By Larry Davidson

The Recovery Movement: Implications For Mental Health Care And Enabling People To Participate Fully In Life

ABSTRACT The recovery movement, which broadly recognizes the ability of people with mental illnesses to participate in the mainstream of society, stems from a confluence of factors, including longitudinal data showing that many people eventually recover from serious mental illness. Perhaps as important to the emergence and growth of the recovery movement has been the increasing role that people "in recovery" have played in advocating for person-centered care, greater self-determination for those with mental illnesses, and an enhanced focus on restoring functioning for individuals above and beyond symptom reduction. The Americans with Disabilities Act of 1990 redefined serious forms of mental illness as disabilities, which led to the development of a range of accommodations to enable people with psychiatric disabilities to live in their own homes, work, go to school, and perform other normative adult roles such as parent and parishioner even while suffering symptoms. The Affordable Care Act provides additional levers for expanding the use of peer health navigators and shifting care to a collaborative model in which people can play active roles in their own care. While stigma and discrimination continue to pose formidable obstacles, the foundations have been laid for mental health practice to come closer to resembling health care for other medical conditions.

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The US government mandate for what has come to be called recovery-oriented care was stated unambiguously seventeen years ago in Surgeon General David Satcher's 1999 report on mental health: "All services… should be consumer oriented and focused on promoting recovery…. [T]he goal of services must not be limited to symptom reduction but should strive for restoration of a meaningful and productive life."[1]

Given the robust development of recovery support services by and for people in recovery over the past decade as part of a new recovery advocacy movement in addiction,[2,3] there is every reason to believe that a similar mandate will be stated in relation to care for substance use disorders in the upcoming surgeon general's *Report on Substance Use, Addiction, and Health.* However, it should not be inferred from the 1999 report or other federal documents[3,4] that the recovery vision was introduced, or is being promoted primarily, by policy makers.

Instead, the recovery movement has the potential to become the first reform of mental health policy and practice based on the perspectives of people with mental illnesses. The movement broadly recognizes the right of such people to participate fully in mainstream society, and it has the following two core principles: that people with mental illnesses can lead productive lives even while having symptoms, and that

many will recover from their illnesses. Evolution of the concept of recovery and eventual calls for services and systems to be reoriented toward its promotion first emerged from the increasingly visible advocacy efforts of people with mental illnesses who were dissatisfied with the care they received. While other factors have contributed, the primary impetus for transforming mental health came from the US mental health consumer movement, which began to coalesce in the late 1970s. This movement emphasized lessons learned from the life experiences of these people as they found their way—often without assistance from, and in some cases despite, mental health services—to leading "meaningful and productive" lives in their communities.

Recognizing that the recovery movement arose from the struggles of people with mental health conditions, inside and outside of treatment, does not suggest that the concept of recovery is based solely on anecdotal evidence. The other major contributor has been a growing body of longitudinal research that has called into question much of the conventional wisdom about the course and outcomes of mental illness. Once thought to be disabling conditions from which very few people would ever recover, mental health disorders have come to be seen as health conditions that many people can at least learn to manage over time, if not recover from fully. This research also has confirmed that many of the processes involved in recovery unfold over time outside of formal treatment settings.

For example, in stark contrast to the long-standing belief in inevitable deterioration in schizophrenia, studies conducted around the world found that up to 67 percent of people diagnosed with this condition experience significant improvements over time, and many recover fully.[5–11] In those who did not recover fully, significant diversity was found in outcomes both within and across individuals.[12] Some people improved in certain areas (for example, employment) while not in others (such as symptoms), while the 33 percent who did not substantially improve could be characterized as being at various points on a broad spectrum, ranging from deterioration to clinical stability.[13]

Since outcomes in developing countries have been found to be superior to those in Western industrial capitalist societies,[14] the role of formal treatment in effecting these positive outcomes has also been called into question. Questions about the role of treatment in recovery have been reinforced more recently by studies suggesting that some people with long-term use of antipsychotic medications do less well over time than those who are not on long-term medications.[15,16]

By the late 1980s, data on long-term outcomes, combined with first-person accounts and an expanding network of visible role models of recovery, led to a reconceptualization of the course of mental illness from one of inevitable decline to one of considerable heterogeneity. A body of scientific evidence had emerged that not only allowed for, but also in fact promoted, a vision of recovery as involving processes in which people found ways to lead meaningful lives either by recovering from mental illness entirely or by having learned how to live with it.[17] Full recovery was possible, but it was also possible for those who had yet to recover fully to be "in recovery"—that is, to live meaningful lives despite, or in the face of, the residual effects of these conditions.[18]

As the possibility of these forms of recovery began to gain traction, advocates who were "in recovery" joined forces with other disability rights advocates to lobby for passage of the Americans with Disabilities Act (ADA). The passage in 1990 of this landmark legislation, which redefined serious mental illnesses as disabilities, may be considered a watershed event in ushering in the recovery movement. For when serious mental illnesses became defined as disabilities, then all of the rights and responsibilities of community membership that were ensured for people with physical disabilities were extended to people with these illnesses as well. They are to be afforded lives in the communities of their choice, as are other citizens, and should accommodations be needed to afford a person access to such a life, the law requires that they be provided (as long as they can be considered "reasonable").

For people with physical disabilities, the ADA's term *reasonable accommodations* refers to such things as handrails in bathrooms and Braille signs in elevators, as well as the provision of personal care attendants. These accommodations are intended to enable people with various forms of impairment to access public spaces and participate in community activities as fully as possible. In extending this disability model to people with mental illnesses, the ADA insists that they need not be cured of their mental health conditions before accessing and contributing to community life. Inclusion in community life is not to be delayed or made contingent upon recovery; instead, it is conceptualized as providing the foundation for recovery to become possible in the first place.[18,19]

More so than the effects of the mental illness itself, the major barriers to inclusion identified by people in recovery are those of the social stigma and discrimination that have pushed many people with mental illnesses out onto the margins of the community.[4] The first, and least controversial, step in the transformation of mental

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health care to have a recovery orientation is therefore to address and eliminate the stigma and discrimination historically associated with these conditions. Passage of the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008—since reinforced by passage of the Affordable Care Act (ACA)—was an important step in this direction, but much work remains to be done.

Against this historical backdrop, some of the steps the recovery movement has taken over the twenty-six years since passage of the ADA have been in identifying, developing, implementing, and evaluating services and accommodations that will be effective in ensuring that all Americans with mental illnesses are provided with the opportunities and resources needed to enter into and sustain recovery. These are described below.

The Americans With Disabilities Act: Is There A Mental Health Equivalent To A Wheelchair?

Assuming that US society makes progress in eliminating stigma and discrimination toward people with mental illnesses, what additional steps will be required to promote their recovery and inclusion in the community? What accommodations should the ADA ensure access to for people with disabling conditions?

The ADA paved the way for what has become ubiquitous wheelchair access. But thus far, most attempts to devise a parallel to "wheelchair access" for people with disabling mental illnesses have been in the form of other people offering support in natural community settings. That is, the primary prostheses for people with mental health conditions are social in nature and involve having access to caring, trusted, and knowledgeable people who can support them over time in pursuing their hopes and aspirations in the community contexts of their choice.

The provision of community-based supports to promote participation in naturally occurring activities and settings was first established in the

Assertive Community Treatment (ACT) model developed in Madison, Wisconsin, in the 1970s, which coincided with the establishment of the Community Support Program at the National Institute of Mental Health. Indeed, many of the interventions that are now increasingly being called "recovery supports"[20] can be traced conceptually back to the community support movement inaugurated by the administration of President Jimmy Carter. These interventions include supported housing and supported employment, along with the provision of community supports in such domains as education, parenting, socialization, and spirituality.[21–25]

There are a few differences, though, between supported housing or employment when provided as a "recovery support" and when provided by the staff of an ACT team. ACT teams are multidisciplinary intensive case management teams comprising mental health clinicians and other practitioners. Their primary functions are resolving crises, reducing symptoms, and developing life skills so that people with serious mental illnesses can be supported outside of hospitals. The first, and most important, difference is that recovery supports are provided in response to a choice on the part of the person with mental illness who has expressed a desire to live on his or her own or to work competitively. Instead of being prescribed as an intervention to "stabilize" a patient in the community, supports are provided to enable the person to participate as fully as possible in a life of his or her choosing.

Second, again in the former case, the supports are not provided as part of a continuum through which a person has to make progress to gain his or her independence, as was the case when a person had to move from a group home to a halfway house and then to a shared apartment before getting his or her own apartment.[22] As in the newer models of community support known as housing first[26] and individual placement and support,[21] people are always considered ready for living independently and working. What remains to be done is to provide the supports on site at the apartment or job where the person wants to live or work.

Any of these supports can be provided separately from and independently of clinical care (that is, the recipient does not have to comply with other treatments), but they can also be integrated with the person's other care when desired, through the use of a personal recovery plan that spans different programs and agencies.[27] The supports are to be provided for as long as they are desired (there are no artificial time limits), and the person is free to change his or her supporter in the same way that people with physical disabilities can change personal care attend-

ants.[28] Finally, these supports are increasingly being offered by people in recovery themselves, as the advantages of "peer support" are becoming recognized and appreciated.

Eclipsing the importance of both recovery supports and changes to clinical practice, the recovery movement is often identified with—and at times seen as involving no more than—the rapid growth of peer support. In its current form, the training and hiring of people who are in recovery from a mental illness to provide support to others within the mental health system began around the same time as passage of the ADA. Initial attempts were a natural outgrowth of the increasing presence of self-help or mutual support groups that were a central part of the mental health consumer movement, as providers hoped that some of the benefits they witnessed people deriving from peer-to-peer relationships outside the mental health system could be imported into that system.

At first, volunteer positions were created through which people who were doing well could mentor others who were struggling. But by the early 1990s, paid positions were being created for peers to play a variety of roles, from those of case manager aide or housing support staff to the new roles of recovery educator or advocate.

Since then, people in recovery have developed a variety of approaches to peer support inside and outside of mental health settings. Whether offered in the clinic or on the street, all of these approaches have the following features in common: the importance of the peer staff members' instilling hope through their own self-disclosure and role modeling of recovery; activating and educating the person for self-care; and assisting the person in accessing other services and supports of his or her choosing to help rebuild a life in the community.[29] And they all place value on promoting the person's empowerment, even within the context of emergency or inpatient care, with the peer becoming an advocate for the person's own preferences and wishes (for example, as stipulated in a psychiatric advance directive). Research has found this form of peer support to reduce the rate and length-of-stay of costly readmissions, substance use, and depression while increasing hope, empowerment, well-being, quality of life, and engagement in self-care.[30,31]

The phrase "in its current form" is used above because earlier parallels to what is now being called "peer support" can be found throughout the history of mental health—starting as early as the moral treatment era that emerged in the eighteenth century, when asylum patients were first unshackled and treated with dignity and respect.[32] But the growth of the current form of peer support—in which people in recovery are trained, certified, hired, and supervised in providing various forms of support to their peers—has been nothing short of extraordinary. The Department of Veterans Affairs alone hired over 1,200 peer staff members over the past decade.[33] With over thirty-five states now using Medicaid reimbursement to fund peer support, it can be considered the fastest-growing component of the behavioral health workforce.[33]

As of this writing, however, there has been more progress made in envisioning a "recovery-oriented system of care"[3] than in implementing one. Although firm conceptual and empirical foundations have been established for such programs as supported employment, for example, current estimates of its penetration rate within statewide systems of care hover around 2 percent (while unemployment rates among people with serious mental illnesses continue to be around 80 percent).[34] And while thousands of people in recovery have been hired as staff members, it remains unclear how many of them are actually providing the kind of peer support for which they have been trained. A lack of role clarity and discrimination on the job are but two of the barriers that peer staff face in trying to put their training into practice once they are hired.[33]

The Affordable Care Act: Levers For Person-Centered Clinical Care

One hope among recovery advocates is that the ACA may provide several levers for person-centered clinical care. For example, the person-centered health home model is a central strategy of the ACA for improving the quality and outcomes of health care while decreasing overall costs. One required component of this model is the use of "health navigators." These are paraprofessionals who are trained and hired to assist patients who have complex medical needs or a history of difficulty accessing needed services to support them in making effective use of available care and in their self-care, or both. Given the twenty-to-twenty-five-year discrepancy in life span for people with serious mental illnesses, many peers are now being trained in health navigation (in addition to other aspects of peer support) and are joining health home teams that serve such people.

Home health teams may be based either within primary care (medical homes) or in community mental health settings (behavioral health homes). In either case, the main aim is the same: integrating primary and behavioral health care within a holistic or "whole health" model that improves outcomes across all health domains. Addressing the need for this kind of integration

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is a central requirement of the new Certified Community Behavioral Health Clinics created by the Protecting Access to Medicare Act of 2014. The act authorizes a demonstration program for up to eight states to pilot these new clinics before bringing them to scale nationally. The intent of the program is to develop and evaluate clinics that could replace current community mental health centers using a prospective payment system supported by Medicaid.[35] To the degree that peer staff members can bring their first-person perspective and credibility to this expanding role, they will become valued and sustained members of the behavioral health workforce.

Two other main features of the ACA are the expansion of Medicaid to cover millions of people who would not have been eligible for it in the past and the funding of recovery supports—such as supported employment and peer support—that would not have been considered to meet the "medical necessity" criterion previously.[36] While not all states will choose to take advantage of the Medicaid expansion and the funding of recovery supports, penetration rates of recovery supports can be expected to increase significantly in states that do participate. However, if state legislatures or governors use Medicaid expansion to justify cutting state funds allocated to recovery supports—without choosing to include these supports in their Medicaid plans—it is likely that penetration rates will decrease.

Beyond the addition of peer staff members and recovery supports, more work remains to be done in achieving the transformation to recovery called for by the President's New Freedom Commission on Mental Health in 2003.[4] The commission's report resulted in development of a federal action agenda that describes the vision of a transformation to recovery as "nothing short of revolutionary," implying "profound change—not at the margins of a system, but at its very core."[37(p5)] In terms of the nature of this "profound change," the federal agenda suggests that

"a keystone of the transformation process will be the protection and respect of the rights of adults with serious mental illnesses."[37(p3)] Apparently there is more to the restoration of rights to people with mental illnesses reflected in the ADA than the provision of accommodations through Medicaid expansion to fund peer and other recovery supports.

What is needed to speak to the core, instead of to the margins, of the mental health system is full restoration of, and respect for, each person's right to self-determination as well as to community inclusion. That is, people with mental illnesses retain their right to make their own choices except in those circumstances when they are found to pose imminent risk to themselves or others or are determined to be gravely disabled. And this right to self-determination is not only to be respected in terms of where people choose to live and how they spend their time, but within the mental health system itself as well.

It is here where a second component of the health home model central to the ACA has the potential to become a major driver of transformation. The ACA envisions the care to be provided through the health home as being person-centered and involving collaborative decision making between caregivers, patients, and their loved ones. Mental health transformation will be significantly advanced to the extent that this model is taken to apply to mental health in much the same way as it does to general medical care. Within mental health, the challenge is to transform a system in which practitioners have been the sole experts and primary decision makers to one in which both people with mental illnesses and their loved ones are respected for the expertise they bring to the table and in which all parties are expected to view each other as partners in the shared pursuit of promoting the health and well-being of the person with mental illness.

While the practitioner's expertise in preventing, treating, and managing mental illnesses may be obvious, the nature of the expertise that the person with mental illness brings to the encounter might not be. This is especially true in instances in which the person appears to be significantly disabled by the illness. In this respect, it is important to recall the surgeon general's statement that "the goal of services must not be limited to symptom reduction but should strive for restoration of a meaningful and productive life."[1]

Practitioners have been trained in reducing and managing symptoms; they have not necessarily been trained in restoring a meaningful life. Even if they have been, it remains primarily up to the patient and his or her loved ones to decide what life needs to involve for it to be meaningful.

This is true regardless of the acuity of symptoms, since even people who are acutely ill are still also likely to have periods of relative stability in which they will be able to articulate their personal preferences and interests within the context of a trusting relationship.

It is within this arena that the person and his or her loved ones bring relevant expertise that must be taken into account. They have the most intimate, in-depth knowledge of how the condition or conditions in question have affected the person's life, how treatments and interventions may impair or improve that life, and what kind of life the person aspires to lead. In the end, it also is the person who primarily will bear the effects and consequences of the choices made, at least for his or her own health and well-being.

It is for these reasons—as well as because people are more likely to adhere to treatments that they have had a role in choosing[38]—that the recovery movement, like the ACA, follows the Institute of Medicine's recommendations in promoting person-centered care.[39] It also is for these reasons, along with concerns about cost and the inefficient use of health care resources, that the ACA and the recovery movement emphasize the need for health care providers to promote self-care in people with long-term conditions.

Promoting self-care in people with mental illnesses requires not only challenging the legacy of paternalism in medicine but also overcoming the discrimination and internalized stigma alluded to above—in this case, on the part of mental health practitioners. But the mainstreaming of mental health care[40] that the ACA aims to bring about will succeed only to the extent that underlying assumptions that separated mental health from the rest of medical care in the first place (that is, the belief that mental illnesses are moral failings instead of health conditions) are overcome as well. In this regard, the increasing number of public education and media campaigns that aim to "change the conversation" about mental health, such as those led by First Lady Michelle Obama and Her Royal Highness the Duchess of Cambridge,[41] are both timely and necessary.

In the meantime, recovery-oriented clinical practice should engage people with mental illnesses, their loved ones, and the others who support them (such as their employers and landlords) in planning and evaluating care. It also involves identifying and building on people's strengths and the opportunities and resources that exist in their communities, and equipping and empowering people to play an active role in the management of their conditions. Finally, it emphasizes being attentive to the impact of trauma and the importance of culture in both the help-seeking and care delivery process and their expected outcomes.[29]

While this recovery-oriented model of collaborative practice is consistent with the tenets of the ACA, there is little in the ACA itself that will move care in this direction in the absence of concerted efforts to change the beliefs and attitudes of practitioners and the general public. This may take a generation or two, as new generations of youth with mental illnesses question existing conventions that either socialized previous generations into passive resignation or drove them away from the mental health care system.

Conclusion

As the Americans with Disabilities Act and the recovery movement mark more than a quarter-century in existence, much work remains to be accomplished in eliminating stigma and discrimination related to mental illness, transforming clinical practice to be person-centered and aimed at the restoration of functioning, and both designing and funding recovery supports that enable people to participate fully in community life. Instead of making recovery passé—as some had feared would happen—the core provisions of the ACA provide several powerful levers for moving health care systems closer, eventually, to achieving the vision of being recovery oriented in all aspects of care. ∎

NOTES

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