

Research Project 1

Research Project

Recovery From Mental Illness: Three Perspectives

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Abstract

This paper is submitted as part of the requirement for HCE 615 to research an identified need by an involved party, requiring an minimum of twenty five semester hours, and relates to some aspect of the Psychosocial Rehabilitation course work. This paper will review recovery from mental illness from three perspectives: the consumer/ psychiatric survivor's perspective, family member perspective, and the mental health systems / professional perspective. It will utilize course materials, Internet resources, materials from Boston University's Center for Psychiatric Rehabilitation, and other professional journals, course texts, and related sources.

### Introduction

“Recovery is a common human experience. We all experience recovery at some point in our lives from injury, from illness, or from trauma. Psychiatric disability has a devastating impact on the lives of people who experience it. It is devastating because people with psychiatric disability are left profoundly disconnected from themselves, from others, from their environments, and from meaning or purpose in life. While the illness itself causes people to feel disconnected, stigma (negative personal, professional, and societal values, attitudes, and practices) further disconnects people and represents a serious barrier to building new connections.” (Spaniol, Koeler, Hutchinson 1994, Introduction)

Recovery is an ongoing process through which a person adjusts ones attitudes, perceptions, roles, beliefs, feelings, and goals in life. It is a very emotional process, which creates a new vision of ones self. “The emergence of the concept of recovery in the 1990’s has been fueled by three basic forces: a change in the conceptualization of serious mental illness and disability; the development of alternatives to large long stay psychiatric hospitals and the rise of consumerism” ( “n.d.” Farkas, Gagne, Anthony, p. 2). Farkas (1996, p.6) addresses that “the field has begun to understand that serious psychiatric illness does not necessarily mean life long disability. In fact, the term ‘chronic mental illness’ may be becoming an anachronism.”

The recovery process has largely been consumer driven. Many psychiatric survivors have published information about their own experiences and provide support to others who are in the process of recovery. Many of these individuals have entered the mental health field professionally to change the course of service delivery systems, to advocate, and to provide mental health services. Some of these individuals include

Patricia Deegan, Ph.D., Virginia R. Wentworth, Ph.D., Richard Weingarten, Betty F. McDermott, and Andrea Schmook.

“Historically, the psychiatric community has not lent much credibility to first hand accounts of recovery from mental illness. These were often dismissed as inaccurate portrayals of patients who have been misdiagnosed or who were not as healthy as they wished to appear” (“n.d.” Farkas, Gagne, Anthony, p.4). Although recovery needs to be studied further to better understand the process, many previous studies have revealed that recovery has occurred but have not used “recovery” as its’ definition. Recovery has been described as “no current signs or symptoms of mental illness, no current psychiatric medication, and lack of vocational and social dysfunction” (1994 Harding & Zahniser, 140-146).

My research in this area has led me naturally to a three pronged approach. This paper will review the process of recovery from three perspectives; the consumer/ psychiatric survivor, the family, and mental health system/ professionals and how the role of each party can facilitate the process.

#### Consumer/Psychiatric Survivor Perspective

Hatfield and Lefley (1993, p. 134-141) highlight some of the factors that have assisted individuals in the recovery process. These include: acceptance, responsibility, hope, support, professional services, and mental health services. Consumers discuss learning coping skills to assist them in their daily lives. Spaniol and Koehler, (1994, p. 1-2) outline four foundations of coping which are hope, acceptance, courage and humility. Coping skills include having someone believe in you helps you to believe in yourself. Acceptance is a harder task that acknowledges all aspects of ones self without devaluing the self.

Courage is presented as the ability to make a commitment to an imperfect process. Humility requires courage, personal strength, confidence, and a belief in ones self. These areas are built upon one another to facilitate the process.

Patricia Deegan (1994, p.56) writes eloquently about the recovery process. Deegan states, “It is important to understand that for most of us recovery is not a sudden conversion experience. Hope does not come to us as a sudden bolt of lightning that jolts us into a whole new way of being. Hope is the turning point that must quickly be followed by the willingness to act.” In The Experience of Recovery, (1994, p.16) an anonymous author talks about her illness in these terms, “I think I’ve come to see my limitations in terms of my emotional and physical feelings, their effects on my abilities and functioning, and my self image. I have developed new attitudes and philosophies that allow me to take advantage of my new insights and to take actions based on them.” Rae Unzicker (1994, p.62) describes her recovery in terms of her self and with others’ input as, “...rarely one thing. It’s a process, like life is a process. It was a thousand events, people, challenges, and mysteries. The mental patients’ liberation movement, and especially the people in it, have given me a philosophical and political framework that is extremely valuable.” Virginia Wentworth (1994, p.83) shares her thoughts, “In other words I had to take responsibility for my life. It meant further that I needed to forgive and wish good for the people who had, I believe, harmed me with their misunderstanding and rejections. Healing has been my ongoing and deepest motivation.” These individuals have chosen life over patient-hood. Carling (1995) states, “They chose hope and recovery over the addiction of

helplessness, terminal dependence, and despair- an addiction so deep that it has led them to discount those who take on their own recovery and speak out.”

Many recent changes in the mental health service system have precipitated new directions for people receiving psychiatric services which include; deinstitutionalization, the consumer self-help movement, the Americans With Disabilities Act, supported employment initiatives, empowerment, and overall community integration.

Consumers/ Psychiatric Survivors have become involved in compiling consumer directed initiatives which have assisted in the recovery process. According to CMHS (1997, p.2) twenty initiatives are being supported. Some of these include: Consumer / survivor training and education, developing effective advocacy skills, countering stigma, consumer / survivor- operated services. In the August 1996 Harvard Health Letter, published by Harvard Medical Society, it has cited research that “consumers who were informed and involved in their care had improved health.”

Consumer / survivors want and now demand the opportunity to know what effects the medications they are taking do to their bodies. Many consumer studies and interviews have talked about the effects of medication on their daily lives and the mental health systems perception of its’ role in the ‘patients’ life. Jim Gottstein (1998) discusses recovery on the Alaska Mental Health Consumer Web, and states, “this will mean finding a medication regime that works and following it.” He also states, “In many cases, medication is nothing more than a “chemical straight-jacket” that leaves the consumer a zombie.” I agree with this statement and others like it which I have read and discussed with the consumers I serve. One takes medication to alleviate the symptoms of mental illness, and

more medication to off set the side effects of the medication. I believe that each individual is able to know their own bodies which can be achieved through informed choice, education, and working collaboratively with a mental health professional. Personal empowerment, control over the process of change, and informed choice are facilitators of recovery.

### Family Member's Perspective

Researching this segment of the paper was difficult due to the intrinsically complex role the family member assumes as the liaison between the consumer and the mental health system. Hatfield and Lefley (1995) state that, "Family member's treatment by professionals (or their lack of it) has in turn affected their relationships with their loved ones." The etiology of ones' mental illness for many years was the relationship between the 'patient' and their parents, in particular the mother/child relationship. Caplan & Hall-McCorquodale (1985, p. 610-613) reviewed literature and stated, "mothers continue to be lambasted for a range of sins, including but by no means limited to the creation of major mental illness." It is easy to see how the family, especially the major caregiver, the mother, has had an extremely difficult time supporting their child with mental illness without adequate, if any, education, knowledge, or understanding of what their loved ones were experiencing.

Literature and studies about the families' perspective of mental illness is a relatively new concept. A grassroots, self-help, non-profit, support and advocacy organization was created in 1979 for and by consumers, families, and friends of people with severe mental illness who call themselves the National Alliance for the Mentally Ill (NAMI).

NAMI is an organization with 185,000 members that seek equitable services for people with mental illness. “Working on the national, state, and local levels, NAMI provides education about severe brain disorders, supports increased funding for research, and advocates for adequate health insurance, housing, rehabilitation, and jobs for people with serious psychiatric illnesses.” (NAMI Fact Sheet)

I recently had the opportunity to attend a NAMI focus group at the University of Maine/Orono. This was one of three in Maine that met with family members of people with mental illness, to talk about their needs, wants, and service delivery systems. The facilitator sought information from the group. Seventy-five percent of the attendees knew and/or had attended a NAMI function. As noted in a study by Spaniol and Zipple (1988, p. 37-45) “Family and Professional Perceptions of Family Needs and Coping Strengths” families do not receive adequate information about medications, or their side effects, or are informed about appropriate dosages. Overall, the focus group of family members felt frustrated by the mental health system. These frustrations were a result of the lack of funding for their loved ones care, lack of services in rural areas, and issues of confidentiality which left their “hands tied” about the services family members were receiving. Many attendees spoke about the support they received by other NAMI members through support groups, educational sessions, and networking for legal changes in the mental health system.

The facilitator tried to obtain information from the group about their stressors and coping skills. The discussion touched briefly on this topic only to continue discussing their loved ones. The Spaniol and Zipple (b) study reviewed the symptoms of increased



stress by family members which included; increases in anxiety, frustration, worry, sense of burden, depression, grief, fear, and anger. The study also indicated that 45% of family members were moderately or very dissatisfied with mental health services in general, which closely correlated the NAMI focus group. Sources of support for both the study and focus group included self-help support groups, mental health professionals, and close friends. The study concludes a high dissatisfaction with mental health services because the “services do not provide the kind or quality of support that families need.” (Spaniol and Zipple c) These supports include direct information, practical advice, and emotional support they need to cope well. However, according to the data, family members continue to look to the mental health system for help.

Spaniol and Zipple (“n.d.”) address the “Family Recovery Process” which highlights the fact that family members too experience their own recovery, just as the family member with mental illness. Six general characteristics outline this process. “Recovery is a growth process. The particular impact of the illness differs in family members. Each person in the family recovers at his or her own rate. Families need to be aware of each others phase of recovery. Each phase has its own reactions and its own developmental tasks. Recovery is not linear, so family members will recycle themselves through the phases as they gradually complete tasks that will facilitate moving ahead. Emotional reactions of family members during the process are natural ones.” As in the psychiatric survivor experiencing recovery, stages for family members are discovery/denial, recognition/acceptance, coping, and personal and political advocacy.

Family members who are empowered about their loved ones' mental illness are better able to cope successfully with the illness. Empowerment includes education about the illness which includes symptomology, medications, behaviors associated with the particular disease, and knowing how to deal with these issues. Political advocacy and personal advocacy were also noted as empowering agents.

Studies of families, psychiatric survivors, and the mental health system have been completed by professionals in most cases. Separating the three involved parties of the mental illness triangle can be difficult since the relationships are entwined. The next section will discuss the mental health system and mental health professionals in relation to itself, family members, and psychiatric survivors.

#### Mental Health Professionals and the Mental Health System's Perspective

The basis for mental illness for many years has been the relationship between the 'patient' and the family, especially the mother. Caplan & Hall-McCorquodale (1985) reviewed literature that indicates, "mothers continue to be lambasted for a range of sins, including but by no means limited to the creation of major mental illness." Arieti (1981, p. 271-284) states that, "...after almost twenty five years of working with persons with schizophrenia, that 75-80% of the mothers he encountered do not remotely fit the descriptions of "schizophrenogenic." Family pathology persists in literature, clinical case conferences, rehabilitation practices, and in the media. Terms used to describe psychiatric survivors; working with a diagnosis instead of the person as an individual, or the family as

a unit, not listening to the consumers needs, wants, goals or dreams are regular occurrences in the field. The Disability Rights Movement along with consumers who are service providers, members of advisory boards, advocates and researchers have begun to influence mental health practice, programs and policy. With this type of input, it is “clear that systems also require the flexibility to integrate their services, whether treatment, rehabilitation or other, in a more fluid manner to accommodate the cyclical nature of recovery process, rather than the traditional step-wise approach to systems planning.” (“n.d.”

Farkas, Gagne, Anthony) The mental health system in general needs to be overhauled.

Deinstitutionalism, the Americans With Disabilities Act, and the Rehabilitation Act are legislation with power that have dramatically changed the course of what consumer/survivors and their families now need as people re-enter society, in some cases after many years of isolation. It is the goal of these three groups is to assure implementation of these actions. Carling (1995, p.140) makes a very simple, yet powerful, statement in his book, Return to the Community, “Find the people, ask them what they want, give it to them.” This is the direction the mental health field must take if we, as professionals, caregivers, and survivors are to provide the real services to the people who need them. If ones’ attitudes are not in line with this philosophy, perhaps it is time to find another vocation.

It also needs to be stated that the recovery process has not been fully researched. Anthony’s (1993, p. 11-23) study, Recovery from Mental Illness: The Guiding Vision of the Mental Health Service System in the 1990’s. This article is a direct hit for

professionals to begin to understand their role in the recovery process. Anthony discusses the concept of the comprehensive support system (CSS) combining with the rehabilitation model's more comprehensive understanding of the impact of severe mental illness, laying the conceptual groundwork for a new vision for the mental health service system. I feel this premise gives mental health professionals, consumer/survivors, and families a place to begin to overhaul the mental health system.

Anthony's 1993 study addresses eight major points which are:

- 1.) "Recovery can occur without professional intervention. Professionals do not hold the key to recovery; consumers do. The task of professionals is to facilitate recovery; the task of consumer is to recover.
- 2.) A common denominator of recovery is the presence of people who believe in and stand by the person in need of recovery. Recovery can be everybody's business.
- 3.) A recovery vision is not a function of one's theory about the causes of mental illness. Whether the causes of mental illness are viewed as biological and/or psycho-social generates considerable controversy among professionals, advocates, and consumers.
- 4.) Recovery can occur even though symptoms reoccur.
- 5.) Recovery changes the frequency and duration of symptoms. That is, symptoms interfere with functioning less often and for briefer periods of time.
- 6.) Recovery does not feel like a linear process. Periods of insight or growth happen unexpectedly.
- 7.) Recovery from the consequences of the illness is sometimes more difficult than recovering from the illness itself. The barriers brought about by being placed in the category of "mentally ill" can be overwhelming.
- 8.) Recovery from mental illness does not mean that one was not "really mentally ill." A provider of specific services recognizes, that crises may destroy opportunities for recovery; that rights protection not only assures legal entitlements, but also that entitlements can support recovery."

Recovery needs to be facilitated by the mental health system through creative programming and settings that are structured to create 'triggers' for recovery. Intense emotions are seen as a normal part of the recovery process for all peoples recovering from

catastrophes other than mental illness. Too often people who are recovering with a psychiatric diagnosis are easily denied their emotions because of symptomology related to their illness. Mental health providers must allow these emotions to be experienced in a nonstigmatizing and understanding environment. Consumers, caregivers and professionals who have a better understanding of the recovery process will be more knowledgeable in facilitating a positive environment. "Person first" must be the basis for changes to occur on all levels of services which must include all concerned parties; the consumer, family members, professionals, and the community.

### Discussion and Closing Remarks

Recovery is a relatively new concept to the mental health field. The rise of the consumer/survivor movement, the creation of the National Alliance of the Mentally Ill (NAMI), and other support groups has spurred the mental health system to take notice of those individuals experiencing mental illness in a new holistic way. The Center for Mental Health Services (1993) statistics show that 48 million Americans are estimated to have some mental disorder in a single year. Of these, approximately, 5.5 million are disabled by severe mental illness. The majority of the 29,000 Americans who commit suicide each year are believed to have a mental illness. Nearly one third of those who are homeless (estimates range from 600,000 to 3 million) are believed to have a serious mental illness. More than one in four jail inmates have a mental illness. The numbers speak volumes.

Services need to become more consumer directed, giving the people what they want. This can be seen in any civil rights movement where people take a stand based on their own needs. The time has come for all concerned parties to act together. The Center

for Psychiatric Rehabilitation, consumer/ survivors, A. Hatfield, H. Lefley, and Paul Carling's work have been leaders in this emergence of consumer driven services. The Psychosocial Rehabilitation field has opened new doors long closed to people with a psychiatric history. This field includes mental health services, housing, community integration, employment, and status in society. Psychiatric survivors have now demanded their rightful place in society, where they belong.

While compiling my research for this paper I found inspiration in music. The Allman Brother's Band have a song, "Everybody's Got A Mountain to Climb" (Epic Records 1994) whose lyrics complemented this research. "Everybody's got a mountain to climb, this road we're traveling gets tough sometimes, sometimes I know you feel like ya can't go on, ya need someone to help you get back home."

Carling (1995, p.112) draws it close to psychiatric survivors, " Most mentally ill people can't live independently. In actuality, it is probably the case that *no one* in our society can live independently. If relationships, income, a job, a home, and all of the usual supports were taken away from an individual with or without a disability, that person would be in extraordinarily difficult straits. The common thread that runs through this and similar concerns, of course, is the pervasive failure of society to help people find the places they want to be, and then to support them unremittingly once they are there."

What do Abraham Lincoln, Mike Wallace, Mozart, Barbara Bush, Beethoven, Bette Midler, Rod Steiger, Leo Tolstoy, Kristy McNichol, John Keats, Tennessee Williams, Van Gogh, Issac Newton, Ernest Hemingway, Sylvia Plath, Michelangelo, Winston Churchill, Betty Ford, Ben Franklin, Dick Cavett, Patty Duke, and Charles Dickens have in common? They all had a serious mental illness.

## References

- \_\_\_ Alaska Mental Health Consumer Web, <http://akmhcweb.org/recovery/system.htm>  
Jim Gottstein jimgotts@tochngo.com
- \_\_\_ Allman Brothers Band, 1994, Where It All Begins, Epic Records
- \_\_\_ Anthony, William. (1993) Recovery From Mental Illness: The Guiding Vision of the Mental Health Service System in the 1990's. Psychosocial Rehabilitation Journal Vol. 16, Number 4: April 1993, 11-22.
- \_\_\_ Arieti, S. (1981) The Family of the Schizophrenic And It's Participation in the Therapeutic Task. In S. Arieti & K.H. Brodie, (Eds), American Handbook of Psychiatry, (2<sup>nd</sup> ed., vol. 7, pp.271-284) New York: Basic Books.
- \_\_\_ Caplan, P.J. & Hall-McCorquodale, I. (1985) The scapegoating of mothers: A call for change. American Journal of Orthopsychiatry, 55, 610-613.
- \_\_\_ Carling, Paul J. (1995) Return to the Community: Building Support Systems for People with Psychiatric Disabilities. New York, London: The Guilford Press.
- \_\_\_ Center For Mental Health Services (1993) Mental Health Statistics. Rockville, MD: Author.
- \_\_\_ Consumer Affairs Bulletin, Vol. 3, No. 1, Winter 1997.  
<http://www.mentalhealth.org/consumer/cabvo198/road.htm>.
- \_\_\_ Farkas, M. (1996). Recovery, Rehabilitation, Reintegration: Words vs. Meaning. WAPR Bulletin Vol. 8 No. 4, October 1996
- \_\_\_ Farkas, M., Gagne, C., Anthony, W. (n.d.) A Paradigm for the New Millennium.

\_\_\_\_ Harding, C.M., Zahniser, J., (1994) Empirical correction of seven myths about schizophrenia with implications for treatment., Acta Psychiatrica Scandinavica, 90 (384), 140,146.

\_\_\_\_ Hatfield, A.B., Lefley, H.P., 1993. Surviving Mental Illness: Stress, Coping, and Adaptation. New York, London: The Guilford Press.

\_\_\_\_ National Alliance of the Mentally Ill, Fact Sheet, <http://www.nami.org/history.htm>.

\_\_\_\_ Spaniol, L., Koehler, M., (1994) The Foundations of Coping for People with Psychiatric Disability. Innovations and Research, 3(2), 1994.

\_\_\_\_ Spaniol, L., Koehler, M., (Eds). (1994) The Experience of Recovery, Boston: Center for Psychiatric Rehabilitation, Sargent College of Allied Health Professions/Boston University.

\_\_\_\_ Spaniol, L., Koehler, M., (Eds). (1994) The Recovery Workbook: Practical Coping and Empowerment Strategies for People with Psychiatric Disability, Boston: Center for Psychiatric Rehabilitation, Sargent College of Allied Health Professions/Boston University.

\_\_\_\_ Spaniol, L., Zipple, A.M., (1988). Family and Professional Perceptions of Family Needs and Coping Strengths. Rehabilitation Psychology, Vol. 33, No.1, 37- 45.

\_\_\_\_ Spaniol, L., Zipple, A.M., (n.d.) The Family Recovery Process. The Journal, p.57-58.

\_\_\_\_ Spaniol, L., Zipple, A.M., (1994). Coping strategies for families of people who have mental illness. In H.P. Lefley & M. Wasow (Eds.). Helping Families Cope With Mental Illness. , 131-145.



