Review of Recovery Literature

A Synthesis of a Sample of Recovery Literature 2000

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Ron Manderscheid, Ph.D., Director of the CMHS Survey and Analysis Branch, developed the partnership to fund and support this project and several others that are known jointly as the Recovery Project. Previously, Dr. Manderscheid supported presentations on recovery at both the National Conference on Mental Health Statistics and the Southern Regional Conference on Mental Health as well as at other conferences and meetings.

The Recovery Project represents the melding of several strands of interest in recovery. The MHSIP Policy Group was concerned about how to measure the concept of recovery and sponsored a major effort to address this issue. On a parallel track, the NASMHPD President's Task Force on Performance Measures included the concept of "recovery/ hope/personhood" in its framework of performance indicators which are being developed and tested in the CMHS-funded, 16-state study.

Funding for the Recovery Project supported three tasks: (1) establishment of a Recovery Advisory Group of consumer leaders (funds provided by the CMHS Survey and Analysis Branch),(2) development of a compendium of instruments that measure recovery (funds provided by The Evaluation Center@HSRI) and (3) development of the *Review of Recovery Literature* (funds provided by NTAC/NASMHPD).

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It was a pleasure and a delight to chair this group and to benefit from its members' diverse knowledge and experience.

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PREFACE

Recovery has been a major interest expressed by consumer and other members of the Mental Health Statistics Improvement Program (MHSIP) Policy Group, which has made this topic one of its areas of emphasis. The *Review of Recovery Literature* is one of three projects that make up the Recovery Project. The other two are the establishment of a Recovery Advisory Group of consumer leaders and the development of a compendium of instruments that measure recovery. The Recovery Project is jointly supported by the MHSIP Policy Group, the Survey and Analysis Branch of the federal Center for Mental Health Services (CMHS), The Evaluation Center@HSRI and the National Technical Assistance Center for State Mental Health Planning (NTAC) of the National Association of State Mental Health Program Directors (NASMHPD).

The Recovery Advisory Group was composed of a number of consumer leaders from across the country who met by teleconference once a month, with financial support from the CMHS Survey and Analysis Branch. They discussed recovery from their own perspectives and the perspectives of the consumers with whom they worked. They exchanged, read and discussed a tremendous amount of material about recovery, both published and unpublished.

A major outcome of these teleconferences is The Recovery Advisory Group Recovery Model, which is discussed in the section on models in this publication. In addition the group recommended that the thoughts, experiences and materials discussed during these teleconferences be collated, coordinated and put into an organized format to inform the mental health community about the types of literature being produced on the concept of recovery. This was the beginning of the *Review of Recovery Literature.*

An in-depth view of consumer writings about recovery, research on recovery and measurement of recovery was developed as a background paper for the 1999 *Mental Health: A Report of the Surgeon General.* This and other background papers written by consumers are scheduled to be published in an upcoming issue of *Psychiatric Rehabilitation Skills*.

The Recovery Advisory Group also initiated an intensive search for instruments to measure recovery and recovery-related areas and to discover information about consumer involvement in the development of these instruments and documentation about the testing of the instruments with appropriate populations. This effort resulted in the document *Can We Measure Recovery? A Compendium of Recovery and Recovery-Related Instruments* published by The Evaluation Center@HSRI. This has become the basis for a major initiative to develop and test a measure of recovery and the recovery environment through the 16-state study funded by the Center for Mental Health Services.

A wealth of other information and literature is available about recovery that did not arise from research or measurement, but that is valuable and informative nonetheless. Thus using the resources described above and adding the wider collection of information and material developed on recovery became the focus of the *Review of Recovery Literature*.

A major development has been the interest policy makers have expressed in the concept of recovery and the various ways this is implemented. Can this interest—and the collaboration of consumers, providers and policy makers—result in a paradigm shift in the mental health system that actually encourages and supports recovery? Let us hope so.

Ruth O. Ralph, Ph.D.

INTRODUCTION

There is a great deal of interest in recovery throughout the mental health community. Consumers of mental health services who discover that there is such a concept are given hope that they can reach some level of normal life. Providers are realizing that to have their clients recover is to their advantage, not only so that the people they serve can enjoy better health, but also so that they can have enough staff and time to assist those who are coming into the system. Payers for mental health services (e.g., health maintenance organizations [HMOs], Medicaid) are most interested in being able to reduce services and costs. Funders of services (e.g., state mental health agencies, federal programs, legislators) want to see their dollars produce success. Thus, recovery has become the latest "buzz word" in mental health circles. What it is, how it is defined and how it is accomplished is the subject of many discussions, writings and presentations.

The purpose of this paper is to review the different types of literature on recovery in mental health, both published and unpublished, and to provide examples of each type.

We will start with a brief review of the origins of the concept of recovery in mental health and continue with some definitions of recovery. Types or categories of recovery literature will be described, with illustrations of each category. Finally, we will attempt to summarize what we have learned and draw conclusions from the content of the literature, including making recommendations for further study.

It should be noted that the recovery literature discussed in this paper is only a small part of the total body of literature about recovery and thus provides examples of what can be found in this expanding field. Although efforts have been made to identify, collect and review recent publications, presentations and unpublished papers, this review should be thought of as a "point-in-time" summary because the recovery literature is growing daily at an enormous pace.

Emergence of the Concept of Recovery

It should be noted that recovery is a foreign concept to many in the mental health field. Until recently, recovery was not thought possible by many family members, providers, researchers and funders of services. In fact, the possibility of recovery is still debated by some.

"The concept of recovery is rooted in the simple yet profound realization that people who have been diagnosed with mental illness are human beings" (Deegan, 1996). The simple fact that this statement was made in a recent publication indicates the extent of the belief that people with mental illness do not recover, will always remain a burden on society and must be "taken care of" rather than encouraged to become independent, contributing members of society. It also indicates the extent of the need for the systematic and extensive study of how people become well and how they stay well in spite of, and perhaps because of, the barriers they face.

In the early 1980's, the term recovery seldom appeared in articles or concept papers. For example, Houghton's (1982) personal account was titled "Maintaining Mental Health in a Turbulent World," and Leete's (1989) was

called "How I Perceive and Manage My Illness." The Well-Being Project (Campbell & Schraiber, 1989) never mentions recovery, although it is a study of how consumers view their struggle and how they define well-being. The phrase "from patient-hood to person-hood" was a theme in this study. Some non-consumers became convinced that recovery is possible, or at least were ready to listen, as they read and heard consumers' personal stories about their struggle with and overcoming of the difficulties they faced. Others adopted the term to describe the success of the intervention or interventions they felt "worked" for people with mental illness. In the late 1980's and early 1990's, the word recovery was introduced in consumer writing by Deegan (1988) in "Recovery: The Lived Experience of Rehabilitation" and in non-consumer commentary by Anthony (1993) in "Recovery from Mental Illness: The Guiding Vision of the Mental Health Service System in the 1990's."

Recovery Defined

The word recovery means "to get back: regain" or "to restore (oneself) to a normal state" (*Webster's II New Riverside University Dictionary,* 1984). It has been used extensively in the field of substance abuse where the concept of "recovery" means people go back to pre-drinking or pre-drugging lives.

Recovery in mental health is defined in the writings of consumers. The following quotations were included in a paper on recovery (Ralph, 2000) prepared as background information for *Mental Health: A Report of the Surgeon General (1999).* These selected comments illustrate both the diversity and the commonalities of consumers' perspectives on recovery.

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

- "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 reestablish 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).

- "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 reconnection which included the following four key ingredients: connection, safety, hope, and acknowledgment of my spiritual self" (Long, 1994, p. 4).

- "What there is now that is new is the beginning of trust that the bad times will pass and the underlying strength will prevail. What there is now is insight about how externals affect me and how to better manage myself in connection with outside factors. What there is now is acceptance. I reinforce what I learn with an annual life review" (Caras, 1999, p. 2).

- "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).

Some consumer descriptions of recovery include activities or actions that move the person toward wellness and enable or enhance recovery.

- "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 included in these personal definitions of recovery. Unzicker (1989) describes her reaction while 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" (Unzicker, 1989, p.72). In addition to constructive anger, recovery also includes advocacy for self and others, acceptance of personal responsibility and asking for and accepting help (Ralph, 1997).

Other descriptions include:

- Recovery is a continuing, deeply personal, individual effort that 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).

- It includes physical and mental health, and economic and interpersonal well-being (DeMasi et al., 1996).

- Recovery includes personal empowerment and a spirituality/philosophy, which gives meaning to life. 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).

Recovery Does Not Describe What Happens

Many consumers/survivors of mental health services feel that the word recovery does not truly or fully describe the journey through mental illness 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. 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.

Caras writes: "I am not recovered. There is no repeating, regaining, restoring, recapturing, recuperating, retrieving. There was not a convalescence. I am not complete. What I am is changing and growing and integrating and learning to be myself. What there is, is motion, less pain, and a higher portion of time well-lived" (Caras, 1999, p. 1).

There is continued discussion about what would be a better word than recovery. "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, quoted in Fisher and Deegan, 1998, p. 6).

Cohan and Caras (1998) introduced the word transformation as a substitute for the word recovery:

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. 10).

TYPES OF RECOVERY ACTIVITIES

Several types of activities are connected with, describe, interpret or may have an impact on recovery. The following examples are not intended to be the total of what is available. The types of literature associated with these activities will be discussed in the next section.

First, there is the continuation of the writing and collecting of personal accounts–stories written or told that describe the struggle with and overcoming of mental illness and accompanying social challenges. These may be included in presentations at conferences and workshops, exchanged on the internet, printed in consumer newsletters or included in peer-reviewed journals. For example, the periodicals *Psychiatric Services, Psychiatric Rehabilitation Journal* and *Psychiatric Rehabilitation Skills* regularly publish personal accounts.

Second, there are activities that offer consumers and mental health providers information about how to recover. Consumer conferences in a number of states have either focused on recovery as their primary theme, or have included sessions on recovery. Some of these conferences have been funded or sponsored by state mental health agencies. The annual national Alternatives Consumer Conference includes many sessions about recovery, wellness and making your own and others' lives better. Consumer newsletters also provide this type of information. Workshops and training in how to recover have been developed and are conducted by consumers and non-consumers. Presentations on recovery definitions and methods are made at local and national conferences. Papers are written and distributed. Personal accounts often include information about how to recover and how to continue to be well.

Third, both consumers and non-consumers conduct research focusing on recovery. These include a wide variety of methods and focuses, including consumer surveys, qualitative studies, outcome studies, development and testing of specific interventions, both quantitative and qualitative instrument development, and model development and testing.

Fourth, there are policy development activities. Many state mental health agencies are seeking ways to implement policies and procedures to promote recovery. Federal agencies are funding the development of "indicators" of success in various areas of the mental health system. Recovery is one of these areas, and indicators are being sought to ensure that recovery has taken place and that mental health systems are providing an environment in which recovery can occur.

TYPES OF RECOVERY LITERATURE

Literature about recovery includes:

- personal accounts that continue the telling of personal stories by consumers to illustrate the many and varied ways recovery takes place;
- educational materials to teach concepts and methods of recovery and self-care;
- development of models to show how and when recovery happens;
  research;
- development and testing of measurement tools;
- policy development; and
- general discussion and opinion.

PERSONAL ACCOUNTS

Consumers continue to tell personal stories of their struggle with mental illness, the methods they learned to cope with their illness, the barriers they faced and their journeys to wellness. This is one of the ways that mental health consumers have used to communicate to other consumers and non-consumers that recovery can and does take place. These often include definitions of recovery and descriptions of processes, supports and activities that have enabled or enhanced their recovery.

Ridgeway (1999, unpublished manuscript) analyzed four early consumer recovery narratives (Lovejoy, 1982; Deegan, 1988; Leete, 1989; Unzicker, 1989) with a constant comparative method to find common themes. These themes are as follows:

- Recovery is the reawakening of hope after despair.
- Recovery is breaking through denial and achieving understanding and acceptance.
- Recovery is moving from withdrawal to engagement and active participation in life.
- Recovery is active coping rather than passive adjustment.
- Recovery means no longer viewing oneself primarily as a mental patient and reclaiming a positive sense of self.
- Recovery is a journey from alienation to purpose.
- Recovery is a complex journey.
- Recovery is not accomplished alone–it involves support and partnership.

In a review of recovery literature, Ralph (2000) identified the following four dimensions of recovery found in personal accounts:

***Internal factors*:** factors that are within the consumer, such as awareness of the toll the illness has taken, recognition of the need to change, insight about how change can begin and determination to recover;

***Self-managed care*:** an extension of the internal factors in which consumers describe how they manage their own mental health and how they cope with the difficulties and barriers they face;

***External factors*:** include interconnectedness with others; the supports provided by family, friends and professionals; and having people who believe that they can cope with and recover from their mental illness; and

***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" (Ralph, 2000).

How to Recover

Information about how to recover and maintain mental health is often found in personal accounts. The author describes the things he/she learned to put in place in order to regain and maintain mental health. This is called self-managed care by Fisher (1996) and Ralph (2000).

Houghton (1982) provides an excellent example of self-managed care, which can be appreciated only in part by the following quotes:

- "My illness taught me (the hard way) the importance of meaningful work, good patterns of rest and sleep, exercise, diet, and self-discipline. Once freed from the regulating shackles of medications, I had to substitute a reasonable routine, a slower pace, and a calm atmosphere."
- "I began my new life by setting up a schedule for myself, by providing a structure for everyday living."
- "Exercise and physical activity not only strengthen the body but serve as an emotional safety valve. Mental illness is often negative energy turned inward, exercise provides a healthy release from this energy."
- "I view writing as a healthy form of transference. It purges my mind of information that interferes with action and helps to organize my thoughts into patterns of action."
- "Another essential change in my life has been learning to set reasonable goals and to reach them. (I still struggle with what's 'reasonable.') I learned that any change—such as a business trip or vacation—which drastically altered my routine, was stressful. Deadlines, other- or self-imposed, were harmful, especially if they were unrealistic (pp. 549-550)."

In addition to the examples and advice provided in personal accounts, information about recovery can be found in manuals, workbooks and training materials. Some of these materials describe their methods as models. Copeland (1994, 1997, 1999) has produced a number of books and manuals, and she also conducts

training activities and workshops. Spaniol and Kohler (1994b) have developed a workbook and training for recovery group leaders as well as a collection of personal accounts (1994a). Knight and colleagues conduct "Recovery Dialogues" and provide participants with materials (unpublished) to help them remember the points learned (personal communication). Numerous articles and presentations have been prepared by Fisher (e.g.,1996, n.d.), many of which have been published in the National Empowerment Center Newsletter.

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).

TYPES OF RECOVERY RESEARCH

Research on recovery from mental illness is relatively new and results vary, in part, due to the way the concept is operationalized. Some progress has been made in the theoretical description of recovery through the development of models.

MODELS

When a search of the literature is made for models of recovery from mental illness, both treatment models and theoretical models are described. The choice has been made here to address only theoretical models, which in some way attempt to visualize the processes or the outcomes of recovery. Three theoretical models were found which have been developed to describe recovery. Only one of these has been tested empirically (DeMasi, et al., 1996). However, the other two models provide the basis for discussion and further description.

DeMasi and colleagues (1996) developed a model based on their review of the literature that explains recovery in terms of three areas of well-being: health (both physical and mental health), psychological (self-esteem, hope, coping and confidence) and social (economic and interpersonal quality of life). A number of scales were used to develop the Self-Help Survey which was mailed to individuals in New York state who used either traditional services only, self-help services only or a combination of traditional and self-help. The scales used were: the Colorado Symptom Index (Coen, Wilson, Shern & Bartsch, 1989) to measure symptoms of mental illness; Rosenberg's (1965) Self-Esteem Scale; the Mental Health Confidence Scale (Carpinello, et al., 2000); the Ways of Coping Scale (Folkman & Lazarus, 1988); the Hope Scale (Snyder et al., 1991) and several items to measure economic and interpersonal quality of life. The survey was mailed to a statewide sample of 956 individuals, with a total of 612 people returning a completed survey, a 64 percent return rate. Using confirmatory factor analysis, the structure of the hypothesized model was tested and supported. The results indicate that recovery spans beyond the mental health system into all human services, is supported by a combination of support services (e.g., health, housing, fiscal resources) and emphasizes the importance of a partnership between clinician and client and between traditional and alternative services.

Several versions of a recovery model have been published by Dan Fisher of the National Empowerment Center.[1] This model was first called the Empowerment Vision of Recovery from Mental Illness, (Fisher, 1994) and later the Empowerment Model of Recovery from Mental Illness (Fisher & Ahern, 1999). The narrative that accompanies the diagram that illustrates this model includes the following concepts:

- People are labeled with mental illness through a combination of severe emotional distress and insufficient social supports/resources/coping skills to maintain the major social role expected of them during that phase in their life.

- The degree of interruption in a person's social role is more important in affixing the label mental illness to someone than his or her diagnosis.

[1] The National Empowerment Center is a consumer-operated technical assistance center funded by the federal Center for Mental Health Services.

- ▣ Recovery is possible through a combination of supports needed to (re)establish a major social role and the self-management skills needed to take control of the major decisions affecting one's life.

- ▣ This combination of social supports and self-management helps the person regain membership in society and regain the sense of being a whole person (Fisher & Ahern, 1999, p. 13).

The Recovery Advisory Group Recovery Model (Ralph et al., 1999) was developed as a result of a series of monthly teleconferences with a group of consumer leaders who discussed recovery from their own experience, the experiences of those with whom they worked and their review of a considerable amount of literature on recovery. This model describes and defines recovery through a number of stages: anguish, awareness, insight, action plan, determination to be well and well-being/recovery. The path is not linear, and people do not simply move through one stage to the next, but may move back and forth among the various stages.

Consumers who developed this model indicate that recovery is both internal and external. The internal is what happens within oneself, while the external includes interactions with others. The following dimensions were chosen to describe the internal aspects of recovery: cognitive, emotional, spiritual and physical. The external dimensions consist of a person's actions and reactions to external influences, and interactions with people and situations as one moves across and through the stages of recovery. The following dimensions were used to describe the external aspect of recovery: activity, self-care, social relationships and social supports. Insight into oneself, "self talk" and growth must take place, but there also needs to be interaction with the world in which one lives. External influences (e.g., family, friends, community, mental health system) are also important for recovery, and they can support or deter recovery.

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 they generated a list of abilities, behaviors and activities that were important to their recovery. These indicators, used in a pilot study in Ohio with 71 service recipients and in another study 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). Both Ohio and Maine participants selected the same top four indicators.

1. The ability to have hope
2. Trusting my own thoughts
3. Enjoying the environment
4. Feeling alert and alive
5. Increased self-esteem
6. Knowing I have a tomorrow
7. Working with and relating to others
8. Increased spirituality

9. Having a job
10. Having the ability to work

The consumer group in Ohio also developed a set of statements to rate the impact of mental health professionals on their recovery. Clients in the Ohio county mental health system rated these statements from greatest to least impact:

1. Encourage my independent thinking
2. Treat me in a way that helps my recovery process
3. Treat me as an equal in planning my services
4. Give me freedom to make my own mistakes
5. Treat me like they believe I can shape my own future
6. Listen to me and believe what I say
7. Look at and recognize my abilities
8. Work with me to find the resources or services I need
9. Are available to talk to me when I need to talk to someone
10. Taught me about the medications I am taking

An examination of these statements identifies key issues which also arise in other accounts of recovery, such as encouragement, belief in abilities, empowerment (treating as equal), listening and believing, and free choice.

The Well-Being Project (Campbell & Schraiber, 1989) is a landmark effort in which mental health consumers conducted a multifaceted study in California to define and explore factors promoting or deterring the well-being of persons who were diagnosed with mental illness. The project developed research protocols that engaged consumers and survivors in development of research questions, instruments and methods. Four basic research strategies were utilized:

- review of relevant psychiatric literature,
- quantitative survey research,
- focus groups, and
- oral histories.

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 percent had been hospitalized; of the 53 family member respondents, 91 percent reported that their relative had been hospitalized. Nearly 60 percent 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 were to: write down their thoughts or talk the problem out (50 percent); eat (52 percent); call or see friends (52 percent); relax, meditate, take walks or a hot bath (54

percent); and call or go see a mental health professional (62 percent). Campbell (1993) defines the essential elements of 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 on recovery from mental illness and the influence that mental health services, rehabilitation services in particular, have on recovery is the 32-year longitudinal study of patients from the Vermont State Psychiatric Hospital reported by Harding and colleagues (1987). George Brooks, superintendent of the hospital, selected a cohort of 269 chronic patients 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 patients had been ill for an average of 16 years, totally disabled for 10 years and hospitalized continuously for 6 years. They participated in a pioneering rehabilitation program and were released in a planned deinstitutionalization process with community supports in place. These clients were followed up 32 years later (262 were traced, 97 percent of the original 269 patients). Thirty-four percent of the living people with a diagnosis of DSM-III schizophrenia experienced full recovery in both psychiatric status and social functioning, and an additional 34 percent of the people who attended the rehabilitation program were significantly improved in both areas. The definition of recovery used in this study is as follows:

The universal criteria for recovery is defined as no current signs and 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 & Zahniser,1994).

A follow-back study matched a selection of patients hospitalized in Maine to the Vermont patients by age, sex and diagnosis, and compared outcomes between the two groups (DeSisto et al., 1995). 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" (DeSisto et al., 1995, 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 percentage of patients assessed as clinically recovered ranged from a low of 6 percent to a high of 66 percent, with an average of 28 percent and a

median of 26 percent. The percentage of patients who showed a social recovery ranges from a low of 17 percent to a high of 75 percent, with an average of 52 percent and a median value of 54 percent. "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).

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 how these outcomes are affected by the different types of assistance (i.e., traditional or self-help). Involvement in self-help was found to have positive effects on self-concept and interpersonal quality of life. The strongest negative effects on self- concept and quality-of-life outcomes were found to be exacerbating symptoms. Traditional services were found to have a negative relationship with self-concept as well as with quality of life (Markowitz, et al., 1996).

The role of social relationships in recovery was studied by Brier and Strauss (1984) with 20 patients who had been hospitalized for a psychotic decompensation. Initial interviews in the hospital focused on obtaining a history of each person's psychiatric problems and identifying any apparent relationships between these problems and 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 patients described specific ways in which social relationships were beneficial. From these interviews, 12 categories were identified:

Ventilation**:** conversing with others;

Reality testing**:** assisting to maintain clear distinctions between reality and psychotic distortions;
material support: helping with financial, housing and transportation problems;

Social approval and integration**:** receiving reassurance when people accept them and provide a sense of belonging;

Constancy**:** associating with people they knew before hospitalization, connecting current identity with pre-hospital identity and giving roots to existence;

Motivation**:** receiving encouragement to achieve higher levels of occupational and social functioning;

Modeling**:** observing the behavior of others and incorporating 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**:** being understood by people important to them;

***Reciprocal relating*:** becoming an equal partner, able to share and be of assistance to others; and

***Insight*:** acquiring more complete and accurate understanding of themselves.

The authors also identified two phases through which patients go toward their recovery from a psychotic episode: (1) convalescence–getting over the experience of the psychotic episode–and (2) rebuilding–putting one's life back together, making plans for a new life and beginning an identity shift to being an "ex-mental-patient."

The Consumer Leadership Education Program (LEP) is a 16-week psychoeducational program that prepares mental health consumers for leadership positions on community agency boards and committees. The LEP was designed in a participatory process with a consumer advisory group of 10 mental health consumers, research and program personnel who provided information about topics helpful to promote recovery. The curriculum design also utilized information from consumer interviews and focus groups addressing the recovery process. The training curriculum includes 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 and colleagues (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. In comparison with control groups, trainees showed significant improvement on measures of consumer-rated symptoms, self-efficacy, empowerment and community living skills. Training participants reported significant improvement in their (1) ability to control negative and social symptoms of their psychiatric illness, (2) social relationships, (3) personal care and vocational skills and (4) personal power. There was also a trend toward improvement in overall attitude about recovery from mental illness, using the Recovery Attitude Questionnaire (Borkin et al., 1998).

The recovery process of incest survivors was studied by Godbey and Hutchinson (1996). A sample of 10 adult women who were incest survivors was recruited through word-of-mouth snowball sampling. Women were excluded if they had experienced suicidal ideation within the last 6 months or 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 other incest survivors were coded along with the interviews. Using grounded theory method, data were coded line by line. 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, but one that results in long-term satisfaction. They indicated that in order to accomplish this, 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 identified 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 phases is discussed and illustrated based on information provided by the interviewees. The researchers conclude that reincarnating is accepting the experience of incest and all the associated life-experiences and weaving these experiences into an integrated life. The following words of a participant illustrates this point:

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 (p. 309).

Measurement of Recovery and Healing

A compendium of recovery and related measures (Ralph, Kidder & Phillips, 2000) includes published and unpublished measures of recovery and other areas related to recovery. There are relatively few instruments that attempt to measure recovery compared with the number of instruments that measure other areas in mental health, for example, symptoms or satisfaction. Instruments in this compendium may measure something *about* recovery rather than recovery itself, or they may have been used in qualitative studies to define or identify perceptions about recovery. Thus three of the instruments in this compendium measure attitudes or personal vision, two are qualitative question sets and three provide Likert-type rating scales that may result in the measurement of recovery. All of these instruments ask for responses from the consumer. Because most of these instruments are works in progress, they provide little information about change over time or use of the instrument with an intervention. Further work needs to be done to assess the effectiveness of these instruments in measuring the impact of specific interventions to measure the course of recovery through the assistance of the mental health system. Cultural and geographic effects on recovery need to be examined, and measurements must reflect these concerns.

The following instruments, scales or qualitative question sets have been developed to study or measure recovery or healing. More detailed information about each one can be found in the compendium of recovery and related measures (Ralph, Kidder & Phillips, 2000).

The Crisis Hostel Healing Scale (Dumont, 2000) was developed through concept mapping with consumers and providers who were operating and using the Crisis Hostel in the federally funded Crisis Hostel Project.

Recovery Assessment Scale (Corrigan et al., 1999) was developed by analyzing four consumer stories of recovery, and items were developed from the identified concepts.

Rochester Recovery Inquiry (Hopper, Auslander & Blanch, 1996) is an open-ended, qualitative questionnaire.

Recovery Attitudes Questionnaire (RAQ) (Borkin et al., 1998; Steffan et al., 1999) was developed by a team comprising mental health consumers, professionals and researchers of the Hamilton County (Ohio) Recovery Initiative.

Personal Vision of Recovery Questionnaire (PVRQ) (Ensfield, 1998) "was designed to measure consumers' beliefs about their own recovery."

The Recovery Interview (ILGARD Research Team, 1998) is a qualitative questionnaire developed by the research team at the Ohio University Institute for Local Government Administration and Rural Development.

Agreement with Recovery Attitudes Scale (Murnen & Smolak, 1996) was developed by Knox County (Ohio) researchers in collaboration with consumers to assess change in attitudes with regard to movement toward a recovery process.

The Recovery Scale (Young & Ensing, 1998) was designed to be a comprehensive recovery measure, based on Young's work with consumers.

Measures Related to Recovery

The following instruments are examples of scales that measure concepts thought to be related to recovery. The involvement of consumers in the development of these scales was one criterion for selection.

The *Leadership Education and Training Assessment* (Bullock et al., 2000) included a number of scales (e.g., Making Decisions Empowerment Scale, Community Living Skills Scale, Recovery Attitudes Questionnaire) to measure the effectiveness of the Leadership Education and Training program in Ohio in which consumers were trained to take leadership roles on boards and committees.

The Well-Being Scale (Campbell & Schraiber, 1989) was developed by consumers and used with more than 350 consumers in a wide variety of settings (including psychiatric hospitals) in California.

The Mental Health Confidence Scale (Carpinello et al., 2000) was constructed and used as part of the data collection strategy in a study focused on factors that predict participation and nonparticipation in self-help groups.

The *Hearth Hope Scale* (Hearth, 1992) and the *Hope Scale* (Snyder et al., 1991) were developed by non-consumer researchers but were selected to use in studies of recovery because of the importance of hope.

The Staff Relationships Scale (Hornik, Ralph & Salmons, 1999) was developed because project leadership from the Albany and Boston sites of the Supported Housing Initiative Cross-Site Study felt that this topic was an important area of influence for recovery in people who were moving into supported housing.

Making Decisions Empowerment Scale (Rogers, Chamberlin, Ellison & Crean, 1997; Wowra & McCarter, 1999) was developed by a group of consumers with consultant researchers for the purpose of studying the empowerment of making decisions on self-help. After extensive development and pilot testing, a 28-item scale was tested with 271 members of 6 self-help programs in 6 states.

The Consumer Empowerment Scale (Segal, Silverman & Temkin, 1995) was 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. The scale was tested with 310 members of 4 self-help organizations.

RECOVERY IN MENTAL HEALTH SYSTEM POLICY

Anthony (1991, 1993) introduced recovery as the guiding vision for the mental health system after reading and listening to consumers' personal accounts of their struggle through and recovery from mental illness. He traces the progress of the mental health system from deinstitutionalization through the establishment of community support and rehabilitation services, with recovery envisioned as the next step in the process. Anthony notes that while deinstitutionalization focused on new uses for buildings and facilities, the community support system was planned as a network of essential services to support persons with psychiatric disabilities, and the field of psychiatric rehabilitation emphasized treating the consequences of mental illness. However, recovery speaks about how recipients of services will live and choose the services they need and want. He emphasizes that service providers must be understanding and tolerant of the range of intense emotions experienced by consumers during recovery without diagnosing behavior as abnormal or pathological. The mental health system must provide the environment that stimulates and encourages recovery (Anthony, 1993).

A number of states have included the word recovery or the concept of recovery in documents such as mission statements, guiding principles and descriptions of treatment programs. Some states are trying to incorporate recovery into the way mental health services are provided.

Ohio has been a leader in this effort. In 1993 the Ohio Department of Mental Health (ODMH) conducted a series of dialogues throughout Ohio and across the nation with consumers, family members and providers, including clinicians, to explore the philosophy of recovery and to determine elements that contribute to the recovery process. In 1994 a Recovery Conference was followed with a discussion about the importance and use of recovery in the mental health system by the Community Support Program Advisory Committee, composed of clinicians, consumers and family members. They produced the report *The Recovery Concept: Implementation in the Mental Health System* (Beale & Lambric, 1995).

The recommendations of this report were organized by the key themes of jobs, empowerment, stigma, peer support, family support, community involvement, access to resources, education, and clinical roles and relationships. Members of the state Office of Consumer Services, collaborating with other members of ODMH and the community, have continued to sponsor annual recovery conferences and recovery dialogues. They have also established regional Consumer Quality Review Teams and local collaborative partnerships through which consumers can voice their opinions about the quality and effectiveness of services and promote the development of service alternatives that best meet their needs. A result of this continued dialogue and emphasis on recovery is the development of the *Mental Health Recovery Process and Best Practices Model,* which is described in the publication *Emerging Best Practices in Mental Health Recovery* (Townsend et al., 1999).

In 1996 the Governor of Wisconsin authorized a Blue Ribbon Commission on Mental Health Care, whose purpose was to develop a long-term plan for mental health services in Wisconsin for children, adults and elderly adults. "The Blue Ribbon Commission adopted the concept of recovery, that is, the successful integra-

tion of a mental disorder into a consumer's life, as the key tenet of the redesigned mental health system" (DeSantis & The Blue Ribbon Commission, 1997, p.iii).[2]

In a report prepared for the Commission, Jacobson (1998) conducted semi-structured telephone interviews with key staff in 12 states, asking how they operationalized and implemented recovery in their state mental health systems. Jacobson obtained her sample by identifying states that were purported to be leaders in this area and was referred to other states through a snowball sampling process. She indicated that states are at different stages in planning and implementation and that approaches to incorporating recovery differ from state to state. "Some states seem to be repackaging their old service models (e.g., CSPs, supported education, rehabilitation services) using the recovery language; others are wholly re-inventing themselves" (p. 1).

Jacobson and Curtis (2000) summarize the findings from this study, describing the process taken by states to develop a "recovery oriented" service system and the areas or strategies selected to do this. The process is described as an effort to understand the concept of recovery and to determine its viability and value within clinical and financial constraints. The development of a vision statement is done through the establishment of a task force or work group that includes diverse stakeholders. Multiple sources of information are tapped to assist in understanding the concept and developing a vision statement incorporating a working definition of recovery and making recommendations to implement the principles identified.

Jacobson and Curtis (2000) comment:

With vision statements in hand, some states simply rename their existing programs....Community support services, vocational rehabilitation or housing support are now described as 'recovery-oriented' services. This renaming process demonstrates a lack of understanding of recovery; in particular, a failure to acknowledge the necessity for a fundamental shift toward sharing both power and responsibility (p. 335).

Strategies to implement and operationalize recovery in the mental health system in states that have moved beyond the service name-changing stage include:

. . . education, consumer and family involvement, support for consumer operated services, emphasis on relapse prevention and management, incorporation of crisis planning and advance directives, innovations in contracting and financing mechanisms, definition and measurement of outcomes, review and revision of key policies, and stigma reduction initiatives (p. 335).

In describing the implementation of a rehabilitation-recovery philosophy in the Illinois mental health system, Barton (1998) indicates that all of the disciplines involved in providing mental health services must collaborate with consumers, and with each other, to assist consumers in conceptualizing, setting and reaching their recovery goals. Barton summarizes: "The consumer-centered recovery philosophy is the umbrella over all models, disciplines, practices, and activities in the hospital and the community" (p. 177). Barton also recognizes the

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[2] Note: Most consumers who are thinking about the definition of recovery would not accept this definition.

need for professionals and policy makers to reexamine, reevaluate and redefine their own professional identity and role.

State and federal initiatives to identify successful mental health services include recovery as one of the areas that must be addressed. Although specific recovery indicators have not been identified yet, there is great interest in finding and using measures of recovery that can help the mental health system determine whether people with mental illness are experiencing improvements in their quality of life.

A draft report of work done by the National Association of State Mental Health Program Directors (NASMHPD) Technical Workgroup on Performance Indicators (1998) includes Recovery/Personhood/Hope as one of nearly 50 indicators for adults with serious mental illness. This indicator is identified as "developmental" in that there are no identified measures for this as yet, but it is deemed important enough to be included and to search for or develop some way of measuring this indicator.

State Indicator Pilot Grants were awarded by the federal Center For Mental Heath Services (CMHS) to 16 states in 1998 to pilot test 32 selected performance indicators incorporated from the CMHS Five-State Feasibility Study and the NASMHPD Framework of Mental Health Performance Indicators. A subgroup of these states plans to work on the indicator for Recovery/Personhood/Hope.

In a survey of state mental health agencies about consumer involvement in state surveys, Kaufmann (1999) asked if the state included recovery in its consumer survey. Of the 49 states and territories that responded, 67 percent indicated that they did so. However, the majority of these states indicated that they defined recovery the same as the Mental Health Statistics Improvement Program (MHSIP) and used the outcome measures from the MHSIP Report Card as recovery measures. The Report Card was not developed as a measure of recovery, and is not considered an adequate measure of recovery.

Jacobson and Curtis (2000) conclude their article with several important and thought provoking questions about recovery. They are included in their entirety here because they represent the challenges faced by individuals and systems as recovery is studied and as programs and systems attempt to implement and operationalize a recovery-oriented system:

- "How can we deepen our understanding of recovery as an individual process? What stimulates and sustains the process? What hinders or smothers it? What are the best methods for answering such questions?"

- "Can recovery be measured? Should recovery be measured? What are the risks of doing so? Of not doing so?"

- "How can we transfer our knowledge about recovery as an individual process to our policy-making and service-planning activities? How do specific policies and services affect individual recovery?"

- "How will we know if we are creating a recovery-oriented system? By what criteria should the system be judged? Should we measure individual gains? Aggregate outcomes? System-level change? Over what period of time?"

- "How can we balance recovery as an individual, singular process, with the system's need for standardization? Can we formulate a generalized concept of recovery and still respect the process as unique?"

- "For what should we hold the public mental health system accountable? Are we willing to trade off some system liability for the increased self-determination and personal responsibility that seem to be the hallmark of recovery?"

- "What barriers stand in the way of implementing a recovery orientation? What forces sustain the status quo?"

- "Should recovery be the foundational principle of the mental health system?"

Jacobson and Curtis sum up their views in this way:

These problems start with problems of epistemology—how best to study and measure recovery. But they end in problems of politics and values—what is to be our society's approach to helping persons with psychiatric disabilities? For recovery to herald a real change in our assumptions and practices, and to make a difference in the lives of people living with severe and persistent mental illness, it is vital that all of these questions be engaged. How we choose to answer them will shape mental health services in the coming decades (p. 339).

COMMENTS, SUMMARY AND CONCLUSIONS

Recovery can be defined as a process of learning to approach each day's challenges, overcome our disabilities, learn skills, live independently and contribute to society. This process is supported by those who believe in us and give us hope.

However, many consumers/survivors report that recovery is not an adequate word to describe the journey through and to overcome their mental illness, or the accompanying social consequences; nor does it describe the results or outcome of that journey. While many agree that no one term is adequate, words such as healing, transformation and overcoming have been suggested.

There are a number of activities in the area of recovery, with accompanying written material to contribute to our understanding. Personal accounts of recovery journeys written or told by consumers/survivors are one of the most important contributions to the recovery literature. Here you have not only the account of what happened but also the inner feelings, the insights and the actions taken to overcome and conquer. Some consumers/ survivors have used their own and others' experiences and insights to create training and educational materials to teach others how to recover and manage their lives. Thus opportunities are provided to learn how to overcome and to manage on a daily basis. Research on recovery is increasing. This includes efforts to define recovery more concretely, to find out whether and to what degree consumers agree with these definitions, to determine what outcomes are possible and to develop measurements of this phenomenon. Finally, efforts are being made at the state and federal levels to create a recovery-oriented environment in the provision of mental health services and to hold providers of mental health services accountable for doing so.

Attempts to measure recovery or aspects related to recovery are very recent, and work in this area is only beginning to be published or presented at conferences. It is refreshing to hear that recovery measures are being developed in collaboration with consumers, although the extent of the collaboration has not generally been specified. There is little information about change over time or use of the instruments with specific interventions. Further work is needed in using these instruments to measure the effects of specific interventions and to measure the course of recovery with assistance from the mental health system. This needs to be done in a thorough fashion by consumer researchers in collaboration with consumer advocates, consumer policy experts and consumers who are currently using mental health services. It is also important to review the impact of culture and geography on recovery and to study how the measurement of recovery can be sensitive to these aspects.

Consumers/survivors who live "normal" lives feel they have accomplished a great deal by overcoming both their illness and the barriers they have faced. While they welcome and recommend a recovery environment in the mental health system, they are reluctant to have the mental health system "label" people as "recovered" and thus have "evidence" to remove the psychological and psychosocial supports that are necessary for them to remain well. The measurement of recovery is not only a complex task, but it also raises questions about whether this measurement gives the mental health system a tool to withdraw services from people who are "recovered" by some standard.

Although recovery activities and literature are increasing at an enormous pace, it is still a young and tender concept that is not fully developed. Achieving a recovery-oriented public mental health system will take a tremendous amount of dialogue, study, listening to each other and implementing the actual precepts of recovery including working together; treating each other with respect and dignity; and allowing, helping and encouraging consumers/survivors to "stay in the driver's seat" and take control of their lives.

RECOMMENDATIONS

The most important recommendation is that consumers/survivors, researchers and policy makers work together and learn from one another. Non-consumers need to read and listen to personal accounts of those who have experienced recovery, and to hear and value the opinions of consumers/survivors even if they are not fully versed in the methodology or politics of research and policy. The questions posed by Jacobson and Curtis (2000) included above must be addressed *together* by all of us who are dedicated to making life better for those who face the challenge of mental illness.

Another important area for research is the development and testing of measurement tools. This must be done in full collaboration with consumers/survivors. Although a number of instruments are already developed, they need further testing to determine if they are applicable to diverse populations and whether they measure change over time.

Although it is important to continue to study outcomes of the interventions developed and provided by the mental health system, this is difficult to do in any comprehensive way until the definition(s) of recovery are more precise and measurement tools have been developed and tested. However, this should not deter mental health agencies from searching for ways to implement this paradigm shift to a recovery environment.

There is also a need for systematic and consistent reporting of mental health system attempts and successes in implementing a recovery environment. Success will only come when knowledge about what works is exchanged and when leadership learns from others and implements what they have learned in their own systems.

Finally, there is a need to continue the collection, review and cataloging of recovery literature, both published and unpublished. Many individuals and organizations now have their own collections, but there is no central repository for a complete collection. There needs to be a central library to house this collection, along with facilities and continuous funding for both periodic review and dissemination of recovery literature. If we are ignorant of the work and discoveries of others, we cannot progress to greater heights in the development of knowledge or deepen our understanding of this most important concept, which can change lives and improve society.

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