



MENTAL HEALTH

transformation trends

A Periodic Briefing

In This Issue

Recovery Is Happening	1
State Profile: Ohio	2
Federal Partner Spotlight: Centers for Medicare and Medicaid Services . . .	3
Consensus on Recovery Achieved	4
Self-Direction: Consumer Choice in Action	5

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Recovery Is Happening

Bill Schneider, diagnosed with schizophrenia in 1977, endured many years of ineffective treatment, discrimination, homelessness, and despair. Finally, with the help of a mental health provider who became Bill's partner in recovery, he was able to get case management, Social Security benefits, clothing, food, and housing in an assisted living facility. Bill became independent and learned to advocate for himself. He learned that "Recovery is an individual thing. No one can tell you how to do it—the important thing is to know you can. You have the power and ability to make recovery a reality."

The Substance Abuse and Mental Health Services Administration (SAMHSA) Center for Mental Health Services (CMHS) is committed to creating a mental health system that will maximize opportunities for consumers to participate in their own mental health care. In a recovery-oriented system, all services will be geared toward facilitating individuals' journeys to recovery and full, productive lives in the community. As Nancy Fudge from FloridaSDC, the self-directed care program highlighted in this issue, describes:

The real issue isn't about whether a person needs assistance or not, but that they have a voice...and choice...and access to services based on their individual needs at all levels of care. Every opportunity of choice is a seed that will grow into a healthy, empowered self-directed life.

Recognizing that consumers need a voice and choice in mental health care, we are, for the first time, working to reorient the Nation's entire mental health system toward recovery. The recovery vision rests on the fundamental belief that people with mental illnesses can and should take charge of their own lives.

In 2004, SAMHSA/CMHS committed to explore consumer-driven and consumer-operated approaches to achieving recovery and community integration. Now we *are doing* it. The Mental Health Transformation State Incentive Grant program is helping States make *systemic* changes needed to meet multiple consumer needs and foster recovery. The Statewide Consumer Network Grant program develops and supports State and community consumer leadership. In addition, CMHS provides a wide array of technical assistance, including a toolkit on *Illness Management and Recovery*, a pamphlet for consumers on *Competence Issues in Self-Directed Care*, and *Stepping Stones to Recovery*, a soon-to-be published case manager's manual for assisting adults who are homeless to apply for Social Security disability benefits. Approaches to *defining and measuring* recovery are also being developed.

We encourage you, too, to take on the challenge of transformation to a recovery-oriented system. Do not let uncertainty stop you from starting on the journey. Through your efforts, you can help change the system...one person, one program at a time...until the point when recovery is the expected outcome for all. Together, we can make it happen across America!



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
Center for Mental Health Services
www.samhsa.gov

STATE PROFILE:

OHIO FINDS TRANSFORMATION REQUIRES SHARED LEADERSHIP AND CAPACITY FOR CHANGE

How do you transform a mental health system that is managed through 50 county-based local authorities serving more than 250,000 individuals annually through more than 500 provider agencies? This is the task faced by Ohio, a large, diverse State with many big cities but also extensive rural areas.

Ohio's behavioral health leaders believe that the answer may rest in a commitment to shared leadership and to creating capacities for change at every level.

For 25 years, Ohio has worked to make the processes of care and reform inclusive. Ohio has invested in consumer and family organizations at both the State and local levels. In a decentralized system with empowered consumer and family leadership, having everyone "at the table" was necessary. Having vibrant and strong consumer and family organizations (e.g., NAMI Ohio, Ohio Advocates for Mental Health, Mental Health Associations, Depression and Bipolar Support Alliance, Family Advocates for Children's Mental Health) facilitated change.

The development of Ohio's recovery framework is an example of shared leadership and creating capacities for change at every level. The framework has evolved through several cycles of State-funded, collaboratively evaluated, and consumer-driven recovery demonstration projects. Recovery-oriented programs and practices are now widespread—although scarcely universal. To sustain and promote these efforts, Ohio created the Adult Recovery Network (ARN) in 2003.

ARN provides a framework for both local and statewide leadership on recovery practices. It began its work

with a general statewide meeting for current providers of recovery services in November 2003. At the meeting, participants presented overviews of their various approaches to recovery services. The reports provided a benchmark for the next three years of planned progress. Equal numbers of consumers, family advocates, and provider/administrators were invited to serve on ARN's advisory board to assist in developing strategies for giving Ohio's mental health system a stronger recovery focus.

Now ARN has a Web site, [adult-recoverynetwork.org](http://www.adult-recoverynetwork.org), that describes each of the recovery projects that have been identified. In addition, the Web site offers access to recovery workshops and publications, such as *Building Better Tomorrows: Recovering from Mental Illness*. It publicizes local events and trainings, such as *Celebration Recovery* events that honor organizations, programs, or individuals that embody the concept of recovery. Consumers also may express themselves on the Web site.

Capacity for change also depends on Ohio's strategy to promote the use of evidence-based and best practices through its nine Coordinating Centers of Excellence sponsored by the Ohio Department of Mental Health (see www.mh.state.oh.us/medicaldiv/ccoguide.pdf). Both the recovery and best practices change strategies build the capacity for change on a coordinated, decentralized basis.

Developing leadership capacity at many levels, shared learning and problem solving, and information and measurement approaches (such as Ohio's Consumer Outcomes system at <http://www.mh.state.oh.us/oper/outcomes/outcomes.index.html>) are



tools for transformation in Ohio. Supporting research and promoting relevant research findings are tasks Ohio has done well for many years. (See www.mh.state.oh.us/offices/oper/tbp.html for examples of publications communicating research results to the field in Ohio.)

But the question remains: What else is needed to advance transformation successfully?

As consumer experts have observed, many people can support one individual's recovery. However, individuals themselves do the hard work to make their own progress. Ohio has found that this is true for mental health transformation as well. To achieve transformation, supports and leadership must be provided, but participants must commit to change.

Moreover, both transformation and recovery depend on a dynamic balance of stability and change. Neither is about change alone. Just as recovery is exceedingly difficult for someone without stable housing, providers and local systems cannot transform without a foundation of stable resources and relationships. Ohio's transformation strategies reflect these dynamic tensions. Leaders are providing resources, practical tools, hope, and relationships while structural changes are carried out. These beliefs and strategies are leading to successful mental health system transformation in Ohio.

FEDERAL PARTNER SPOTLIGHT:

Centers for Medicare and Medicaid Services (CMS)

The Centers for Medicare and Medicaid Services (CMS) within the U.S. Department of Health and Human Services have launched several programs and initiatives to facilitate the transformation of our Nation's mental health system.

Real Choice Systems Change Grants

CMS's Real Choice Systems Change Grants program is a key initiative that responds to the Supreme Court's *Olmstead* decision. In FY 2004, the solicitation specifically included Mental Health Systems Transformation grants to promote ways to empower consumers to manage recovery from mental illness. Grantee proposals offered several approaches that use evidence-based practices and focus on person-centered strengths and opportunities for self-direction in recovery. Some proposals included using peer supports to help transition persons into the community and home-based care. Awardees are MA, NH, OR, MN, OK, NC, ME, VA, DE, PA, OH, and MI.

Mental Health in Primary Care

Integrating behavioral health services into primary care has been a major barrier to the creation of a seamless system of health care for all Americans. Currently, the CMS, SAMHSA, and Health Resources and Services Administration (HRSA) Primary Care Workgroup is identifying policies or practices that have impeded integration, such as real or perceived cost containment or quality control difficulties, and also incentives and program models to promote inclusion of behavioral health services in Medicare and Medicaid-funded systems.

Self-Direction Activities

Examples of CMS activities to promote self-direction and consumer

empowerment in Medicare and Medicaid services include the following:

- Assisting States in developing self-direction initiatives for persons with mental illness using Medicaid.
- Promoting demonstration projects that allow Medicaid participants with mental illness to use day treatment or psychosocial rehabilitation funding for self-directed services.
- Encouraging self-directed treatment initiatives under Real Choice Systems Change Grants.
- Working with SAMHSA to promote public and State program understanding of funding mechanisms for self-directed mental health care.

Independence and Employment Initiatives

- **Infrastructure Grants.** Forty-two States and the District of Columbia are participating in the Medicaid Infrastructure Grant (MIG) program. This program, created by the Ticket to Work and Work Incentives Improvement Act of 1999, funds States to build and enhance the infrastructure necessary to support people with disabilities in employment. As part of the 2005 MIG program, CMS awarded additional funds to all States that have MIG grants and a Medicaid buy-in program, which enables individuals to increase their work effort, leave Social Security benefits, and keep their health insurance by buying into the Medicaid program. More than half of the participants in the 32 States with these programs have mental illness diagnoses.
- **Demonstration Programs.** CMS is operating "Demonstration to Maintain Independence and Employment" programs in six States. The purpose of these programs is to test whether the provision of health

care and other support services can forestall or prevent the onset of disability and the need for cash disability assistance. Three of the six States are focusing on individuals with mental illness diagnoses.

Preadmission Screening

The Preadmission Screening and Resident Review (PASRR) regulation helps prevent inappropriate admission to Medicaid nursing facilities of individuals with serious mental illness. CMS is assessing experience under the PASRR regulation, preparing guidance on problem areas, enhancing technical assistance, and establishing outcome measures.

Homeless Initiatives

- To assist the significant number of individuals with mental illness who are chronically homeless, CMS partners with other HHS agencies and the departments of Housing and Urban Development (HUD), Veterans Affairs, and Labor to sponsor policy academies and technical assistance that support State team efforts to develop and implement Action Plans. *Improving Medicaid Access for People Experiencing Chronic Homelessness: Examples* can be accessed at www.cms.hhs.gov/promisingpractices.
- CMS, along with HUD and other Federal partners, created the toolkit *First Step on the Path to Benefits for People Who Are Homeless* to provide information on mainstream services for persons who are homeless, their case managers, and outreach workers. It is available on CD or at <http://aspe.hhs.gov/homeless>.

For more information, contact Peggy Clark at 410-786-5321, or visit www.cms.hhs.gov/Medicaid.

Consensus on Recovery Achieved

The President's New Freedom Commission on Mental Health called for recovery to be the "common, recognized outcome of mental health services." But what does "recovery" mean? Recovery has been written about, researched, and debated for decades. Many individuals, organizations, and States have adopted their own definitions. However, to focus everyone's collective energies on transforming America's mental health systems, a commonly understood concept of recovery is needed.

Last December, SAMHSA and the Interagency Committee on Disability Research (ICDR) held a conference to work out a consensus on defining mental health recovery and to identify the fundamental elements and principles that comprise recovery. A national group of over 110 expert panelists—including consumers,

family members, providers, advocates, local public officials, and eight Federal agencies—were invited to participate.

To guide the deliberations, over 20 contributing authors and presenters prepared a series of technical papers and reports on topics such as recovery across the lifespan, definitions of recovery, recovery in cultural contexts, the intersection of mental health and addictions recovery, and the application of recovery at individual, family and community, provider, organizational, and systems levels. The panelists also received guidance from an earlier meeting in November that focused on recovery and resiliency for children with mental health problems.

The result of the panelists' efforts is a National Consensus Statement on Mental Health Recovery that is scheduled to be released later this

year. This Statement will be a key tool to orienting all stakeholders on the goal of recovery and to assist them with policy formulation, program development, quality improvement, and systems transformation—to achieve the promise of recovery as the "common recognized outcome."

Sneak preview of the Consensus Statement

The expert panelists agreed that recovery is an individual's journey of healing and transformation to live a meaningful life in a community of his or her choice while striving to achieve maximum human potential.

THE FEDERAL PARTNERS

SAMHSA/CMHS greatly appreciates the collaboration, leadership, and support of all our Federal Partners in helping to create and implement transformed mental health care for all Americans.

- Department of Agriculture
- Department of Defense
- Department of Education
- Department of Health and Human Services
- Department of Housing and Urban Development
- Department of Justice
- Department of Labor
- Social Security Administration
- Department of Transportation
- Department of Veterans Affairs

Resource Corner

The Resource Corner identifies printed materials and Web sites that may be helpful in promoting mental health systems transformation. Listing here does not imply endorsement by SAMHSA or any other agency of the U.S. Government. For all funding announcements, see www.samhsa.gov or www.grants.gov.

Technical assistance resources are available for States and localities developing and operating self-directed care programs for people with mental illness. Here are some examples:

Web casts that provide information and training on implementing self-directed care are at www.connectlive/samhsa/events

Free to Choose: Transforming Behavioral Health Care to Self-Direction—for an overview of self-directed care and its application to behavioral health services. To obtain a copy, call (800) 789-2647 or download it from www.mentalhealth.samhsa.gov/publications/publications_browse.asp?ID=4&Sort=Format

National Research and Training Center on Psychiatric Disability at www.psych.uic.edu/UICNRTC/default.htm

Centers for Medicare and Medicaid Services grants, funding, and technical assistance for self-directed care at www.cms.hhs.gov/promisingpractices/selfdir.asp

SELF-DIRECTION: Consumer Choice in Action

What could transform mental health systems more than having consumers and families choose what services and providers they want? Self-directed care calls for a real shift in power as well as a true acceptance and implementation of values and principles critical to consumers and families and their mental health care.

Why consider self-directed care?

What are the benefits of self-directed care and why should public and private providers consider it? Self-directed care offers a truly transformative approach that gives persons with mental illnesses and families of children with serious emotional disturbances the opportunity to choose their providers of care and have greater control over funds spent on these supports.

Too often consumers and families do not control their own paths of recovery. Without availability and the choice of acceptable options for services and supports, people with mental illnesses are less likely to engage in services, and more likely to have poor outcomes.

Placing financial support under the management of consumers and families will enhance their mental health care choices. Having a choice of services and supports with control of funding can encourage and facilitate personal responsibility, create an economic interest in obtaining and sustaining recovery, and promote learning, self-monitoring and accountability. Most important, choice and control can lead to recovery and improved quality of life.

What is self-directed care?

Self-directed care is an approach used for more than a decade by people with developmental and physical disabilities and older adults. Research has shown that it results in higher client satisfaction and an increased number of needs being met. The following five values serve as the foundation for this approach:

- Freedom to live a meaningful life in the community.
- Authority over dollars needed for one's own care and support.
- Support for participants' efforts to make the choices that are best for them.
- Responsibility for managing finances, choosing services, handling the tasks of daily living, and wise use of public funds.
- Confirmation through participation—the opportunity for service recipients to participate in decisionmaking about the delivery system.

Under self-directed care, informed consumers or families with children with serious emotional disturbances, in partnership with support and information brokers or coaches, can do the following:

- Assess their needs.
- Establish an individual plan of care.
- Budget funds to meet their needs.
- Choose how and by whom these needs will be met.
- Monitor the quality of services they receive.

They may use vouchers to pay for services, or they may use financial management services that track and monitor their budget and handle billing. Supports brokerage, which can provide education and assistance with organizing resources, is also a feature of self-directed care.

FloridaSDC

The Florida Self-Directed Care (SDC) program is just one example of how focusing on recovery through choice truly transforms the mental health system.

The Florida Self-Directed Care program is based on:

- the individual's ability to have control and choice in the services deemed necessary to facilitate recovery;
- a community advisory board that is composed of true stakeholders; and
- the safety of the participants as well as the community.

These are the results of a 100-participant study of FloridaSDC:

- In the first 19 months of the program only 16% of participants were hospitalized.
- Participants spent a significantly greater number of days in the community (i.e., not in jails or hospitals) after joining the program compared to the year before.
- Many of the participants engaged in a productive activity such as paid employment (34%), vocational skills training (19%), volunteer activities (16%), post-secondary education (7%), and General Equivalency Diploma classes (3%).
- Only 10 individuals who joined the Florida Self-Directed Care program chose to return to traditional case management services.