

Recovery as Policy in Mental Health Services: Strategies Emerging from the States

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The concept of recovery has emerged as a significant paradigm in the field of public mental health services. This paper outlines how the concept is being implemented in the policies and practices of mental health systems in the United States. After a brief overview of the historical background of recovery and a description of the common themes that have emerged across the range of its definitions, the paper describes the specific currently strategies used by the states to implement recovery principles. The authors conclude by raising key questions about the implications of adopting recovery as system policy.

Conceptualizing Recovery

Medical professionals have long recognized that people can recover from physical illnesses. Treatments for disease commonly take recovery—defined as return to the pre-morbid state—as their goal. Most people have had the experience of coming to terms with traumatic or stressful life events. In common parlance, this experience is also called recovery. As alcoholism and other addictions have been reconceptualized as diseases (rather than failings of character), the word recovery has been applied to the process of learning to live a full life without alcohol or drugs. The meaning of “recovery” has different nuances: restoration of normal health and functioning; a strength of character born of surviving tough times; the challenge of not allowing a serious or long-term condition to consume or dominate one’s life. Conceptualizing recovery as

possible leads to the development of specific interventions and practices to promote it. Thus, the possibility of recovery becomes an expectation.

Application of recovery concepts to psychiatric disorders is comparatively recent and stems largely from two interrelated sources: the consumer/survivor/ex-patient movement, a grassroots self-help and advocacy initiative with overtly political or social justice goals (Brown 1981; Chamberlin 1984; Chamberlin 1990; Everett 1994); and psychiatric rehabilitation, a professional approach to mental health services provision (Anthony 1991; Anthony 1993).

Like many other social movements that emerged in the 1960s and 1970s, the consumer/survivor/ex-patient movementⁱ began with a claim for a unique group identity and desire for broad recognition of the lack of civil and human rights granted to members of the group. Activists demanded that society recognize the oppression and marginalization of people with psychiatric disorders and called for liberation. The liberatory goals of the movement were encapsulated in the notion of empowerment, understood both systemically—as a redistribution of the power held by the state and the institution of psychiatry, and individually—as the consumer taking control and responsibility for his or her own life.

Psychiatric rehabilitation initiatives, on the other hand, have been traditionally the work of professionals and mental health advocates. These initiatives have helped to shape the emergence of community resources and best practices in treatment for persons with psychiatric disabilities by 1) recognizing the value of community and work in the lives of persons diagnosed with psychiatric disorders, and 2) demonstrating that a person's ability is based on more than diagnosed pathology or the intensity of symptoms, but is the product of interactions between the individual and the environment (Anthony, Cohen, and Farkas 1990).

The conceptualizations of recovery to come from these two sources reflect their different orientations. For many, “recovery” has a political, as well as personal, implication: to recover is to reclaim one's life, to validate one's self in order that one may be validated as an autonomous, competent individual in the world. Recovery can be viewed as one manifestation of empowerment. In psychiatric rehabilitation terms, recovery refers in large part to functional ability. To recover is to improve and maintain personal capacity in one or more of the major domains of life—work, housing, relationships, recreation—and by so doing to “[live] a satisfying, hopeful, and contributing life even with limitations caused by illness...[and to develop] new meaning and purpose in one's life” (Anthony 1993, 15)ⁱⁱ. Recovery from disability and limitations commonly associated with psychiatric disorders is the desired outcome of a mental health services system that has fully incorporated psychiatric rehabilitation and community support principles and practices.

The contrast between these notions was explored in a 1988 article by Patricia Deegan, a clinical psychologist and an activist who identifies herself as having a psychiatric disability. Drawing from her own experience and from the disability rights movement, Deegan made a crucial distinction between rehabilitation and recovery:

Persons are not passive recipients of rehabilitation services. Rather, they experience themselves as *recovering* a new sense of self and of purpose within and beyond the limits of the disability.... Rehabilitation refers to the services and technologies that are made available to disabled persons so that they may learn to adapt to their world. Recovery refers to the lived or real life experience of

persons as they accept and overcome the challenge of the disability (Deegan 1988, 11).

Deegan further described that “lived experience” as “a process, a way of life, an attitude, and a way of approaching the day’s challenges” (p. 15) and, paraphrasing the poet Roethke, as “the urge, the wrestle, and the resurrection” (p. 15).

The different conceptualizations of recovery have been supported by evidence from both research and anecdote. Long term studies of the impact of serious mental illness on individuals have shown that a psychiatric disorder does not necessarily take a course of inevitable deterioration and that, for a significant number of people, a return to full ability is possible (Harding et al. 1987). Further research (e.g. Campbell and Schraiber 1989; Copeland 1992, 1994) and first-person narratives of consumer/survivor/ex-patients (e.g., Unzicker 1989; Leete 1989) have illustrated the practical resilience of persons diagnosed with psychiatric disorders, identified various pathways of healing, and articulated factors which enhance or detract from this healing process. Increasingly, recovery has become both a subject of mental health services research (e.g., Hatfield and Lefley 1993; Sullivan 1997 [1994]; Ralph 1996) and a term that is emblematic of many of the goals of the consumer/survivor/ex-patient movement (e.g., Fisher 1994).

Several themes have emerged as particularly salient across the different conceptualizations of recovery:

- Recovery is generally seen as a *process*. That is, it represents not a cure-like endpoint, but a state of being and becoming, a path rather than a destination.
- The course of that path is understood to be highly *singular* or *unique*; no two people will have identical paths or use the same benchmarks to measure their journeys.
- In contrast to the passivity of being a patient or a voiceless recipient of services, recovery is *active* and requires that an individual have personal responsibility for his or her own recovery, often in collaboration with friends, family, supporters, and professionals.
- A recovery orientation includes an emphasis on *choice*, a concept that encompasses support for autonomous action, the requirement that the individual have a range of opportunities from which to choose and full information about those choices, and increasing personal responsibility for the consequences of choice.
- The emotional essence of recovery is *hope*, a promise that things can and do change, that today is not the way it will always be.
- A key theme is that of *meaning*, or the discovery of purpose and direction in one’s life. The search for meaning is highly personal. For some people meaning may be reflected through work or social relationships. Others derive meaning from advocacy and political action. For others, the pursuit of meaning takes on strongly spiritual elements.

Policy and Programming: Strategies for Implementing Recovery Concepts

Prompted by advocates, the emerging literature, and concurrent demands to improve the effectiveness of public mental health services, a few state mental health systems have introduced recovery into the public policy lexicon (Beale and Lambric 1995; Legislative Summer Study Committee of the Vermont Division of Mental Health 1996; State of Wisconsin Blue Ribbon

Commission on Mental Health 1997; State of Nebraska Recovery Workteam 1997; Barton 1998). In many states, the introduction of recovery concepts into mental health policy has coincided with a shift towards a managed care approach to services financing and system accountability. In this context, recovery is envisioned as a set of guiding principles whose application that can result in cost effective behavioral healthcare and which suggest measurable treatment outcomes.

How are state and regional mental health authorities incorporating recovery into policy and practice?ⁱⁱⁱ As with any important system change initiative, the first steps include understanding the concept and ascertaining its viability and value within clinical and financial contexts. Many states are beginning by developing recovery vision statements, written statements meant both to explain recovery and to demonstrate a real commitment to it (Schmook [undated document]). In order to develop such vision statements, mental health authorities typically establish a work group or task force comprised of a diverse set of stakeholders. The group studies the literature and solicits advice from many sources and experts—including first-person testimonials. It then develops a document that provides a working definition of recovery and makes recommendations for implementing its principles.

With vision statements in hand, some states simply re-name their existing programs. The actual services offered remain the same. Community support services, vocational rehabilitation, or living support are now described as “recovery-oriented” services. This re-naming process demonstrates a lack of understanding of recovery: in particular, a failure to acknowledge the necessity for a fundamental shift toward sharing both power and responsibility.

States that have moved beyond such cosmetic efforts tend to focus on several specific strategies for operationalizing and implementing recovery. These strategies include education, consumer and family involvement, support for consumer-operated services, emphasis on relapse prevention and management, incorporation of crisis planning and advance directives, innovations in contracting and financing mechanisms, definition and measurement of outcomes, review and revision of key policies, and stigma reduction initiatives. Examples of state efforts in each of these approaches are presented below.

Education

A number of states are stimulating discussion and understanding about recovery through structured education initiatives, conferences, newsletters, and changes to academic curricula. Recovery education may be designed for consumers, family members, service providers, or administrators. States are developing their own educational programs, or are using one or more of the emerging curricula (e.g., Copeland 1992, 1994, 1997; Curtis, 1999a; Center for Community Change 1996; Spaniol, Koehler, and Hutchinson 1994). The content of the educational programs varies depending on the intended audience. Recovery education emphasizes basic information about mental illness and the mental health system, strategies for self-management of symptoms and self-advocacy, and the development of peer support (Hatfield & Lefley 1993, Muser & Gingerich 1994; McFarlane et al 1995). Education for providers and administrators focuses on exploring the concept of recovery, challenging assumptions, and presenting information about the role of workers in stimulating and facilitating the process (Curtis, in press). Several states (e.g., New York, Massachusetts) have incorporated modules on recovery into their statewide core curricula.

Recovery education/training sessions are often conducted by consumer/survivors who have been trained as recovery educators, who work either independently or with a mental health worker as a co-trainer. The content of these programs is enhanced by the role modeling and inspiration provided by consumer/survivor trainers. Curtis (1999a), Copeland and the Center for Community Change (1996; see also State of Vermont [undated]) have developed a variety of training-of-trainers programs for consumer/survivors and mental health professionals.

A key component of many recovery education initiatives is cross-training. Workers with different disciplinary backgrounds, consumers, family members, and administrators join together as learners with a shared investment in understanding more about recovery. Each group is encouraged to contribute its unique expertise and knowledge. One innovative educational strategy—developed in New York in the early 1990s—is the recovery dialogue, in which groups of providers and service recipients meet as equals on neutral ground to discuss recovery (Blanch et al 1993; New York State Office of Mental Health [undated documents]). States may use recovery dialogues as one-time events, or they may become part of an on-going process of consciousness raising, education, and change. Bluebird (in press) has developed a format for facilitating these dialogues among diverse groups of stakeholders.

Another source of recovery education is the increasing number of state, regional, and national conferences on recovery. Such meetings have been held in Vermont, New Hampshire, Nebraska, and Pennsylvania. Early in 1998, the National Technical Assistance Center for State Mental Health Planning (NTAC) and the Nebraska Mental Health Planning and Evaluation Council co-sponsored a regional training conference on recovery (NTAC 1998). The National Empowerment Center (NEC) has presented a series of “Learning From Us” conferences which bring people together and help to stimulate awareness and dialogue about recovery (1997). The Alternatives conferences sponsored by the Center for Mental Health Services (CMHS) has a long tradition of providing consumers/survivors/ex-patients with a forum for exploring various pathways to recovery, consumer leadership and political action.

Consumer/Family Involvement

One success of the consumer/survivor movement and of the family movement has been to increase recognition that these groups are critical stakeholders and must be key players in mental health system design and service delivery. At no other point in the history of mental health system reform have consumers and family members played such an active and valued role in influencing the direction of reform.

Organizations and systems are seeking to increase the involvement of consumer and family representatives in most aspects of policy planning and service delivery. Consumers are being hired to design and conduct mental health services research (Campbell and Schraiber 1989; Scott 1993), including evaluations of service effectiveness (Srebnick et al. 1990; Ferry 1996; Campbell 1997). They are being recruited to serve on the boards of service organizations. Some states now require consumer and family participation on agency boards of directors and other decision-making bodies (e.g., Vermont, Rhode Island, New Hampshire, Nebraska, California). Many states are establishing state-level offices of consumer affairs that are led and staffed by consumers or are creating consumer liaison positions within existing departments (e.g., Wisconsin, Arkansas, South Carolina, New York, Connecticut, Nebraska, New Hampshire). Elsewhere states are contracting with existing consumer organizations to provide technical

assistance and advisory functions (e.g., Oregon, Illinois, Vermont). Many consumers have found that political action is an important component of personal recovery as well as a strategy for system change (Carling 1997; Deegan 1992; Friere 1997).

Many service providers are hiring consumers to work as staff (e.g., Curtis, 1999b, Mowbray et al 1997, Abbot et al 1995). The move to hire consumers/survivors is grounded in assumptions about their unique value: for example, consumer advocates assert that because they have life experience that is unlike that of traditional professionals, they can bring special expertise to the work. They contend that for many, the very presence of consumer staff can stimulate hope and images of successful recovery. Research into the efficacy of consumer staff in case management services has demonstrated enhanced service outcomes (Soloman and Draine 1995; Felton et al 1996).

Increasingly, it is being recognized that the recruitment and involvement of consumers, without adequate and parallel capacity building, runs the risk of being reduced to tokenism.

Organizations and consultants have sprung into the gap, providing technical education and leadership training to ensure that consumer participation has value beyond the symbolic (Nichols and Palmer 1997). Additionally, some states are recognizing the need for accommodations that allow consumers and families to participate fully in policy-making activities, such as scheduling meetings for weekends or evenings so that people who cannot take time away from their jobs may attend (Anderson 1994; Curtis et al. 1991; Valentine and Capponi 1989).

Consumer-run Services

These services, also described as “user-controlled alternatives,” are one manifestation of the self-help ideology of the consumer/survivor/ex-patients movement (Chamberlin, 1990). Their specific offerings may include peer-support and self-help networks, drop-in centers, wellness programming, crisis and respite care, and hospitalization alternatives. Founded, governed, and run by consumers (although some have a degree of non-consumer involvement as well), they are typically organized non-hierarchically and emphasize mutual aid and support (Gartner and Reissman 1997 [1982]). Proponents argue that, because of their ideological heritage, such programs are the only truly “recovery-oriented” services available (Chamberlin 1984; Fisher 1994). With the current emphasis on recovery, several states (New Hampshire, Vermont, Rhode Island, Nebraska, Ohio, Missouri) are looking to consumer-run and self-help services as essential elements of the core service array and are considering mechanisms by which consumer-operated services may be reimbursable through Medicaid.

As with consumer involvement, there is a growing awareness that support for consumer-run services requires more than just lip service (Solomon et al. 1998). Several states are exploring how to support these services through adequate funding, leadership and management training and mentoring, and accountability mechanisms that reflect the spirit of a self-help orientation (e.g., West Virginia, Nebraska, New Hampshire, Ohio). Bringing consumer-run services into the mainstream of mental health services can be problematic. For example, accepting public funding means finding a way to balance “from the heart” mutual aid and professionalized services with mandates for accountability, demonstrable outcomes, and adequate staff credentials.

Relapse Prevention/Management

In several states (e.g., Vermont, New Hampshire, Maine, California) the education and self-help strategies for promoting recovery are prompting growing attention to preventive self-care and relapse prevention. Recovery education curricula directed at consumers emphasize techniques for recognition and management of symptoms and relapse triggers (Spaniol, Koehler, and Hutchinson 1994; Copeland 1992, 1994, 1997). In many places, support for recovery means providing financial support for the dissemination of such information and techniques among the consumer and family population. Some academic curricula train professionals to help individuals to develop effective relapse management and crisis prevention plans (e.g., Program in Community Mental Health at Trinity College of Vermont; Center for Psychiatric Rehabilitation, Boston University).

Crisis Planning and Advance Directives

Crisis planning is premised on the argument that proactive and prudent decision-making can mitigate the negative consequences of crisis situations and diminish the use of coercive interventions such as involuntary commitment, use of restraints and seclusion, and forced medication. While they are doing reasonably well, consumers develop plans for managing future crises. Building upon the recognition of triggers and the self-management skills emphasized in relapse prevention, crisis plans usually specify the signs and symptoms that the individual typically exhibits when in crisis and the individual's preference for disposition at that point—including preferred treatment facility and medication. They may appoint a representative to advocate for the interests and wishes of the individual and to maintain their daily affairs—e.g., call employer, pay rent and other bills. (Collier 1994; Copeland 1997.) Such crisis plans may serve as guidelines, or they may be formalized as legal documents, for example as advance directives or through establishing a durable power of attorney for healthcare. States are promoting crisis planning either by encouraging consumers to formulate plans or by making such planning a requirement in certain treatment programs (e.g. Missouri, California, New Hampshire, Vermont). Vermont recently passed a state law which states that legally established advance directives can be overridden by court orders for involuntary treatment only after the plan outlined in the advance directive has been given a opportunity to work. Although the idea of crisis planning has gained considerable support from many consumer advocates and providers, the use of advance directives and durable power of attorney to direct psychiatric healthcare preferences—particularly in emergency situations—will likely come under judicial review in most states.

Contracting and Financing Mechanisms

In many locales the shift to a recovery orientation has been coincident with initiatives to move public mental health services into a managed care model (Mechanic 1998). There is some trepidation about the fit between managed care—often perceived only as a cost control and service access mechanism—and the needs of the population of persons with severe and persistent mental illness for quality care. Some advocates have asserted that the adoption of a managed care model—with its emphasis on rationalizing each level of care in order to ensure effective service delivery and improved outcomes—in fact represents the best chance for real mental

health reform (Fisher [undated document]). Certainly there is congruence between the managed care principle of minimizing high-cost, maintenance-oriented services, and the recovery principle of helping people to have “real lives” rather than subsisting in custodial programs. However, many of the elements which consumers describe as fundamental to establishing and maintaining recovery (such as work, good relationships, pets, spiritual connections) are not typically considered medically necessary. Capitation can give healthcare authorities increased flexibility to offer individualized such recovery-oriented supports, but an overly narrow conceptualization of recovery may provide latitude for managed care organizations to restrict access inappropriately or to terminate services prematurely.

States and regional mental health authorities are seeking, quite literally, to write recovery principles into their contracts with managed care organizations (e.g. California, Washington, Ohio, New York, Massachusetts). Contracts may specify that the organizations must demonstrate a recovery orientation: for example, by requiring that they maintain a certain level of consumer representation on their advisory boards or that a certain proportion of their funding be devoted to consumer-run services.

The lynch pin of any contract is the phrase “medical necessity.” Recovery advocates seek to expand the definition of “medical necessity” to encompass recovery oriented psychiatric services like housing, employment and educational support, wellness programs, recreation and spiritual opportunities, and other interventions and activities that can diminish the need for high cost services like hospitalization (e.g. Ohio, Rhode Island, California). New Hampshire has drafted a preliminary set of clinical practice guidelines for adults in community support programs that include standards for facilitating recovery and maintaining and extending gains (Torrey and Wyzik, 1997)

Outcomes

Managed care initiatives and new Federal requirements emphasize the measurement of outcomes as a strategy for ensuring the accountability of mental health providers to the purchasers/funders of behavioral healthcare and to regulatory bodies. The emerging emphasis on recovery principles in mental health services suggests that recovery should be captured as a measurable outcome. Across the country, health services researchers and medical information systems experts are trying to turn the concept of recovery from an abstraction into an instrument (e. g. Rhode Island, New Hampshire, Ohio, Vermont, Wisconsin). The process of developing such measures involves first specifying the dimensions of recovery—often through the use of qualitative or participatory action research methods—then finding ways to operationalize and measure them reliably and validly across time. The challenge is to find variables that appropriately capture the unique “lived experience” of recovery in ways that can satisfy the demands for system accountability. Harding (1994) identifies inherent complexities in this effort. She suggests that viewing recovery as an outcome or endpoint defies its highly individual and fluid character and often overlooks cultural and developmental aspects of its course. Such outcomes should be reframed as benchmarks or “markers of course” (p. 164).

Policy Revision

As recovery comes into the mainstream, it is stimulating a process of reflection and appraisal at the systems level as well as reassessment of “what works” on a programmatic and personal level.

Policymakers are looking at such issues as informed consent, confidentiality, involuntary commitment, and risk sharing, seeking ways to make actual practices congruent with the philosophy embedded in recovery (e. g., Maine, Massachusetts, Ohio, Vermont). Similarly, at the level of service provision, providers are reviewing treatment practices, identifying best practices, and developing guidelines that make manifest the principles of recovery (Curtis 1997). For example, Jennings (1994), Rose (1991) and others are helping service systems to understand the prevalence of trauma histories among persons with mental illness and how many existing policies and practices can be very injurious to service recipients. For those who are survivors of trauma, experiences in the service system are, in effect, re-traumatizing and perpetuate the exact symptoms or problems the services are intended to ameliorate.

Stigma Reduction

There is an increasing recognition of the deep level of stigma against persons with mental illness within the system (Reidy 1994). For many consumers, this stigma is internalized, and contributes to the debilitating process of becoming a “mental patient” (Deegan 1990). Recovery advocates suggest that such external and internal stigma can be reduced through the strategic application of recovery principles. For example, they argue, respect for the strengths of consumer-run services will follow the legitimization implied by making them eligible for Medicaid reimbursement. Respect for persons with mental illness will increase as their expertise is recognized and they become not “patients” or “clients,” but co-workers and equal participants in the policy and service arenas (Mowbray et al. 1997; Solomon et al. 1998).

Finally, the concept of recovery looks beyond the service provider and the mental health system, construing a society that stigmatizes and discriminates against persons with mental illness as one that it is itself in need of recovery. Stigma reduction, conceptualized as an application of recovery to the broader community, involves increasing awareness of the negative stereotypes of persons with psychiatric disabilities, denouncing such images as destructive, and then moving forward through such measures as community education and media campaigns.

Key Questions

The current period of transformation in mental health services is fraught with both dangers and opportunities. The States’ efforts to operationalize and implement recovery reflect both extremes. Some critics view the recent initiatives as a co-optation, an attempt to force the sometimes ineffable magic of recovery into a standardized and measurable model of traditional services. Consumer advocates have expressed concern that the movement to bring a recovery-orientation to mental health policy is little more than a fad, a passing fashion. As state-level policymakers become enamored with recovery, they warn, recovery will become little more than a new label on an old bottle—simply another name for professionally-driven rehabilitation programming. Their message is that without fundamentally reconceptualizing the relationship between individual consumers and the system, we risk promulgating a cosmetic initiative that maintains the dependence of individuals on the system.

The possibilities reside in the strategies that are being used to integrate recovery-oriented principles into service system design. So far, these policies and programs are in good faith, but preliminary efforts in moving toward recovery as a guiding principle for behavioral healthcare. Much remains to be learned about recovery. Among the questions that must be answered:

- How can we deepen our understanding of recovery as an individual process? What stimulates and sustains that process? What hinders or smothers it? What are the best methods for answering such questions?
- Can recovery be measured? Should it be measured? What are the risks of doing so? Of not doing so?
- How can we transfer our knowledge about recovery as an individual process to our policy-making and service planning activities? How do specific policies and services affect individual recovery?
- How will we know we are creating a recovery-oriented system? By what criteria should the system be judged? Should we measure individual gains? Aggregate outcomes? System-level change? Over what period of time?
- How can we balance recovery as an individual, singular process with the system's need for standardization? Can we formulate a generalized concept of recovery and still respect the process as unique?
- For what should we hold the system accountable? Are we willing to trade off some system liability for the increased self-determination and personal responsibility that seem to be the hallmark of recovery?
- What barriers stand in the way of implementing a recovery orientation? What forces sustain the status quo?
- *Should* recovery be the foundational principle of the mental health system?

These questions start with problems of epistemology—how best to study and measure recovery. But they end in problems of politics and values—what is to be our society's approach to helping persons with psychiatric disabilities? For recovery to herald a real change in our assumptions and practices, and to make a difference in the lives of people living with severe and persistent mental illness, it is vital that all of these questions be engaged. How we chose to answer them will shape mental health services in the coming decades.

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ⁱ The phrase “consumer/survivor/ex-patient movement” is, we realize, a simplification. As several authors have pointed out, there are ideological distinctions between people who identify themselves as consumers and those who call themselves survivors or ex-patient. Barbara Everett (1994) writes that “people who call themselves survivors feel that consumers are dupes for believing that the mental health system has any value at all while survivors are tough freedom fighters...consumers believe that there is no shame in working for change from within the mental health system and that, in fact, the survivor brand of loud, rude criticism only delays reform.” (p. 63)

ⁱⁱ That Anthony credits this description of recovery to the writings of consumer/survivors is one example of the interrelatedness of the consumer/survivor/ex-patient and psychiatric rehabilitation movements.

ⁱⁱⁱ The research upon which this paper is based was conducted by the first author during the first six months of 1998. Information was gathered using semi-structured telephone interviews of key informants at states identified as having an interest in recovery. Initially, this identification was made through the visibility of the state in the national recovery movement. As the study continued, however, more informants were identified--in the manner of a snowball sample--through referral. A second source of data was the collection, by both authors, of state-level policy documents. References to specific states are given for the purpose of example only. The aim of the paper is to provide a comprehensive overview of *strategies*, not of the states that are implementing them.