ADVOCACY, RECOVERY, AND THE CHALLENGES OF CONSUMERISM FOR SCHIZOPHREНИA

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CONSUMERISM/ADVOCACY: OF WHAT IMPORTANCE?

Until few years ago, persons with schizophrenia and other forms of serious mental illness were considered to have such disabling conditions that society generally functioned without much concern for or interaction with this group of persons. American trained psychiatrists for the most part abandoned the business to care for these persons in the years immediately after World War II. The American Psychological Association (APA), Washington, DC, had no organizational entity for psychologists interested in serving the seriously mentally ill until the early 1980s. The professions that did show some responsibility for these people, social work, and to a lesser degree nursing, tended to view these problems as a function of poverty or family dysfunctionality.

As the end of the twentieth century approaches, however, tremendous changes are occurring in the manner that this country operates its overall health care system. This of course includes mental health (increasingly being referred to as behavioral health care).

The proportion of the nation’s Gross Domestic Product (GDP) devoted to health care has increased more than threefold since the late 1960s. Beginning in the mid 1980s a critical mass of business and governmental opinion began to come together decrying the soaring costs of

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Medicare, Medicaid and of health care generally. Doctors were said to have "an unnecessarily broad monopoly over the practice of medicine. The health care industry was seen as inefficient and wasteful." Government and industry began to initiate mechanisms for examining health care with an eye toward reining in costs and initiating greater efficiencies. Mental health care appeared to be a particularly easy target for cuts. Demands were forthcoming for objective measures of outcomes and psychiatric care seemed to be particularly ill prepared to withstand demands for nonsubjective, economically oriented measurement.

One reason professionals may want to learn more about the formation and dynamics of the consumer-advocacy movement is that the voices of the advocates are increasingly affecting the thinking of politicians, the business and governmental bureaucrats, and others responsible for financing health care. Those controlling the purse strings are saying that they will no longer pay for health care services unless those services can be shown to translate into positive outcomes for the recipients of those services. Payers are increasingly demanding that recipients of services, particularly mental health services, are going to have greater input concerning decisions being made as to what is best for them. The days when groups of doctors or other providers could make decisions without input from representatives of their patients are rapidly fading. What follows in this article is a brief review of the development and dynamics of the consumer-advocacy movement, and an overview of issues that are currently of concern to the parties involved in this process. First, however, I will relate how I came to be involved in this arena. In doing so I hope to also establish my credentials as a bona fide consumer advocate who also happens to be a credentialed psychologist experienced in treating persons with disabilities such as my own.

PERSONAL EXPERIENCES

Various accounts of my being diagnosed with paranoid schizophrenia and my many adventures with psychosis have been published elsewhere. Therefore, I will not go into much detail here. I will say that despite my illness and repeated hospitalizations, I was able to earn four degrees, including a doctorate in psychology. I went on to work most of my adult life as a psychologist or administrator in Ohio’s state psychiatric hospital system.

As my career progressed, it gradually occurred to me that, one of the most difficult aspects of having a serious mental illness was having to deal with the stigma that patients faced when they left the hospital. I realized that as long as persons who recover fairly well, myself included, continued to remain secretive about mental disorders, then the image would continue to be perpetuated that virtually all persons with these conditions were disruptive, dangerous, and unwelcome in mainstream
society. Later, I was to find that mine was a view shared by other recovering persons as well.\textsuperscript{3, 14, 33, 40}

Sometime during the mid 1980s I began to make a slow, but determined effort to become more open about my disability. I began by volunteering to become the first consumer appointed to serve on the local mental health board (in Akron, Ohio). Then I started to briefly refer to my diagnosis and experiences as a psychiatric patient during presentations. Before long, I was being asked to make presentations focusing primarily on these experiences, and on my views as a psychologist who had personal experience with mental illness. Later, I discovered that there were others, like myself, who were also beginning to be more open about their conditions.\textsuperscript{14, 15, 33, 39, 40} I, then, began to affiliate with organized groups of openly recovering persons.

As a function of these activities, during the past decade I have found myself holding leadership positions in developing local and statewide consumer groups as well as with national organizations such as Reclamation, Inc, the National Mental Health Consumers’ Association (NMHCA) and the National Alliance for the Mentally Ill (NAMI).

Although there is some published literature reflecting various views of those of us who have been active in the consumer advocacy movement, I primarily draw from my personal interactions with other recovering persons and their family members, in order to portray as best I can the complexities of mental health consumer advocacy as it exists in the United States today.

**EMERGING VOICES**

Before neurobiologically oriented scientists and practitioners began delivering reasonably effective treatments, and before modern management techniques began to bring the promise of more efficient allocation of resources, persons struck down with serious mental illness faced one of two rather unappealing futures. On the one hand, they could become physically isolated from the rest of society for most of their lives, being housed, fed, and by various other mechanisms, controlled, in isolated institutions or in similar facilities in the community. Often this meant being maintained along with large groups of persons whose behaviors were bizarre, frequently disruptive, and sometimes threatening. Those who had lesser degrees of disability could leave these facilities and attempt to blend into society. However, if one decided on this route, it was important not to reveal that you were, or had been, mentally ill. The stigma associated with these conditions was so great, that even persons who could somewhat recover were systematically shunned by the system of laws and customs. Indeed, the stigma was so ingrained that relatives of mentally ill persons would usually go to great lengths to hide the fact that they had insanity in the family. As long as persons with schizophrenia and their family members were too ashamed to openly identify themselves, practically speaking, no one who had any
personal experience with these disorders could give any effective feedback concerning their satisfaction, or lack thereof, with the mental-health services.

One of the consequences of more effective treatments for serious mental illness is that as persons with these disorders improve, they will have an increasing ability to express their views and to identify what they see as barriers to their recovery and acceptance by society. Quite naturally, as persons recover and increasingly take more control of their lives, their plans and desires can be expected to conflict occasionally with those of their caretakers.

HISTORICAL ROOTS

As long as there have been facilities for the mentally ill, there have been voices of recovering persons expressing disenchantment, and frequently revulsion, about their treatment. Prior to the mid-20th century, these views tended to be isolated "voices in the wilderness," having little impact on mainstream treatment approaches.23, 24 One consumer’s voice that did make an impact during this time was that of Clifford Beers.6 Beers was a college graduate, who had experienced several psychotic episodes during his twenties, being hospitalized in both public and private facilities. His writings were initially quite graphic, but he was persuaded to tone down his criticisms and to become an advocate for a much broader approach to psychiatric care. These efforts became known as the mental hygiene movement. Beers was active in organizing groups to speak out about the ways the mentally ill were being treated. His accomplishments included the founding of the National Committee for Mental Hygiene that later became the National Mental Health Association.24 Although the organization identifies itself as an mental health advocacy organization, until recently, relatively few openly mentally ill persons or family members, other than Beers himself, have had much influence concerning the organization’s positions or priorities. Subsequent to the activities of Beers, who relapsed in 1939 and remained hospitalized until his death in 1943, no other consumer voices seriously affected mental health services in this country until the second half of this century.

Beginning in the mid 1950s the stage began to be set for the emerging of today’s consumer-family advocacy movement. Since before the Civil War, publicly operated psychiatric hospitals had become the major locus for treatment for the mentally ill. From just a few thousand in the mid-1800s, the total population of these facilities had reached 558,239 in 1955. From that point, however, a rapid and truly remarkable exodus began. By 1994 only 71,619 patients remained in these facilities. Considering that there has been an approximately 65% increase in the population of the United States over this 40-year period, these figures signify that approximately 92% of those who were, or who would have been, in the public hospital system found themselves not living there.47 Many
of these people remained seriously disabled. Many found their way into nursing homes or into jails or prisons. Others were cared for by their families. Still others were simply abandoned to live in the streets, exposed to the weather, too often being reduced to eating from garbage cans.\footnote{45}

A small number of those, who had been inpatients recovered sufficiently, were able to speak up about their experiences. Shortly after the massive patient migration from the hospitals began, some of the more capable, recently released psychiatric patients began meeting among themselves and sharing their views. This occurred in several different parts of the country. During the political times of the 1960s many of these individuals began to see themselves as being members of a rejected, excluded, and oppressed minority group. They began to see similarities between themselves and members of other traditionally excluded and oppressed racial, religious, and ethnic groups. (Later some would also begin to identify with the aims of the women’s and the gay and lesbian movements.\footnote{4}, \footnote{11}) Slowly they began to organize in different sections of the country. Usually they gave themselves names that reflected their mutually shared desire for liberation. These included the Mental Patients’ Liberation Project in New York, the Mental Patients’ Liberation Front in Boston, the Vermont Liberation Organization, the Alternatives to Psychiatry Association of Southeast Florida, and the Network Against Psychiatric Assault in San Francisco. In order to establish their identities as oppressed persons, it was necessary, to characterize the nature of the oppression they faced. Many of these former patients had been forced into treatment and felt they had been abused during the experience. They believed that they had not been given respect or dignity while they were hospitalized. Many became angry at the psychiatric establishment, and looked for examples of psychiatry being portrayed as uncaring and oppressive.

These early advocates did not have to look far. During the first half of the 20th century, two Nobel prizes had been given for innovations in treatment of the mentally ill. Julius Wagner von Jauregg won the prize in 1927 for developing a technique of taking blood from patients with tertian malaria and injecting it into patients with paresis. He reported some success. According to Valenstein,\footnote{90} interests in his technique spread rapidly and numerous attempts were made to apply this technique to schizophrenics, but with much less success. The other Nobel Prize awarded for psychiatric treatment during the first half of the century went to Egas Moniz in 1949 for developing the prefrontal lobotomy. This was a technique that was to become widely used in the United States, with as many as 5,000 such operations being performed each year during 1948 to 1952. Although the annual figure had dwindled to about 300 by 1970, consumer advocates could easily portray the most celebrated treatment techniques of the recent past generation as being barbaric and of highly questionable effectiveness.\footnote{24}, \footnote{90}

Another frequently mentioned historical development, that added to the image of the psychiatrists as oppressors, later became the focus
of a book by Lenny Lapon. This author, and others presented evidence that in the late 1930s, the German government initiated a project it called the \textit{T4 program}. As a result of this project, some 80,000 to 100,000 mentally deranged persons were reported to have been rounded up and killed in a variety of ways. Virtually the entire German psychiatric community was accused of having at least condoned, if not actually having participated in these endeavors. Even though the T4 program was disbanded after protest from churches in 1941, American consumer activists could claim that the widely publicized techniques used to kill Jews and other minorities in the Nazi concentration camps, had actually been initiated and developed with the complicity of the psychiatric profession.

Since characterizing psychiatrists as having been insensitive, cruel, and even diabolic in their earlier willingness to expose their patients to malaria, lobotomies, and death by burning, by the 1960s, even the angriest activists saw such measures as historical, or at least disappearing, precludes to what they viewed as the still existing major tools of the oppressive mental health system. Indeed, the two most commonly mentioned objects of resentment continue to be widely employed today. These are the use of mandated treatment and the employment of electroshock therapy (ECT). To this day many of the best-known activists in the consumer movement, particularly those who identify themselves as survivors, stridently oppose the use of any involuntary treatment and call for the abolition of all forms of ECT. The latter remains the case even though many other consumers frequently request ECT, which they often see as the only therapy from which they have benefited in the past.

\textbf{ADVOCACY EFFORTS GATHER MOMENTUM}

Before long the government began to take notice of these activities. In 1976 the President’s Commission on Mental Health was established. This 20-member body acknowledged that “groups composed of individuals with mental or emotional problems are in existence or are being formed all over the United States.” In 1978, one of the consumer/survivor advocates, Judi Chamberlin wrote a volume entitled, \textit{On our own: Patient Controlled Alternatives to the Mental Health System}. In this book, she laid out the justification and the blueprint for the activities of the consumer-advocacy movement. She focused on consciousness-raising, how treatment recipients could fight the indignities they faced, and particularly how consumer-controlled treatment alternatives to the traditional mental health model could be established. A few years after publication of Chamberlin’s work, a group of her fellow expatients finished \textit{Reaching Across}. This volume, edited and mostly written by Sally Zimman, Howie the Harp, and Su Budd, former psychiatric patients who became leaders in the consumer/survivor movement, became another landmark manifesto for the consumer movement. It detailed how former mental health patients could work effectively together. More
specific and detailed than the Chamberlain book, *Reaching Across* laid out specific instructions as to how to keep records, raise funds, publish newsletters, conduct public relations, and just about anything else that one might need to know in order to establish and run a self help enterprise.

In 1985, the federal government's Community Support Program began funding national conferences where consumer advocates could gather, exchange views, and make plans to expand their influence. These were called the alternatives conferences. Since their beginning in Baltimore in 1985, they have been held every year in various parts of the country, each attended by anywhere from a few hundred to almost two thousand participants.

**DIVERGING VIEWS**

Any early hopes of forging a unified expatient movement came apart, however, shortly after the initial Baltimore conference. Various consumer leaders met in Pottstown, Pennsylvania. During that meeting a schism occurred, effectively breaking the consumer-advocacy movement into two factions. One group, declaring itself to be opposed to forced treatment under any condition, originally identified itself as the National Association of Mental Patients (NAMP). The other group, under the leadership of Joseph Rogers, called itself the National Mental Health Consumers' Association (NMHCA). The latter organization was slightly more moderate concerning the forced treatment question in that it decided not to take an official position on the issue. These factions have both had alterations in their identities since their inceptions. NAMP's members decided that they preferred the title, "survivor," for persons who had received psychiatric treatment. Consequently NAMP changed its name to the National Association of Psychiatric Survivors (NAPS). A few years ago this organization disbanded due to internal organizational difficulties. But many of the members remain active and continue to identify themselves as survivors. One former NAPS leader, David Oaks, continues the spirit of NAPS by publishing a bimonthly newsletter, *Dendron News*, which has to some degree become the current voice of psychiatric survivors.

NMHCA too has had organizational difficulties, and currently there is some question as to whether the group continues to be viable. Its founder, Joseph Rogers, no longer leads the group, but with federal financial support, heads a similarly named entity called the National Mental Health Consumers' Clearinghouse, which among other advocacy activities publishes a bimonthly newsletter, *The Key*.

There have been, and continue to be, other national organizations made up primarily of former psychiatric patients, with the purpose of voicing consumer concerns. These include such disease specific groups as, the Anxiety Disorders Association of America, the National Depressive and Manic Depressive Association, the Obsessive Compulsive Foundation, Schizophrenics Anonymous, and several other, mostly
smaller or newer, organizations. But the activists who came together to forge and expand the NMHCA and the NAMP/NAPS efforts must be considered among the most notable activists of the early, and to some degree, the current, broad spectrum, consumer/survivor advocacy movement.

THE FAMILY MOVEMENT

During the time former patients were organizing to protest ECT, forced treatment, and establishment psychiatry in general, organizing efforts among family members of the mentally ill also began. Throughout the 1970s there had been various independent groups of family members meeting. In 1977, Harriet Shetley and Beverly Young, both mothers of adult mentally ill children, met in the basement of a Congregational Church in Madison, Wisconsin. They began making plans for having a national gathering for family members interested in forming a nationwide family advocacy organization. Some 2 years later, in 1979, over 250 persons, mostly parents of adults with serious mental illness, met in Madison, and inaugurated what was to become one of the fastest growing advocacy groups in the history of American healthcare. This group adopted the name, the National Alliance for the Mentally Ill (NAMI). There were many factors accounting for the establishment and rapid growth of the NAMI organization, but certainly one of the most powerful was that psychiatric orthodoxy held that a major cause of schizophrenia was the unfortunate way the patients had been raised by their parents, particularly their mothers. A major school of thought in mental health held that the cause of decompensation into schizophrenia was the "schizophrenogenic mother." This mother was seen as being cold, aloof, and love withholding. The mechanism by which these malicious mothers were seen as breaking their vulnerable children into the helpless state of psychosis, was the double-blind communication. For some time a primary modus operandi of many mental health practitioners was to blame the mother for the disorder and, further, many felt they tried to ensure that the patients and their families knew that it was the mother that was seen as responsible for the condition. In many treatment facilities strict separation from the influence of the parents, sometimes irreverently referred as parentectomy, was seen as a sine qua non for treating schizophrenia. One clear, motivating factor for many of those who helped form or subsequently joined the NAMI organization was a determination to diminish tendencies toward the "family blaming" that so many of them had experienced in their dealings with mental health professionals.

About the time NAMI was founded, however, organized psychiatry itself was undergoing major changes. A few years before a small group of biologic researchers had begun uncovering evidence to establish that the psychoses were, in fact, caused by neurochemical imbalances in the brain. Thanks to constantly improving technologies and advances in brain research, what was starting to be called the catecholamine hypothesis
of mental disorders in the 1960s, was, by the 1980s, beginning to blossom into a full-fledged theory of the biologic underpinnings of mental disorders.\textsuperscript{12} This tremendous expansion in the importance of neurologic factors is reflected in the phenomenal growth of the Society for Neuroscience that expanded from its initial membership in 1970 of 1100 to more than 17,000 members in 1990.\textsuperscript{49} Of course, if mental illnesses could be seen as being biologically based, then biologic interventions held hope. NAMI advocates were determined that the focus of care would shift from helping patients recover from poor parenting, to restoring balance to their improperly functioning neurotransmitters.

The newly organized mothers and other family members felt they had a just cause for their activities, and they had an increasingly influential ally, that is, the biologically based \textit{new psychiatry}. Working cooperatively with this ally, the size and influence of NAMI grew rapidly. In less than two decades, the membership of NAMI has grown to more than 165,000 nationwide with over 1,200 affiliates, in every state.

The objectives of NAMI were clear. In addition to advocating for improved services for those with the most serious mental disorders, NAMI wanted it well understood that serious mental illness, particularly schizophrenia, was a biologically based disorder and that no one in the families had done anything to cause the tragedies that they were experiencing. It was to be biology and not poor parenting or character flaws that was to be seen as the real cause of these disorders. Initially, NAMI had wanted attention given to mental illnesses, as opposed to mental health, which was viewed as not prioritizing persons with serious mental illnesses. More recently, NAMI has begun to argue that these diseases should not even be called mental illnesses however. Mental illness is now being seen as a term used before we recognized the biologic underpinnings of these disorders. NAMI is now stressing that these disabling conditions should have a name that reflects current understandings. The organization currently prefers to employ the term, neurobiologic disorders (NBD) instead, and currently is in the process of distancing itself from the older term by officially changing its name from, The National Alliance for the Mentally Ill to the NAMI.

\textbf{CONSUMER–FAMILY FRICTIONS}

It did not take long after the founding of NAMI, and its developing alliance with biologic psychiatry, for it to begin to clash with the voices of the consumers, especially those calling themselves survivors, many of whom tended to identify themselves as being antipsychiatry. For many of these survivors, opposition to coerced or involuntary psychiatric treatment for anyone had become a cornerstone of their efforts.\textsuperscript{3, 11, 44} On the other hand, the primary NAMI goal was to ensure delivery of appropriate treatment for their disabled family members, even when such family members did not agree that they needed treatment. Disputes between family and consumer/survivor advocates were inevitable. To
better understand this complexity of the advocacy movement, one should realize that it is the nature of these disorders that the afflicted persons frequently do not agree they have a disorder. Accordingly, some of the most active and effective consumer/survivors hold views and attitudes that family members and others have difficulty appreciating.

Being that as it may, for the purpose of better understanding the consumer advocacy movement, we can sum up the major areas of concordance and of discordance among the principle players as follows. Both the consumer/survivor advocates and the members of the NAMI organization want major changes in the way the mental health system functions. NAMI wants family-blaming approaches to treatment terminated. NAMI sees that there are biologically based, and other, effective therapies for their afflicted family members and NAMI wants such treatments available for them. Often NAMI families view their afflicted members as being in denial of their illnesses. They frequently see them resisting the treatments that are most likely to help them to get better. NAMI members often aggressively advocate for the delivery of effective treatment for these loved ones.

The leaders of the consumer/survivor movement tend to be of two schools. One school views recovering persons as “consumers” and wants these consumers to be treated with more respect and to be afforded more control and more choice in their lives. Empowerment is a particularly valued concept for those advocates who are comfortable with the term, consumer. On the other hand, those who see themselves as victims of oppression, primarily value liberation and generally prefer to be called, survivors. Survivors tend to play down the value of treatment and focus heavily on human rights, most particularly the right not to be forced into treatment. Just as NAMI has found natural allies in the re-emerging medical or biological model of psychiatry, the survivors find natural allies among lawyers, for whom human rights are a primary value. Further, because lawyers are ethically bound to represent the stated interests of their clients, even when their clients may be taking questionable positions. Therefore, as NAMI sees it, we occasionally see the family oriented advocates clashing with the views of persons who have enlisted members of the legal profession in an attempt to interpret and alter laws in such a way as to be consonant with their own creative, but not always practical, positions concerning treatment approaches.

Probably nowhere has the clash between these two advocacy forces been as pronounced as it is concerning mandated treatment and the related topic of informed consent. These issues have major implications not only for the delivery of treatment but also regarding the issue of patients’ granting authorization for their participation in clinical research. If research cannot be conducted with patients, then progress in the development of newer, more improved treatments, is going to be impeded. E. Fuller Torrey, an influential NAMI leader, has recently criticized those who call themselves psychiatric survivors, but his comments generated considerable counter-reaction from the survivors and their defenders.
Although there are these points of friction between NAMI and the survivors, it is important to understand that many other consumer advocates, generally those who stress empowerment, tend to be willing to work with families and understanding professionals in an effort to modify and improve current systems of service delivery.

INCREASING COMMUNALITY OF INTERESTS

Despite the differences between NAMI and survivor advocates in the past, we are recently seeing changes that are diminishing the effects of these differences. For one thing, virtually all advocacy groups are coming to realize that it is not particularly beneficial to concentrate on their mutual differences. More and more activists focus on issues where they can reasonably agree. One of these issues is that of stigma, or discrimination, against the mentally ill. In early 1996, the NAMI organization launched a 5-year antistigma campaign. The campaign started with donations of several million dollars and has been budgeted for some $40 million over the 5-year period. Consonant with NAMI's concern for the delivery of improved treatments, a major effort of the campaign has been to pass legislation requiring that health insurance coverage for mental illness be comparable with that available for physical illnesses. NAMI and its allies have seen very rapid success at the federal level in the adoption of the Domenici-Wellstone parity amendment to House Resolution 3666, which mandates that annual and lifetime maximum coverage amounts for mental illness be the same as those for physical illnesses. This national law is scheduled to take effect in January 1998, but many feel it has too many loopholes. For instance, although insurance companies must offer equal coverage for mental illness if they offer mental health coverage, they are not required to offer such coverage. As a result of such shortcomings, more stringent requirements are being mandated by laws that have passed in some 15 states as of December 1997. Similar initiatives are being proposed in most other states. Although primary consumer advocates tend to see the stigma issue more in terms of how the mentally ill are portrayed in the media, and how they are accepted by employers, schools, and society, they also recognize the strong symbolic value of mental illness being treated fairly by the insurance industry. As a result, consumer advocates of all kinds have been generally supportive of these efforts to obtain more equal insurance coverage.

Another area where advocates have been particularly effective in recent years has been in having mental disabilities included in the Americans with Disabilities Act (ADA). The primary consumers, and particularly the survivors, took a very strong role in supporting the enactment of the ADA. NAMI has also been a strong supporter of this effort. This support was particularly in evidence when, in the spring of 1997, the Equal Employment Opportunity Commission (EEOC) finally got around to writing guidelines as to how employers should accommo-
date those with psychiatric disabilities. The EEOC’s statements ran into
considerable opposition in the media, which printed numerous ridicul-
ing editorials and cartoons portraying the mentally ill as ax murderers,
Napoleon impersonators, and other traditional pejorative stereotypes.
NAMI devoted considerable efforts to countering these unfortunate
characterizations of mentally ill persons.

Many persons identifying themselves as survivors are have been
attracted to the writings of Thomas Szasz,41 and more recently to those
of Peter Breggin.27–8 Both these psychiatrists question the efficacy of
biologic treatments and even the validity of the concept of mental illness.
These authors, among other things, assert that there is no physiologic
evidence for the existence of mental illness. Because the meanings of
research findings are always to some extent debatable, the evidence
during the past few decades has been mounting rapidly that the more
serious mental illnesses have biologic causes.12 Indeed, although the
Nobel Prizes awarded during the first half of the century were for
malarial injections and lobotomies, at least fifteen neuroscientists were
given the award, for significantly less controversial innovations during
the second half of the century.49 Since then scientific progress has been
even more remarkable. With increasing acceptance of the neurologic
basis for mental illness, and the efficacy of biochemical treatments,
enthusiasm for the concept of “the nonexistence of mental illness,” even
among the most ardent in the antipsychiatry movement, hopefully will
continue to ebb.

Still another development that is tending to erode the intensity of
the “no forced treatment” ideological underpinnings of survivor adv-
cacy is the introduction of the use of “advanced directives” or “Ulysses
Contracts.”37,52 These are documents whereby a person who is subject to
psychotic episodes, but currently in remission, can give instructions as
to how he or she wishes to be treated when he or she relapses. These
devices would seem to be particularly valuable for persons who become
excessively suspicious or for other reasons refuse to accept treatment
that they would accept if their rational facilities were not impaired by
the psychotic processes operative during their relapse. Dan Pone, a
senior attorney at Protection and Advocacy, Inc., in Sacramento, Califor-
ia, has written, in 1995, about the potential use of this type of instru-
ment in his state.35 He refers to an instrument referred to as a “durable
power of attorney for healthcare (DPAHC).” He points out that although
he had conducted training on the advantages of possibly employing the
DPAHC for mental health clients, their actual use had yet to be tested.
He feels they should be a useful tool by which clients can better ensure
that their voices are heard. As Bruce Winick, a professor of law at the
University of Miami Law School pointed out in his article in 1996,52
advanced health care instruments have generally been accepted, but
problems have arisen in extending their use to the mental health arena.
He, like others, sees their possible future use as having therapeutic
advantages. Paul Sherman38 has also done considerable work in this
area. Recently he has listed numerous clinical, legal, and financial advantages for employing these instruments. These include:

1. enabling the patient to to some degree “direct” aspects of mandatory care,
2. allowing them to provide important information to their providers regarding treatment decisions,
3. lessening the burden on judges regarding their having to guess concerning consumer preferences,
4. reducing overall costs of the involuntary care.

Sherman has also developed computerized methods for making their use more efficient. Dr. Sherman agrees with many others who have investigated this arena and feel that steps should be taken to incorporate advanced directives as a tool for persons subject to involuntary psychiatric interventions. Recently he has listed a series of barriers he sees that have kept these instruments from being employed more widely. He divides these barriers into groups of educational, logistical, legal, consumer behavioral, and enforcement issues.

In recent years William Anthony, the director of Boston University’s Center for Psychiatric Rehabilitation, has suggested a vision that he feels transcends the argument as to whether serious mental illness is caused by physical or psychosocial factors. The central thesis of Anthony’s vision is that persons with psychiatric disabilities can recover even though they may still be symptomatic, without regard to whatever may be the cause of their illness or even whether they agree that they have an illness. This “accentuate the positive” approach he is calling the “recovery revolution in the mental health field.” This approach views traditional mental health approaches as focusing on psychopathology and deficits. The recovery approach focuses on the person and their experience with the illness. Special attention is given to how the person copes, moves on with his or her life, and identifies barriers and facilitators to this process. Frese has published a list of 12 coping skills for persons with schizophrenia which emphasize a recovery approach to viewing this disorder. These include

1. Recognizing the difficulties in accepting that one has the condition
2. Maximizing one’s understanding of the disorder
3. The importance of medications and the dangers of street drugs
4. How delusional thinking comes about
5. Differences in social and communication strategies
6. The tendency to “replay” and rehearse for difficult situations
7. Expressed emotion
8. The effects of stress and excitement
9. The value of music and hobbies
10. Aspects of stigma and discrimination
11. The question of whether or not to reveal your condition to others, and
12. The value of networking
Because time will tell how revolutionary the recovery concept will become, it certainly has been the focus of considerable attention during the past few years, even among influential NAMI members. In that such notable survivor advocates as Daniel Fisher, Patricia Deegan and Judi Chamberlin, have long-standing associations with the Boston University Center, or have written articles supporting this initiative, the recovery concept has the promise to become another common ground for agreement among the various advocate factions.

In the longer term, one of the more important factors that will diminish the fractiousness between NAMI and primary consumer advocates is the fact that more and more of the consumers are joining and being welcomed into the NAMI organization. NAMI now officially recognizes that it is a family and consumer organization. Consumer perspectives are systematically being reflected in NAMI policies and activities. In 1985, NAMI established an organizational division for consumers initially called the NAMI Client Council, a name later changed to the NAMI Consumer Council. This group has been growing larger and more influential with each passing year. Recently NAMI has been making special efforts to recruit consumers and to give them more visibility in the organization. Recently, a consumer served as the NAMI president and currently five of the members of the 16-member NAMI Board of Directors are consumers. Increasingly, survivor advocates find themselves confronting fellow recovering persons when they challenge NAMI's advocacy initiatives.

Finally, another major development is that many celebrated persons are now openly acknowledging that they have personally been experiencing serious mental illness. Pattie Duke, Charlie Pride, and Ted Turner have all recently revealed that they suffer from bipolar disorder. In 1994 the Nobel Prize in Economics was awarded to John Nash, who is disabled with schizophrenia. Tom Harrell, the noted jazz musician, is another person with schizophrenia. Professionals who serve the seriously mentally ill are also beginning to openly identify themselves as consumers and survivors. Psychiatrists, Dan Fisher, Carol North, Beth Baxter, and Suzanne Vogel-Scibilia, have written or made formal presentations about their diagnoses and experiences as patients. Psychologists, Ron Bassman, Patricia Deegan, Kay Jamison, Al Siebert, Lauren Slater, Wendy Walker Davis, and others have begun writing from their personal perspectives about living with the challenge of serious mental illness. Many of these doctoral level professionals have been, and are becoming, active in the advocacy movement. As more professionals demonstrate they will no longer be intimidated by the stigma associated with these disorders, and lend their voices to advocacy efforts, the hope for a partnership among consumers, families, and caring professionals becomes brighter. Professionals who have personally experienced serious mental illness are becoming talented translators for interpreting and blending the various voices in the advocacy movement. Perhaps even more importantly however, they are beginning to be seen as role models for others with these disorders. In this capacity, they are providing living
examples of hope for multitudes of previously hopeless victims of these perplexing conditions.

Numerous other persons in recovery from serious mental illness also are becoming involved in caring for others who are more disabled from these conditions. Often these activities are often referred to as self-help activities. Under this rubric, recovering persons are employed as peer counselors or assistant case managers in various types of outreach activities. Increasingly recovering persons manage or assist in managing drop in centers, self-help businesses, and consumer organizing entities. Also, as treatments improve, recovering persons are increasingly completing programs and becoming certified in social work, counseling, nursing, occupational and recreational therapy, and other fields in which they can be part of the traditional service delivery team caring for persons with disorders similar to their own.

CONCLUSION

The consumer-advocacy movement has become an important force in determining plans and policies for the delivery of care for persons with schizophrenia and other forms of serious mental illness. Although there has been discordance among the various voices in the consumer advocacy community, recent developments bring the promise of toning down the stridency among activists with differing views. Psychiatrists and other mental health professionals are encouraged to lend their support to what often may seem to be a cacophony of diverse advocacy voices. Helping patients, consumers and survivors to become better enabled to respectfully re-enter society can be a frustrating task, but increasingly this task is being seen as more central to the mission of those in the caring professions. Hopefully, mental health professionals will increasingly see themselves as much as advocates as they are scientists and practitioners in the work of serving persons with serious mental illness.

References

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