

## Recovery

Ruth O. Ralph

*Edmund S. Muskie School of Public Service  
University of Southern Maine*

There is a great deal of interest in the concept of recovery in mental health circles. While some indicate it can never happen for people who are seriously mentally ill, others say improvement can take place, and still others insist that people can fully recover. The following review of literature on recovery provides definitions of recovery from the writings of those who have lived it, and describes studies that show people do recover and how people recover. There is vast and growing literature on recovery, both published and unpublished, of which this article is only an introduction. The overwhelming conclusion from both those who have lived recovery and those who have tried to systematically study it is: that recovery is possible, and that it takes both individual determination and the support of others in order to be accomplished.

Until recently, severe mental illness was generally considered to be a lifelong condition. Healing and recovery were invisible to those who only saw people when their symptoms were most severe, and when they were enrolled in the service system. Thus, while the concept of recovery is common in the fields of physical illness, physical disability, and addiction, it has seldom been used in the definition and measurement of mental health outcomes.

Requests for reprints and additional information should be addressed to Ruth O. Ralph, Research Associate, Edmund S. Muskie School of Public Service, The University of Southern Maine, 96 Falmouth St., P.O. Box 9300, Portland, ME, 04104-9300.  
Email: [Ruthr@usm.maine.edu](mailto:Ruthr@usm.maine.edu).

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## Definitions of Recovery

The concept of recovery was introduced and continues to be defined in the writings of consumers. The following quotations illustrate both the diversity and the commonality of the consumer perspective of recovery.

Recovery is a process, a way of life, an attitude, and a way of approaching the day's challenges. It is not a perfectly linear process. At times our course is erratic and we falter, slide back, regroup, and start again. ...The need is to meet the challenge of the disability and to re-establish a new and valued sense of integrity and purpose within and beyond the limits of the disability; the aspiration is to live, work, and love in a community in which one makes a significant contribution (Deegan, 1988, p. 15).

One of the elements that makes recovery possible is the regaining of one's belief in oneself (Chamberlin, 1997, p. 9).

Recovery is an ongoing process of growth, discovery, and change (Stocks, 1995, p. 89).

Having some hope is crucial to recovery; none of us would strive if we believed it a futile effort...I believe that if we confront our illnesses with courage and struggle with our symptoms persistently, we can overcome our handicaps to live independently, learn skills, and contribute to society, the society that has traditionally abandoned us (Leete, 1988, p. 52).

A recovery paradigm is each person's unique experience of their road to recovery. ...My recovery paradigm included my re-connection which included the following four key ingredients:

connection, safety, hope, and acknowledgment of my spiritual self (Long, 1994, p. 4).

To return renewed with an enriched perspective of the human condition is the major benefit of recovery. To return at peace, with yourself, your experience, your world, and your God, is the major joy of recovery (Granger, 1994, p. 10).

Other consumer descriptions of recovery include activities that enable and enhance recovery. The following quotations are examples.

Creativity in my life has been my salvation (McDermott, 1990, p. 13).

Advocacy for others has had a positive effect on my mental health (Weingarten, 1994, p.370).

Anger and its energizing effect are also part of these descriptions. Unzicker (1989) describes reading Judi Chamberlin's book, *On Our Own: Patient-Controlled Alternatives to the Mental Health System* (1978):

...it was Judi's story of suffering and survival that jump-started my rage...Judi's book awakened in me a spirit of defiance, will, and courage that I am still uncovering, like opening a perpetual birthday present. (p. 72)

Other descriptions from the literature include the following: It is a continuing, deeply personal, individual effort, and leads to growth, discovery, and the change of attitudes, values, goals, and perhaps roles (Anthony, 1993). It involves hope, courage, adaptation, coping, self-esteem, confidence, a sense of control or free will (Blanch et al., 1993), personal empowerment, and a spirituality/philosophy which gives meaning to life (Beale & Lambric, 1994). It includes physical and mental health, and economic and interpersonal well-being (DeMasi et al., 1996). Recovery also includes constructive

anger, advocacy for self and others, acceptance of personal responsibility, and asking for and accepting help (Ralph, 1997). It is accomplished one step at a time. It is deeply personal, and can be done only by the individual who is recovering (Beale & Lambric, 1995).

### *The Word "Recovery" Does Not Describe What Happens*

Still, there are some who feel that the word "recovery" does not truly nor fully describe the recovery journey or the results of the journey. One survivor of childhood sexual abuse commented that recovery implies that you return to something you were before the illness. "But I have no before!" she cried. (Anonymous, personal communication, March, 1999). Many consumers whose lives have been interrupted by bouts of mental illness feel that they have gone beyond where they were when the illness struck. Many have started or continued their education, reached new heights in their careers, or begun new careers.

Healing is seen as broader than recovery. Healing often emphasizes the healing from an injury or trauma or hurt in life. Healing is more suggestive of the mind/body split. Healing implies that the self has a role in the process. Recovery connects more with the 12-step programs (Jeanne Dumont, as quoted in Fisher & Deegan, 1998, p. 6).

Cohan and Caras (1998) have introduced the word transformation:

Our lives seem not to follow a traditional linear path; our lives appear to be like advancing spirals. We relapse and recuperate, we decide and rebuild, we awaken to life and recover/discover, and then we spiral again. This spiral journey is one of renewal and integration...the dynamic nature of this process leads to what can only be

described as transformation. ...Recovery and rehabilitation imply that something was once broken and then was fixed. Transformation implies that proverbial making of lemonade after life hands you lemons. It is the lesson, hard learned, of the opportunity available in the midst of crisis that evokes a substantive change within ourselves. (p. 1)

After describing her spiritual journey through and past mental illness, Clay (1994) provides this summary.

I really do not want to be called recovered. From the experience of madness I received a wound that changed my life. It enabled me to help others and to know myself. I am proud that I have struggled with God and with the mental health system. I have not recovered. I have overcome. (p. 7)

### ***Dimensions of Recovery***

Dimensions or aspects of recovery from mental illness include:

1. internal factors—those factors which are within the consumer, him/herself
2. self-managed care which is an extension of the internal factors
3. external factors—the interconnectedness with others, including the kinds of supports which can be provided by professionals, family, and friends
4. empowerment—a combination of internal and external factors—where the internal strength is combined with interconnectedness to provide the self-help, advocacy, and caring about what happens to ourselves and to others.

*Internal Factors:* A common theme in recovery accounts is the determination to do something—to get out of bed, to get well, to go to school, to do something to improve his/her life. In a study where she interviewed 30 consumers about their recovery process, Deegan (1998) found a number of recovery themes. Of these, "Awakenings and Insights," which are followed by an "Action Plan" and a "New Way of Talking to Oneself" demonstrate internal factors that need to be present if recovery is to take place. These can be both dramatic and life changing. After the person has recognized the situation (awakening), and that there is something better for them (insight), a plan is formulated (action plan), and then they literally talk themselves through the plan (self-talk). Sometimes the self-talk begins with the awakenings and carries through the recovery process. Deegan provides some vivid examples. This is only one of them:

...at that point I was lying in bed when...one of the nurses came up to the other end of the ward. I remember looking up and seeing her walking up. Her face was so distorted. ...I started saying to myself (this was going on in my head) "I don't like this world that I've come into....I'm in hell....And gee, if I don't do something, I'll die. Do I want to live? Yeah. I do want to live." I said, "Yeah, I don't want to give up my life. I want to get well. Is there anything I can do? Is it possible?...It's got to be possible. Maybe if I touch the real world, the real world will come back to me." And that's how I began my recovery—by just touching things. I'd touch the table. Took a deck of cards, shuffling them. Touching the blankets and feeling them...Then the next day I got up and I wanted to make the bed. So I got up. And I remember I couldn't walk. So I was holding onto the bed with one hand and pulling the blankets up with the other...I started with phys-

ical activity. I said, "I've got to learn to walk." So I started to walk holding onto the walls and trying to get my balance back. (p.3-4)

In addition to the determination and self-talk which leads to action, in many of these recovery accounts there is a sense of believing in God or a higher power, and in asking for help from that source.

Recovery indicators developed by consumers in Ohio (Ralph, Lambric, & Steele, 1996) include internal factors important to consumers in their recovery. These are: the ability to have hope, trusting my own thoughts, enjoying the environment, feeling alert and alive, increased self-esteem, knowing I have a tomorrow, and increased spirituality.

Throughout the discussions and studies of recovery, the importance of hope is emphasized. "When one lives without hope, (when one has given up) the willingness to 'do' is paralyzed as well" (Deegan, 1988, p. 13). In the report on the Ohio study of recovery indicators, Ralph and colleagues (1996) comment:

For those who may have lost hope—for recovery, for some kind of normalcy in their life, for something better than they have—hope is an important ingredient. Providers can build hope and recovery, or they can dash hope and exacerbate illness. (p. 5)

*Self-Managed Care:* Self-managed care is defined by Dan Fisher (1998) as follows:

Self-managed care is consumer-directed, multi-level, strength-building planning to genuinely assist a person to gain a meaningful role in society. This planning is contrasted to maintenance-based treatment planning which by its nature is professionally directed to correct pathology. (p. 37)

Consumer written literature includes descriptions of how the person manages his/her own mental health, as well as ideas, strategies, and advice to others. Knight (1993) advises that one of the most important things is not to panic when the first signs of something unusual are in your mind. He continues with strategies:

Techniques which involve the use of one's attention can reduce the panic feeling. Being aware of one's body and immediate environment and the rhythm of one's breath will bring one back in contact with immediate surroundings and pull one out of the unhelpful things going on in one's mind. Ways of training one's attention include mindfulness meditation from Buddhism, the inner smile of Taoism, the Hezachist or Jesus prayer in Christianity, and any number of words used in relaxation response—peace, love, or any other word the person likes. (p. 2)

Knight advises people to identify unhelpful feelings and thought patterns as if they are objects in the world. To keep oneself going - a sense of movement is helpful. Also helpful is facing the anxiety, finding out what the immediate threat is, and deciding you can live through it.

Houghton (1982) indicated that she had to adopt a new, healthier style of living. "By learning about myself, my limits, and weaknesses and strengths, and by making changes in my way of life, I have been able to maintain my health and prevent a recurrence of mental illness." (p. 549) Houghton expanded on this to identify things she needed to incorporate into her life: good patterns of rest and sleep, exercise, diet, self-discipline, minimizing food stimulants such as sugar and coffee, planning a reasonable routine, a slower pace, a calm atmosphere, defining her own limits, and setting reasonable goals. She also indicated that mental stimulation and meaningful work were important aspects of a healthy lifestyle.

Being in control is the way Deegan (1993) manages her life.

To me recovery means I try to stay in the driver's seat of my life. I don't let my illness run me. Over the years I have worked hard to become an expert in my own self-care. Being in recovery means I don't just take medications...Rather I use medications as part of my recovery process...Over the years I have learned different ways of helping myself. Sometimes I use medications, therapy, self-help and mutual support groups, friends, my relationship with God, work, exercise, spending time in nature—all these measures help me remain whole and healthy, even though I have a disability. (p. 10)

In a study of 120 people who agreed to share their strategies for living with depression and manic depression, Copeland (1998) learned strategies helpful for her own life. She found that people who blamed their instability on everyone else had difficulty in maintaining their lives, while those who were taking responsibility for their own lives were getting well and staying well. She learned she had to advocate for herself, decide what she wanted for herself, set goals, and figure out strategies to make them happen. She began to educate herself about her illness, medication, treatments, and alternate resources. She was able to recognize early warning signs, tell health care professionals what she needed and expected from them, and developed a plan that instructed certain people to make decisions for her if she couldn't make them herself. She got connected with the national movement of psychiatric survivors as well as local supporters. She gets outside to walk everyday, recognizes the impact light or lack of it has on her, and supplements her outside activities with a light box. She realized, "I create my thoughts and I can change them." (p. 3)

Early insight is defined by Heinrichs, Cohen, & Carpenter (1986) as a person's ability, during the early phase of decompensation, to recognize that he or she is beginning to suffer a relapse of his or her psychotic illness. In a study of 39 outpatients diagnosed with schizophrenia, clinician notes were reviewed to determine whether the person had early insight as to their imminent relapse and whether they avoided re-hospitalization. Of the 39 persons hospitalized, 24 were judged to have early insight, and 22 of these were restabilized successfully as outpatients without the need for re-hospitalization. In contrast, seven of the 14 people who did not have early insight required re-hospitalization.

Several studies have surveyed people with schizophrenia about their techniques for coping with hallucinations. Forty people living in the community who reported hearing voices at least once a day for a period of at least a year were interviewed by Falloon and Talbot (1981). They were asked what methods they used to decrease auditory hallucinations. A wide range of behaviors was reported, including pacing, jogging, eating, drinking, telephoning friends or family, and playing sports and games. Other methods to minimize physiological arousal were relaxation, listening to music, or blocking sensory input by wearing earplugs.

A similar approach was used by Tarrier (1987) who interviewed 75 outpatient clients who were receiving phenothiazine medication. Seventy-two percent could identify strategies they used to cope with their hallucinations. These included distraction or attention switching, thought stopping, increasing or decreasing activity, and increasing external stimulation (mainly by playing music). Tarrier's study showed a significant association between multiple strategy use and strategy effectiveness.

Twenty hospitalized persons with mental illness with a wide range of diagnoses were interviewed by Breier and Strauss (1983) to determine whether they used self-control mechanisms, which symptoms they tried to control, and how they

attempted to control them. They found a variety of psychotic symptoms were targets for self-control efforts, and many types of methods were used. Self-monitoring for affective signals (e.g. feeling fatigued, depressed, or anxious) was found to be particularly useful in anticipating decompensation.

A popular Dutch television show presented a woman talking with her psychiatrist about hearing voices. People who also experienced auditory hallucinations were invited to react to the program by telephone and respond to a questionnaire. Romme and Escher (1989) analyzed the responses from 450 people. Those who said they could not cope with hallucinations generally experienced the voices as negative and aggressive, whereas those who were able to cope experienced them as positive and friendly.

Convenience samples of 33 adult outpatients with schizophrenia were interviewed to elicit what self-help strategies they used for coping with auditory hallucinations (Frederick & Colanch, 1995). A total of 72 self-help techniques were used by the 33 participants with 73 percent using two to three different techniques. Broad ranges of self-help techniques were used, such as physical activity, leisure activities, interacting with others, or sleeping. Commonalities in the coping strategies were classified as: changes in behavior—reading, listening to music, drawing, or work activities, (e.g., housecleaning and yardwork); changes in physiological arousal level—increase in body movement, (e.g., walking, pacing, jogging, or decrease in physiological arousal through substance use); and cognitive processes—talking back to voices or ignoring them. The authors concluded:

While viewed as socially inappropriate, talking back to the voices is, for some patients with schizophrenia, an effective strategy....It may be necessary for psychiatric nurses and other mental health professionals to broaden their perspective about which behaviors are acceptable for patients with schizophrenia....self-help tech-

niques operate through the processes of focusing, distraction, and anxiety reduction. ...One conclusion is that treating auditory hallucinations as strictly pathological phenomena is not effective in helping patients cope with them. ...It is important to help patients adopt a frame of reference that will encourage them to accept and cope with their hallucinations. (p. 223)

Through her own experience in coping with voices and through listening to other consumers who report hearing voices and using coping strategies, Deegan (1995) has developed a self-help guide to help others learn techniques to enable a person to gain control over or eliminate voices that are distressing. In the introduction she comments:

The good news is that we no longer need to be alone and isolated with our voice hearing experiences. We do not have to be passive victims of distressing voices. We can take a stand, find our own voice, and *do* something to help ourselves overcome distressing voices and reach our personal goals. (p. 1)

Through both personal accounts and clinical studies it can be seen that people with mental illness can recognize their symptoms and learn or develop ways to cope with them. Personal accounts identify strategies to increase and maintain mental health which are important in order to be productive, contributing citizens. Fisher (1996) summarizes: "Self-managed care draws on the power of each individual to direct their own healing." (p. 12)

*External Factors:* A necessary ingredient in the recovery process is the inter-connectedness with others. These "others" may be family members, professionals, colleagues, and both consumer and non-consumer friends. DeMasi et al. (1996) found that interpersonal well-being was one of three critical

factors in recovery. Recovery is supported by social supports and empowerment by them (Beale & Lambric, 1995). Maintaining or developing connections to valued activities and people is critical (Blanch et al., 1993). In his formal and informal interviews about what helps people recover, Fisher (1997b) cites several examples of the importance of having a person who believes in them, and has confidence that they can do what they want to do. These studies support the personal accounts of consumers, which describe the positive effects mental health professionals have when they listen and believe.

Beall (1992) describes a visit to a professional which she had resisted going to, but finally relented at the insistence of her husband and daughter.

...Finally I went into the office and said that I was there under duress, that I did not believe there was any help for me. He replied that if he could not help me in short order, he was indeed the wrong person, and I should not come back... He listened and talked to me as if I were a real person and his equal. He told me he had treated several hundred people like me, but I was the only expert on my situation. My healing began then, at that moment... (p. 16)

One of the most revealing and vivid accounts of the effects of a professional's behavior is described by Ware (1995) in her discussion of the value of case management:

...And then this woman from the mental health clinic came out to my home. That had never happened to me....She said she was my "case manager," that her name was Kaylene, and that she'd be back. And she did come back, and she didn't patronize me. Then the coolest thing happened. She drank my iced tea. Now I'm telling you, to drink iced tea made by a mental health patient you don't know very well takes either a

great amount of courage or a great amount of confidence that the tea wasn't made with weird or dirty stuff in it. That's when I knew Kaylene was one smart cookie, because I've always made great tea. But what was more important was that she believed in me. Never in my life had anyone associated with the mental health profession believed in me. In fact, I was certain that mental health professionals were required to take at least two courses in patronization, and at least three in "You can't believe a word that comes out of a mentally ill mouth." ....Great things began happening.... (p. 1231)

Francisco (1997) describes harmful treatment by a therapist who read his diagnosis in an eight-year-old record, and labeled him as suicidal and severely depressed. The result was that the therapist saw crisis where there was only need for consistent care, and called the crisis team out three times in five months. The fourth time, the therapist did not notify Francisco, he did not answer the door, and the crisis team called the police who transported Francisco to the psychiatric emergency ward. As a result, Francisco did not seek out treatment for two years because of fear of similar treatment. Finally, needing immediate care, he entered an inpatient unit with "a good psychiatrist and other good staff members who believed me when I spoke to them, and I recovered after a lengthy stay." He comments further,

What works for me is having a psychiatrist who thinks of me as being just as human as he is and who respects my intelligence and intellect. ...We need therapists who can see us for who we are and hear us for what we have to say. (p. 1522)

Riffer (1997) makes the following suggestions as to what can be helpful, particularly in reference to the use of medication.

- Support my efforts to develop my own way of talking about my experience. Don't insist that I use your categories or starting points.
- When you talk about brain disease, explicitly acknowledge that you are using what is just one of many available frames of reference. Recognize that from my point of view, it addresses only one aspect of my experience.
- Find out my values and talk about medication in terms of what it has to offer in relation to what I want to accomplish.
- Recommend medication based on what will alleviate my mental illness and give me the greatest sense of comfort. Contentment may be as important as reducing symptoms.
- Listen closely to how the side effects I have relate to my values. Honor my courage and persistence when I persevere despite side effects. Never belittle the sacrifices that taking psychiatric medication requires.
- If I do not want to take medication at this time, help me find other means for achieving my goals. Do not approach me with the assumption that medication is the only sensible choice. Although medication may be an important component in my recovery, it will never be sufficient.
- Encourage me to do whatever I am willing to do that may be beneficial. Assist me in developing the ability to recognize what works for me and what doesn't. *Honor my self.* (p. 774)

Deegan (1988) emphasizes the importance of the support, caring, and love from families, friends, and professionals:

We do remember that even when we had given up, there were those who loved us and did not give up. They did not abandon us. They were powerless to change us and they could not make us better. They could not climb this mountain for us but they were willing to suffer with us. They did not overwhelm us with *their* optimistic plans for *our* futures but they remained hopeful despite the odds. Their love for us was like a constant invitation, calling us forth to be something more than all of this self-pity and despair...One day, something changed in us. A tiny, fragile spark of hope appeared and promised that there could be something more than all of this darkness...This is the mystery. This is the grace. This is the birth of hope called for by the possibility of being loved. (p. 15)

Mental health professionals, family members, and friends can make a tremendous difference in the lives of the people they touch. As they listen to disclosures and see the personal pain, they can believe, they can encourage, they can provide hope, and they can treat people who have mental illness with respect and dignity. And by so doing, they can help the healing/recovery process begin and continue.

*Empowerment:* The concept of empowerment grew out of the consumer movement which protested against the shared feelings of disenfranchisement and powerlessness resulting from perceived abuse by service providers and human rights violations through involuntary commitment and forced treatment.

Empowerment was evoked as a means to correct those violations and the pervasive debilitating consequences of their encounters with the men-



tal health system. Thus empowerment came to mean self-determination and control over their entire lives, not only their treatment (McLean, 1995, p. 1069).

Rappaport (1985) begins his definition of empowerment with a sense of humor, but continues in a more serious vein:

Empowerment is a little bit like obscenity: you have trouble defining it but you know it when you see it. It seems to be missing in people who feel helpless. Although it is easy to intuit, it is a very complex idea to define because it has components that are both psychological and political. ... It suggests a sense of control over one's life in personality, cognition, and motivation. It expresses itself at the level of feelings, at the level of ideas about self-worth, at the level of being able to make a difference in the world around us, and even at the level of something more akin to the spiritual. (p. 17)

Segal and colleagues (1995) describe empowerment as a process of "gaining control over one's life and influencing the organizational and societal structure in which one lives." (p. 215)

Empowerment also includes the building of an environment of public policy and mental health service delivery which allows and encourages people with mental illness to take control and be in control of their lives and their mental health.

If empowerment is our aim, we will find ourselves questioning both our public policy and our role relationship to dependent people. ... It will cause us to confront the paradox that even people most incompetent, in need, and appar-

ently unable to function require more, rather than less, control over their own lives (Rappaport, 1985, p. 18).

Clay (1990) discusses "Patient Empowerment" in terms of personal empowerment, social empowerment, and civil empowerment. She points out that Webster's II New Riverside University Dictionary (1984) defines it as "to give official authority or legal power to." In this sense, the right of a citizen to vote is an example of empowerment. Clay goes on to define personal empowerment:

In recent years, empowerment has acquired a wider application and a more personal, even spiritual, meaning. In this sense, empowerment is the means by which an individual acquires the inner authority to act as a free and useful person. Qualities of inner empowerment include self-esteem, confidence, and respect for others. .... In a larger sense, personal empowerment means that a person has achieved—to some degree—his or her own inner potential. This is the state of happiness and usefulness that every person seeks, that goes beyond what we call 'mental health' to actual sanity. On a very basic level, personal empowerment simply means that a person is in touch with his or her basic goodness, and also recognizes a similar goodness in others. With this awareness, it is possible to reach a lasting mental stability. (p. 1)

Social empowerment includes, for example, decent, affordable housing and meaningful jobs that pay decent wages. It also includes the support of friends and family and services, which foster choice and growth. Civil empowerment includes the assurance of client rights, such as the right to informed consent in treatment, to the least restrictive setting, to information about treatment, to participation in one's own treatment, and

to assert grievances. People with mental illness are also entitled to due process, especially regarding commitment and forced treatment. Clay (1990) concludes:

The person most likely to get well—to become empowered—is the person who feels free to question, to accept or reject treatment, and to communicate with and care for the people who are caring for him. ...Ultimately, patient empowerment is a matter of self-determination; it occurs when a patient freely chooses his or her own path to recovery and well-being. It is the job of mental health services to provide an environment of personal respect, material support, and social justice that encourages the individual patient in this process. (p. 2)

Research studies of empowerment are few, although some of the research on self-help may touch on empowerment. Two efforts have been made to measure empowerment (Segal et al., 1995; Rogers et al., 1997) and are discussed more fully in the measurement section.

A longitudinal, qualitative study of empowerment in a self-help organization is described by McLean (1995). However, McLean cautions, "Evaluation criteria that are structured according to the lines of traditional mental health treatment may be inadequate for tapping the unique features by which consumer-run alternatives can empower and promote recovery in their users." (p. 1069) A similar caution is given by Morrison et al. (1997),

Outcomes research will have to include new, client-driven measures of how effectively programs promote empowerment and strengthen clients' ability to do well in the community and in their personal lives. ... The trick will be to find measures that are meaningful from the clients' point of view (in terms of service provi-

sion that they find genuinely helpful) and from the providers' vantage point, which requires evidence of both effective outcomes and cost effectiveness. (p. 137)

Empowerment is the combination of self-determination to gain control over one's life, the acceptance and provision of an environment in which this can happen, and the building of services and policies in which empowerment can happen. "Empowerment links individual strengths and competencies, natural helping systems, and proactive behaviors to social policy and social change" (Zimmerman, quoted by Rappaport, 1985, p. 18).

### ***Recovery Research***

Research of recovery from mental illness is relatively new and results vary, in part, due to the way the concept is operationalized.

*Definitional Studies:* A consumer-run business in Ohio was asked by a county mental health board to develop and implement an evaluation strategy to identify strengths and weaknesses in the county mental health system. All of the consumers/survivors involved agreed that recovery was important, and generated a list of indicators. These indicators, used in a pilot study in Ohio with 71 service recipients and in Maine with 180 consumers who had been admitted to the state psychiatric institution at least once in the last seven years were rated from most important to least important similarly by both groups (Ralph, Lambric, & Steele, 1996; Ralph & Lambert, 1996). The top four in Ohio were the same top four rated by Maine consumers:

- The ability to have hope;
- Trusting my own thoughts;
- Enjoying the environment;
- Feeling alert and alive.

The Ohio study also asked questions of consumers about barriers to recovery (lack of money and feeling lonely or isolated), aids to independence (the way I spend my free time and have control of my own decisions), the importance of family (who support my recovery and independence), and peer support (having a peer to talk to and having someone to represent consumers' rights and needs) (Ralph, Lambric, & Steele, 1996).

In New York, a model was developed using the person's life as the organizing construct rather than focusing on pathology (DeMasi et al., 1996). The model, developed after a review of the literature, explains recovery in terms of three areas of well-being: *Health* (physical health and mental health), *Psychological*, (self-esteem, hope, coping, and confidence), and *Social* (economic and interpersonal quality of life). DeMasi and colleagues (1996) used a number of scales to develop the Self Help Survey used in this study: The Colorado Symptom Index (Coen, et al., 1989) to measure symptoms of mental illness; Rosenberg's (1965) Self-Esteem Scale; The Mental Health Confidence Scale (Carpinello, Markowitz, & Knight, 1995; Carpinello et al., 2000); the Ways of Coping Scale (Folkman & Lazarus, 1988); the Hope Scale (Snyder et al., 1991); and some items to measure economic and interpersonal quality of life. In a New York statewide sample, 956 individuals who received services from traditional outpatient programs and/or self-help groups were contacted. A total of 612 people returned the mailed survey for a 64 percent return rate. Using confirmatory factor analysis the structure of the hypothesized model was tested and supported. The results indicated that recovery spans beyond the mental health systems, is supported by a combination of support services, and emphasizes the importance of a partnership between clinician/client and between traditional and alternative services.

The *Well-Being Project* (Campbell & Schraiber, 1989) is a landmark effort in which mental health consumers conducted a multi-faceted study to define and explore factors promoting or deterring the well-being of persons diagnosed with men-

tal illness in California. Four basic research strategies were utilized: (1) review of relevant psychiatric literature; (2) quantitative survey research; (3) focus groups; and (4) oral histories. The project developed research protocols that engaged consumers and survivors in development of research questions, instruments, and methods. Respondents were interviewed in psychiatric hospitals, skilled nursing facilities, residential treatment centers, drop-in centers, mutual support groups, and on the streets. Of the 331 clients who responded, 87% had been hospitalized; of the 53 family member respondents, 91% reported their relative had been hospitalized. Nearly 60% of the clients surveyed indicated they could always or most of the time recognize signs or symptoms that they are having psychological problems (i.e., insight), and almost half reported that they can always or most of the time take care of the problem before it becomes serious. The most favored coping and help-seeking practices of consumers were to: write down their thoughts or talk the problem out (50%); eat (52%); call or see friends (52%); relax, meditate, take walks or a hot bath (54%); and call or go to see a mental health professional (62%). Campbell, (1993) defines well-being as follows:

In response to questions that elicited what factors are essential to well-being, clients reported that it comes from good health, good food, and a decent place to live, all supported by an adequate income that is earned through meaningful work. We need adequate resources and a satisfying social life to meet our desires for comfort and intimacy. Well-being is enriched by creativity, a satisfying spiritual and sexual life, and a sense of happiness. (p. 28)

*Outcome Studies:* The classic outcome study about recovery from mental illness, and the influence that mental health services (rehabilitation services in particular), have on recovery is the 32-year follow-back longitudinal study of per-

sons with mental illness from the Vermont State Psychiatric Hospital reported by Harding and colleagues (1987). George Brooks, superintendent of the hospital, selected a cohort of 269 very chronic people who had "sifted out of all the hospital admissions to the back wards" (Harding, Zubin, & Strauss, 1988, p. 478). At the time of their selection for the study in the mid-1950s, these people had been ill for an average of 16 years, totally disabled for ten years, and hospitalized continuously for six years. They participated in a pioneering rehabilitation program and were released in a planned deinstitutionalization with community supports in place. Followed up 32 years later (262, or 97% of the original 269 persons were traced), the living DSM-III schizophrenia sample showed that 34 percent had achieved full recovery in both psychiatric status and social functioning, and an additional 34 percent were significantly improved in both areas. Harding and colleagues defined the universal criteria for recovery as an outcome as: no current signs or symptoms of any mental illness, no current medications, working, relating well to family and friends, integrated into the community, and behaving in such a way as to not being able to detect having ever been hospitalized for any kind of psychiatric problem (Harding & Zahnheiser, 1994).

DeSisto and colleagues (1995) replicated Harding's follow-back study with a selection of persons hospitalized in Maine matched to the Vermont group by age, sex, and diagnosis, and compared the two groups. It was found generally that Vermont subjects were more productive, had fewer symptoms, and displayed better overall functioning and community adjustment. "...it can be argued that the differences in outcome are likely to be attributable to the Vermont (rehabilitation) program, since it provided an opportunity for community adaptation in the context of an array of residential, work, and social opportunities which were all managed to ensure continuity." (p. 337)

In an overview of World Health Organization (WHO) studies on schizophrenia, de Girolamo (1996) found that

"independent from the setting and contrary to the beliefs held in the psychiatric field for decades, there is a remarkable percentage of patients who recover from the illness." (p. 224) In 27 major long-term follow-up studies (including Harding's) published between 1960 and 1991, the percent of people clinically recovered ranged from a low of 6% to a high of 66%, with an average of 28% and a median of 26%. The percentage of individuals who showed a social recovery ranged from a low of 17% to a high of 75%, with an average of 52% and a median value of 54%. "...some authors have proposed a challenging view of the very concept of chronicity, stating that a variety of environmental and psychosocial factors can affect patient outcome and induce a misperception of chronicity" (Harding et al., 1987, p. 725).

In considering how traditional services (hospitalization, therapists) and the "empowerment oriented" approach of participation in self-help groups affect self-concept and social and economic outcomes, Markowitz and colleagues (1996) used data from the Self Help Survey (DeMasi et al., 1996) to examine these relationships. Involvement in self-help was found to have positive effects on self-concept and interpersonal quality of life, while symptoms were found to have the strongest negative effects on self-concept and quality of life outcomes. Traditional services were found to have negative effects on self-concept as well as quality of life (Markowitz et al., 1996).

The role of social relationships in recovery was studied by Breier & Strauss (1984) with 20 people who had been hospitalized for a psychotic decompensation. Initial interviews in the hospital focused on obtaining a history of the person's psychiatric problems and any apparent relationships these problems might have with work, friendships, and family status. Data on social relationships during the one-year follow-up period were obtained from semi-structured monthly interviews. All of the individuals described specific ways in which social relationships functioned in a beneficial way. From these interviews, 12 categories were identified:

- ventilation - conversing with others;
- reality testing - assist to maintain clear limits between reality and psychotic distortions;
- material support - help with financial, housing, and transportation problems;
- social approval and integration - reassurance when people accept them and provide sense of belonging;
- constancy - associate with people they knew before hospitalization, connects current identity with pre-hospital identity, and gives roots to existence;
- motivation - encouragement to achieve higher levels of occupational and social functioning;
- modeling - observe the behavior of others and incorporate it into their own behavior;
- symptom monitoring - having others alert them to manifestation of symptoms;
- problem solving - discussing problems and getting concrete feedback;
- empathic understanding - value of being understood by people important to them;
- reciprocal relating - becoming an equal partner, able to share and be of assistance to others;
- insight - acquire more complete and accurate understanding of themselves.

The authors also identified two phases through which people go toward their recovery from a psychotic episode. These are *convalescence* - getting over the experience of the psychotic episode, and *rebuilding* - putting one's life back together, making plans for a new life, and beginning an identity shift to being an "ex-mental-patient."

A consumer training program in Ohio is significant in that it was specifically designed to empower consumers in the roles of board and committee members, and to enhance recovery. The Consumer Leadership Education Program (LEP) was designed in a participatory process with a consumer advisory

group of 10 consumers of mental health services, research personnel, and program personnel. Members provided information about topics helpful to promote recovery. Information from other consumer interviews and focus groups addressing the recovery process was also utilized in the design of the curriculum. The LEP is a 16-week psychoeducational program which prepares mental health consumers for leadership positions on community agency boards and board committees. The training curriculum is divided into three segments: (1) attitude and self-esteem; (2) group dynamics and group process, and (3) board/committee functions and policy development. In the evaluation of the LEP, Bullock et al. (2000) used wait-list groups as control groups, and conducted pre-, post, and six-month follow-up assessments. In addition, qualitative as well as quantitative data were gathered to assist in understanding the change processes as well as the outcomes of the LEP. Analysis of CoVariance (ANCOVA) analyses used participants' post-training scores as the dependent variable and the pre-training scores as the co-variate. In comparison to control groups, trainees showed significant improvement on measures of consumer rated symptoms, self-efficacy, empowerment, and community living skills. Training participants also reported significant improvement in their ability to control negative and social symptoms of their psychiatric illness, improved social relationships, more personal power, and improvement in personal care and vocational skills. There was also a trend toward improvement in overall attitude towards recovery from mental illness.

The recovery process of incest survivors was studied by Godbey & Hutchinson (1996). A sample of 10 adult women incest survivors was recruited through word-of-mouth snowball sampling. Women were excluded if they had had suicidal ideation within the last 6 months or if they had been hospitalized for emotional difficulties in the last year. Formal, semi-structured in-depth interviews focused on the healing process. Additional data from the autobiographical accounts of incest survivors were coded along with the interviews. Using ground-

ed theory method, data were coded line by line. The interpretive process of the researchers moved the coding from substantive to categorical to theoretical coding. The authors explain their theory of burying the integral self:

Shengold (1989) called parental sexual and physical abuse soul murder, because children must literally bury, conceal, and lay away part of the self physically to survive. The work of recovery is to recognize that part of the self, the integral self, has been buried because of the pain of the abuse, and to resurrect the buried self. (p. 306)

Participants in this study described the resurrecting of the buried self as a complex, long, and arduous process, with results of long-term satisfaction. They indicated that in order to do this work, they needed to work with a trusted therapist, have emotional support from family and friends, and most importantly, have a real commitment to healing. Through careful analysis of the interview narratives, the authors developed a series of phases through which survivors must pass in their efforts toward recovery. These are: (1) reappearing, (2) revivifying, (3) resuscitating, (4) renovating, (5) regenerating, (6) reanimating, and (7) reincarnating. Each of these are discussed and illustrated from information provided by the interviewees. They conclude that reincarnating is accepting the experience of incest and all the associated life-experiences and weaving these experiences into an integrated life. This is illustrated with the following quote from a participant:

To me at this point in my life (I'm 47) it means I'm one hell of a warrior. It means I am one incredible, powerful, magnificent being. I wouldn't relive a day of it. Yet I honor it at the soul level . . . and I honor what I've done with that. I honor every tear, every grief, every feeling

. . . it has made me a tremendous therapist, a tremendous minister. It has led me on my path even when I was amnesic. It's leading me on my path, and I walk a magnificent path. (Godbey & Hutchinson, 1996, p. 309)

### *Measurement of Recovery*

Attempts to measure recovery are quite recent, and not yet well developed in terms of the exploration of concepts or themes of recovery, whether recovery is an outcome or a process, and how a person's life changes over time as recovery takes place. The following instruments have been developed for different purposes, but generally measure some aspect of recovery. More information about these and other instruments can be found in a compendium of recovery and recovery related instruments (Ralph, Kidder, & Phillips, 2000).

*Recovery Attitudes Questionnaire (RAQ)* (RAQ-16 Borkin et al., 1998; RAQ-7 Steffen et al., 1999) was developed by a team comprised of mental health consumers, professionals, and researchers at the Hamilton County (Ohio) Recovery Initiative to measure attitudes toward recovery as well as individuals' progress in this process. In the initial effort, 21 items reflecting the recovery process were piloted with 825 consumers, family members, mental health professionals, and students. Psychometrically the measure was found to have good inter-item reliability (alpha .838). Factor analysis identified two factors: *recovery is possible and needs faith*, and *recovery is difficult and differs among people* that were underlying the scale accounting for 54% of the variance. Seven items had high loadings on these factors.

Through an iterative series of factor and item analyses, four separately normed, valid, and reliable versions of the RAQ have been developed, one each for consumers, family members, mental health professionals, and students (Steffan & Wishnick, 1999). Factor structures of the various respondent groups were explored, and it was shown that different items are

seen as varying in importance by the different groups. The different attitudes of each group are reflected in the RAQ-16, which was developed from the original 21 items. It is self-administered, and measures attitudes within groups.

*Personal Vision of Recovery Questionnaire (PVRQ)* (Ensfield et al., 1998) was designed to measure consumers' beliefs about their own recovery. Developed by a team of professional and consumer researchers through a participatory process, the scale was "created to capture the consumer perspective of this highly personal, multifaceted process" (Ensfield in Steffan & Wishnick, 1999, p. 10). Factor analysis identified the final 24 items and the five factors of: (1) support (alpha .70); (2) personal challenges (alpha .65); (3) professional assistance (alpha .63); (4) action and help-seeking (alpha .61); and (5) affirmation (alpha .57). Convergent construct validity was addressed through comparison with a number of other measures. Low to moderate correlations were found among these measures with the factors of the PVRQ indicating the instruments are tapping modestly related but separate aspects of recovery related outcomes. Normative data are available from a sample of 251 mental health consumers in Hamilton County, Ohio (Steffan & Wishnick, 1999).

*The Making Decisions Empowerment Scale* (Rogers et al., 1997) was developed by a group of consumers with consultant researchers for the purpose of studying this aspect of self-help. After extensive development and pilot testing, a 28-item scale was tested on 271 members of six self-help programs in six states. Factor analysis revealed five factors: 1) self-efficacy-self-esteem; 2) power-powerlessness; 3) community activism; 4) righteous anger; and 5) optimism-control over the future. Empowerment was related to quality of life and income, but not to demographic variables. In the evaluation of the Consumer Leadership Education Program, (Bullock et al., 2000) consumer trainee scores on The Empowerment Scale showed significant improvement pre-post training compared with control group scores.

The *Personal/Organizational/Extra-organizational Empowerment Scales* (Segal, Silverman, & Temkin, 1995) were developed from a definition of empowerment based on writings and practice theories of leaders in the self-help mental health movement and theoretical constructs in community psychology, and were tested with 310 members of four self-help organizations. They concluded that:

1. they measured two components of the empowerment construct:
  - a. personal empowerment and
  - b. organizationally/extra-organizationally derived empowerment;
2. dimensions of empowerment are related to different functional outcome domains:
  - a. quality of life and independent social functioning are most likely to be related to personal empowerment,
  - b. while organizational empowerment is more related to involvement in work, both paid and volunteer; and
3. self-efficacy proves to be the bridging construct between the two dimensions of empowerment.

The three dimensions of empowerment look at the control the individual has over his or her material situation and his or her experiences in exercising control within and outside of the self-help organization (Segal, Silverman, & Temkin, 1995).

Consumers developed and used the *Well-Being Scale* (Campbell & Schraiber, 1989) with over 350 consumers in a wide variety of settings (including psychiatric hospitals) in California. Three items asking about physical health, mental health, and well-being have been found to be strong predictors of well-being (J. Campbell, personal communication, May, 1994).

*The Crisis Hostel Healing Scale* (Dumont, 2000) was developed through concept mapping with consumers who

were operating and using the Crisis Hostel in the Crisis Hostel Project and piloted with 110 people from local day treatment and social club services. While pattern matching and factor analysis did not strongly support the constructs in the concept map, the instrument shows strong internal consistency reliability (alpha .89) and test-retest reliability at 6 months with the non-treatment control group (.67). It has also shown significant changes over time for the treatment group.

*The Mental Health Confidence Scale* (Carpinello et al., 2000) was constructed and used as part of the data collection strategy on a study focused on the factors that predict participation and nonparticipation in self-help groups (Carpinello et al., 2000). Using a cross-sectional approach, participants (n = 554) were sampled from outpatient mental health services settings and from self-help groups having a clear mental health focus. A scale of 62 confidence statements was generated to assess mental health self-efficacy beliefs (Carpinello et al., 1995). Items were reviewed by a panel experienced in mental health and self-help, and piloted with people from self-help groups. Ultimately the scale was reduced to 16 measures of efficacy beliefs presented as confidence statements. The questions cover three major areas - optimism, coping, and advocacy, and ask participants how confident they are about their ability to deal with those things which commonly influence their lives.

*The Mental Health Statistics Improvement (MHSIP) Report Card* (Hornik et al., 1994; Ganju et al., 1996) was developed by a group of people who work with mental health data systems, and some consumers. It is considered "consumer oriented" because consumers did not have full control of its development. It is a measure of satisfaction with mental health services.

## Conclusion

Contrary to the general opinion that recovery is a "buzzword," and everyone talks about it, but no one knows what it is - there has been careful thought and study about this concept. Consumers have reflected and written about what it is in their own lives to assist them to leave mental illness behind them and to move on to being a "normal citizen." Consumers have also researched areas of importance to the concept of both recovery and empowerment. Clinical researchers have explored with clients and persons who are hospitalized various theories about how recovery comes about and what influences it. It should be noted that what is described here is only a sample of both published and unpublished literature. Focus has been on writings and studies by consumers, and the selection of studies has been made from a consumer perspective. It is refreshing and assuring to see that many clinical researchers have come to conclusions that are similar to what consumers have concluded from their own experiences: **that recovery is possible, and that it needs both internal determination and external support.**

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