

# MENTAL HEALTH POLICY IN THE UNITED STATES

## THE COMMUNITY SUPPORT PROGRAM AND BEYOND

By

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Abstract: This lecture provides a brief historical overview of the effort to correct the flaws of deinstitutionalization by instituting the Community Support Program. It covers the key elements of community support: supportive housing, psychiatric rehabilitation, inpatient and outpatient treatment, crisis services, case management, and the use of Medicaid as the primary source of funding for community-based services for adults with long-term psychiatric disabilities. It also provides an overview of major changes to CSP over the past 40 years.

By the mid-1970's it was clear that deinstitutionalization had been a disaster for many people with serious and persistent mental illness and that major changes were needed in mental health policy. Some advocates, notably family members of people with serious mental illness and the unions representing state hospital workers, argued that deinstitutionalization should be undone and that state hospitals should again become the primary resource for people with serious and persistent mental illness. Most other advocates supported improving community mental health systems instead.

In part for clinical and ideological reasons and in part because a return to institution-based policy would have been exceedingly costly and a great financial burden on the states, community-based policy prevailed. And from the late 1970's until today, a variety of efforts have been made to correct the flaws of deinstitutionalization by providing a **comprehensive range of community support and treatment services** and by devising **systems of care** to link them.

This shift from deinstitutionalization to community support was called "The Community Support Program" (CSP). It was put forth by the National Institute of Mental Health (NIMH) in 1977 and was adopted by the states beginning in about 1978, prior to and independently from the Mental Health Systems Act, which was enacted at the end of the Carter administration in order to put CSP into Federal law.\* Despite the repeal of the Act at the beginning of the Reagan administration, the major themes of CSP were

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\* The Act was largely inspired by the First Lady Rosalind Carter's personal interest in mental health policy,

largely implemented through the efforts of NIMH to pressure and modestly help the states to develop community support systems.

### **The CSP Model**<sup>1</sup>

The CSP model was built from a fundamental insight that state psychiatric hospitals were total institutions that provided a range of supports for people with serious mental illness who need help to survive. This included a place to live, food, clothing, social opportunities, psychiatric treatment, rehabilitation, and medical treatment.

The question that had been inadequately answered by deinstitutionalization was how to provide and organize services and supports in the community so that people with serious and persistent mental illness who were no longer in hospitals had access to the same range of support and treatment services they had in the hospital.

Community mental health centers (CMHCs) fell far short of providing the needed supports not only because so few of them were built but also because so many of them focused on people with neurotic conditions rather than serious and persistent mental illnesses. They also fell short in fundamental concept. They were originally required to provide five essential services—inpatient, outpatient, partial hospitalization, crisis services, and community education. All of these are important services, of course, but they do not address several critical needs.

Most importantly, the required services did not include **safe, stable housing**—clearly a precondition for having a decent life in the community. The required services also did not recognize the importance of **social welfare benefits** and **services focused on reducing disability and increasing quality of life** (“psychiatric rehabilitation”). In general, the requirements for community services under the Community Mental Health Centers Act, focused on treatment and seemed oblivious to the fact that **it takes more than treatment to help people with psychiatric disabilities to have stable, satisfying lives in the community.**

Deinstitutionalization also did not address the critical question of how to coordinate the full range of services. Yes, **continuity of care** from the hospital to the community was a theoretical requirement of deinstitutionalization. But that **is difficult to achieve even when services are all under the control of a single organization; when dispersed among different providers for a broad range of support and treatment services, it becomes almost impossible.**

The Community Support Program attempted to address these failures of deinstitutionalization with a model that included housing, social welfare

benefits, rehabilitation, psychiatric treatment, crisis intervention, and medical treatment,\* as well as case management, which was devised (1) to facilitate access to services and supports, (2) to encourage the use of available services, (3) to intervene in times of heightened need or crisis, and (4) to coordinate care among a diverse array of providers who rarely had contact with one another—except on paper.\*\*

## **The Evolution of CSP**

America's mental health system is still largely defined by the concepts that were the basis of the Community Support Program. Over the past forty years, states have continued (1) to reduce the number and size of state hospitals; (2) to moderately increase the number of short-term psychiatric beds in local, general, and specialty psychiatric hospitals; (3) to significantly increase outpatient psychiatric services, especially clinics; (4) to develop and expand special housing for people with serious, long-term mental illness; (5) to expand psychiatric rehabilitation services; (6) to use Social Security Disability Insurance (SSDI) and State Supplemental Income (SSI) to provide income supports; and (7) to use various forms of case management to avert fragmentation of care.

As a result, life is better for a great many people with long-term psychiatric disabilities—but not for everyone. CSP has, unfortunately, proved inadequate, for example, for those who have experienced transinstitutionalization to nursing and adult homes or to jails and prisons; those who are homeless; those caught up in the criminal justice system; and those who have avoided mental health services that they experience as unhelpful, intrusive, or even abusive.

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\* Despite the inclusion of medical services in the CSP model, mental health policy makers did little to address the physical health needs of people with serious and persistent mental illness. Physical health care was not part of the responsibility of state departments of mental health; that was the job of health departments. Community mental health providers, with a few exceptions, did not address physical health because they were paid to provide mental health services and because attention to physical health was generally not included in their licensing or accrediting requirements.

Failure to fund mental health providers for physical health care or to provide financial incentives for physical health care providers to give special attention to people with serious and persistent mental illness would prove to have horrendous consequences in the long run. People with serious and persistent mental illness die 10-25 years younger than the general population. The lack of decent medical treatment is one of the reasons they die prematurely.

\*\* For many years providers have been required to exchange letters of agreement indicating that they will serve each other's clients and collaborate regarding their care. This is subject to audit by licensing and accrediting bodies; but in my time, and perhaps now too, auditors only checked for recent letters; they did not check to be sure there was actual collaboration. This failure contributed to what came to be called "fragmentation" and "falling between the cracks".

Many changes have been undertaken to overcome inadequacies of CSP. Several of the most important follow.

### **New Housing Models**

The first housing programs for people with serious mental illness were designed to ease the transition from living in a hospital to living independently in the community. It was believed that it would be helpful for people leaving hospitals to move from more to less supervised settings—from “quarterway” houses to “halfway” houses to scatter site apartments to independence.

Soon it became clear that the transitional housing model had many problems. Most importantly, it erroneously assumed a straight line of recovery rather than the more common pattern for people with serious and persistent mental illness of recurrent acute episodes for which intensive, protective treatment, often in a hospital, was generally believed to be necessary. Although patients discharged to community residences were often far better off than those discharged directly to the community, many ended up in the so-called “revolving door” from hospitalization to discharge to recurrent acute episodes to rehospitalization, and so forth. Indeed, because the transitional housing model ignored the emotional difficulty of moving from place to place, (whether or not one has a serious mental illness), it may have contributed to recurrent acute episodes.

Residential staff were often more aware than policy makers of how difficult it was to make the transition from living in a residential setting with supervision and support to living independently. And they often did not perceive their residents as “ready to” live on their own. As a result, residents did not move on at the rate anticipated by public officials, contributing to substantial backlogs even as more units were developed.

In addition, the development of new housing proved exceedingly difficult. Most communities fear and resist special housing for people with mental disabilities “in their backyards”. The politics of community resistance vastly limited the number of stand-alone community residences that could be developed.

Over time, it became apparent that community residences just did not work for many people with serious mental illness who needed help to get safe and stable housing. Residences, which in many ways resembled college dormitories had shared rooms, weekly community meetings, assigned chores, etc., They had little appeal for people who saw themselves as grown-ups or who valued privacy or just wanted to live on their own.

Recognition of these facts contributed to a **shift from transitional, supervised housing to “supported” and “supportive” housing**. The goal became to provide **permanent** homes, some of them in large congregate living facilities with onsite support staff and some in apartments dispersed in the community, preferably in “mixed-use” housing, i.e., buildings that are not entirely filled with people with mental illness. For those living in scatter-site settings, supportive services were provided in residents’ homes to help them to lead personally satisfying lives and especially to avoid re-hospitalization. Very importantly, people who live in supported or supportive housing have the right to return home after hospitalization when it cannot be avoided.

Supportive housing is particularly useful for people with serious mental illness who otherwise would be homeless, a population that exploded in the early 1980s due to loss of low-income housing stock and increasingly restrictive eligibility for SSDI. So, much advocacy for ending homelessness focused on the development of more and more supportive housing. But it also focused on increasing the supply of low income housing and getting access to such housing for homeless people with psychiatric disabilities.

As the struggle to provide safe, stable housing continued, some state mental health commissioners—such as Richard Surles in NYS—argued that providing housing should not be the responsibility of the mental health system. They believed that the right to housing should be affirmed and defended so that people with serious mental illness could have access to housing just like anyone else.

But despite some support for this view as a matter of ideology, it was generally clear that people with serious mental illness fared poorly in the competition for low income housing despite their “rights” under The Fair Housing and The Americans with Disabilities Acts, both of which prohibit discrimination against people with disabilities.

When housing for people with serious mental illness was first developed, it was generally believed that people had to be “ready” for it. That meant that they were able to participate cooperatively in the life of a residence, live peacefully with a roommate, attend a program, work, or go to school outside the residence during the day, and avoid drugs and alcohol and other high-risk behaviors. Some residences would not admit people with serious mental illness with histories of substance abuse unless they had been abstinent for six months while living outside a hospital—a rare achievement. In New York, the Office of Mental Health (OMH) leaned on the agencies that it funded to take potentially difficult residents, and they favored agencies that had less restrictive admission policies to be the recipients of funding for new housing. In addition, OMH created “state

operated community residences” on the grounds of state hospitals for people with histories of co-occurring substance abuse so as to be able to demonstrate that some patients leaving state hospitals who did not appear “ready” for a community residence actually were.

The difficulty of placing some people being discharged from state hospitals into supportive housing led to a very important change—the development of the **Housing First** model.<sup>2</sup> This model rejects the concept of readiness. It is based on the realization that **stable housing is the single most important need for people with serious mental illness**. Apartments are provided for people without regard to “readiness”, particularly without regard to substance use. Rather than insisting on abstinence, Housing First programs take a harm reduction approach and accept recreational use of alcohol and drugs. When residents are at risk of uncontrolled psychosis or dangerous substance use, case managers are available to visit them in their homes and help them deal with personal crises as well as to connect them to useful services. This program has been the subject of much research and has proved to be remarkably successful.

Currently, there is a mixed strategy to make housing available to people with psychiatric disabilities, including (1) assertion of rights to generic, low income housing, (2) subsidies (such as Section 8) to make rent affordable, (3) the development of permanent housing for people with serious mental illness and other special populations such as those who are homeless, are HIV+, etc., (4) growing use of the housing first model, and (5) continued support of transitional housing.

Very importantly, families continue to be major providers of housing for their offspring and siblings with serious mental illness. Providing support for the families is often noted as a major need, but the provision of family support services remains quite limited.

### **Psychiatric Rehabilitation**

Like housing programs, psychiatric rehabilitation has undergone substantial changes since the beginning of the community support program. At that time there were three major forms of psychiatric rehabilitation—vocational training and job placement, sheltered workshops, and clubhouse programs with transitional employment. Training and sheltered work models are now largely gone. Clubhouse programs have continued to thrive, and a variety of new models have emerged.

Because early forms of psychiatric rehabilitation were modeled on physical rehabilitation, they tended to focus on recovering or developing skills,

particularly those needed to hold a job and to live independently in the community. This included skills such as shopping, cooking, housecleaning, and personal hygiene. Early rehabilitation programs also provided social opportunities for people at risk of isolation.

As it became clear that skill-based psychiatric rehabilitation was of limited value, a form of rehabilitation emerged that was highly individualized. Psychiatric rehabilitation as conceptualized by the Boston University Center for Psychiatric Rehabilitation emphasized individualized rehabilitation plans based on personal goals and interests. Most importantly, it was based on a concept of "recovery" that insisted that people with ongoing, serious mental illness could lead lives that they found personally satisfying and meaningful.<sup>3</sup>

Another model that emerged over time is "employment first".<sup>4</sup> Like housing first, this model rejects the need for "readiness" prior to working. It focuses on placing people in jobs that they can do now if they have some supports and later developing additional skills that they need to achieve personal goals.

Over the past 30 years or so, there have been disputes about the value of clubhouse programs in comparison to more individualized rehabilitation. Clubhouses provide (1) lifetime membership, (2) volunteer work opportunities that help prepare members for transitional, competitive employment and give members a valued and meaningful role in the clubhouse, and (3) social opportunities and a safe, pleasant place to be for people who are not ready or interested in work. Many clubhouses also provide housing for their members.

Criticisms of clubhouses focus on (1) their acceptance of lifetime participation rather than enforcing an expectation that people move on over time and (2) their use a transitional employment model instead of employment first.

Nevertheless, clubhouses have thrived because they are well-liked by, and provide stability for, people with long-term psychiatric disabilities.

Paying for psychiatric rehabilitation has been a problem because for the most part it has not been covered by Medicaid. Increasingly state Medicaid programs have found ways to use the "rehabilitation option" in the Federal Medicaid law. Nevertheless, rehabilitation gets a very small portion of Medicaid and other funds for mental health services, which are targeted to "treatment" services.

## **Outpatient Services**

The Community Mental Health Centers Act called for two forms of outpatient services—clinics and partial hospitalization.

Clinics are places where people with mental health issues can get verbal treatment (psychotherapy), individually or in groups, and medication therapy. The general expectation is that people will come to these places rather than receiving services at home or elsewhere in the community. The usual process is for people to get an assessment prior to beginning treatment and then get verbal therapy once a week, or less, and medication management monthly or less.

Clinics have been criticized for long waiting lists that delay the beginning of treatment, for not providing “off-site” services, for not providing services at times that are possible for working people and children in school, for being located in neighborhoods that can be difficult for some people to reach, for not providing crisis services outside of regular office hours, for the traditional nature of the services they provide, and especially for generally failing to provide integrated treatment for co-occurring disorders. They also have been criticized for not meeting the needs of people with serious and persistent mental illnesses, who frequently do not benefit from psychotherapy.

Despite these criticisms, clinics have remained the most common form of outpatient program, in part because most practitioners want to be psychotherapists and in part because they draw enough patients/clients to fill their capacity.

In recent years a new model has emerged on a demonstration basis. Certified community behavioral health clinics<sup>5</sup> rectify some of the failures of traditional clinics by providing treatment for both mental and substance use disorders, by being open beyond traditional office hours, and by being responsive to crisis among their clients even outside of regular office hours.

Day Treatment: Although partial hospitalization originally included night hospitalization as well as day programs, night hospitalization quickly disappeared (unfortunately in my view) and partial hospitalization came to mean day treatment. These are programs that offer a “full day” (usually 5-6 hours) of therapeutic activities for people with serious and disabling mental disorders, some of whom are back to normal within a year or less and some of whom stay in treatment for long periods of time. Realization that some people can be in and out quickly, while others need long-term treatment, led to differentiation of two sorts of day treatment programs. Short-term programs mostly continued to be called “partial hospitalization”

while long-term programs were renamed. In New York State, for example, they were called “continuing day treatment programs”.

Day treatment for people with serious and persistent mental illness has been criticized for accepting mere maintenance (i.e., community tenure) as a treatment goal rather than working on functional improvement and recovery. Payers, especially Medicaid, became concerned that providers had an incentive to have patients/clients come to program every day and to stay all day rather than to help them develop satisfying and productive lives in the community. This has led to efforts to change payment from a fee for a day to hourly fees and also to replace day programs with more individualized forms of rehabilitation. In New York State this included the development of Individualized Psychiatric Rehabilitative Treatment (IPRTs) and Personal Recovery Oriented Services (PROS).

Financing partial hospitalization/day treatment has always been difficult. Payers generally prefer to pay for less costly clinic visits unless it is clear that day treatment is a real alternative to inpatient treatment.

### **Crisis Services**

Before and after deinstitutionalization, the hospital-based emergency room has been the primary place to provide treatment for people experiencing a psychiatric crisis. It is, of course, convenient to have a single point of crisis response for a community where both physical and behavioral needs can be addressed. But there are significant problems. First, emergency rooms, especially in urban areas, are often overcrowded and unpleasant, not at all the kind of environment to help a person in psychiatric distress to calm down. Second, many emergency rooms, especially in suburban and rural areas, do not have psychiatric staff immediately available. Often psychiatrists—if there are any—have to be called in from the community while patients are managed by health care staff who have little to no training in dealing with people in acute psychiatric distress. Third, while waiting, people who are already agitated and frightened may be watched by a guard with no training regarding psychiatric crises and also may be handcuffed or otherwise restrained, a very disturbing experience. Fourth, personnel in the emergency room frequently are unfamiliar with community resources and as a result either discharge people without follow up services or send them for unnecessary inpatient treatment. Finally, many people in emotional distress could be helped in their homes if there were a mobile crisis team that can get to them quickly, thus avoiding the very unpleasant experience of the emergency room and admission to inpatient treatment.

To respond to these problems, special psychiatric crisis services have been developed in some communities. These can include: mobile psychiatric teams, specially trained police psychiatric teams, trained staff in emergency

rooms, separate sections in emergency rooms for people in psychiatric crisis, short-stay beds that do not require a formal hospital admission for people who need a bit of time to “stabilize”, linkages to community-based services, etc. In some communities, outpatient providers have been required to develop the capacity to respond to their patients who experience a crisis when the program is closed rather than merely having a message to call 911. In addition, some people getting treatment in the community have case managers who are expected to be available in times of crisis.

Communities that have comprehensive psychiatric emergency services are generally better able to respond to psychiatric crises than communities that rely on the local, generic emergency room. But providing humane, competent crisis intervention remains difficult. Mobile crisis teams generally are not available 24 hours a day 7 days a week. In some cases, it can take days for them to make a home visit. Training for police and the development of crisis intervention teams has been limited, although there is now a national effort to improve this. Providing competent psychiatric intervention without long waits in emergency rooms that are not themselves agitating and frightening has been a largely elusive ideal. Linkages between emergency rooms and community providers are often non-existent except for formal letters of agreement. Outpatient providers still refer to 911 for off hours or off-site interventions.

As of July, 2022 a national psychiatric crisis number—988—has been put in place. Over time this will be combined with considerable expansion of crisis intervention teams that rely on mental health professionals rather than the police whenever possible. But as I write this, this transformation is just beginning and is having the struggles that new programs usually have. So, dealing with psychiatric crises humanely and effectively remains one of the greatest challenges for the mental health system.

### **Inpatient Services**

Deinstitutionalization has resulted in continuing reduction of state hospital beds, which have declined over 90%. To a very limited extent they have been replaced by psychiatric units in general hospitals. These facilities generally provide short stays, often less than a week and almost entirely less than a month. Their goal is to stabilize patients and to help them connect with resources in the community.

This approach has been subject to much criticism by advocates who believe that the reduction of long-stay hospital beds has led to homelessness, incarceration in jails and prisons, and inappropriate placement in nursing homes. These advocates also call for the increased use of involuntary inpatient and outpatient commitment.

Other advocates argue that what is needed are not more long-term hospital beds but more housing in the community with strong community supports. They also argue for criminal justice reform so as to avoid unjust incarceration of people with serious mental illnesses.

The dispute between these two groups of advocates continues unabated and, in my opinion, fosters ineffective advocacy by a mental health community divided against itself.

There is, of course, a real question of how many hospital beds are needed. Unfortunately, there is no needs methodology that can give a reliable answer to this question if only because the “need” for inpatient treatment often reflects an absence of community alternatives rather than an inherent need for hospitalization.

### **Hard-To-Serve Populations**

Although many people with serious and persistent mental illness willingly use traditional inpatient, outpatient, and rehabilitation services, a significant number do not. Some are simply too disorganized mentally to keep appointments at clinics or to follow a schedule of day treatment. But others deny their need for help or reject the help that is offered. This includes people who have experienced abuse in mental health programs, especially state hospitals. It also includes younger, more active, independent, and obstreperous people who have not been institutionalized for long periods of time, if at all, and who do not fit in to traditional treatment models.

In addition, there are people whom mental health providers are reluctant to serve. This includes people who are “non-compliant” and difficult to cope with. It also includes people who are addicted to alcohol or illegal substances such as cocaine or heroin, people who have committed serious crimes, or people who have histories of violence.

Over the years, various efforts have been made to engage these “hard-to-serve” populations in treatment and/or rehabilitation. For example, as I noted in my comments about housing, government has pressured providers to serve people they find difficult by tying contracts to specific populations. Some providers have thrived by taking on the challenges willingly; others have had contentious confrontations with their funders.

There have also been significant efforts to create programs that fit the people who might use them rather than to force people to fit into programs that really don’t work for them. Joe Rogers, a former homeless mentally ill person who became Director of the MHA in Philadelphia, used

to point out that McDonald's does not demand compliance from "Big Mac resistant" customers; they create products customers want to buy. Similarly, creative mental health providers and government regulators have worked at developing service models that people who reject traditional programs will use.

Outreach and Engagement: Perhaps most fundamental to engaging hard-to-serve populations has been reaching out to them rather than waiting for them to come to a clinic or day program. One of the most successful models of this approach is known as "assertive community treatment" (ACT). Developed in the early days of deinstitutionalization in Dane County, Wisconsin, it took many years for ACT teams to become a major element of the mental health system. These are interdisciplinary teams including case managers, clinical social workers, psychiatrists, nurses, rehab counselors, etc., and they go into the community to find, engage, and serve people who cannot or will not go to a place that is identified as a mental health program.

Outreach efforts like ACT teams are one way to engage people reluctant to use the mental health system in treatment or rehabilitation. Another way is involuntary outpatient commitment, often called euphemistically "assisted outpatient treatment". This involves taking a person who rejects treatment and who does not meet the standard of dangerousness required for involuntary inpatient treatment to court, where a judge mandates that the mentally ill person accept treatment and that the treatment be made available to them.

The use of involuntary outpatient treatment has stirred up great controversy. On one side are people, including many family members of people with serious mental illness, who want to protect the people they care about from the dangers they face when they are acutely psychotic—dangers such as homelessness, isolation, living in unsanitary conditions, and the pain of angry voices and other hallucinations and delusions. Of course, there are also concerns about violent or other criminal behavior; but the major reason advocates for coercive interventions push for involuntary outpatient commitment and the like is to protect people with serious mental illness themselves.

On the other side of the issue of coercive intervention are advocates for the rights of people with mental illness, particularly the right to liberty except in dire circumstances such as (1) the commission, not the threat of but the actual commission of, a crime or (2) clear and imminent dangerousness to self or others. These advocates remind us of the abuse that people with serious mental illness have historically suffered in so-called "asylums". They also remind us that liberty has its hazards, especially the hazard of poor decisions. In addition, they often express

skepticism about whether involuntary outpatient treatment works. Yes, they argue, people forced into treatment often have better life outcomes; but, they ask, is that because they were mandated into care or because they were able to get care they would have accepted voluntarily if it had been available without a court order.

In my view, this debate has been one of the sources of counter-productive schisms among mental health advocates

### **Recognition of Special Populations**

In the years after CSP was developed for adults with serious and persistent mental illness (SPMI), several “special populations” became significant concerns. These included children and adolescents with serious emotional disturbance (SED), “minorities”, now referred to as “people of color”, and people with co-occurring mental and substance use disorder.

Children and Adolescents: A counterpart to CSP called the Child and Adolescent Service System Program (CASSP) was developed for the SED population. It emphasized prevention of placement in hospitals and in residential services and helping families to keep children safely at home whenever possible. In essence CASSP was deinstitutionalization for kids.

CASSP, of course, focused on the need for more and better community-based mental health services. But it also emphasized on “preventive” services in the child welfare system, i.e., services designed to avert the need for placement out of the home. It also emphasized the expansion of special education with a preference of “mainstreaming” or “inclusion”. And it emphasized changes in the juvenile justice system to reduce the use of detention and to provide relevant services in the community instead.

The concept of **systems of care** was central to the CASSP model. The idea was, and is, to bring the mental health, education, child welfare, and juvenile justice systems together in coordinated efforts to meet the needs of this population, who often failed in school, got into trouble with the law, and needed improved parenting. Whether the systems of care model has worked adequately on a large scale is open to some question. More about all of this in the lecture on children and adolescents.

Minorities: During the period after the introduction of CSP, there was also growing awareness of racial and ethnic disparities in mental health care. “Minority” populations, i.e., Blacks, Latinos, Asians, and Native Americans were, and still are, less likely to get mental health service than Whites. And they are far less likely to be mental health professionals, to be promoted into supervisory or management positions, or to participate in the top levels of the mental health power structure. In response, efforts

began to improve access to mental health services for people of color, to increase the use of "minority" staff, to promote them, and to increase participation of people of color on boards of directors, on governmental advisory groups, and in leadership positions.

I refer to this period of the effort to address racial and ethnic disparities as the period of "affirmative action." Over time the emphasis shifted from efforts increase to role of people of color in the mental health system and to focus on "cultural competence". This included recruiting staff from diverse cultures whose language skills and cultural knowledge matched the language and culture of the people who needed, but generally did not get, mental health services.

Cultural competence is built on the premise that there are different "pathways" to help (Lloyd Rogler's expression)<sup>6</sup> in different cultures and that it is crucial for mental health providers to connect with culturally accepted points of help so as to engage populations who do not find it natural to use mental health services. This requires speaking their language, appreciating cultural differences in norms and behavior, and adapting diagnosis and treatment to cultural differences.

Cultural competence, of course, is a far broader concept than affirmative action in that it includes people from many cultures with many different first languages and not just racial and other groups protected by the Civil Rights Act. And, as important as it is, it may be that the concept of cultural competence waters down efforts to address racism and discrimination and to pursue equity for populations that have been victims of discrimination in the past. New efforts to address racism are now emerging under the rubric of "anti-racism". More about this in the lecture on race and mental health.

Co-occurring Mental and Substance Use Disorders: People with co-occurring mental and substance use disorders are of major concern because many, if not most, people with serious and persistent mental illness also misuse substances at some point in their lives. The best treatment for this population integrates treatment for mental and substance use disorders. Unfortunately, the decision made in the mid-1970s to separate treatment systems for people with mental illness and for people with substance use disorders has made integrated treatment difficult to provide.

Over the years there have been quite a number of proposals to bridge the mental health and substance abuse systems. These have ranged from mergers of the governmental bureaucracies to building expertise into both types of programs, to co-location, to developing mechanisms of communication, cross-training, and so forth. Despite this, shortage of integrated treatment remains a major problem today.

## **“Consumer” Movements**

Until the late 1970s people with mental illness and their families mostly did not play major roles as mental health advocates. “Patients” were generally regarded as unable to “speak for themselves”, and family members, especially mothers, were often seen as causes of the patients’ disorders.

First, parents with grown children with serious and persistent mental illness began to organize and speak out and a bit later people with mental disorders themselves did the same. Parents formed the National Alliance for the Mentally Ill, now named the National Alliance on Mental Illness (NAMI).<sup>7</sup> People with mental illness formed a number of groups, many of which are now members of The National Coalition for Mental Health Recovery.<sup>8</sup>

**Both family organizations and groups of people with histories of mental illness originally tended to be hostile to providers, seeing them as, at best, arrogant, aloof, and patronizing and at worst as abusive.** Both types of groups demanded respect from professionals and to be partners in treatment, in program development, in policy, and in advocacy.

As with in the civil rights movement, groups of people with histories of mental illness have been insistent on using language that conveys respectful appreciation of the humanity of people regarded as mentally ill. Most reject the word “patient” as demeaning. They feel that “patient” implies that they should passively accept treatment and comply with orders from mental health professionals who think they know what is best for them. For similar reasons, they reject the terms “treatment-resistant and “non-compliant”.

Different groups have come up with different terms to describe themselves. “Consumers”, “recipients”, “ex-patients”, “people diagnosed with mental illness”, “survivors”, etc. Each alternative name reflects a shade of difference on how people with histories in the mental health system see themselves.

Despite many battles about terminology, virtually all agree that they do not want to be referred to as “**the** mentally ill”, an amorphous mass of undifferentiated, troubled people. They want first to be seen, and referred to, as people. So “people with mental illness” or “people diagnosed with mental illness”, which leaves it ambiguous whether they have an illness or have just been regarded by others as having a diagnosable condition,

became preferred expressions. These days, "person with a psychiatric disability" is the preferred expression of the recovery and rehabilitation community. **A person with "lived experience"** has recently become a popular way to talk about a person with a history of mental illness.

Consumer movements were about much more than language. Both families and people with histories of mental illness wanted to be respected partners, full participants in treatment and in the workings of the mental health system. They each developed advocacy agendas and had significant impact on the political process through which policy is made.

Of particular note is the fact that consumers have become providers. NAMI provides a great deal of education and support for family members, "family to family" as one program is called. And people with histories in the system now have jobs as "peer advocates", "peer counselors", "peer bridgers", "peer case managers", "peer care managers", etc. They have been so successful at being incorporated into the system as providers that Medicaid now reimburses for some of the services that they provide.

Also of particular note is the fact that all official policy planning groups include both family members and people with "lived experience" in the system. They may not yet have achieved full respect, but they have achieved positions of influence.

### **"Recovery"**<sup>9</sup>

The concept of "recovery"<sup>10</sup> is one of the most important outcomes of consumer movements led by people with histories of mental illness. People like Ed Knight and Patricia Deegan<sup>11</sup> among many others, who acknowledge having schizophrenia or bi-polar disorder, have noted that the expectation that serious and persistent mental illness is permanent is built into the diagnostic system and does not reflect the reality that a great many people with persistent disorders do quite well in the long term. They recover.

The meaning of "recovery", as developed by people with mental disorders like Drs. Deegan and Knight and by rehabilitation experts such as William Anthony at Boston University's Center for Psychiatric Rehabilitation, is subtle. Recovery does not necessarily mean that the illness is gone, although that does happen. Recovery means that people with serious mental disorders can develop lives that they personally find satisfying and meaningful. Hope and choice are at the heart of recovery. Being able to shape your own life within your real, rather than assumed, limits is what recovery is all about.

This concept of recovery has become so important that a Presidential Commission on Mental Illness convened by George W. Bush shortly after he

was elected concluded that the mental health system needs “transformation” and that the essence of the transformation should be to create a system that is “recovery-oriented” and “person-centered”.

### **Reliance on Medicaid**

As noted, the CSP model was developed and promulgated by NIMH, but it was primarily implemented by the states. Some state funds had to be used to pay for housing and rehabilitation; but whenever possible, states used Medicaid to pay for services so as to maximize federal financial participation.

Although Medicaid did enable states to expand their service capacity outside of institutions considerably, it paid primarily for medical model treatment and not for housing, rehabilitation, or case management. As a result, expansion of services in the community focused more on treatment than on support of safe and decent living arrangements and efforts to improve quality of life.

Some argue that the expansion that took place using Medicaid tilted the system of care in the wrong direction—“over-medicalized” it. Others argue that Medicaid was the only way to increase capacity and that growth of outpatient and local inpatient services was extremely important and beneficial. Proponents of reliance on Medicaid also worked successfully, if slowly, to change Medicaid rules. Now Medicaid does cover some rehabilitation, housing, case management and other non-medical services critical to people with serious and persistent mental illness.

A critical observation here is that **because funding is necessary to provide services, providers tend to do what the funders pay them to do and not to do what they do not get funding to do.** Obvious perhaps, but often overlooked in efforts to bring about changes in service systems.

As noted above, changes in Medicaid rules have been critical to getting federal financial support for a broader and broader range of services. Over time, states have become increasingly skilled at renaming and remodeling services so that Medicaid will pay for them. For example, some years ago NYS developed a rehabilitation model it called “individualized psychiatric rehabilitative treatment”, which passed muster as a treatment service that Medicaid would cover at a time when it would not pay for rehabilitation, especially “vocational” rehabilitation. Did such new models result in the loss of important social dimensions of rehabilitation? Probably.

The growth of Medicaid and other governmental funds for community mental health services also contributed to a competition for funds between

organizations that served people with serious and persistent mental illness and those that served people with less severe mental illnesses.

It is worth noting that the success of the states in drawing more and more federal funds into mental health services is one of the reasons that conservatives push to change Medicaid from an entitlement program to block grants that would place a cap on federal financial exposure. This proposal has been around for years, most dangerously during the Reagan administration. Mental health and other health policy advocates have succeeded in fighting it off repeatedly, most recently during the Trump administration's campaign to repeal the Affordable Care Act. But Republicans will undoubtedly try again, and the risk is high. Hopefully, we will continue to succeed to fight it off.\*

Rejection of converting Medicaid to a block grant program in the past did not end governmental efforts to hold down Medicaid expenditures for mental health services. As an alternative to capping Medicaid expenditures arbitrarily, state governments, with federal approval, introduced various forms of **Medicaid managed care**. This has included systems of care management that use capitation instead of fee-for service payment methods. It has also included various "preferred drug programs" that are designed to hold down state costs for psychiatric medications, which consume about 30% of all mental health expenditures. Major efforts are underway around the country to devise and implement complex new forms of managed care and to develop "value-based" payment methodologies. More about this in the lecture on behavioral health finance.

### **Outcomes of CSP**

It is my view the CSP has been and continues to be the core of mental health policy regarding people with serious and persistent mental illness. I say that even though there have been significant changes over the past 35 years, changes which have led others to say that CSP has been replaced by other community-based policies. This is not a critical dispute. Everyone agrees, even opponents of it, that community-based policies have dominated the mental health system since the 1960s.

These policies have been remarkably beneficial to millions of people with serious and persistent mental illness and their families. **Better living conditions, expanded service capacity, more hope of recovery, more respectful inclusion in the system—these are not minor achievements.**

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\* Some "Medicare-for-all" proposals may include a threat to Medicaid as entitlement, not only because they would end the Medicaid program altogether, but also because they include the use of global budgeting to control costs. It is not clear what the difference is between block grants and global budgeting; both set annual limits on spending.

However, it is exceedingly clear that people with serious and persistent mental illness and their families still face tremendous problems. These include:

- Transinstitutionalization to nursing and adult homes
- Incarceration in jails and prisons where about 350,000 people per day with serious mental illness now live and suffer
- Continuing Shortages of Safe, Stable Housing, which are needed by people with serious mental illness who are homeless, live in housing that is squalid and unsafe, are incarcerated in jails and prisons, or are unnecessarily in adult and nursing homes
- Shortages of outreach services such as ACT teams for people who reject service or are rejected for service because of substance abuse, criminal histories, or non-compliance
- Failure to close the “mortality gap”, i.e., to increase life expectancy for people with serious mental illness, who die 10-25 years younger than the general population
- Failure to substantially increase work opportunities for people with serious and persistent mental illness, roughly 85% of whom are unemployed
- Continued fragmentation among mental health providers, between mental health and substance abuse providers, between behavioral and physical health providers, and between mental health and long-term care providers.
- Continued need to develop and spread the use of evidence-based practices including both treatment and community supports.

So, my generation of advocates can be proud of what has been achieved so far through largely limited incremental gains over several decades. But there is much left to be done, and in the current political climate, continued progress is more than a little challenging. Hopefully a new generation of advocates will achieve more in the decades ahead.

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<sup>1</sup> [NIMH Community Support Program: Pilot Approach to a Needed Social Reform\\* | Schizophrenia Bulletin | Oxford Academic \(oup.com\)](#)

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<sup>2</sup> Tsemberis, S. (2015). *Housing First: The Pathways Model To End Homelessness For People With Mental Health and Substance Use Disorders*. Simon and Schuster.

<sup>3</sup> Anthony, W. (1993). "[Recovery from Mental Illness: The Guiding Vision for the Mental Health System in the 1990s](#)" in *Psychosocial Rehabilitation Journal*.

<sup>4</sup> [Employment First - Association of People Supporting Employment First \(apse.org\)](#)

<sup>5</sup> [What is a CCBHC? - National Council for Mental Wellbeing \(thenationalcouncil.org\)](#)

<sup>6</sup> Rogler, L. and Cortes, D. (2006). "[Help-Seeking Pathways: A Unifying Concept in Mental Health Care](#)" in *The American Journal of Psychiatry*, April 1 2006.

<sup>7</sup> [National Alliance on Mental Illness](#) website

<sup>8</sup> [National Coalition for Mental Health Recovery](#) website

<sup>9</sup> Friedman, MB. (2022) "[The Triumph Of Recovery](#)" in Behavioral Health News, Spring 2022.

<sup>10</sup> Anthony, W. (1993). Op. cit.

<sup>11</sup> Deegan, PE. (1987). "[Recovery, Rehabilitation, and the Conspiracy of Hope](#)".