

Chapter 3: A Consumer-Driven, Recovery-Focused, Trauma-Informed Service System

The purpose of this chapter is to illustrate the principles of consumer-directed, recovery-focused, trauma-informed service systems, based upon a synthesis of recent research and current thinking in the field. The concept of “recovery” particularly is one that has a different history and different meaning in the fields of mental health and substance abuse. Rather than attempting to merge the two, we have described each separately below.

A. Principles of Recovery-focused Service Systems

Recovery in the Context of Addiction and Substance Abuse

While the term “recovery” is of course widely used in the addictions field, the concept has a longer history and has traditionally been used in a somewhat different way than the term is currently used in the mental health field. The Alcoholics Anonymous (AA) 12-step self-help program, founded in the late 1930s, introduced the term “recovery” into the lexicon of the alcohol and drug addiction field, using it to refer to the process of attaining and maintaining sobriety. The World Health Organization (WHO) defines “recovery” as “Maintenance of abstinence from alcohol and/or other drug use by any means.” These definitions see recovery as primarily a matter of severing one’s relationship with a particular substance, whether through the support of one’s peers, as in AA, or through medical treatment, professional counseling, or other methods.

White and Kurtz (2005) more expansively define recovery as “the process through which severe alcohol and other drug problems...are resolved in tandem with the development of physical, emotional, ontological (spirituality, life meaning), relational and occupational health.” White and Kurtz are not merely describing the elimination of dependence, they point out that recovery also includes the process of inner healing and growth, and development of life skills that help one cope with life’s stresses without dependence on drugs or alcohol. As Daniel Laguitton (1993) puts it, “It is a recovery of personal integrity, the end of personal fragmentation and of denial. It is a movement towards conditions that are favorable to personal growth. Under this definition, abstinence from alcohol for an alcoholic can be called recovery only if is accompanied by a resumption of personal growth.”

The definitions offered by White and Kurtz and by Laguitton are reflective of a more nuanced understanding of recovery from addiction, and seem to have a good deal in common with the recovery concepts of Deegan (1988, 2004), Ridgway (2004) and other people with psychiatric histories, discussed below. Like these ex-patient researchers, White and Kurtz state that recovery is not a straightforward linear process, but that there are multiple pathways and styles of recovery. If recovery is to be successful, each individual must find the approach or combination of approaches that works for him or her.

Recovery in the Context of Mental Health

In its final report, “Achieving the Promise: Transforming Mental Health Care in

America,” the President’s New Freedom Commission (2003) called for a transformation of the nation’s mental health system that would “involve consumers and families fully in orienting the mental health system toward recovery.” The report noted that currently “consumers and families do not control their care,” and went on to make recommendations for creating a recovery-oriented system that is driven by the self-defined needs of people who use mental health services.

Since the mid-1980s, much has been written about recovery and the environmental factors necessary to promote it, particularly by people with psychiatric histories (see, for instance, Campbell, 1989; Deegan, 1988; Zinman, et. al, 1987; Chamberlin, 1984, Penney, 1998). However, the idea has only recently begun to gain general acceptance in the public mental health field. In the last few years, there has been much discussion (and much confusion) about recovery within the field, but little in the way of concrete action to make the changes necessary to transform the system. This dearth of action may be due, in part, to a general lack of clarity among public mental health officials and clinicians about what is meant by recovery, and about what changes in policy, assumptions, attitudes, funding streams, and service delivery are required to create a system that will facilitate recovery.

What is “recovery?”

What is meant by the term “recovery” in the context of a diagnosis of serious mental illness? In general terms, “recovery” is short-hand for the idea that such a diagnosis need not preclude one from living a satisfying and productive life; that serious mental illness is not an inevitably deteriorating condition with a poor prognosis that results in life-long disability and dependency. It is the idea that most people with psychiatric diagnoses can, in fact, “get better;” that they are capable of moving beyond their illness labels, out of the socially de-valued role of “mental patient,” and can build their own lives as self-directed members of their communities.

The President’s New Freedom Commission (2003) defines recovery as “the process in which people are able to live, work, learn, and participate fully in their communities.” The National Association of State Mental Health Program Directors (NASMHPD/NTAC, 2004) calls recovery the “basic human right to feel better.” According to consumer/researcher Ruth Ralph, “Recovery can be defined as a process of learning to approach each day’s challenges, overcome our disabilities, learn skills, live independently and contribute to society. This process is supported by those who believe in us and give us hope.” Ralph, along with an eight-member Recovery Advisory Group of consumer/survivor leaders (1999), developed a complex model of the recovery process. This model is based on the assumption that recovery is a highly individualized, non-linear process that is strongly affected by internal and external influences (both positive and negative), in which a person moves from despair toward healing, well-being and wholeness. Shery Mead and Mary Ellen Copeland (NASMHPD/NTAC, 2004) refer to “life change and transformation—not returning to a former way of being, but going forward to create a new, exciting, and rewarding life.” Patricia Deegan (2004) writes of “the innate self-righting capacity, or resilience, of people with psychiatric disabilities.” Resilience, a central premise in the conceptualization of recovery, is defined by Priscilla Ridgway (2004) as “the capacity of people faced with adversity to adapt, cope, rebound, withstand, grow, survive and even thrive.”

Is recovery really possible?

Hundreds of personal accounts of madness and recovery have been published by ex-patients over the centuries, the earliest of these in the 14th century (Hornstein, (2002). The anthropologist Gregory Bateson (1974) uncovered and re-printed with commentary the amazingly detailed account of the self-directed recovery of John Perceval, a 19th century Briton who spent many years in asylums. In the U.S., a number of 19th century mental patients privately published their own stories, and in 1909, Clifford Beers, a recovered patient who founded what became the National Mental Health Association, published his story, *A Mind That Found Itself*. The literature of the ex-patients' movement over the last 30 years is heavily focused on personal descriptions of recovery (see, for example, Campbell, 1989; Deegan, 1988 & 2004; Zinman, et. al, 1987; Fisher, 1994; Walsh, 1996, Penney, 2003) .

In addition to first-person accounts, there is significant empirical evidence from a number of longitudinal studies across the globe demonstrating that between one-half and two-thirds of people diagnosed with schizophrenia either significantly improve or completely recover over time. In the seven such longitudinal studies from the 20th century compared by Harding and Zahniser, (1994), the criteria for recovery were: “no significant signs or symptoms of any mental illness, no current medications, working, relating well to family and friends, integrated into the community, and behaving in such a way as to not be able to detect [their] having ever been hospitalized for any kind of psychiatric problems,” a standard much more rigorous than the definitions discussed above. Patricia Deegan points to even earlier studies demonstrating that recovery is not a modern phenomenon. She cites an 1881 study at Worcester State Hospital in Massachusetts that found that 51% of those discharged between 1833-1840 remained well as long as they lived; a follow-up study found that 58% of patients discharged between 1840 and 1893 remained completely recovered (NASMHPD/NTAC, 2004). The evidence shows that recovery rates have remained fairly constant for the last 170 years, despite many changes in treatment philosophy and the introduction of psychiatric medications in the 1950s. It appears that something other than treatment must be involved in recovery.

What impedes and what promotes recovery?

What is known about the factors that create an environment that encourages and supports recovery? There is widespread agreement among practitioners and authors who are actively involved in the recovery field that many common practices of the existing mental health system do not promote recovery, but in fact create impediments to the process. These practices include a lack of consumer choice in treatment, service provider, housing, and the use of medication; the lack of meaningful consumer and family involvement in decision-making, both at the system level and in their own service plans; focusing on people's perceived deficits rather than on their strengths; requiring consumers to fit into rigid program models that do not meet their individual needs; policies and service designs that ignore the fact that most psychiatric patients are trauma survivors; and the use of coercive measures such as restraint and seclusion, inpatient and outpatient commitment, forced medication, and the linkage of housing to treatment adherence (Onken, et. al, 2002; Ralph, 2000; Ralph & Recovery Advisory Group, 1999;

Penney, 1997). Some of these problems are also endemic in the substance abuse field.

Patricia Deegan (NASMHPD/NTAC, 2004) finds that the biggest obstacle to recovery is “the creation of service models, and the organizing of services around models, as opposed to encouraging individualized supports with individual budgets for living in the community.” She notes that “services should be a means to an end—living a full and meaningful life in the community... Recovery is a person-centered phenomenon. You can’t ‘do recovery’ to someone. You can’t ‘do services’ that will force someone to recover. Recovery-based services will always be one small part or one small ingredient for a person with psychiatric disabilities to achieve a meaningful life in the community.”

Bill Anthony (2004) believes that “the vision of recovery is foreign to what has been masquerading as the mental health vision for the last century... If we are serious about the vision of recovery, then the mental health system of the last century—which for the most part was a system characterized by low expectations, control, and no consumer-based vision—must disappear.” Anthony points out that these changes will not happen until leaders of mental health systems adopt the values that underlie a recovery orientation, and ensure that all of the decisions they make about policy, budgeting, human resources, and other matters are fully consistent with recovery values. He argues for a concept he calls “Values-based Practice,” which is grounded in people-first values such as choice, flexibility, consumer preferences and rights protection (Anthony, 2005). Anthony also emphasizes that consumers and family members must be integral to the planning process if a transition to a recovery-oriented system is to occur.

Among the values discussed in the literature as essential to a recovery-promoting environment are self-determination; hope; risk-taking and the freedom to fail; real choice among genuine alternatives; availability of self-help and peer support services; full and genuine partnership between consumers and providers; recognition that each person’s recovery journey is unique; putting people (not program needs) first; enhancing each person’s growth potential; dealing honestly with issues of power and control; and listening to consumers and understanding them in the context of their lives (Farkas, Gagne, Anthony, & Chamberlin, 2005; Deegan, 2004; NASMHPD/NTAC, 2004; Ridgway, 2004; Penney, 1997; Deegan, 1988).

Implementing these recovery values will mean re-thinking most of the current assumptions under which the mental health system operates. Anthony (2004) notes that one way to determine whether a system is moving toward a recovery orientation is to look at its mission and policy statements. “To assist people to improve their functioning so that they are successful and satisfied in the environment of choice” is a recovery-oriented mission statement, he says; “To provide continuous and comprehensive services to mentally ill clients” is not. Creating an environment in which recovery can flourish is primarily a matter of changing assumptions and attitudes, abandoning policies and program structures that create barriers to recovery, and creating a system that has the flexibility to respond effectively to individual wants and needs.

B. Existing Resources/Strengths

Office of Consumer Affairs

In recent years, ODMHSAS has introduced several initiatives designed to promote a recovery-oriented system. Most importantly, the Office of Consumer Affairs was established in 2003. Offices of Consumer Affairs (OCAs) exist in almost 40 state mental health authorities around the country; their purpose is to improve state mental health systems by working to support and expand the consumer/survivor voice within mental health policymaking, planning and practice. OCAs are headed by a self-identified consumer/survivor who serves as part of the senior management team and is a system change agent. Areas of responsibility for the OCA include policy and regulation development, program planning, evaluation and monitoring, training, and developing and promoting recovery-oriented, consumer-driven services.

OCA staff at ODMHSAS prepared a successful CMS Real Choice Systems Change grant, in collaboration with OHCA which TOfund the roll-out of two SAMHSA-identified Evidence-Based Practices: Family Psychoeducation and Illness Management and Recovery. The Real Choice grant also funds a Recovery Support Specialist Coordinator within the OCA, who, along with a grant-funded employee within the Oklahoma Health Care Authority (OHCA), will propose policy changes to establish Medicaid-reimbursable peer services in Oklahoma. The OCA also includes a staff member specializing in co-occurring mental health and substance abuse disorders, funded by Oklahoma's federal Co-Occurring State Incentive Grant (COSIG).

Among the accomplishments of the Office of Consumer Affairs in its first two and a half years of operation was the development of Recovery Support Specialist positions within the mental health system.

Recovery Support Specialists

The introduction in 2004 of Recovery Support Specialists (RSSs) into the service system's staff mix is a promising step toward transforming the system into one that is consumer-centered and recovery-oriented. RSSs are people in recovery trained to provide peer support and advocacy services for consumers in emergency, outpatient or inpatient settings. The RSSs perform a wide range of tasks to assist consumers in regaining control of their lives and recovery processes, and all CMHCs are required to have at least one FTE (Full Time Equivalent) RSS on staff.

Consumers who had Recovery Support Specialists (RSS) in their programs were uniformly pleased with the performance of these staff; those who did not have access to RSSs expressed an interest in working with them. Most program staff and managers were equally supportive; one program manager said "Consumer reactions are positive. One RSS gets consumers involved in conferences and advocacy groups. These positions show consumers that recovery is possible, that they can recover, too." Several providers said that they would like to have more RSSs working in their programs.

Exemplary Programs

It was clear from site visits and focus groups with staff, managers and consumers that some CMHCs and other providers understand and are strongly committed to the values and practices of recovery-oriented services. In such agencies, the leadership modeled these principles, encouraged staff to learn and practice attitudes and skills that are consumer-centered, and valued the role of their Recovery Support Specialists, if they had them. These organizations fully involved consumers in the development of their

treatment plans, and sought their input through other mechanisms: “We have a consumer advisory committee that meets every two weeks and takes up issues that require discussion and problem-solving, such as staff retention, consumer rights, member participation, investment of resources in new activities, and evaluating what we are doing to support recovery,” one program manager said. “We run focus groups each year on our annual plan and budget, and we involve consumers on all our committees,” said another. Consumers in these programs were decidedly more enthusiastic about the services they received than consumers in other programs. While these exemplary programs were not in the majority, their accomplishments can serve as models for other programs.

Role of Persons in Recovery Providing Substance Abuse Services

Unlike the mental health field, the addiction and substance abuse field has a long history of people in recovery working within the service system. While mental health has only started to appreciate the value of the experiential knowledge of people with psychiatric histories, recovering alcoholics’ and addicts’ lived experience has been recognized as a valuable asset in the delivery of substance abuse treatment services for at least the last thirty years. As ODMHSAS moves forward in developing a recovery-oriented service system, it will be important to maintain and enhance the utilization of the lived experience of people in recovery as a key factor in the delivery of substance abuse treatment services.

C. Needs and Existing Barriers

Consumers, advocates, and some program managers and staff pointed out a number of barriers that interfere with efforts to move the system in a recovery-oriented direction. The most frequently identified obstruction was the wide-spread lack of understanding of the nature and extent of change needed to move the system in that direction. “People use the buzzwords, but really don’t know what they mean, or how different things would have to be if the system really adopted recovery values,” an advocate said. “We’re all so trapped in the current system, it’s hard to imagine what a good system would be,” a program manager said, “There are some who just don’t believe that recovery is possible.” Several program managers and staff noted that people in the field are eager to get more education about recovery values, in addition to specific skills training that would help re-orient local agencies toward a recovery model. Several consumers and advocates stated that “There is only one accepted view of ‘recovery’ in Oklahoma. If you are not on meds, you are judged as not being in recovery.” An RSS said, “I was told not to tell other consumers I don’t take medication, because people will then not believe that they should take their meds.”

Another frequently mentioned barrier was what many respondents saw as either indifference or outright hostility to change that would give consumers and families more control over their services. “Some [providers] see recovery as a threat to the system,” one consumer said. “They think us staying sick keeps the system well.” Another person noted, “There will always be someone else in line to fill the slot [at provider agencies], so why do they resist working toward recovery?” At several programs, staff were very clear that they did not support any changes that would lead to more consumer choice or

involvement. Often this was just one or two staff members out of a larger focus group, but in several groups, the entire staff and management expressed these feelings.

Consumers and advocates also stated that consumer involvement in policy and planning at the state-level remains at a token level. People said that if they are invited to the table at all, it is in later stages, after the direction of an initiative had been set. It was also noted that the same handful of consumers and family members are the only ones asked to participate. Several RSSs and advocates stated that there is a need to mentor new consumer leaders at the local level, in order to increase the breadth and depth of consumer involvement in local agencies and at the state level.

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