Integrating Evidence-Based Practices and the Recovery Model

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Consumer advocacy has emerged as an important factor in mental health policy during the past few decades. Winning consumer support for evidence-based practices requires recognition that consumers’ desires and needs vary for various types of treatments and services. The authors suggest that the degree of support for evidence-based practices by consumer advocates depends largely on the degree of disability of the persons for whom they are advocating. Advocates such as members of the National Alliance for the Mentally Ill, who focus on the needs of the most seriously disabled consumers, are most likely to be highly supportive of research that is grounded in evidence-based practices. On the other hand, advocates who focus more on the needs of consumers who are further along their road to recovery are more likely to be attracted to the recovery model. Garnering the support of this latter group entails ensuring that consumers, as they recover, are given increasing autonomy and greater input about the types of treatments and services they receive. The authors suggest ways to integrate evidence-based practices with the recovery model and then suggest a hybrid theory that maximizes the virtues and minimizes the weaknesses of each model. (Psychiatric Services 52:1462-1468, 2001)

Shortly after the National Institute of Mental Health was returned to the National Institutes of Health in 1989, President George H. W. Bush declared the “Decade of the Brain.” Federal funding for research on the brain was greatly increased during that time, resulting in remarkable scientific progress (1). The 1990s saw advances not only in our understanding of the working of the human brain but also in our approaches to the treatment of the mental illnesses that are caused by brain abnormalities. During the past decade, confidence in scientific research, with its objective observations and measures, has increased considerably in the mental health arena.

Evidence-based practices

In recent years, this increased confidence in scientific treatment methods for mental illnesses has given rise to a movement that calls for more widespread adoption of treatment approaches that are scientifically grounded. This movement has been developing under the rubric of “evidence-based practices” (2-7). Under this concept, the call for greater reliance on scientific evidence is being extended to treatment approaches that are supported by psychological and sociological evidence as well as by the findings of biological research.

In an earlier article on evidence-based practices, Drake and associates (3) provided an overview of the topic, outlining the research findings and philosophical underpinnings of the evidence-based practice movement. They spelled out specific reasons for the special focus by Psychiatric Services on evidence-based practice interventions. These reasons include the belief that routine mental health programs do not provide evidence-based practices, that implementation of services resembling evidence-based practices may lack fidelity to evidence-based procedures, and, especially, that in the context of limited resources consumers have a right to interventions that are known to be effective. So described, evidence-based practices appear to be unassailable. Who could object to promoting the use of treatments that work rather than those that do not?

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stance use disorders. The authors stressed that “mental health services for persons with severe mental illness should reflect the goals of consumers.”

Drake and colleagues further stated that “mental health services should not focus exclusively on traditional outcomes such as compliance with treatment and relapse or rehospitalization prevention, but should be broadened to include helping people to attain such consumer-oriented outcomes as: independence, employment, satisfying relationships, and good quality of life.” Finally, they allowed that evidence-based practices “do not provide the answers for all persons with mental illness, all outcomes, or all settings” (3).

In light of this characterization of evidence-based practices, particularly the openness to consumers’ needs and aspirations, one might expect that the consumer advocacy community would be pleased that the views of consumers are emerging as a major matter of interest. This move beyond traditional, “provider-centric” factors seems to be a healthy, consumer-friendly development. In consumer advocacy circles, “Nothing about us without us” has increasingly been adopted as a slogan for expressing the desire for more dignity and autonomous control for the recipients of mental health services (8). This reaching out for consumer input should be a welcome development.

The recovery model

At the same time that the Decade of the Brain initiatives and evidence-based initiatives have been emerging in the mental health arena, a more personalized and subjective approach to caring for persons who have mental illness has also been emerging—the recovery model.

William Anthony, a major supporter of the recovery model (9), describes recovery as “a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life, even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness.” Sullivan (10) called for “a broad definition of recovery, one that not only focuses on the management of the illness, but also highlights the consumer's performance of instrumental role functions and notions of empowerment and self-directedness.”

The recovery model emphasizes that responsibility for and control of the recovery process must be given in large part to the person who has the condition. Indeed, some advocates for the recovery model have stressed that overdependence on others prevents recovery. The locus of control thus becomes less external. Mental health interventions are designed to be empowering, enabling the persons themselves to take responsibility for decisions about their lives (11,12). Recently, some states—e.g., Wisconsin and Ohio—have been redesigning their mental health systems to stress recovery-model values, such as hope, healing, empowerment, social connectedness, human rights, and recovery-oriented services (12).

Although the recovery model has been garnering support among consumer advocates and mental health administrators, objections to this approach have recently been raised among mental health professionals. Pointing out that the recovery model is subjective, not data based or scientific, Peyser (13) suggested that it may in fact interfere with treatment. He pointed out that psychotic illnesses and similar illnesses can subvert the thinking process to the point that the patient’s self is taken over by the disease. He asked how we can speak about empowerment and collaboration in such cases and suggested that there are “dangers in going too far” toward fashioning a model that focuses primarily on hope, empowerment, and human rights.

Two apparently very different approaches to treatment of mentally ill persons are emerging. The scientific, objective, evidence-based approach emphasizes external scientific reality, whereas the recovery model stresses the importance of the phenomenological, subjective experiences and autonomous rights of persons who are in recovery. The two models will conflict under many circumstances. Obviously, when consumers make decisions about treatment, they will sometimes make choices that are not evidence based. Treatment decisions cannot be made entirely on factual, scientific grounds. Rather, treatment decisions involve both medical facts and choices based on values.

Science can identify alternative possible treatments and an outcome-probability distribution of efficacy and adverse effects for each treatment option. The decision as to which combination of anticipated improvement and anticipated adverse effects is preferable is a value judgment. Consumers’ decisions about treatment will be more likely to reflect their values than will decisions by treating professionals, even when professionals attempt to determine consumers’ preferences. Thus evidence-based treatments may differ from treatments that are based on the recovery model insofar as they reflect different judgments of the value of various treatment outcomes by service providers and consumers.

The recovery model has found significant support in the mental health field, particularly among consumer advocates. Thus the question arises as to whether these apparently opposed approaches to mental health care can coexist. And can efforts to expand the influence of evidence-based practices somehow accommodate the more subjective philosophical thrust of the recovery movement?

Increasing the use of externally derived interventions while maximizing individual empowerment that emanates from an internal locus of control will be a challenge. However, if we are to win consumer advocacy support for evidence-based practices, we should accommodate the insights of the recovery movement.

Integrating the recovery model and evidence-based practices

One approach to reconciling scientific and subjective approaches to treatment was recently suggested by Munetz and Frese (14). They suggested that the traditional evidence-based approach—the “medical model”—can be compatible with the recovery model. In their view, the evidence-based, medical model has been highly paternalistic, emphasize-
Munetz and Frese suggested an approach consonant with the observations of Csernansky and Bardgett and others. After surveying recent research on the pathophysiology of the brain, Csernansky and Bardgett (20) pointed out that the degree of impairment in serious mental illnesses falls somewhere on a continuum that ranges from severe, refractory psychosis to less serious, responsive psychosis and on toward normality.

Munetz and Frese (14) pointed out that many individuals are so disabled with mental illness that they do not have the capacity to understand that they are ill. Giving such individuals the right to make decisions about their treatment is tantamount to abandonment. They noted that it is “inconsistent with the recovery paradigm to allow incapacitated individuals to remain victims of their serious mental illness.” For these persons, measures must be taken so that they become well enough to be able to benefit from the recovery model. That is, one treatment goal whose significance should be accentuated by evidence-based practices is enhancement of the consumer’s ability to make autonomous decisions about treatment as a means of gaining control of his or her treatment.

Thus persons who are very disabled by mental illness are those most likely to benefit from objective, evidence-based approaches to treatment. For these persons there is less of a need to focus on the person-centered principles of the recovery model. However, as such persons begin to benefit from treatments, they should be afforded opportunity for greater autonomy. As they progress along the road to recovery, their growing capacity for autonomy should be respected, eventually to the point at which treatment personnel assume the role of consultants and virtually all decisions about treatment are in the hands of the persons who are making the journey of recovery.

Persons who have substantially recovered can be viewed as those likely to benefit the most from the autonomy-centered recovery model. Alternatively, such persons could be viewed as having sufficient capacity for autonomy to have the same right to make their own decisions about treatment—even if those decisions are not evidence based or maximally therapeutic—as is routinely accorded to persons who are viewed as having no decision-making impairments.

Consumers’ views
An important and logical step in increasing consumer empowerment is to identify the concerns of the consumer. Attempts to determine how psychiatrically disabled persons perceive their needs is a relatively new concept in mental health. Until the latter part of the 20th century, persons with schizophrenia and other serious mental illnesses were generally viewed as being so delusional or otherwise cognitively impaired that they were incapable of providing substantive input about their care. Although many such persons did recover, the opprobrium they faced was so ingrained that few of them, or even their family members, would openly acknowledge their experiences with these conditions. As is the case today, there were significant disincentives to make such disclosures for those who were, or had been, considered “insane.” A similar stigma discouraged openness by persons who had “insanity in the family.”

However, beginning in the 1960s, some persons who had been subjected to treatment for serious mental illnesses began to identify themselves openly. In addition, some of these recovering persons took steps to organize themselves and started to give voice to their views. The advocacy efforts of consumers and family members have mushroomed and today represent a valuable and formidable force that affects all aspects of mental health policy (21).

The National Alliance for the Mentally Ill
Of the consumer advocacy entities that were formed during the past quarter century, the National Alliance for the Mentally Ill (NAMI) is by far the largest. NAMI was founded as recently as 1979. As of the summer of 2001, NAMI had a membership of more than 210,000—with more than 1,200 affiliates—located in all 50 states. NAMI currently supports a full-time staff of more than 60.
NAMI initially functioned as a group that advocated primarily for the families of persons with serious mental illnesses. However, the influence of the consumers in NAMI has become increasingly important. The organization has a large consumer council. During the past several years at least one quarter of the members of NAMI’s board of directors have been consumers. However, despite this growing influence, the tens of thousands of consumer members of NAMI do not speak as an independent organization but blend their concerns with those of the majority of the NAMI members—for the most part, family members.

NAMI has a long and complex policy agenda but recently has given special prominence to what the organization sees as eight particularly important policy issues. These priorities are characterized by NAMI as being “based on the most effective standards and programs demonstrated to empower individuals on the road to recovery.” Published and widely distributed as the “Omnibus Mental Illness Recovery Act: A Blueprint for Recovery—OMIRA” (22), these eight NAMI priorities are participation by consumers and their family members in planning of mental illness services; equitable health care coverage, or parity, in health insurance; access to newer medications; assertive community treatment; work incentives for persons who have severe mental illness; reduction in life-threatening and harmful actions and restraints; reduction in the criminalization of persons who have severe mental illness; access to permanent, safe, and affordable housing with appropriate community-based services.

There is noticeable overlap between NAMI’s policy priorities and the six core interventions outlined by Drake and colleagues. One area—assertive community treatment—is clearly prioritized, under the same term, by both NAMI and proponents of evidence-based practices. The call for prescription of medications within specific parameters is somewhat addressed by NAMI’s prioritizing access to newer medications. Moreover, NAMI was an active participant in the public launch of the findings of the Schizophrenia Patient Outcomes Research Team (PORT), which gave wide distribution to the specific recommended parameters for prescribed antipsychotic medications (23). NAMI also produced and distributed more than 500.00 brochures highlighting these recommendations.

These efforts, which support the PORT results, also highlighted the recommended evidence-based interventions for assertive community treatment and for family psychoeducation. Indeed, although neither is explicitly designated as an evidence-based practice, NAMI has two major training initiatives related to psychoeducation: the Family-to-Family program, which focuses on education of family members, and the Living With Schizophrenia program, which teaches consumers to better live with their disorders. This latter effort primarily involves self-management of illness and thus is also related to another of the designated core interventions of Drake and colleagues.

The fifth core initiative under the evidence-based practice model—supported employment—is encompassed in OMIRA under work incentives for persons with severe mental illness, even though the two are not identical. Finally, although NAMI has yet to develop an explicit policy initiative that calls for integrated mental health and substance abuse treatment, the national NAMI board has been actively weighing the pros and cons of taking a position that supports this initiative.

In a broader yet specific demonstration of support by NAMI for the six evidence-based practice initiatives, the president of the NAMI board recently sent a letter to all 16 national board members that highlighted the importance of the evidence-based practices movement.

NAMI, of course, was started by family members of persons who were very disabled with mental illnesses. The needs of the most disabled persons continue to be the organization’s priority. Many of the consumers for whom NAMI lobbies tend to be too disabled to effectively speak for themselves. Many of them are not ready to benefit from the recovery model. NAMI can be expected to provide strong support for evidence-based practice initiatives but will not necessarily be uncritical. On the other hand, agenda statements have been made by organized groups of consumer advocates during the past decade that have presented the collective voices of persons who are further along in their recovery—persons who are better able to speak for themselves.

The National Mental Health Consumers’ Association
One of the more successful attempts to characterize the spectrum of concerns of recovering persons is embodied in the mission statement and the national agenda of the National Mental Health Consumers’ Association (NMHCA). Although the organization has not been active during the past few years, from the mid-1980s through the mid-1990s it was widely viewed as the most organized and largest independent, non-disease-specific organization for persons who had been treated for serious mental illness.

Consumer advocates all over the country regularly participated in the election of members of the NMHCA board. Meeting monthly via conference call, the board had some claim to reflecting the collective voice of consumers’ concerns nationally because of NMHCA’s organizational structure. In the early 1990s and after lengthy deliberations, NMHCA produced a mission statement and a national agenda. The wording of their documents was approved overwhelmingly by both the board and the NMHCA membership in attendance at their meeting held December 12, 1992, in Philadelphia during the annual national Alternatives Conference. Although the NMHCA mission statement was widely distributed in consumer advocacy circles, to our knowledge it has not previously been published.

Examination of NMHCA’s mission and national agenda statements (see box) reveals that NMHCA’s priorities are, by and large, dissimilar from the evidence-based practice initiatives. Although the latter focus heavily on the use of medications and on other services, NMHCA’s priorities primarily stress factors that should better enable recovering persons to more easily integrate into society. Indeed,
NMHCA mission statement and agenda

Mission statement
Guided by the principles of choice, empowerment, and self-determination, the National Mental Health Consumers’ Association is a human rights organization that advocates for employment, housing, benefits, service choice, and the end of discrimination and abuse in the lives of persons who use, have used, or have been used by the mental health systems.

National agenda

Employment. We support the full implementation of the Americans With Disabilities Act and the Rehabilitation Services Act. We must be given every opportunity to be gainfully employed in occupations where we, with reasonable accommodation, can contribute. We call upon the mental health system to practice affirmative action in training and employing mental health consumers in professional careers in the mental health system.

Housing. All persons, particularly those identified as being mentally ill, are entitled to adequate, permanent homes of their choice.

Benefits. All psychiatrically disabled persons must be entitled to sufficient income, social supports, and comprehensive health care to enjoy an adequate quality of life.

Mental health systems. Recovery and healing, not social control, must be the goal and outcome of the mental health system; therefore, the mental health system must be client driven.

Self-help. We support the full and sustained funding and development of user-run alternatives and additions to the traditional mental health system, self-determined and governed by and for members, in every community.

Discrimination. Discrimination, abuse, ostracism, stigmatization, and other forms of social prejudice must be identified and vigorously opposed at every opportunity.

the six items on NMHCA’s national agenda overlap very little with stated targets of the evidence-based practice core interventions. The NMHCA agenda item on benefits calls for entitlement to comprehensive health care. This may or may not include various types of mental health care; such care is explicitly mentioned only in the items on mental health systems and self-help. In addition, the major focus of these latter items is on more consumer-oriented priorities in the overall structure of the mental health system, particularly on availability of psychiatric services.

The statement of NMHCA’s priorities is, in essence, a call for a reexamination of the philosophy and focus of the mental health establishment. It endorses the primary purpose of the development and implementation of mental health services to be for “recovery and healing,” not for “social control.” The individuals constructing and supporting NMHCA’s statement of its national priorities are apparently reasonably far along in their own recovery. Indeed, they appear to be sufficiently recovered to focus primarily on how they can reduce environmental barriers to recovery rather than on examining which treatments they should be receiving. NMHCA advocates who are mostly recovered clearly argue for a more internal locus of control.

This heavy stress on increased autonomy and other recovery priorities by consumer advocates who are mostly recovered fits well with an approach that increases the consumer’s autonomy as recovery progresses. However, a serious question remains about the degree to which the views of NMHCA activists reflect the concerns of nonactivist consumers who are less recovered and perhaps less articulate. Similarly, some advocates of the recovery model may not reflect the concerns or needs of this latter group of consumers.

To our knowledge, no national attempt has been made to systematically capture the sentiment of consumers who are more seriously disabled. Attempts have been made in several states to survey such consumers about their views on services. One of the more active of these efforts has been under way in Ohio for the past five years or so.

Ohio consumer quality review teams

Beginning in 1996, consumer quality review teams were established by the Ohio Department of Mental Health to determine consumers’ views of the mental health delivery system in 22 of Ohio’s 88 counties. Although a few family members and professionals participated as employees in the teams’ projects, the overwhelming majority of employees were persons in recovery from serious mental illness. The primary method for collecting data about consumers’ perceived needs in this team effort was through consumer-conducted, structured individual interviews, each of which lasted for up to two hours.

From July 1996 to March 1999 some 890 adult consumers of Ohio’s public services for the seriously mentally ill were individually interviewed about their views of mental health services. Consumers volunteered for participation in the project. Their names were drawn in a quasi-randomized, stratified manner from both rural and urban areas of the state.

An analysis of the data gathered from these Ohio consumers indicated three general areas of concern (24). One was services that consumers believed were needed but either were not available or were seriously undersupplied: crisis stabilization, longer-term secure residential programs, clubhouse services, housing, meaningful retraining and job placement opportunities, and consumer-run services, which were reported to be
“highly valued” by consumers.

These consumers, as a group, also indicated that they viewed some services as being both available and particularly helpful. These were emotional support, education and information, social support, treatment, stabilization, and financial support. A third area of consumer interest related to aspects of care that were seen as needing the greatest improvement: access to services, adequate numbers of staff, greater consumer influence, and more considerate behavior from mental health staff. One final finding of note was that a significant proportion of consumers was unsure or unaware of which services were in fact being provided in their areas.

The consumers who were interviewed by the consumer quality review teams were all clients of the public mental health system in Ohio. Attempts were made to ensure a maximally random selection of subjects, so one could conclude that this sample of opinions was more representative of the “typical” person who has serious mental illness than those who structured the N M H C A priorities.

Nevertheless, the consumers stressed several of N M H C A’s priorities. These include housing, consumer-run activities, increased consumer influence, benefits such as financial and social support, and access to treatment and health care services. However, unlike the N M H C A advocates who are further recovered, these consumers expressed a desire for services that resembled evidence-based practice interventions. These include the explicit mention of medication, presumably in appropriate dosages; education and information, similar to training in illness self-management and family psychoeducation; retraining and job placement opportunities, which could include supported employment; and more staff as well as staff who are more understanding, both of which are, or should be, components of assertive community treatment.

Thus, the findings of the consumer quality review teams suggest that consumers who are probably not as far into their recovery may be more receptive to the types of services that make up the core interventions of the evidence-based practice model. More detailed and current information about the Ohio consumer quality review teams can be found on the Web sites www.qsan.org and www.qrsinc.org.

**Discussion and conclusions**

Over the past three decades, increasingly influential consumer voices have emerged and have advocated for improvements in the treatment of persons who have mental illness. Two recently developing philosophical forces are competing for the support of these newly enfranchised consumers. One of them is based on science, premised on the identification and implementation of modalities that have been demonstrated by scientific evidence to be effective. The other is the recovery model, which emphasizes the personal nature of the recovery journeys and insists that the final arbiter of how one should recover should be the person who is recovering.

This article has reviewed the viewpoints of three groups of consumers. Although there are numerous similarities, such as a unanimous call for adequate housing, the positions of the various consumer advocates largely reflect the degree of disability of those for whom they are advocating. Those who represent the most disabled, such as family members who believe that they are advocating for those who are not capable of speaking rationally for themselves, tend to be very supportive of evidence-based practice initiatives. Consumers who themselves have recovered fairly well tend to stress the importance of taking control of their own lives. Such persons value their own ability to make choices and even their ability to risk failure. For them, the improvements in treatment that accompany evidence-based practices may be important, but not as important as the rights of consumers to make their own decisions about what services are best for them. As they see it, they themselves—and not more detached scientific researchers—must be the final arbiters of how they will go about their recovery.

Examining the views of consumers who tend to be sufficiently recovered to be able to rationally discuss their opinions, but not so recovered as to have become “advocates,” we find the desire for a little of both worlds. These consumers want better treatments, but they also desire more influence and autonomy.

These observations have several implications for those who are interested in garnering maximal support for evidence-based practice initiatives. N A M I members and other advocates who sometimes speak for “those who cannot speak for themselves” are likely to be very receptive to evidence-based practice initiatives. Indeed, the N A M I leadership already has indicated a willingness to help support and implement evidence-based practice interventions. Those who are interested in encouraging consumer advocacy support for evidence-based practices are likely to find significant assistance here.

On the other hand, advocates who speak for consumers who are further along the recovery process often belong to this group of consumers themselves. They tend to be more focused on regaining personal control, placing a higher priority on rights and opportunities to improve quality of life. They also desire more interaction and influence with the groups that make mental health decisions that affect their lives.

To better gain support from these consumer advocates, a number of actions might be considered. First, more consumers can be invited to participate in groups that are responsible for conducting, overseeing, and implementing evidence-based practice activities. As changes to treatments are being considered, having consumers “at the table” goes a long way toward letting them feel that their contributions are valued and that the decision-making process is fair.

Second, because participation in discussions of scientific matters usually requires familiarity with scientific methods and principles, better efforts should be made to encourage graduate and professional schools that train and accredit mental health providers to recruit consumers in recovery. Such efforts could help increase the number of consumers who are able to contribute to the development and implementation of evidence-based
practice interventions. Some academic entities, such as the Nova Southeastern University Center for Psychological Studies and the Program in Psychiatric Rehabilitation of the University of Medicine and Dentistry of New Jersey, have made good starts in this direction, but the number of such efforts is woefully small.

Third, a small but growing number of psychiatrists, psychologists, social workers, and other mental health professionals who are in recovery from mental illness have decided to openly identify themselves as such. Psychiatrists Carol North (25), Dan Fisher (26), and Suzanne Vogel-Scibilia (27) have all publicly declared that they have experienced serious mental illness. Psychologists Ronald Bassman (28), Al Siebert (29), Kay J amison (30), and Wendy Walker Davis (31) and social workers Donna Orrin (32) and David Granger (33) have made similar disclosures. In all probability, many other such professionals are also in recovery. If these professionals could begin to be more open about their experiences and those of their family members, consumer advocates could better realize that mental health policy and research decisions are not being made as much in isolation from consumer influence as it may appear.

Most consumers fall somewhere between the two ends of the cognitive impairment spectrum. These individuals, when asked, appear to desire more control and influence but also seem to realize that they need more and better treatment. In that this is the group that probably constitutes the majority of those served by public facilities, advocates for evidence-based practices would probably be well advised to meet often and frequently with public-sector mental health professionals and administrators. In this regard, it would probably also be judicious to include recovering persons in such discussions. Although we all should embrace maximization of choice and the rights of consumers to make mistakes, we also need to ensure that enthusiasm for the recovery model does not become so sweeping as to deny the benefits of scientific progress to persons who need treatment.

In summary, the main thesis of this article is that consumers who are more severely disabled, particularly in their decision-making capacity, can best be treated with evidence-based approaches and perhaps with less attention to recovery-model considerations. However, for those whose mental illnesses become less disabling, the principles of the recovery model become increasingly applicable. ♦

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