

The Top Ten Concerns About Recovery Encountered in Mental Health System Transformation

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The notion of “recovery” has recently taken center stage in guiding mental health policy and practice. However, it is not yet clear what the term means and what is to be entailed in transforming the nation’s mental health system to promote it. The authors discuss the various meanings of recovery as applied to mental illness and list the top ten concerns encountered in efforts to articulate and implement recovery-oriented care. These concerns include the following: recovery is old news, recovery-oriented care adds to the burden of already stretched providers, recovery involves cure, recovery happens to very few people, recovery represents an irresponsible fad, recovery happens only after and as a result of active treatment, recovery-oriented care is implemented only through the addition of new resources, recovery-oriented care is neither reimbursable nor evidence based, recovery-oriented care devalues the role of professional intervention, and recovery-oriented care increases providers’ exposure to risk and liability. These concerns are addressed through discussion of the two overarching challenges that they pose, namely the issues of resources and risk. (*Psychiatric Services* 57: 640–645, 2006)

“Don’t tell me that recovery is not evidence based. I’m the evidence.”—
Woman with serious mental illness

With the publication of the President’s New Freedom Commission report, *Achieving the Promise: Transforming Mental Health Care in America* (1), the notion of “recovery” has taken center stage in guiding mental health policy and practice. With the combination of

the commission’s recommendations and those of the Surgeon General’s unprecedented *Report on Mental Health* (2)—which emphasized that all mental health care should be consumer- and family-driven and have as its overarching aim the promotion of recovery—policy makers, program managers, and practitioners are finding themselves under increasing pressure to make services more “recovery oriented.”

However, it is not entirely clear what

the term “recovery” means in this context or what precisely is to be entailed in transforming America’s mental health system to promote it (3–6). This lack of clarity is likely related to a deeper ambiguity about what the term recovery means as applied to mental illness. Recovery, which has been used with various connotations for the past two decades, has been the object of debate among advocates, providers, family members, and other stakeholders. The only thing about which these diverse groups appear to agree at present is that the term can be confusing and, at times, even contradictory (3).

To begin to clarify the range of issues involved in use of the term recovery in relation to mental illness, we offer a brief discussion of this term and a list of the top ten concerns we have encountered in attempting to articulate and implement care based on such a vision. Although we consider all ten concerns worthy of examination (7), within the context of this article we limit our discussion to the two overarching challenges that appear common to these concerns—namely, issues of resources and risk—and suggest possible ways to address them in the work of systems change.

A brief introduction to recovery

Given the broad heterogeneity that has been found in the outcome of serious mental illness (8–10), several different meanings of the term recovery are relevant for people with this condition. For the fortunate persons

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who have only one episode of mental illness and then return to their previous functioning with little, if any, residual impairment, the usual sense of recovery used in primary care is the most relevant. Such people recover from an acute episode of psychosis or major depression in ways that are more similar to, than different from, recovery from acute medical conditions. Persons who recover from an episode of major affective disorder but who continue to view themselves as vulnerable to future episodes may instead consider themselves to be recovering in ways that are not unlike recovering from a heart attack.

Many others will recover from mental illness over a longer period, after perhaps 15 or more years of disability, constituting an additional sense of recovery found in relation to some other medical conditions, such as asthma. Individuals who are concerned as much with the effects of having been diagnosed with a mental illness as with the effects of the illness itself might also consider themselves to be recovering from the trauma of having been treated as a mental patient, whereas those who view taking control of their illness and minimizing its disruptive impact as the major focus of their efforts might find the sense of recovery used in the addiction self-help community to be most compatible with their own experience. Such a sense of recovery has been embraced, for example, among persons with co-occurring psychiatric and substance use disorders who consider themselves to be in “dual recovery.”

To further complicate the picture, there is at least one additional meaning of the term, which is derived by some individuals with a history of serious mental illness from the Independent Living Movement led by people with physical disabilities (11). This vision is focused more on the fundamental rights of people with disabilities—primarily rights to self-determination and community inclusion—than on their clinical or functional status per se.

It is useful in considering this final sense of recovery to recall that individuals with other forms of disability were not always accorded a life in the

Editor's Note: This article is the second in a series of papers addressing the goals that were established by the President's New Freedom Commission on Mental Health. The commission called for the transformation of the mental health system so that all Americans have access to high-quality services that promote recovery and opportunities to pursue a meaningful life in the community. The series is supported by a contract with the Substance Abuse and Mental Health Services Administration (SAMHSA). Jeffrey A. Buck, Ph.D., and Anita Everett, M.D., developed the project and are overseeing it for SAMHSA. The series will feature 15 papers on topics such as employment, housing, and leadership, which will be solicited by the journal's editor and peer reviewed. Also planned are case studies from each of the states that received a SAMHSA-funded State Incentive Mental Health Transformation Grant.

community to the same degree that they are today. Before passage of the Rehabilitation Act of 1973, in fact, there were no legal assurances for people with mobility impairments that they would find curbs cut into sidewalks or other means of access, such as wheelchair ramps and bathrooms equipped with handrails, when they attempted to participate in community life alongside their nondisabled peers. The Independent Living Movement played a key role in passage of the Americans With Disabilities Act of 1990, which established that a person with paraplegia need not regain use of his or her legs and a person with a visual or auditory impairment need not regain use of his or her eyes or ears for that person to have access to a safe, dignified, and full life in the community (12). It is this vision of social inclusion and self-determination that lies at the heart of this most recent sense of recovery for an increasing number of individuals

living with what have come to be considered “psychiatric disabilities.”

In the context of this vision, serious mental illness is viewed more in terms of the prolonged disability, impairment, or secondary consequences that result from the illness rather than in terms of the illness per se. This concept of recovery—a concept we suggest be considered “recovery in” serious mental illness as opposed to “recovery from” serious mental illness (7)—is not to be confused with cure but rather calls for the provision of accommodations and supports that enable people with psychiatric disabilities to lead safe, dignified, and full lives in the community. Once the rights and responsibilities of citizenship have in this way been restored to people with mental illness, the major challenge becomes identifying and providing the accommodations and supports the person needs in order to participate fully in the community in ways that he or she chooses. To capture the shift in practice required by this form of recovery, we have defined care oriented to these goals as that which “identifies and builds upon each individual's assets, strengths, and areas of health and competence to support the person in managing his or her condition while regaining a meaningful, constructive, sense of membership in the broader community” (3).

Even if we achieve conceptual clarity in these distinctions between various forms of recovery, confusion is reintroduced by virtue of the fact that a person may experience more than one form of recovery at any given time, as well as move in and out of different forms of recovery over time. So robust is the heterogeneity found in mental illness, and so little is known about what determines individual outcomes, that there is considerable fluidity between these various forms of recovery. As one way of reducing this complexity for the purpose of formulating policy and guiding practice, we propose accepting this final definition of recovery as having the most profound and far-reaching implications for the work of transformation.

We believe that there are two fundamental reasons that this definition is the most inclusive. First, this form

Top ten concerns about recovery in serious mental illness

10. Recovery is old news. "What's all the hype? We've been doing recovery for decades."
9. Recovery-oriented care adds to the burden of mental health professionals who already are stretched thin by demands that exceed their resources. "You mean I not only have to care for and treat people, but now I have to do recovery too?"
8. Recovery means that the person is cured. "What do you mean your clients are in recovery? Don't you see how disabled they still are? Isn't that a contradiction?"
7. Recovery happens for very few people with serious mental illness. "You're not talking about the people I see. They're too disabled. Recovery is not possible for them."
6. Recovery in mental health is an irresponsible fad. "This is just the latest flavor of the month, and one that also sets people up for failure."
5. Recovery only happens after, and as a result of, active treatment and the cultivation of insight. "My patients won't even acknowledge that they're sick. How can I talk to them about recovery when they have no insight about being ill?"
4. Recovery can be implemented only through the introduction of new services. "Sure, we'll be happy to do recovery, just give us the money it will take to start a (new) recovery program."
3. Recovery-oriented services are neither reimbursable nor evidence based. "First it was managed care, then it was evidence-based practice, and now it's recovery. But recovery is neither cost-effective nor evidence based."
2. Recovery approaches devalue the role of professional intervention. "Why did I just spend ten years in training if someone else, with no training, is going to make all the decisions?"
1. Recovery increases providers' exposure to risk and liability. "If recovery is the person's responsibility, then how come I get the blame when things go wrong?"

of recovery speaks most directly and forcefully to the issues of civil rights and membership in society—issues that people with serious mental illnesses have identified as even more entrenched and difficult to address than those posed by the illnesses themselves (13,14). These issues are discrimination, second-class citizenship, inclusion, self-determination, and, most fundamentally, power. As suggested by its parallel in the Independent Living Movement, this form of recovery requires that persons with serious mental illnesses remain in control of their own lives, including their own mental health care, until, unless, and only for as long as there are clear and convincing reasons, grounded in law, for their sovereignty to be handed over temporarily to others. This requirement does not mean merely that they can no longer be confined to hospitals against their will for protracted periods of time. It also means that they can make their own decisions; pursue their own hopes, dreams, and aspirations; and select and participate in

the activities they enjoy or find meaningful in the settings of their choice, even while disabled.

Just as it is unreasonable and unethical to insist that a person with paraplegia regain his or her mobility to live independently or that a person with visual impairments regain his or her vision to be gainfully employed or attend school, it is both unreasonable and unethical to insist that a person with a serious mental illness no longer experience symptoms or no longer have functional impairments to have sex or attend church. The fact that this principle applies to anyone with a serious mental illness, regardless of the severity of the illness or the various types of recovery accessible to the person, suggests the second reason that we propose the civil-rights sense of recovery in mental illness as the most inclusive. Focusing solely on promoting recovery from mental illness runs the risk of abandoning people with severe disabilities—people who in this sense are not recovering—to repeated failure and despair. On the other hand, restoring to peo-

ple their civil rights and focusing on their hopes and participation in the enjoyable and meaningful activities of their choice would not seem to run the risk of leaving anyone behind. In fact, research suggests that identification and pursuit of activities consistent with a person's interests and learning ways to manage and minimize the destructive effects of the illness contribute to the process of recovering from serious mental illness—over a period of weeks, months, or years (15,16). For example, a focus on learning how to live with auditory hallucinations appears to result in a decrease in their severity and frequency (17), while simply waiting for the symptoms to disappear leaves a person inactive, isolated, and alone.

With this brief introduction in mind, we can now turn to our list of top ten concerns. They are listed in brief form in the box above.

The top ten concerns about recovery

The concerns listed in the accompanying box have been culled from a series of presentations, discussions, and training sessions conducted over the last several years as the state of Connecticut has moved toward a recovery-oriented system of care (18). As the work of transformation can at times elicit tensions and conflict, the rubric of "top ten concerns"—derived from *Late Night With David Letterman*—was chosen to introduce some levity into the situation. Because of space limitations, we cannot take each concern separately but will address, and offer alternatives to, the two most significant challenges that appear common across the specific concerns—namely, those of resources and risk.

Recovery and resources

Many of the concerns about recovery derive from a misunderstanding of the nature of the processes involved and who is responsible for which aspects of the recovery process. In our training, we have found it useful to discuss the various meanings of recovery as they relate to mental illness (as we did above) but also, and perhaps even more important, to distinguish be-

tween recovery, which pertains to the role and responsibility of the person with a serious mental illness, and recovery-oriented care, which pertains to the role and responsibility of mental health providers.

Recovery is a process in which the person engages to figure out how to manage and live with his or her disorder. It is not a fad, an added burden, or a new and as yet unproven practice imposed on already stretched providers. As such, it is neither something providers can do to or for people with mental illness, nor is it something that can be promoted after or separate from treatment and other clinical services. Rather, the New Freedom Commission has argued for recovery to be adopted as the overarching aim of all mental health services (with the exception of forensic services for offenders with mental illness, the primary aim of which may be containment or community safety). It is thus insufficient for mental health providers to agree that they could do more to enhance quality-of-life domains among people with mental illness if they had new or additional resources. Many providers, for example, are happy to open new "recovery programs" or to decrease caseload size if offered the requisite resources. But recovery-oriented care cannot be conceptualized as an add-on to existing services.

Providers who argue that they must provide treatment first and can then perhaps focus on offering rehabilitation (if there is the time or resources), should be asked: If what you are offering is not oriented to promoting recovery, then what is it for? And if there are ways in which what you offer could be more recovery-oriented, and thereby more effective at achieving its aims, would you not want to learn about it and try it?

We are not suggesting that offering recovery-oriented care does not require the expenditure of resources. However, we cannot afford to have a recovery-oriented system grow up parallel to, and distinct from, existing systems of care, conceptualized as an adjunctive or ancillary service. Resources will be needed to fund services and supports and to carry out the staff training and

consultation needed to retool the mental health workforce, but these resources will have to be derived, in large part, from the resources currently allocated to fund existing services, supports, and training.

Rather than being contradictory to recovery, this approach is one way in which the current emphasis on evidence-based practices can be used to promote recovery-oriented care. If there is no evidence supporting the effectiveness of a given practice in promoting an individual's ability to manage, overcome, or live with his or her mental illness, then why should scarce resources be used to fund it? Why should those resources not be reallocated to support practices that are more effective in achieving the overarching aim of the system of care? In this respect, it makes no sense to ask whether recovery or recovery-oriented care is "evidence based." There is ample evidence, documented extensively over 30 years, that people can and do learn how to live with and recover from serious mental illness in the various senses described above (19). The question about evidence-based practices is which interventions, provided by whom, are most effective at promoting which of these various forms of recovery under what circumstances. It is true that new or existing resources will need to be devoted to answering this question in the future if transformation is to be optimally effective in achieving its aims.

Recovery and risk

The second commonly expressed concern about recovery involves issues of ethics and risk. How can the idea of recovery be relevant to someone experiencing an acute episode of psychosis or mania? It would seem that such a person would need to get better first before recovery can be discussed or even considered. Similarly, some staff question the ethics of focusing on strengths, hopes, and dreams when a person may be faced with such urgent needs as safety, shelter, and stabilization. Self-determination and client choice are touted as cornerstones of the recovery process. But what sense does it make to afford choices to a population of individuals

whose judgment is impaired by the very conditions we are charged with treating? Doesn't honoring the choices of someone with an acute or severe mental illness involve abandoning him or her to the ravages of the illness, often to the streets? Doesn't this amount to leaving a vulnerable population of people "to rot with their rights on" (20)? Finally, providers ask, How can you tell us to promote client choice and self-determination on one hand while holding us responsible for adverse events on the other? Doesn't increasing client choice increase provider risk?

Most people who may be described as in recovery from mental illness neither think nor talk about the term "recovery" at all. They talk about getting a job, making friends, having faith, living on their own, and generally getting their lives back. Their engagement in this process is equally relevant to all phases and forms of treatment, although the goals of each phase or form may differ. For example, in terms of acute episodes, recovery doesn't start after the episode resolves, nor can it be put on hold while the person is receiving treatment. From the person's perspective, it is rather that the acute episode has temporarily disrupted his or her ongoing process of recovery (or it may be an anticipated part of the process), and care received during this period can more or less promote or undermine that process.

Recovery requires reframing the treatment enterprise from the professional's perspective to the person's perspective. In this regard, the issue is not what role recovery plays in treatment but what role treatment plays in recovery. This shift has important implications for how we conceptualize and deliver care and the degree to which this care is acceptable to, and effective for, the people we serve. For example, if we accept the premise that mental illness is a condition that many people can learn to live with, our emphases on choice and self-determination become inevitable rather than optional. How else can people learn how to manage their condition in particular, and their life more generally, if they are not allowed to make their own decisions?

But mental illness is different from other illnesses, providers suggest, because of the issue of risk. To this concern we have several responses. First, a majority of people with mental illness pose no risks to the community (21–23). In fact, surveys have shown consistently that this population is much more likely to be victimized than to victimize others (24,25). These findings suggest that people with mental illness—like all other American citizens—should be presumed innocent until proven otherwise. In the realm of choice, this presumption means being allowed to make one's own decisions unless and until there are clear and persuasive grounds for imposing restrictions on this most fundamental of our civil rights (26). A core principle of the recovery paradigm is the appropriate application of established constructs of informed consent and permission to treat to a majority of individuals with serious mental illness a majority of the time. Application of this principle means that—as in other forms of medicine—no matter how expert or experienced the provider, it is ideally left up to the person and his or her loved ones to make informed decisions about care. It is not the practitioner's role to make such health care decisions for the person.

But doesn't such an approach result in devaluing or disregarding the knowledge and expertise of the professional? We suggest, to the contrary, that a recovery-oriented approach brings psychiatry closer to other medical specialties in which it is the specialist's role to assess the person's functioning, diagnose his or her condition, educate the person about the costs and benefits of the effective interventions available to treat the condition, and then, with provision of informed consent and permission to treat, competently provide the appropriate interventions. If mental illness is an illness like any other, it should be treated as such, by medical staff as well as by the general public. If this basic tenet is accepted, it is difficult to understand how providers could view their roles as any less important, or as requiring any less skill, than those of other specialists, such as cardiologists or oncologists.

However, given that one of the obligations of public mental health systems is to protect the community, we understand, and insist, that—just as in other forms of medicine—there are exceptions to this rule. These exceptions, as clearly delineated in federal and state statutes, invariably involve a person who poses some degree of risk, either to him- or herself or to others. In these cases, just as in emergency medicine, the issue of informed consent and permission to treat is suspended temporarily to perform life-saving measures. These cases do not contradict recovery but pose important challenges to it—challenges that may in the future be addressed through such mechanisms as psychiatric advance directives or other creative means to enable people to retain control over their lives, even in such extenuating circumstances. In the interim, rather than arguing about whether or not recovery-oriented care increases risk (an issue about which we do not yet have data), we suggest that it is more useful to highlight the ways in which a recovery-oriented approach clarifies and reinforces the need that already exists for appropriate risk assessment and management. Within the context of a recovery-oriented system of care, the competent conduct of risk assessments will be needed precisely in order to identify the rare circumstances in which people cannot be allowed to act in ways that put others or themselves at risk.

By defining the cases or periods of time in which people pose sufficient risk to have others step in and make decisions for them (to protect them and the public), competent risk assessment leads to the additional byproduct of delimiting a domain of behavior and a population of people for whom there is no such need. This byproduct is important, because the recovery vision emphasizes not only the rights of people with mental illness but also the responsibilities they carry associated with community membership. In a majority of circumstances in which people do not pose immediate risks to self or others, it is not only their right to make their own decisions but also their responsibility. As Deegan (27) has suggested, people

need to have “the dignity of risk” and “the right to fail” in order to learn from their own mistakes. Given the social climate in which mental health care is currently offered, it will be primarily through the appropriate use of risk assessment and management strategies that this latitude will become possible. For this reason, advocates are neither afraid of nor do they dismiss the scrutiny of risk assessment. They welcome it. But they welcome it on the condition that, in a majority of cases, when people are found not to pose serious or imminent risks to themselves or others, they are allowed to make their own choices and, by necessity, their own mistakes. Thus, although a recovery orientation might in fact increase risk, it is primarily the person's access to opportunities for taking risks that needs to be increased, not necessarily the provider's or the community's exposure to risk.

Conclusions

Recovery-oriented systems of care will not stop offering active treatment to reduce the signs and symptoms of mental illness, nor will they stop offering rehabilitative interventions to address functional impairments. What primarily will be different about recovery-oriented systems of care, as we envision them, is that these interventions and supports will be provided in ways much more similar to than different from other health care services for other health conditions. The people receiving these services will likewise continue on with their ordinary lives, either recovering from the illness when possible or, when not yet possible, gaining access to the technologies, tools, and environmental accommodations they need to incorporate the illness or disability into their lives as only one component of a multidimensional existence and multifaceted sense of personal identity. In doing so, they will have to face no more discrimination or externally imposed threats to their personal sovereignty (as opposed to threats posed by the nature of the illness itself) than people with diabetes, asthma, or arthritis.

Some well-meaning providers believe that this form of recovery-ori-

ented care is something that is already being provided, and perhaps in some exemplary communities it is. Systemic transformation, however, will take time, and we expect that the paradigm shift involved will require at least a generation to materialize in any substantive way. In the interim, it is ironic, perhaps, that taking the risk of offering recovery-oriented care promises to be one of the few ways possible to increase available resources. The more that programs implement elements of choice and self-determination and a focus on life goals and aspirations, and the more data are collected to demonstrate effectiveness, the better are our chances of advocating successfully for more adequate funding of care. The more responsive our care, the more likely it is that people in recovery and their loved ones will join us in these advocacy efforts and support—rather than challenge—the legitimacy of the work we do.

Finally, the more effective our efforts at promoting community inclusion, the less people will need from mental health care, allowing us to reduce caseload sizes and spend more of our time in pursuit of the aims that brought us into the field to begin with. Once it is firmly established, the recovery vision will allow us to see, albeit in retrospect, that the costs incurred by not taking such risks—the costs of chronicity, institutionalization, and homelessness—far outweigh the costs of doing so.

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