <u>Psychological Medicine</u>, 25(3), 605-617.

Maton, K.I., Leventhal, G.S., Madara, E.J., & Julien, M. (1989). Factors affecting the birth and death of mutual-help groups: The role of national affiliation, professional involvement, and member focal problem. <u>American Journal of Community Psychology</u>, 17(5), 643-671.

Meissen, G.J., Gleason, D.F., & Embree, M.G. (1991). An assessment of the needs of mutual-help groups. American Journal of Community Psychology, 19(3), 427-442.

Miller, W.R. & Rollnick, S. (1991). <u>Motivational Interviewing: Preparing People to</u>
Change Addictive Behavior. New York: The Guilford Press.

Mosher, L.R., & Burti, L. (1992). Relationships in rehabilitation: When technology fails. Psychosocial Rehabilitation Journal, 15(4), 11-17.

Mowbray, C.T., Chamberlain, P., Jennings, M., & Reed, C. (1998). Consumer-run mental health services: Results from five demonstration projects. <u>Community Mental Health Journal</u>, <u>24(2)</u>, 151-156.

Mowbray, C.T., & Tan, C. (1993). Consumer-operated drop-in centers: Evaluation of operations and impact. Journal of Mental Health Administration, 20(1), 8-19.

Mueser, K.T., Corrigan, P.W., Hilton, D.W., Tanzman, B., Schaub, A., Gingerich, S., Copeland, M.E., Essock, S.M., Tarrier, N., Morey, B., Vogel-Scibilia, S., & Herz, M. (in press). Illness management and recovery: A review of the research. <u>Psychiatric Services</u>

Munetz, M.R., & Roth, L.H. (1985). Informing patients about tardive dyskinesia.

<u>Archives of General Psychiatry</u>, 42, 866-871.

Phelan, J., Link, B.G., Stueve, A., & Moore, R.E. (1995). Education, social liberalism, and economic conservatism: Attitudes toward homeless people. <u>American Sociological Review</u>, <u>60(1)</u>, 126-140.

Rappaport, J., Seidman, E., Paul, T.A., McFadden, L.S., Reischl, T.M., Roberts, L.J., Salem, D.A., Stein, C.H., & Zimmerman, M.A. (1985). Collaborative research with a self-help organization. Social Policy, 15, 12-24.

Segal, S.P., Silverman, C., & Temkin, Tanya. (1995). Measuring empowerment in client-run self-help agencies. Community Mental Health Journal, 31(3), 215-227.

Seltzer, A., Roncari, I., & Garfinkel, P. (1980). Effect of patient education on medication compliance. Canadian Journal of Psychiatry, 25, 638-645.

Silverstein, S.M., Valone, C., Jewell, T.C., Corry, R., Nghiem, K., Saytes, M., & Potrude, S. (1999). Integrating shaping and skills training techniques in the treatment of chronic treatment refractory individuals with schizophrenia. Psychiatric Rehabilitation Skills, 3(1), 41-58.

Solomon, P. & Draine, J. (2001). The state of knowledge of the effectiveness of consumer provided services. <u>Psychiatric Rehabilitation Journal</u>, 25(1), 20-27.

Resources

For more information about illness self-management, please check the following:

National Empowerment Center

599 Canal Street

Lawrence, Massachusetts 01840

Phone: (800) 769-3728 FAX: (978) 694-9117

URL: http://www.Power2u.org

- o Consumer technical assistance center
- National directory of mutual support groups, drop-in centers, and Statewide organizations
- o Networking and coalition-building
- o Workshops, public speaking, and training to providers

National Mental Health Consumers' Self-Help Clearinghouse

1211 Chestnut Street

Suite 1207

Philadelphia, Pennsylvania 19107

Phone: (800) 553-4539 FAX: (215) 636-6312

E-mail: info@mhselfhelp.org
URL: http://www.mhselfhelp.org

- Consumer information and referrals
- o On-site consultation
- o Training events
- o Teleconferences and national conferences
- Consumer library
- Newsletter
- o Consumer and consumer-supported nationwide database

Consumer Organization and Networking Technical Assistance Center (CONTAC)

West Virginia Mental Health Consumers Association

1036 Quarrier Street

Suite 208A

Charleston, West Virginia 25301 Phone: (888) 825-TECH (8324)

(304) 346-9992 FAX: 304-345-7303

E-mail: Shanebelcher@contac.org
URL: http://www.contac.org

- Resource center for consumers/survivors/ex-patients and consumer-run organizations across the United States
- Services include materials development and dissemination, training, skill development, interactive communication opportunities, networking, and other activities to promote self-help, recovery, and empowerment
- Technical assistance to organizations in identifying and exemplifying points of entry into consumer programs
- o Outcome orientation for non-traditional services
- Leadership and organizational development
- o Information sharing through a national web network

National Consumer Supporter Technical Assistance Center

National Mental Health Association

1021 Prince Street

Alexandria, Virginia 22314-2971

Phone: (800) 969-6642 FAX: (703) 684-5968

E-mail: consumerTA@nmha.org
URL: http://www.ncstac.org/

- Information and referrals
- o Technical assistance on site and by phone
- Resource library
- Coordination of local coalitions
- o Training conference

Other resources on illness management skills:

University of Chicago Center for Psychiatric Rehabilitation

7230 Arbor Drive Tinley Park, IL 60466 Phone: (708) 614-4770 FAX: (708) 614-4770

URL: http://www.ucpsychrehab.org

- o Workshops, seminars, academic courses, and training to providers
- o Technical support on all aspects of psychiatric rehabilitation.
- o Special expertise in helping advocacy groups and public policy concerns with issues of stigma and discrimination.

National Research and Training Center on Psychiatric Disability and Peer Support

104 South Michigan Avenue

Suite 900

Chicago, Illinois 60603 Phone: (312) 422-8180 FAX: (312) 422-0740

URL: http://www.psych.uic.edu/uicnrtc

- O Psychiatric rehabilitation research and training in 9 major areas: peer support and consumer service delivery, treatment models, vocation rehabilitation, managed care, women's issues, HIV/AIDS, familial experience, diversity issues, and transition-age youth
- o Extensive dissemination and technical assistance at replacement cost or no cost
- o Workshops, seminars, academic courses, and training to providers
- Technical assistance to federal, state, and local agencies for public policy initiatives