Debate

BUILDING BLOCKS FOR REACHING THE SUMMIT OF MENTAL ILLNESS RECOVERY

by
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The Nation's Voice on Mental Illness

In previous articles in *The Rostrum*, we have described the broad chasm between the promises of evidence-based services and supports for people with serious mental illnesses on the one hand and the gaps in the actual availability of these services and supports on the other. To stem the tide of neglect and discrimination toward individuals with serious mental illnesses, we need to close the canyon-like gaps between what we know about treating mental illness and the discriminatory policies that dismiss individuals with such disorders as second-class citizens and abandon them to cruel and unnecessary suffering. What can we offer people who are looking up from a swirling river of neglect and rapids of despair and hopelessness. What would a model system of recovery look like that helps people climb out of an abyss and reach the plateau of recovery and dignity?

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Over millions of years, the Grand Canyon was created by the driving force of the Colorado River and by upheaval in the earth's crust. The layers of the canyon represent a stage in time that helped create the look and colors of the canyon. Sadly, for many people with mental illness, their worlds must be like looking up from the bottom of a wide and deep canyon, with no hope of securing needed care and support. The plan we offer to policymakers and the public, is one that helps people with mental illness climb out of the canyon and reach the stability of the plateau above. This article describes the layers of services and supports that can help consumers and families reach solid ground – and like the Grand Canyon, we believe it is a uniquely American approach to solving the mental illness crisis.

Layer One – Access to Needed Medications

Individuals with serious mental illnesses must have access to medications that have been recognized as effective by the Food and Drug Administration and the National Institute for Mental Health. In the past decade, there has literally been a revolution in the development of new medications for treating schizophrenia and other serious mental illnesses. Known as atypical antipsychotic medications, these medications are both more effective in treating the symptoms of brain disorders such as schizophrenia and bipolar disorder, and have fewer negative side effects. Because of this, most clinical guidelines today recommend newer antipsychotics as the drugs of first choice.

Yet, public and private sector health plans may place restrictions on access to these medications because they cost more than the old medications – without regard to their clinical effectiveness in alleviating the most damaging symptoms of these mental illnesses. Access to the newest and most effective medications is crucial for successful treatment and recovery. These medications serve as the cornerstone of treatment and offer hope for recovery to consumers. Ultimately, denying access to these medications as a cost containment strategy leads to greater costs for consumers and for society as a whole.

Layer Two – Providing Inpatient and Long-Term Care Options

In recent years, inpatient treatment options for people with serious mental illnesses have disappeared in many communities as more and more emphasis has been placed on downsizing and closing hospitals. In some areas, hospital admissions are limited to those individuals who have deteriorated to the point of meeting criteria for involuntary hospitalizations. Hospital beds for voluntary patients are virtually nonexistent. Requiring people seeking inpatient treatment to deteriorate to the point of possible dangerousness to self or others before inpatient treatment can occur is cruel and very poor public policy.

Several states have responded to shortages in inpatient treatment options by placing large numbers of people with serious mental illnesses in nursing homes or unlicensed, substandard "adult care homes." These placements are often no better or even worse than the institutional settings that preceded them.

In 1999, the U.S. Supreme Court, in the case of *Olmstead v. LC* , held that people with mental illness should receive services in the most integrated setting appropriate to their needs(1). In the spirit of this landmark decision, a continuum of residential options and supports must be available that maximize individual potential and recovery, while ensuring that individuals who are most severely disabled by mental illnesses do not "fall through the cracks."

Layer Three – Crisis Intervention Services

Emergency and crisis services should be readily available 24 hours a day, seven days a week, for people with serious mental illnesses who need them. These services should include a crisis phone line (with a toll-free line); a mobile crisis team that will go to any location; face-to-face assessments, access to local inpatient beds; and alternatives to hospitalization such as 24-hour companions, and crisis respite housing.

Additionally, since police officers are frequently called and respond to people with mental illnesses in crisis, these officers should be educated about mental illness, trained to respond effectively to a mental health crisis, and work cooperatively with mobile mental health crisis teams and other community services.

The Memphis Police Crisis Intervention Team (CIT) Model is considered one of the premier programs in the country. It is law-enforcement based, consumer and family driven and cost effective. The goal of the program is to provide a safer intervention for consumers and police officers while redirecting individuals with mental illnesses from arrest and incarceration for nonviolent behaviors directly attributable to their illnesses into appropriate treatment and services(2). Because of the remarkable success of these programs, CIT programs have been replicated in many jurisdictions across the country.

Layer Four – Assertive Community Treatment (ACT) Programs

ACT programs are effective, evidence-based, outreach-oriented service-delivery models for people with serious mental illnesses. Using a 24-hours-a-day, seven-days-a-week , team approach, ACT programs deliver comprehensive community treatment, rehabilitation, and support services to consumers in their homes, at work, and in community settings. Consumers in the ACT programs receive all services from the ACT team, not from loosely linked mental health, substance abuse, housing, and rehabilitation agencies.

Through its multidisciplinary structure, ACT provides an integrated approach offering:

- Direct provision or coordination of all medical care, both psychiatric and general health care
- Help in managing symptoms of the illness
- Immediate crisis response
- Up-to-date, careful use of medications
- Supportive therapy
- Practical on-site support in coping with life's day-to-day demands including: Help in obtaining housing, help with learning how to socialize, job placement, and support, education, and skill-teaching for family members.

Research conclusively demonstrates that comprehensive and aggressive services and supports, such as ACT programs, lead to positive outcomes for people with serious mental illnesses, in terms of higher consumer satisfaction, reduced hospital admissions and reduced involvement with criminal justice systems. Unfortunately these vital services are frequently lacking in many parts of the country.

Currently, 23 states fund ACT programs through their Medicaid programs. The federal government can play an important role by promoting more states to support ACT programs.

Layer Five – Integrating Mental Illness Services with Physical Health Care

The integration of mental illness delivery and care into general health services, particularly at the primary health care level, has many advantages. These include:

· Less stigmatization of consumers and staff, as mental illnesses are seen and managed alongside general health problems;

· Improved screening and treatment, in particular improved detection rates for patients presenting vague somatic complaints which are related to brain disorders;

· Potential for improved treatment of the general health problems of individuals suffering from mental illness, and vice versa; and

· Better treatment of psychiatric aspects of "physical" problems.

For integration to be successful, policymakers need to consider the following:

· All medical and allied health professionals must have the knowledge, skill, and motivation to treat and mange patients suffering from mental disorders;

· Sufficient numbers of physicians must be trained to prescribe psychotropic drugs at primary and secondary levels;

· Effective referral links must be established between primary, secondary and tertiary levels of care; and

· Recording systems must be established to allow for continuous monitoring, evaluation, and updating of integrated services(3).

Layer Six – Integrated Services for Dual Diagnosis

The prevalence of people suffering from co-occurring mental illnesses and addictive disorders is very high, particularly among children and adults at greatest risk. The research is clear that mental health and substance abuse treatment and services must be blended to effectively treat this population. Integrated treatment means mental illness and addictive disorders services and interventions are delivered simultaneously at the same treatment site, ideally with cross-trained staff(4).

Programs providing integrated mental health and substance abuse treatment are in woefully short supply throughout the country. Many programs serving people with substance abuse disorders are not prepared or willing to treat people with co-occurring mental illnesses, and many programs serving people with mental illnesses are not prepared or willing to treat people with co-occurring substance abuse disorders.

At the federal level, a major priority must be the removal of barriers and the creation of incentives within the federal mental health and substance abuse block grants to integrate services for people with co-occurring disorders. Accomplishing this would be a significant step in the right direction. Service providers on both the mental health and substance abuse sides must be required to develop plans for integrating mental health and substance abuse treatment for people with co-occurring disorders to receive federal mental health or substance abuse block grant funds.

Layer Seven – Family Psycho-education and Support

Research demonstrates that family psycho-education and support services should be a part of a continuum of care for consumers. Family psycho-education includes teaching coping strategies and problem-solving skills to families (and friends) of people with mental illnesses to help them deal more effectively with their ill relative. Family psycho-education reduces distress, confusion, and anxieties within the family, and can often help the patient recover. However, family psycho-education is rarely offered in clinical settings and there are limited incentives to do so.

To fill this void, NAMI offers family education through the Family-to-Family Education Program, (a model that has proven effective at improving the experience of families of persons with serious mental illness). Research has shown that this course provides knowledge to families and empowers them to cope with their ill family member and the mental health system in a positive manner, and has lasting positive effects on the entire family.

Layer Eight – Peer Provided Services and Supports for Consumers

The term "consumer" is a misnomer when applied to people with mental illnesses. Being a consumer connotes choice, namely the ability to select from an array of services and supports that work best for the

particular individual. The unfortunate reality is that most health systems are not structured this way at all. Consumers generally have little choice and little role in selecting service providers or helping to shape the design and operation of service delivery systems. Sometimes consumers and their families learn that services do not exist at all.

Research demonstrates that consumers who participate in self-help programs achieve better outcomes in terms of reporting fewer symptoms and fewer hospitalizations. Peer education and support groups, such as NAMI's In our Own Voice and Peer to Peer are effective tools for education and empowering consumers to take more active roles in making fundamental decisions about their own treatment and in helping to design systems of care.

Layer Nine – Supported Employment Services and Vocational Rehabilitation

Vocational rehabilitation for people with serious mental illness was not an issue prior to deinstitutionalization. People with mental illnesses spent much of their lives on back wards in state hospitals or in back rooms at home, and the concept or possibility of rehabilitation was never considered. It was not until antipsychotic medications became available to control the symptoms of these illnesses, and patients were emptied out of hospitals, that it became apparent that many people with even very serious mental illnesses can learn work and skills and seek and retain jobs. Unfortunately, people with serious mental illnesses face numerous barriers to employment, and the unemployment rate for people with serious mental illness is nearly 85 percent, higher than for any other disability group.

Work is exceedingly important to many people in our culture and confers identity, status, and social structure as well as income; in the words of one rehabilitation expert, it is work that transforms patients into people. It is therefore critically important that opportunities and supports be available for people with serious mental illnesses who want to work.

Some individuals with serious mental illnesses require supportive services to help make the transition to work. A number of models have emerged with proven success to help these individuals obtain and maintain employment. For example, a highly regarded program called the Individual Placement and Support (IPS) program has been created which features an IPS employment specialist on a mental health treatment team. The employment specialist collaborates with clinicians to make sure that employment is part of the treatment plan. Then the specialist conducts evaluations, job searches and provides on-going support while the employee is on the job. This program has achieved high levels of success in helping individuals find and stay in jobs(5).

Layer Ten – Affordable Housing and Supports

Access to decent, safe, and affordable housing remains a tremendous challenge for adults with severe mental illnesses. Unfortunately, in virtually every part of the United States people with severe mental illnesses struggle to find good-quality housing they can afford. Many people with the most severe and disabling mental illnesses also need access to appropriate services and supports so that they can successfully live in community-based housing, which promotes their independence and dignity.

Today, only a small fraction of seriously mentally ill individuals have housing conditions that meet minimum acceptable standards. Unfortunately, neither Congress nor the U.S. Department of Housing and Urban Development (HUD) have done enough to increase the availability do little to alleviate this struggle to access community-based housing and supports. Moreover, recent Congressional enactments and administrative decisions by HUD and state and local housing agencies have exacerbated shortages in the availability of appropriate subsidized housing units available to people with severe mental illnesses and other disabilities. Without stable housing linked with services, too many adults with severe mental illnesses will likely end up homeless or remain unnecessarily in inappropriate settings (e.g., homeless shelters and local jails and prisons).

Layer Eleven – Jail Diversion Programs

There are today far more people with serious mental illnesses incarcerated in jails and prisons than receiving treatment in psychiatric hospitals. Most of these individuals people had not committed major crimes, but either had been charged with misdemeanors or minor felonies directly related to the symptoms of their untreated mental illnesses. And, this problem is growing worse each year.

A number of approaches have emerged for diverting these individuals from incarceration (which frequently leads to a worsening of psychiatric symptoms) into treatment, which is both more humane and the best way to reduce the risk of further criminal justice involvement. One example of such an approach are specialty "mental health courts" which have emerged in many communities. These Courts assume jurisdiction of cases involving individuals with severe mental illnesses charged with misdemeanors or nonviolent felonies, with the goal of facilitating treatment instead of incarceration.

Strategies for reducing the "criminalization" of persons with mental illnesses should also focus on improving treatment for individuals while incarcerated as well as ensuring that individuals with serious mental illnesses are linked with appropriate services and supports when they are discharged from jails or prisons.

Layer Twelve – Treating Serious Mental Illness as Chronic Illness Management

The major layers address several services and supports needed to enable persons with serious mental illness to reach their potential. But there is another emerging need that is a challenge and an opportunity for people with serious disorders – chronic illness management. Yes, there are programs we have highlighted like Peer-to-Peer that help people cope with their conditions. The next level that patients can aspire to, with the hope of better information systems and guidelines, is to truly "own" their health conditions and have the confidence and skills to make decisions and changes that lead to better outcomes. Supportive health care organizations and clinicians and supports are a critical part of ongoing and systematic chronic illness management. But working with people with serious mental illness, caregivers can emphasize the crucial role that patients play in setting goals, establishing action plans, identifying barriers to effective self-management, and problem-solving to overcome barriers.

Children's Services and Supports – Going for the Rim

The aforementioned program of services and supports that has been described in this section apply primarily to adults with serious mental illnesses. But while adults are trying to climb out of the canyon on one side of the rim, it is equally important to establish services and supports to enable to children and adolescents with mental illness and emotional disorders to thrive and reach to reach their rim of potential. We know that for many children, their mental illnesses go undetected and thus, untreated. Moreover, the various systems that impact on the lives of children with mental illnesses frequently fail to collaborate or coordinate effectively with one another. In fact, they often work at cross-purposes.

Certainly, more research is needed – research focused on mental illnesses in children. The research funding for these illnesses should directly correlate to the disease burden and the high prevalence rates of mental illnesses in children and adolescents. At the same time, progress has been made in identifying services that work in helping to minimize the negative impact of childhood mental illnesses and helping children who suffer from them maximize their potentials. But, as with adult mental health services, a significant gap exists between knowledge and practice in the children's mental health area.

Efforts must be undertaken at the federal level to bridge the gap between research and practice by disseminating information and promoting effective communication and appropriate sensitivity between and among healthcare and mental health providers, researchers, youth and families. We know that too often children and adolescents are not getting the best evidence-based treatment available because of the information gap. These evidence-based practices include:

· **Early identification and interventions:** There is emerging scientific evidence that early treatment interventions significantly improve the long-term outcomes for children and adolescents with mental illnesses. Early assessment and identification should exist across all of the systems designed to serve children and their families, including but not limited to primary health care, schools, community centers, child welfare, juvenile justice, substance use treatment systems and others. There must be a coordinated effort to break down the barriers to appropriate identification and recognition of children with mental health needs and the factors that interfere with access to appropriate treatments and services. Research increasingly is showing that the failure to intervene and provide early treatment for many mental illnesses accelerates the course of the illnesses and may actually result in increased damage to the functioning of the brain.

· **Multisystemic Therapy (MST)** Multisystemic therapy (MST) is a clinical intervention model that was developed in the late 1970s and has several key features. First, the approach uses an existing knowledge base on the causes of serious clinical problems. What MST does is address the known determinant problems and addresses the whole environment of the youth in considering interventions.

The MST approach provides services where problems exist – in children's homes, schools, and neighborhoods. Services are provided by masters level clinicians that have very low case loads so that they can provide the intensity of services needed by the youth and family. The approach integrates the best of existing evidence-based treatments for youth with mental illnesses — including cognitive therapies, behavioral therapies, family therapies and psychopharmacological treatment. In the MST model, caregivers are viewed as the key to long-term positive outcomes. Clinicians are in and out of youths' lives, but caregivers are there for the long haul. What makes MST different is that the bulk of the resources are dedicated to building the capacity of the caregiver to be the positive change agent for the youth. The MST approach requires a high level of provider accountability for engaging families and getting positive outcomes. It also involves a continual reassessment of whether the outcomes are being achieved, and if not, identifies the barriers.

· **Therapeutic Foster Care -** Therapeutic Foster Care (TFC) is an emerging practice of interest to advocates. TFC is a family-based alternative to residential, institutional and group home care for children and adolescents with serious mental illnesses. The TFC model involves placing youth in private homes with two trained and supervised foster parents for a defined period. The outcomes data for therapeutic foster care indicate that the program is a promising intervention for youth at risk of being placed outside of their home.

· **Wrap Around Programs -** Wrap Around programs, best exemplified by the Wraparound Milwaukee initiative, provide a coordinated system of care through a single public agency that coordinates a crisis team, provider network, family advocacy, and access to 80 different services. The children served by the program are under court order in the child welfare or juvenile justice system (6).

Children offer hope for the future. Children and adolescents with mental illnesses deserve to experience the typical accomplishments of childhood and have the right to thrive in nurturing environments. Mental illnesses, like all childhood illnesses, should be detected early and children should receive appropriate treatment and services targeted to their specific needs. Without proper attention and a real commitment to change at the federal, state and local levels — the tragedies that result from unidentified and untreated mental illnesses in children and adolescents will continue.

Granites of Support – Buttressing the Recovery Plateau through Mental Illness "System" Pillars

Once a person has the ability to access the needed services and supports they have reached one plateau. However, to continue the journey to recovery there needs to exist systems, "granites of support", so that reaching the summit of recovery is not an endpoint – but lasts throughout the life span.

Conclusion

We have the knowledge and tools to help people recover from mental illness. What we lack is the will and resources to use them.

We must invest now in America's future by creating comprehensive, efficient systems for treatment and support of people with mental illness; system that affirms individual dignity and freedom.

The Grand Canyon is a unique American landmark. Let's work together to create a truly unique and innovative delivery system that in its own right, would be a landmark in compassion and caring for people with serious mental illnesses and that all citizens will embrace and marvel at.

Notes

1. Olmstead v. L.C., 119 S. Ct. 2176 (1999).
2. Dupont, R, *Law Enforcement Crisis Intervention for Individuals with Mental Illness: The Memphis CIT Model,* University of Tennessee Department of Psychiatry, 1998.
3. The World Health Report 2001, *Mental Health: New Understanding, New Hope,* 2001.
4. Department of Health and Human Services, *Report to Congress on the Prevention and Treatment of Co-Occurring Substance Abuse Disorders and Mental Disorders*, November 2002.
5. New Freedom Commission on Mental Health, *Interim Report to the President,* October, 2002..
6. New Freedom Commission on Mental Health, *Interim Report,* Id.

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