

## Recovery From Schizophrenia: With Views of Psychiatrists, Psychologists, and Others Diagnosed With This Disorder

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As the concept of schizophrenia began to develop over a century ago, it was accompanied by little hope of recovery. As the second half of the 20th century began, new treatments and changing social conditions resulted in most long-term patients being discharged into the community. Many of these expatients showed more improvement than had been expected. Treatment approaches evolved to help these persons live better lives in the community. In the recent past, psychosocial and psychiatric rehabilitation approaches to treatment have increasingly incorporated perspectives of persons in recovery. These perspectives are explored with emphasis on how they have helped drive federal government and other perspectives on recovery. Particular attention is given to the varying views of psychiatrists, psychologists, and other highly trained persons who have themselves been diagnosed and treated for schizophrenia.

*Key words:* recovery/rehabilitation/consumer/survivor

### Early Background

Recovery from schizophrenia is a concept that has evolved considerably since the early identification of this psychiatric condition. Emil Kraepelin,<sup>1</sup> who is generally given credit as being the first to describe the condition we now call schizophrenia, characterized the disease as one of inevitable deterioration. Kraepelin saw this disease as one that resulted in “profound” and “terminal” dementia. Indeed, his term for the condition was *dementia praecox*. Eugen Bleuler,<sup>2</sup> the individual

said to first to have used the term, schizophrenia, also emphasized this disease’s downward course. These early pioneers did allow for the possibility of some improvement for those with the condition, but Kraepelin tended to see any such improvements as temporary remissions. Bleuler had a similarly pessimistic view of the possibility of recovery, using the terms, “recovery with defect”<sup>2(p186)</sup> and “healing with scarring,”<sup>2(p263)</sup> to describe the occasional patients who were seen to be returning toward normal functioning.

Despite allowing for the possibility of some degree of recovery, these, and other early writers, overwhelmingly emphasized the high likelihood of deterioration for persons with schizophrenia. As a result, this pessimistic view of the condition has dominated the psychiatric profession’s attitude toward this disease until fairly recently.

The pessimistic Kraepelin/Bleuler perspective concerning the prospect of recovery from schizophrenia that prevailed during the early 20th century began to change with the discovery and introduction of antipsychotic medications in the 1950s. One result of this nascent optimism was the discharge to the community of the vast majority of those who were institutionalized because of their disorders. Indeed, as the 21st century began, over 95% of those who were or would have been in government psychiatric hospitals were then “living in the community.”

The early pessimistic view is also not reflected in the current “*Diagnostic and Statistical Manual of Mental Disorders IV-TR*,” which lists “course” indicators of the disorder that contemplate complete recovery or interepisode remissions. Still, many mental health professionals remain pessimistic.

### From the Medical (Disease) Model to the Rehabilitation Models

The increasing presence of seriously mentally ill persons in the community gave rise to the recognition that although some persons with schizophrenia and similar disorders could function, to varying degrees, in society despite their conditions, it quickly became clear that there were difficulties reintegrating serious mentally ill persons into society. Initially, this problem was addressed by caretakers focusing on social as opposed to medical

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aspects of the disorder. The primary goal of care became to increase former patients' ability to "function" in society, as opposed to the traditional focus on attempting to diminish or eliminate the symptoms of the disorder. Interestingly, the term, function, began to include the resources, as well as the skills needed, to succeed in an environment. The term "psychosocial rehabilitation (PSR)" started to be used to describe this approach, which stressed the "rehabilitation" of those with the disability, as opposed to medical "treatment" of the disease. Importantly, stated principles of PSR included emphasis on "client choice," "strengths," and "empowerment of consumers."

Before long, it became apparent to many that "psychosocial" aspects of these disorders could not be divorced from medical considerations. Increasingly, the importance of wellness and a "holistic approach" became to be recognized, and aspects of medical management were enveloped into the PSR concept. As attention to both medical and social factors began to merge, the term "psychiatric rehabilitation" was coined to reflect this integration of social and medical perspectives.

It is important to recognize that this psychiatric rehabilitation approach included attention to psychiatric symptoms, as well as attention to such skills as self-maintenance activities, vocational skills, using public transportation, social interaction skills, and similar variables.<sup>3-5</sup> Also, the concepts of consumer choice and empowerment began to be seen as important aspects of one's ability to function. Overall, the psychiatric rehabilitation approach seemed to allow for more optimism that persons with psychiatric disabilities could improve and increasingly integrate into society, even if they continued to exhibit some of the symptoms of their disorders.

### From the Rehabilitation to the Recovery Approach

As the focus of care was expanding to include input from those with the psychiatric conditions, some of the persons who had been diagnosed and treated for these conditions began to organize. Local groups were put together with such names as the Insane Liberation Front, established in Portland, Oregon, in 1970. New York City's Mental Patients' Liberation Project and Boston's Mental Patients' Liberation Front were both founded the following year. In 1973, the first national meeting of such rights groups was held in Detroit. This gathering was referred to as the Conference on Human Rights and Psychiatric Oppression that met every year through 1985. At these sessions, the participants strategized, focusing primarily on how to gain more dignity and freedom for persons who had experienced what they saw as cruel and demeaning treatment from those in control of the mental health system that had afforded them few rights and subjected them to what they saw as bizarre and often cruel mistreatments.<sup>6,7</sup> Not long after the first organizational meeting,

some of the more educated or articulate of these "persons in recovery" began to produce reports about their own personal experiences, perceptions, and opinions concerning their experiences of recovery. These perceptions and opinions came from collective as well as individual perspectives and were frequently quite different from those of the professionals who had been managing and delivering mental health services. Increasingly, the voices of recovering persons began to demand that their own perspectives and their developing goals should take on more importance than just being additional elements of recovery. Indeed, many of the more strident voices of these recovering persons characterized the treatment they had experienced as oppression, often viewing professionals as part of the oppressive mental health system. Increasingly, these voices began to demand that their views become a stronger force in the determination of their journeys to recovery.

Judi Chamberlin,<sup>8,9</sup> Sally Zinman,<sup>10</sup> and their associates<sup>11</sup> were some of the early, articulate, "persons in recovery" to begin to produce published materials concerning consumer perspectives of their psychiatric conditions. As time went by, numerous additional consumer voices began to be heard, and a virtual national consumer movement began to develop.<sup>12</sup> Often, these consumer perspectives focused on demanding changes in how they were cared for and in how they were perceived by society in general. Increasingly, consumer voices began to incorporate a call for political, as well as mental health-care, changes.

Jacobson,<sup>13</sup> in an overview where she purports to reflect these consumer perspectives, has argued that from a policy perspective there is an aspect of recovery in addition to the medical and rehabilitation approaches. Jacobson sees 2 ideologically driven, polarized views of recovery, differing primarily in the extent to which they emphasize individual or social transformation. She refers to viewing recovery as a process of symptom reduction (medical model), and/or of functional improvement and normalization (psychosocial or rehabilitation model), as being "mainstream" views. She sees these views as being primarily those of individual change, which she contrasts with a more radical perspective that she sees as almost entirely a matter of social change. Jacobson sees the focus on clinical improvement and functional normalization as being of primary concern to the psychiatric profession and other "elite" professionals along with their allies, the pharmaceutical manufacturers.<sup>13(p164)</sup> She contrasts this with seeing recovery as primarily being a matter of social transformation, a view she sees as being linked closely with that of the disability rights movement.

Others also see "recovery" as having both radical and more mainstream interpretations. The psychiatrist Anthony Lehman<sup>14</sup> describes this dichotomy a little more ominously. He refers to recovery not only as being a loaded word conveying an optimistic message leading to healthy fulfilling lives but also a word that can be interpreted

as signaling that patients are victims of an oppressive mental health establishment from which they should be freed.

As the advocacy voices of consumers were beginning to emerge in the early 1990s, William Anthony,<sup>15</sup> who had been championing a psychiatric rehabilitation model approach to addressing the needs of persons with psychiatric disorders, expanded his view of the concept of psychiatric rehabilitation. Anthony's expanded view paid much more attention to concerns being articulated by recovering persons. He issued a call for recovery to become the "guiding vision" as to how we go about structuring our approach to caring for those with psychiatric disabilities. This vision has evolved into what many observers characterize as the recovery model. It is important to realize that by emphasizing the importance of consumer views, which often strongly emphasized the call for societal changes including a transformation of the mental health care delivery system, the emerging recovery movement necessarily embodied calls for the societal (political) changes mentioned by Jacobson, as well as calls for improved medical and rehabilitative care.

### **Impact of the Recovery Perspective on the Mental Health Delivery System**

During the past half century, we as a society have clearly evolved from a position where recovery for persons with schizophrenia was not seen as a reasonable expectation to one where some form of recovery is not only seen as possible but, indeed, is expected. One very significant indication of the impact of this new view occurred with the report of the President's New Freedom Commission (NFC) in 2003.<sup>16</sup> This report designated recovery as the single most important goal in its call for the transformation of the American mental health service delivery system. This was a remarkable development.

Although the NFC emphatically states that recovery was to be the major goal of the transformed system, not surprisingly, there appeared to be various perspectives as to the meaning of the term, recovery. A major attempt at forging a working definition of recovery was addressed on December 16 and 17, 2004, at a consensus conference held by the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration (SAMHSA), a division of the US Department of Health and Human Services. Participants at this conference included a large proportion of persons in recovery from schizophrenia and other serious mental illnesses including Patricia Deegan, Daniel Fisher, and Fred Frese, all mentioned below. Additionally, family members, administrators and professionals from various mental health entities, and other interested parties attended. The following "national consensus statement on mental health recovery" emerged from the deliberations that transpired at the conference.

"Mental health recovery is a journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential."<sup>17</sup>

Additionally, emerging from the consensus conference was a statement of "The 10 Fundamental Components of Recovery." These components were identified and explicitly described in the document produced by SAMHSA in the following manner:

- **Self-direction.** Consumers lead, control, exercise choice over, and determine their own path of recovery by optimizing autonomy, independence, and control of resources to achieve a self-determined life. By definition, the recovery process must be self-directed by the individual, who defines his or her own life goals and designs a unique path toward those goals.
- **Individualized and person centered.** There are multiple pathways to recovery based on an individual's unique strengths and resiliencies as well as his or her needs, preferences, experiences (including past trauma), and cultural background in all its diverse representations. Individuals also identify recovery as being an ongoing journey and an end result as well as an overall paradigm for achieving wellness and optimal mental health.
- **Empowerment.** Consumers have the authority to choose from a range of options and to participate in all decisions—including the allocation of resources—that will affect their lives and are educated and supported in so doing. They have the ability to join with other consumers to collectively and effectively speak for themselves about their needs, wants, desires, and aspirations. Through empowerment, an individual gains control of his or her own destiny and influences the organizational and societal structures in his or her life.
- **Holistic.** Recovery encompasses an individual's whole life, including mind, body, spirit, and community. Recovery embraces all aspects of life, including housing, employment, education, mental health and health-care treatment and services, complementary and naturalistic services, addictions treatment, spirituality, creativity, social networks, community participation, and family supports as determined by the person. Families, providers, organizations, systems, communities, and society play crucial roles in creating and maintaining meaningful opportunities for consumer access to these supports.
- **Nonlinear.** Recovery is not a step-by-step process but one based on continual growth, occasional setbacks, and learning from experience. Recovery begins with an initial stage of awareness in which a person recognizes that positive change is possible. This awareness enables the consumer to move on to fully engage in the work of recovery.

- **Strengths based.** Recovery focuses on valuing and building on the multiple capacities, resiliencies, talents, coping abilities, and inherent worth of individuals. By building on these strengths, consumers leave stymied life roles behind and engage in new life roles (eg, partner, caregiver, friend, student, employee). The process of recovery moves forward through interaction with others in supportive, trust-based relationships.
- **Peer support.** Mutual support—including the sharing of experiential knowledge and skills and social learning—plays an invaluable role in recovery. Consumers encourage and engage other consumers in recovery and provide each other with a sense of belonging, supportive relationships, valued roles, and community.
- **Respect.** Community, systems, and societal acceptance and appreciation of consumers—including protecting their rights and eliminating discrimination and stigma—are crucial in achieving recovery. Self-acceptance and regaining belief in one's self are particularly vital. Respect ensures the inclusion and full participation of consumers in all aspects of their lives.
- **Responsibility.** Consumers have a personal responsibility for their own self-care and journeys of recovery. Taking steps toward their goals may require great courage. Consumers must strive to understand and give meaning to their experiences and identify coping strategies and healing processes to promote their own wellness.
- **Hope.** Recovery provides the essential and motivating message of a better future—that people can and do overcome the barriers and obstacles that confront them. Hope is internalized but can be fostered by peers, families, friends, providers, and others. Hope is the catalyst of the recovery process. Mental health recovery not only benefits individuals with mental health disabilities by focusing on their abilities to live, work, learn, and fully participate in our society but also enriches the texture of American community life. America reaps the benefits of the contributions individuals with mental disabilities can make, ultimately becoming a stronger and healthier nation.

Although SAMHSA has been designated as the lead federal agency in implementing the recovery approaches to mental health treatment, the federal agency that has probably been most aggressive in shifting its resources toward a recovery approach has been the Veterans Healthcare Administration (VHA) of the Department of Veterans Affairs (VA). Shortly after the President's NFC's recommendations were issued, the Serious Mentally Ill Committee of the VHA began to develop a Mental Health Strategic Plan incorporating the recovery vision. This plan developed over an extended period was signed by the undersecretary in 2004 and has been in the process of being implemented by the vast mental health delivery system of the VHA. Recently, this recovery oriented; Mental Health Strategic Plan of the VHA has been mod-

ified and updated with an eye toward streamlining implementation in VA Medical Centers and Clinics with the issuance of a VHA Handbook for Uniform Mental Health Services.<sup>18</sup> Interestingly, this most recent VHA document stresses the importance of the definition of recovery, and its 10 components articulated in the report of the SAMHSA consensus conference.

Clearly, the view of recovery articulated by these federal agencies is highly reflective of the views articulated by those who have had personal experience recovering from these disorders. Indeed, the SAMHSA document is so focused on the perspective of the recovering person that, to some, there seems to be relatively little attention to the nature of the condition from which the person is recovering. An examination of the how the recovery concept is being articulated in the definition and components being proffered by federal government agencies reveals that there is particular importance given to the subjective views of the persons in recovery. The terms, "self-direction", "person-centered", and "hope", strongly suggest that the final arbiter of whether recovery is occurring is the person who is experiencing the process of recovery.

A fairly strong secondary focus in the federal agencies' characterization of recovery is the inclusion of what appear to be societal or political considerations. The descriptions of peer support, empowerment, and respect all relate to the individual's interactions with others, including cooperation with other consumers as well as calling for a significant change in how consumers are perceived by clinicians, providers, and others in the broader society.

It is important to recognize that this federal accentuation of the subjective and societal factors relevant to recovery is a substantial broadening and alteration of both the medical and the rehabilitation approaches to treatment. Diminishing symptoms and increasing an individual's ability to function both lend themselves to objective, scientific measurement of observable processes and factors that are presumably changing for the individual. The federal focus on the subjective and societal factors involved in recovery significantly overshadows the attention traditionally afforded the medical and functional limitations of psychiatric disabilities.

### **Implications for and Involvement of Schizophrenia Professionals**

Reflecting on the impact of the recovery concept, and considering how important the consumer perspective has been in its development, what are some major messages for those referred to by Jacobson as the "elite professionals," working in the area of schizophrenia? How does one accommodate the predominantly subjective and politically oriented recovery model into the objective, scientific approach of professionals working in the field of schizophrenia? One avenue to explore in answering

this question could be the realization that some of these so-called professional elites are themselves persons who have been diagnosed with and treated for schizophrenia. Because of the obvious downside consequences of revealing that one has a personal history with schizophrenia, it is likely that most professionals in this category are unlikely to publicly identify themselves, particularly those younger professionals, for whom such revelations could be career damaging. However, during the past few decades, there have been a number of highly trained professionals who, for various reasons, have been willing to be open and even publish materials related to their conditions and the process of their recoveries.

Indeed, it turns out that many of those who were lending their voices to those of the rising consumer advocacy movement were persons who, despite having been diagnosed with, and undergone treatment for, schizophrenia or schizoaffective disorder, eventually were able to attain sufficient appropriate education to become certified in the mental health field and work as professionals. Many of these persons in recovery became nurses, social workers, occupational therapists, and other mental health professionals. Some had even been able to complete doctoral level training and function as psychiatrists, psychologists, or other professionals in the field. This latter category includes the following.

#### *Psychiatrists*

Carol North, MD, was one of the earlier psychiatrists to self-identify as having been diagnosed with and treated for schizophrenia. Her book, *Welcome Silence: My Triumph over Schizophrenia*,<sup>19</sup> details her experiences as a young person diagnosed with schizophrenia and having the delusions and other symptoms associated with the condition. In her book, North relates her experience of recovery, but she attributes her recovery primarily to dialysis. However, she goes on to explain that research has failed to show that dialysis is a remedy for schizophrenia despite her experience with this procedure. North is particularly sensitive to the stigma accompanying serious mental illness.

Dan Fisher, PhD, MD, was another early voice of a person who had been diagnosed with schizophrenia and began to stress the fact that recovery from schizophrenia was possible, if not likely. Fisher<sup>20-23</sup> had been initially diagnosed with schizophrenia while working as a research scientist in the 1960s. Despite this diagnosis and multiple hospitalizations for this condition, Dan was able to earn a second doctorate, this one in medicine, and went on to complete a psychiatric residency at Harvard University. Although Fisher only gradually disclosed his history of being treated and diagnosed with schizophrenia,<sup>21</sup> he later became one of the appointed commissioners on the President's NFC on Mental Health, where his voice was influential in forging the major recommendation of the Commission. That

recommendation was that the mental health system in the United States be transformed in such a manner that the major goal for the transformed system would become "recovery" for persons with serious mental illnesses. Further details concerning Fisher's advocacy activities can be found at [www.power2u.org](http://www.power2u.org).

Elizabeth Baxter, MD, is a psychiatrist who identifies herself as being diagnosed with schizoaffective disorder. Baxter<sup>24</sup> relates that she has been hospitalized several times for her psychiatric condition, twice toward the end of her psychiatric residency training. She relates that at one time her doctors indicated that the most she "would ever recover would be the ability to put objects into boxes on an assembly line."<sup>24(p32)</sup> She<sup>25(p1298)</sup> refers to "my recovery" and "bright recovery" and attributes her recovery to her persistence, the encouragement of friends, family and caregivers, and spiritual growth.

Although Baxter has published and given numerous presentations discussing her personal experiences with psychosis, in consumer circles she is well known as the cocreator, with Sita Diehl,<sup>26,27</sup> of BRIDGES: A Peer Education Program. BRIDGES, an acronym for, Building Recovery of Individual Dreams and Goals through Education and Support, is a structured peer education program based on the belief that those with mental illness "can and do recover a new and valued sense of self and purpose." BRIDGES was designed with input from over 100 persons in recovery and is facilitated by and offered to persons recovering from mental illness throughout the country. BRIDGES draws heavily both from *Diagnostic and Statistical Manual of Mental Disorders* and other scientifically oriented descriptions of serious mental disorders and from writings of other persons in recovery. The program not only focuses on identifying traditional and other symptoms of mental illness but also embodies personal and advocacy perspectives.

#### *Psychologists*

Patricia Deegan, PhD, a psychologist, is another of the early voices to describe her experiences in overcoming schizophrenia. Deegan<sup>28-32</sup> had been diagnosed with schizophrenia as a teenager, spent considerable time hospitalized in a state psychiatric facility, but was nevertheless able to continue her education, eventually earning a doctorate in psychology from Duquesne University. Of all the persons in recovery who have gone on to become fairly highly educated mental health providers, Patricia Deegan was one of the most effectively articulate. Deegan stressed that those of us in recovery faced a society in which discrimination, stigma, and disrespect were far too common. In a series of published articles, Deegan began to call for a very different focus regarding the concept of recovery from serious mental illness.

Deegan's writings stressed that persons in recovery are not passive recipients of rehabilitation services and in her

words that recovery refers to a "self pole" as opposed to the "world pole" of traditional rehabilitation approaches. She describes her experience of psychiatric treatment as one of dehumanization and depersonalization, spirit breaking, learned helplessness, and of having to overcome humiliating experiences. Deegan stresses the importance of reclaiming and recovering a sense of self after being devalued, dehumanized, and degraded. She emphasizes that every journey is unique and that the task is not to become normal but to become who you are and who you are called to be.<sup>29(p11)</sup> She also repeatedly calls for social justice and civil rights for persons with psychiatric disabilities.<sup>29(p9)</sup> Recently, Deegan has begun calling for more of a partnership model in the delivery of mental health treatment, with the partners being the practitioner and the client. She refers to this approach as a "shared decision making" process.<sup>30</sup> For further information concerning the development of Deegan's views and activities, see [www.patdeegan.com](http://www.patdeegan.com).

F.J.F., PhD, the current senior author, is a psychologist who has been open and public about his being hospitalized numerous times for schizophrenia, since making a presentation about his condition at the Annual Convention of the American Psychological Association.<sup>33</sup> Since becoming open about his condition, he has published works on schizophrenia advocacy, coping skills, recovery, and treatment.<sup>34-39</sup> F.J.F.<sup>34</sup> argues that recovering persons should work cooperatively with providers so that the mental health delivery system treats the mentally ill more effectively but with increased dignity and respect. In the early 1990s F.J.F. served as president of the National Mental Health Consumers' Association. Also in the capacity of an advocate, F.J.F. has served on the boards of several national professional and advocacy organizations, including the National Alliance on Mental Illness (NAMI), the National Industries for the Severely Handicapped (NISH), the Treatment Advocacy Center, and the American Occupational Therapy Association, as well as serving on national committees for both the American Psychiatric Association and the American Psychology Association. During the past few years, he has been serving as a contributor to the Measurement and Treatment Research to Improve Cognition in Schizophrenia (MATRICS) initiative.<sup>40</sup> For more information about activities of F.J.F., see [www.fredfrese.com](http://www.fredfrese.com).

Ron Bassman, PhD,<sup>41</sup> was initially diagnosed with schizophrenia at age 22. He spent 2 extended periods, of 6 and 7 months, in private and public psychiatric hospitals, respectively, as an inpatient being treated for his condition. Nevertheless, Bassman went on to earn a doctorate in clinical psychology and later obtained a position with the New York State Office of Mental Health, where he participated in the development and implementation of a training module for psychiatric staff that emphasized key recovery themes such as hope, self-help, empower-

ment, mutual support, and respectful communication. Bassman also served a term as president of the National Association for Rights Protection and Advocacy.

In his writings, Bassman consistently refers to the iatrogenic effects of hospital treatment, the damage of having a psychiatric label, and the crushed dreams and stigma as being possibly more difficult to overcome than the original condition, itself.<sup>42(p137)</sup> He lists hope, safe niches, natural supports, reconciliation with family, absence of damaging treatment, belief in himself, successful experiences, meaningful work, psychotherapy, intimate relationships, and the passage of time as significant factors moving one toward recovery.<sup>42(p150-151)</sup> For additional information concerning Bassman's views and activities, see [www.ronaldbassman.com](http://www.ronaldbassman.com).

Al Siebert, PhD,<sup>(43-45)</sup> indicates that he was the first clinical psychology doctoral graduate from the University of Michigan to be selected for a postdoctoral fellowship at the Menninger Clinic, then located in Topeka, Kansas. Not long after arriving there, however, he was hospitalized in the nearby VA hospital and given the diagnosis "schizophrenic reaction, paranoid type, acute." He relates how he was kept in a back ward for about 4 weeks, after which he left "against medical advice." Interestingly, Siebert characterizes this experience as a months-long transformational experience that was the best thing that ever happened to him. In Siebert's view, "from 20 percent to 30 percent of the people who go through a 'schizophrenic' period fully and completely recover from the condition and can do so with no medications."<sup>44(p111)</sup> More information about Siebert's views and advocacy activities can be found at [www.successfulschizophrenia.org](http://www.successfulschizophrenia.org).

#### *Other Professional Voices*

In addition to the psychologists and psychiatrists who have been open and active in helping in the development of the recovery approach to treating their conditions, 3 other doctoral level professionals, who are not specifically certified as psychiatrists or psychologists, but who themselves have schizophrenia, have been active in the mental illness/schizophrenia arena, advocating for recovering persons by publishing and making presentations about their conditions.

E.L.K., PhD (sociology), the current second author, indicates that he was first diagnosed with schizophrenia in 1969. Since then, he has been hospitalized at least 14 or 15 times, in addition to having spent some time being homeless. E.L.K.<sup>46</sup> readily acknowledges that he takes medication for his condition. Indeed, he states that without the combination of meditation and medication he would be in and out of the hospital very frequently. E.L.K. believes medications need to be separated from other aspects of the medical model that create helplessness. He believes symptoms are not written in stone,

but the individual can learn to work with them and alter them in positive directions. Anxiety, eg, can be, as Kierkegaard pointed out, a spiritual teacher of letting go of concepts and notions that limit the openness of the present. He says that it has now been over 25 years since the pivotal point that started his recovery by introducing him to a spiritual practice that empowers him to face his difficulties. He has taken medications for schizophrenia for 27 years without interruption. He has also been diagnosed with depression, anxiety disorders, and mania but currently manages these conditions successfully without meds. Meditation helps him maintain balance and lower stress levels in his busy schedule. He practices zazen and centering prayer. Without meditation and prayer regularly, he may get overstressed and develop prodromal symptoms. He keeps them from returning by focusing and letting go of thoughts, ideas, concepts, and images. For "religiosity" or anxiety, eg, he focuses on the breath and as Dogen, the founder of Japanese Soto Zen, says "Thinks not thinking." That is, he lets go of thoughts. This is similar to the recent development of Acceptance and Commitment Therapy of letting go of "mental boxes." When he experiences the prodromal symptoms of mania, such as talking fast or racing thoughts, he mindfully walks slowly and deliberately while letting go of thoughts. As with everything, these states of prodromal symptoms pass. They do not worsen or return unless ignored.

He has not been hospitalized in 25 years. Doctor E.L.K. is currently vice president for Recovery, Rehabilitation and Mutual Support for Value Options, the second largest behavioral managed care company in the United States. He is also involved in research, having worked with several research centers: University of California, Los Angeles; Boston University; Nathan Kline Institute in upstate New York; and National Research and Development Institutes in New York City. His areas of research interest are mutual support, recovery, rehabilitation, and co-occurring substance abuse and mental illness. For further information about mental health activities of E.L.K., go to [www.professored.com](http://www.professored.com).

E.S., JD<sup>47-51</sup>, the current third author, is associate dean and chaired professor of law, psychology, and psychiatry and the behavioral sciences at the University of Southern California Gould School of Law; Adjunct Professor of Psychiatry at the University of California, San Diego, School of Medicine; and Assistant Faculty, the New Center for Psychoanalysis. E.S. has written several books on mental illness and the law.<sup>49-51</sup> Several years after attaining tenure, E.S. produced a volume where she relates that she openly accepts that she has schizophrenia, from which she feels she will never fully recover and for which she willingly takes medication.<sup>47(p334)</sup> (This was after many years of resisting the diagnosis and need for medication.) Reflecting on some of the difficulties of her recovery experience, E.S. states that "Early on after being diagnosed as schizophrenic, I was given the prog-

nosis: grave – the psychiatric equivalent of a death sentence, the assumption that I'd never live or work on my own."<sup>48(pA5)</sup> However, she feels that the humanity and dignity of clients should be at the center of the mental health system and stresses that stigma is a major barrier for persons in recovery, seeing stigma against schizophrenia as perhaps the most profound of all stigmas.

E.S. and her colleagues are engaged in studying high-functioning people with schizophrenia to see if it is possible to identify strategies they have developed to manage their symptoms, hoping such strategies might be both teachable and effective for others.

Professor E.S. serves as a member of the Task Force on Serious Mental Illness and Serious Emotional Disturbance of the American Psychological Association and as a member of the Board for Mental Health Advocacy Services and the Bazelon Center for Mental Health Law.

Robert Miller in 1961 started as a medical student at Oxford University. However, in 1967, he experienced a serious psychotic breakdown that put him out of action as far as developing any other career was concerned, for about 3 years. However, in 1973, he obtained his doctorate from Glasgow. After several periods of postdoctoral study at British universities, he emigrated to New Zealand in 1977 and obtained employment as a lecturer in the Department of Anatomy and Structural Biology, University of Otago. Robert Miller has for many years tried to use his theoretical ideas about normal forebrain mechanisms to shed light on psychosis and the complex disorder called schizophrenia. As a result, he has written many articles on the theory of dopamine-mediated psychosis. He is currently working on an overall theory of schizophrenia, entitled "A neurodynamic theory of schizophrenia and related disorders," which he introduced at a recent scientific conference.<sup>52</sup> Since emigrating to New Zealand, Miller has worked in collaboration with the Schizophrenia Fellowship of New Zealand. He has written autobiographical accounts of his own illness, when he was a young man and also has produced an educational booklet on schizophrenia. He frequently participates in international conferences on schizophrenia research, and in 2007, he was given the "Officer of the New Zealand Order of Merit" award "for services to schizophrenia research."

This article of course could neither begin to examine the entire spectrum of consumer perspectives on recovery from schizophrenia nor does it purport to adequately portray the views of each of the professionals mentioned above. However, a cursory look at the selected published comments of these professionals does allow one to draw certain inferences about the impact of these public disclosures as well as about the perspectives of these professionals concerning their own recoveries from schizophrenia.

Unfortunately, there still continues to exist in professional circles questions concerning the possibility of recovery from schizophrenia<sup>53</sup> and particularly pessimism as to

the possibility of persons with schizophrenia successfully completing academic work at the doctoral level.<sup>54</sup> So, the fact that these professionals have publicly identified themselves as having been diagnosed and in treatment for schizophrenia, but have nevertheless obtained doctorates and are performing as professionals in the mental health field, in and of itself, sends a strong message. By being open about their psychiatric conditions, they are implicitly demonstrating that the diagnosis of schizophrenia no longer means that one will necessarily experience the lifetime cataclysmic consequences once assumed to accompany the disorder. Without necessarily being explicit about the issue, these professionals are establishing a significant functional measure of recovery. And clearly, the greater the number of persons, especially those in the mental health professions, who are willing to be open, and even public, about their conditions, the more normalized schizophrenia becomes. Such increasing numbers could be viewed as positive functional measure of increasing hope for others and for diminishing stigma.

Second, examination of the writings of these professionals reveals a rather wide divergence concerning their perspectives on their recoveries and on recovery in general. For example, Miller and F.J.F. see the biological correlates of schizophrenia as being important. Fisher, Bassman, and Siebert play down or even deny the importance of any biological considerations. E.S., Baxter, F.J.F., E.L.K., and Deegan clearly acknowledge that they have had to struggle with, and continue to experience, at least some of the classic symptoms of schizophrenia. Such symptoms include sometimes experiencing delusions and hallucinations, as well as apathy, avolition, and/or other negative symptoms. Others, such as North, Siebert, Fisher, and Bassman downplay or deny that they currently experience any symptomatology. The latter 3 of these advocates tend to see the need to substantively change health-care and societal conditions, in general, as their primary concern. Indeed, Fisher and Siebert contend that persons diagnosed with schizophrenia can "completely recover" often without the use of psychotropic medications. Views also vary widely concerning such topics as dangerousness, homelessness, cooperation with family members, and the use of coercive treatments. Contrary to the view often articulated by consumer advocates,<sup>55</sup> among these consumer/professionals at least, there is no monolithic "consumer perspective" on many aspects of recovery.

Nevertheless, virtually all these persons stress the difficulty of overcoming pervasive stigma, hostile attitudes, and other societal barriers to their recovery. One strong message that is voiced by these professionals is that they see a major barrier to their recovery as being how persons with schizophrenia have been, and continue to be, treated by society, including treatment by those entrusted with their care. Many do not see that their degree of recovery is primarily a function of how disabled they are but feel

that traditional cultural, attitudinal, and linguistic barriers to their recovery are important factors that must be considered and measured as we address the issue of recovery. Again, Bassman and Fisher see oppression by the mental health system and by society in general as a primary target for change in order for recovery to occur. Siebert, who on occasion has denied the existence of schizophrenia in himself or in anyone else, sees the hostility of the mental health profession as the major impediment to recovery for those labeled with this condition.

### **Weighing of the Value of Medical, Functional, Subjective, and Societal Factors**

Concerning the broad range of views of even the most educated of persons in recovery from schizophrenia, it is not surprising that there exists considerable variation concerning the question of relative weighting of the several approaches to recovery addressed in this article. Medical/biological approaches to psychiatric disabilities include the traditional focus on symptom reducing but increasingly are encompassing other, related health issues, such as obesity, cardiovascular illness, hyperlipidemia, diabetes, and other conditions that may be associated with medication side effects, and other issues affecting morbidity and mortality that may accompany serious mental illnesses.<sup>56,57</sup>

The measurable functional, psychosocial factors, ie, the degree to which individuals can care for themselves and can find a satisfactory role and quality of life in society, continue to be vitally important, but questions concerning the degree these matters as viewed by professionals are weighted, as opposed to the more subjective and societal factors embodied in the recovery model, is a matter that can be approached in a variety of ways by different consumer/survivor advocates. For example, the 3 authors of this article address this question very differently.

E.L.K. addresses the question concerning the weighing of these various factors with comments from a global perspective as well as from his personal experience. He comments:

In a recent international study of schizophrenia, 60% of those with this disorder were working for pay or doing significant household labor, 40% were working for pay, and 20% with moderate to severe disability on Global Assessment of Functioning Scale were working for pay. This latter is called "mixed recovery" by Kim Hopper.<sup>58</sup> Poverty and unemployment are at least as much a function of stereotyping and discrimination of what we label "bizarre" behavior and fear as a society as a medical complication of an illness. Neither does most of India isolate people who exhibit such behavior nor do some other countries, and this is not just rural areas. As American styled culture grows in these areas, it will be interesting to see if this continues. The constant barrage of fearful images in the media has a lot to do with this.

E.L.K. indicates that for him, personally, symptom reduction is about 95% or better from when he was very ill. But this is due as much to his zazen practice as medication. This practice allows him to carefully observe under what conditions prodromal symptoms arise, what sustains them, and when they pass away. Due to this, he is able to immediately recognize any precursors to delusions or hallucinations such as thought patterns that tend to paranoia (thinking he knows others' intentions), racing thoughts, or high anxiety and take appropriate measures.

His social functioning is better actually than preillness (He was painfully shy and withdrawn.) or during illness. He serves as a vice president of a large corporation, a fact that he feels speaks for itself.

- Side effects. E.L.K. indicates that he had to get off typical medication and go to an atypical because of significant dystonia, akathisia, and oculogyric crises. On one atypical, he gained a lot of weight and had to switch to another. He has lost 50 pounds since then with the help of careful diet and exercise. His goal is to lose 15 more pounds, and he is on course to do that. At that point, he will be at 180 pounds, his preillness weight. This has helped tremendously with fatigue and depression and with having energy to do his daily career activities.
- Subjective weighing. Symptom reductions and learning how to "fit in" so as to have "acceptable" behavior by current American standards has been crucial to recovery of E.L.K. He is able to monitor what people's expectations are and express himself appropriately. He has social intelligence to a fairly high degree in his estimation while he maintains personal autonomy and does not introject others' opinions by trying overly to please and thus create resentment in himself. E.L.K. feels he learns very quickly from the consequences of his behavior and adjusts quickly.

One the other hand, F.J.F. takes a very different approach to the question of weighing the various factors involved in recovery. F.J.F. relates that he and 3 other doctoral level consumer/survivors (the others having been diagnosed with conditions other than schizophrenia) have suggested that relative weighing of scientific vs subjective factors should perhaps be a function of the degree of disability experienced by the individual with the serious mental illness.<sup>59</sup> These authors suggest that for very disabled persons, more weight should be afforded to evidence-based, scientifically oriented factors, but as the person experiences increasing recovery, more autonomy (empowerment) should be afforded to the person in recovery to make their own decisions as to how they might best determine the nature of their recovery journey. Not surprisingly, some professionals who have been diagnosed and treated for serious mental illness, including Daniel Fisher,<sup>60,61</sup> mentioned above, have taken issue with this approach to the weighting

of subjective perspectives of those with serious mental illnesses. Once again, while the recovery movement stresses the importance of empowerment and related subjective factors, there is clearly wide divergence in the "educated consumer" community as to the weight to be given to these subjective factors, particularly for the homeless, the imprisoned, and the very disabled in general. This also holds true for the societal/political factors embodied in the recovery concept, as well.

E.S. is somewhere in the middle. As a result of some very degrading and painful treatment, E.S. has described herself as very "pro psychiatry but very anti-force." Like "medical model" people, E.S. believes that mental illness is a medical disease that is often helped by both medication and therapy. Like more radical consumers, she believes that force is almost always a bad solution. Yet, she takes these positions for pragmatic reasons, not because she (or anyone else) has a slam dunk argument about the philosophical issues involved: these views work for her—help her live a good life. E.S. allows that others may be better served by thinking, eg, that the entire problem is social and devising social solutions for themselves.

As for her location on the question of whom the recovery model should be directed toward, she is somewhere between E.L.K. and F.J.F. E.S. believes that the appropriate question is one of capacity, where capacity requires a low level of ability. If someone lacks that low level of ability, we do not and should not respect their self-determining choices a la the recovery model; a benign other should decide for them. (If you think taking medication will cause a nuclear explosion, someone else should decide whether the medicine is right for you.) But if the person has that low level of capacity, their determination of what is best for them should be decisive, even if the medical profession sees that choice as irrational or otherwise substandard. E.S. has devoted a large part of her career to trying to understand and measure capacity.

It is also apparent that some, if not most, of these professionally trained individuals give much more consideration to the symptoms and functional difficulties that have traditionally been seen to accompany schizophrenia than the emphasis these are afforded by the official (SAMHSA) definition of recovery and the listing of components thereof. Baxter, Miller, F.J.F., and E.S. particularly stress the importance of the biological determinants and concomitants of schizophrenia and other serious mental illnesses.

An important point remains, reflected in comments of E.S.—the recovery model's focus on self-determination may be somewhat at odds with its listing of 9 other features of the model. An individual consumer may want to be allowed the agency of making his own choice. But his choice may be to adopt the medical model and ask the doctor paternalistically to decide for him. His autonomous choice may be to be nonautonomous. Or he may want to make his own choice but reject that adopting

a "holistic" approach is a good idea or that "peer support" is an admirable goal. In other words, the focus of the recovery model on the individual's perception of what is good for him may pull against some of the other features of the model.

### Conclusion

Expectation of recovery from schizophrenia is a concept that has evolved to a remarkable degree during the past century or so, since the disorder's initial identification and nosological recognition. Beginning with an extremely pessimistic view, indeed one that emphasized the likelihood of continuous deterioration for those diagnosed with this disorder, we have arrived at a point where at least some degree of recovery is increasingly the expectation for persons with this widely misunderstood condition. Although there would appear to be varying opinions concerning how this term, recovery, should be defined, it is apparent that adoption of the concept by the federal government and other organizational entities is generating considerable interest and even optimism among many consumers, advocates, providers, payers, and others who influence the delivery of mental health services.

Also, there are increasing numbers of mental health professionals, including psychiatrists, psychologists, and other doctoral level practitioners, who are willing to become open about their personal experiences with this condition. Many of these professionals have been dedicating their time and talents in efforts to merge their academic and professional training with their personal experiences. Although there is a wide range of views and opinions as to how these professionals characterize their recoveries, thus far they, along with other advocates, have been able to participate in very substantive changes in our approach to schizophrenia. While many professionals still remain relatively pessimistic about recovery from schizophrenia, emphasizing deficits, impairments, and dangerousness, recovering persons clearly are increasingly being brought into the greater society and increasingly being afforded more dignity and more respectful roles in society, including roles at the professional level.

Thus, our focus on some highly functioning consumers with schizophrenia has allowed 2 points to be brought forward: that the pessimistic view of schizophrenia is belied by their existence and that these consumers have views about recovery somewhat at odds with each other. Another important tack will be to look at consumers with schizophrenia who are not necessarily high functioning according to some external ranking of jobs but who are high functioning in the sense of living up to their pre-morbid potential. E.S. and her colleagues plan to study this population in a follow-up study to their "high-functioning" study being conducted now. Judging living up to one's pre-morbid potential may be difficult, but perhaps one could look at different things—the person's

ability on psychological testing, how high a level they functioned at before becoming ill (Were they a good student?), and perhaps the occupational functioning of family members. None of these is foolproof but may be useful indicators. Studying the views of recovery in this group, too, could shed further light on what the concept means and whether it is a useful concept.

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