



Published in final edited form as:

*SSM Ment Health*. 2023 December ; 3: . doi:10.1016/j.ssmmh.2023.100205.

## Cycles of reform in the history of psychosis treatment in the United States

Preethy George<sup>a,\*</sup>, Nev Jones<sup>b</sup>, Howard Goldman<sup>c</sup>, Abram Rosenblatt<sup>a</sup>

<sup>a</sup>Westat, 1600 Research Blvd, Rockville, MD, 20850, United States

<sup>b</sup>University of Pittsburgh, School of Social Work, 2314 Cathedral of Learning, Pittsburgh, PA, 15260, United States

<sup>c</sup>University of Maryland, School of Medicine, 3700 Koppers Street, Baltimore, MD, 21227, Suite 402, United States

### Abstract

The history of psychosis treatment follows a series of four cycles of reform which provide a framework for understanding mental health services in the United States. The first three cycles of reform promoted the view that early treatment of mental disorders would reduce chronic impairment and disability. The Moral Treatment era (early 1800's to 1890) featured freestanding asylums, the Mental Hygiene movement (1890 to World War II) introduced psychiatric hospitals and clinics, and the Community Mental Health Reform period (World War II to late 1970's) produced community mental health centers. None of these approaches succeeded in achieving the disability-prevention goals of early treatment of psychosis. The fourth cycle, the Community Support Reform era (late 1970's to the present) shifted the focus to caring for those already disabled by a mental disorder within their communities and using natural support systems. This shift embraced a broader social welfare framework and included additional services and supports, such as housing, case management, and education. Psychosis became more central during the current Community Support Reform era partly because individuals with psychosis continued to have disabling life experiences despite efforts at reform. Some degree of recovery from psychosis is possible, and individuals with serious impairment may move towards social integration and community participation. Early intervention for young people with psychosis focuses on reducing the negative sequelae of psychosis and promotes recovery-oriented changes in service delivery. The role of social control, the involvement of service users and their families, and the balance between psychosocial and biomedical treatments play an important role in this history. This paper describes the reform cycles, their political and policy contexts, and what influenced its successes and shortcomings.

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\*Corresponding author. preethygeorge@westat.com (P. George).

CRediT authorship contribution statement

**Preethy George:** Conceptualization, Writing – original draft, Writing – review & editing, Project administration. **Nev Jones:** Conceptualization, Writing – original draft. **Howard Goldman:** Conceptualization, Writing – review & editing. **Abram Rosenblatt:** Funding acquisition, Writing – review & editing.

## Keywords

Mental health services history; Mental health policy; Psychosis; Severe mental illness

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## 1. Introduction

In the United States, states and counties oversee public mental health programs funded by federal, state, and local resources for those with serious mental illnesses, including severe psychotic disorders across inpatient and outpatient settings (Sundaraman, 2009). Examining the history of publicly funded treatment for severe mental illness reveals four historical cycles of institutional reform in mental health policy, with recurrent principles and policies designed to intervene during the early stages of serious mental illness (including psychosis) to prevent acute problems from becoming chronic and disabling (Morrissey and Goldman, 1984).

The first reform cycle, the Moral Treatment Era, highlighted freestanding asylums in the early 19th century (Grob, 1983). Secondly, the Mental Hygiene movement, produced psychiatric hospitals and clinics in the early 20th century (Grob, 1983). Third, the Community Mental Health Support Reform period, introduced community mental health centers during the mid to latter third of the 20th century (Drake and Latimer, 2012). Finally, the Community Support Era (the cycle in which we presently operate) shifted the focus to treating individuals already disabled by serious mental illness with services within their communities accompanied by natural supports to promote quality of life (Goldman and Morrissey, 2020). None of the first three reforms succeeded in achieving its promises of preventing chronicity through early intervention. The fourth reform cycle supports care for already disabled individuals but also highlights the possibilities of early intervention in psychosis before illness becomes entrenched.

Exploring the historical context for these four reform cycles offers an opportunity to identify patterns in methods and outcomes relevant to the public mental health landscape today, particularly related to psychosis. New and sweeping strategies propelled each reform cycle to prevent “chronic” forms of mental illness. Over time, the interventions proved ineffective at preventing disability and added challenges of their own. Many treatment settings disempowered patients and contributed to continued disability and dependency on institutional settings, as many individuals received little more than custodial care (Penney and Stastny, 2008). The reformist ideals supporting each of these movements did not live up to real-world implementation, particularly the promises of preventing disability. Historically, increasing numbers of people with chronic mental illnesses were deemed “incurable” and were relegated to facilities that did not offer effective treatments or community-based supports. The first three cycles of reform produced a legacy of service settings that currently remain: asylums and psychopathic clinics were replaced by psychiatric hospitals; dispensaries shifted into outpatient clinics; and community mental health centers and general hospital psychiatric units continue to deliver services. Examining the challenges of these historical reform movements offers perspectives on the current state of mental health care and implications for future treatment. This paper will describe the cycles of reform as a

framework for examining policy and financing reform. The paper will also extend the work of Morrissey and Goldman by examining implications of mental health service reforms for individuals with psychosis in the United States (Goldman & Morrissey, 2020; Morrissey & Goldman, 1984).

## 2. Moral Treatment Era (early 19th century)

The first major social reform movement to address the care of individuals with mental illness began in the United States during the 19th century. Humanitarian efforts to improve the lives of people deemed less fortunate permeated a variety of social reform movements at the time (Rothman, 1971; Morrissey and Goldman, 1984). For example, the Second Great Awakening (1780–1830), a sweeping Evangelical Protestant revival movement emphasized charitable works and community volunteerism as a path to salvation (Taubes, 1998). Rather than embracing predestinarianism, the movement supported the view that people could be changed through alterations to the physical and social environment. Concurrently, advances in public health and sanitation conceptualized illness as an indicator of poor social and environmental conditions, which further reinforced the idea that improving one’s surroundings would lead to a path of both physical and moral health (Institute of Medicine, 1988). The philosophy of Moral Treatment for mental illness emerged within this social and historical context.

Prevailing conceptualizations of mental illness at the beginning of the 19th century elevated highly stigmatizing views, likening mental conditions to demonic possession or moral deviance, and “mad” people were believed to have no abilities to “reason” and needed to be “tamed” (Penney and Stastny, 2008). Until the 1820s, commonly used “therapies” for serious mental illness included bleeding, cathartics, ice water immersion, restraints, and beatings (Taubes, 1998). The Moral Treatment Movement developed in stark response to these dismal “interventions” by using medical and psychological frameworks to view mental illness as a physical condition that altered behavior through physical changes in the brain (Taubes, 1998). In the mid-19th century, the terminology for categorizing severe mental disorders included conditions we would now recognize as psychotic disorders, including delirium or dementia, as well as mania and toxic psychoses. Some are acute and others are non-remitting. The term “psychosis” was recorded as early as 1845 (Herbermann, 1913). Rather than viewing those with mental illness as “bad” or “immoral,” the Moral Treatment movement promoted the use of psychosocial interventions and viewed mental illness as curable if patients received compassionate treatment in peaceful settings. Work by European reformers, such as Phillipe Pinel and William Tuke promoted humane treatment for those with mental illness and provided a foundation for the development of public asylums in the United States. Asylums were originally envisioned as places where people with serious mental illness could seek rest, refuge, and safety.

“Moral Treatment” offered at asylums aimed to cure “insanity” by sequestering affected individuals into idyllic settings with occupational treatment, recreational activities, and nurturing providers (Morrissey and Goldman, 1984). Privately funded asylums in Pennsylvania and Connecticut implemented Moral Treatment in the late 1810s and early 1820s, and eventually state-run asylums implemented moral treatment for individuals

identified as “mentally ill” who previously resided in jails and local almshouses. Social reformer Dorothea Dix championed rights for individuals with mental illness and advocated for expanding public asylums across the United States. By 1890, every state had at least one publicly supported asylum. However, as construction of asylums expanded, Moral Treatment did not meet its purported goals.

The implementation of Moral Treatment required several factors: (1) small caseloads to foster close therapeutic relationships between staff members and patients, (2) recent onset of illness for admitted patients, and (3) sufficient public funding and political support for facility construction and operation. Societal and cultural forces prevented these implementation factors from materializing, and as such, the quality of care in public asylums eventually declined (Morrisey and Goldman, 1984). The advent of industrialization in the 1840s and 1850s and the large influx of immigrants to the United States from impoverished backgrounds led to rapid increases in urban populations and an increasing demand for psychiatric care. Public officials responded by calling for the construction of larger institutional facilities. Over time, the majority of patients admitted to asylums were disproportionately from lower income groups, including immigrants and incarcerated individuals with chronic mental illnesses, what we would now consider psychosis and chronic alcoholism (Warner, 1994). Stigma and discrimination based on race, ethnicity, and gender influenced who was sent to public asylums and how mental illness diagnoses were assigned (Penney and Stastny, 2008). As the patient population increased, the quality of care declined, and public Moral Treatment asylums morphed from small therapeutic hospitals to large, overcrowded institutions that all but abandoned the goal of treatment in favor of containment.

During the 1850s, stratification between publicly and privately funded institutions emerged and remained deeply embedded. Patients from lower-income and ethnoracialized backgrounds were relegated to publicly funded institutions, whose primary goals supported long-term custodial care for involuntarily admitted patients with what we would now consider psychotic disorders and alcohol use disorders. Privately funded asylums provided quieter, less crowded treatment settings for wealthier and primarily voluntary patients. Over time, publicly funded asylums served to isolate large numbers of patients in custodial care away from the public for the lowest possible cost. Asylums routinely featured overcrowded, deteriorating facilities, staff shortages, and highly restrictive and abusive practices to maintain order. Case studies document how many individuals in state funded asylums remained institutionalized for the rest of their lives without any hope of effective treatment (Penney and Stastny, 2008).

### 3. Mental Hygiene Movement (Early 20th century)

In the 1870s, reformers criticized American psychiatry for the over-crowded conditions of state asylums, the overuse of physical restraints, and the lack innovation in treatment. Documented accounts of conditions within state run asylums published in the early 20th century shocked the public. In his autobiography published in 1908, former patient Clifford Beers described his battle with psychosis and his repeated committals to multiple mental institutions, where abusive treatment by staff members caused additional trauma (Beers,

1908). His work impacted public perceptions of mental hospitals and helped spur reform movements (Parry, 2010).

In 1908, psychiatrist Adolf Meyer conceptualized “mental hygiene” as the biological or pathological origins for mental illness and linked psychiatry with neurology, biology, and physiology. Meyer supported early treatment as a strategy to reduce the severity and reoccurrence of mental illness. In 1909, Clifford Beers, Adolf Meyer and psychologist William James formed the National Committee for Mental Hygiene endorsing mental illness as a treatable condition amenable to early intervention and prevention. Mental hygienists called for the development of “psychopathic hospitals and clinics,” acute care institutions connected to universities and research organizations designed to combine the goals of Moral Treatment with science. The construction of psychopathic hospitals proliferated across the United States; however, they were unable to address chronic mental illness or change the state of mental health care more generally.

To rectify the poor quality of care for severe mental disorders in state and local settings, including local almshouses and state mental hospitals (formerly known as state asylums), state legislators passed a series of State Care Acts, beginning with the New York State Care Act in 1890. These laws required states to assume financial responsibility for the care of individuals considered mentally ill in state mental hospitals rather than in settings operated by local municipalities and counties. The legislation provided a centralized state-run regulatory structure for the administration of asylums and solidified psychiatry as the main form of care for individuals with severe mental illness.

Over time, the original goal of providing treatment in state hospitals diminished, and efforts were placed on admitting older adults experiencing senility for custodial care. Before 1900, aged senile patients and those with chronic mental illness were routinely sent to local almshouses for care. However, local communities saw financial benefits to shifting the burden of caring for patients from town and county almshouses and workhouses to state mental hospitals, thus transferring financial responsibility for their care to the state. As a result of this policy, the patient population in state mental hospitals radically changed from serving primarily acute cases to also serving senile patients, those with chronic mental illness, and other diseases that required long-term or permanent custodial care, such as tertiary syphilis. Yet, state mental hospitals did not provide specific treatments tailored to psychiatric conditions. This transfer of patients from one institutional setting to another resulted in a 240 percent increase in the number of patients admitted to state mental hospitals from 1903 to the mid-20th century (Grob, 1983). The state mental hospitals again became largely custodial care facilities meant to contain individuals who were poor and chronically ill. Despite the promise of forging new scientific advancements with social reform, the psychopathic hospitals did not live up to their early promise.

#### **4. Community Mental Health Movement and Deinstitutionalization (Mid-20th century)**

The decades following World War II helped introduce the Community Mental Health movement and a network of community mental health centers (CMHCs) throughout the

United States (Geller, 2000). World War II itself helped shift public preferences away from institutional care (Crocq and Crocq, 2000). The idea of sending World War II Veterans with post-traumatic stress and combat fatigue to institutions removed from the community did not sit well with either the general public or elected representatives (Grob and Goldman, 2006). Additionally, psychiatrists participating in the military experienced success in providing brief, effective psychosocial treatment close to the front, rather than in distant hospitals, which promoted interest in prevention and the treatment of mental illness within the community. Work by psychiatrist Eric Lindemann in the 1940s showed that patient recovery improved with connections to local supports and provided a framework for community-based care that would soon become the focal point of treatment during this reform movement (Rosenfeld, 2018).

During the war, when federal authorities assigned conscientious objectors to work in state psychiatric hospitals, many accumulated disturbing accounts of unacceptable conditions, including overcrowding, under-staffing, decaying physical infrastructure, and abuse (Taylor, 2009). Journalist Albert Maisel published a scathing exposé in *Life* magazine of life inside two state hospitals that recounted appalling living conditions for patients (Maisel, 1946). The article and accompanying photographs of patients lying unattended on the ground, bound with heavy restraints, and relegated to overcrowded rooms shocked Americans and succeeded in showcasing the hopelessness, abuse, and neglect that many institutionalized patients experienced.

The period following World War II saw the expansion of federal legislation to reshape the mental health system. With the establishment of the National Institute of Mental Health (NIMH) in 1949, policy makers and academic psychiatrists shifted the conceptualization of mental health to a public health concern, one that could include a broad range of mild to severe illnesses with treatments that providers could deliver in outpatient and inpatient settings. Policy makers envisioned treatment distributed across communities in small outpatient settings, rather than centralized in large state-run institutions (Brodwin, 2013), which further advanced the acceptance of a community psychiatry approach.

Other events contributed to the view that large state mental hospitals were obsolete and inadequate as facilities for treatment (Brodwin, 2013). In 1955, chlorpromazine, marketed as Thorazine became the first antipsychotic approved for wide-scale use in the United States, quickly followed by other similar drugs (dopamine antagonists). Up until this point, most treatments for schizophrenia included prefrontal lobotomies, electro-convulsive therapy, insulin coma therapy, and broader psychosocial approaches, like psychodynamic therapy, group therapy for parents, and milieu therapy (Bennet, 1943; Freudenberg, 1947; Fromm-Reichman, 1948; Kahn and Prestwood, 1954; Rioch and Stanton, 1953). With the introduction of antipsychotics, invasive techniques implemented in institutions, such as lobotomies were phased out, and rehabilitative interventions—designed to prepare patients for life in the community—were actively phased in, and increasingly implemented in community-settings (Wallace et al., 1980). The introduction of antipsychotic medications and other community-based interventions further supported the argument to empty inpatient wards, relieve people from long-term hospitalization, and “reintegrate” people back into the community through deinstitutionalization.

Under growing pressure—both from the general public and the increasingly unsustainable costs of the state hospital system—Congress passed the Mental Health Study Act in 1955, funding a “nationwide analysis and reevaluation of the human and economic problems of mental health.” Experts assembled under the auspices of the Act commissioned a series of studies culminating in the Joint Commission on Mental Illness and Health’s seminal report *Action for Mental Health* (Joint Commission on Mental Illness and Health, 1961). The report declared that modern treatment for mental illness should enable patients to maintain lives away from the “debilitating effects of institutionalization” with aftercare and rehabilitation as essential parts of service delivery.

John F. Kennedy signed the Community Mental Health Act (CMHA) into law in 1963, which called for the creation of a national network of 1500 community mental health centers (CMHCs) ostensibly with the goal of providing community-based services for individuals discharged from state hospitals. The promise of reducing the number of patients in state mental hospitals and saving money promoted a policy of deinstitutionalization. Seminal in the shift it set in motion, historians often see the CMHA as a failure in implementation. Only 700 of the planned 1500 centers were built, and CMHCs that were constructed focused on prevention and expanded treatment for those with less disabling conditions, rather than those with severe mental illness. These facilities stood in contrast to state mental hospitals, where the overwhelming majority of inpatients had severe conditions. Echoing the calls by proponents of the psychopathic hospitals of the Mental Hygiene movement, leadership in CMHCs considered it their charge to prevent chronic illness rather than focus on treating those already in need of long-term care. The CMHC’s focus on less chronic cases broadened the opportunity to serve a whole new population of those previously untreated for mental health concerns.

Between 1955 and 1980, the population in state mental hospitals reduced by more than 75% (Geller, 2000). Within a short timeframe, hospitals discharged hundreds of thousands of patients with mental illness, and CMHCs were wholly unprepared and at times unwilling to care for patients with chronic illness. CMHC clinicians admitted and treated many more individuals with conditions other than psychosis; as such, people with psychosis in CMHCs represented a declining percentage of the total compared to what was seen in prior years. The impression was that CMHCs were neglecting individuals with psychotic disorders, although the numbers and rate per 100,000 for those with schizophrenia remained relatively stable (Goldman et al., 1980). Caseloads expanded to serve others with less disabling, but still distressing, conditions.

Despite the promise of community-based care, deinstitutionalization led to tragedies, comparable to horrors in state mental hospitals that deinstitutionalization was intended to address. Many former patients were left homeless, wandering the streets, or living in dirty single room occupancies (Hopper, Jost, Welber, & Haugland, 1997; Myers, 2015). Thousands of former patients in hospitals were transferred to nursing homes, adult group homes, and other institutional settings in the community. Similar to what occurred during the Mental Hygiene movement, patients were transferred from one type of institution to another without the level of support required. Rose (1979) was eviscerating in his charge that deinstitutionalization failed to “provide even minimally adequate aftercare and community

support services anywhere in the nation.” Efforts to eliminate mental hospitals failed to stress the need for alternatives to institutional care, resulting in a host of unintended negative consequences (Bacharach, 1976).

Although psychiatrists, nurses, and paraprofessional staff played primary roles in the direct care of institutionalized patients in state hospitals during the first half of the 20th century, as treatment moved into the community, other professions—namely social work and psychology—came to occupy more significant roles. A battle between psychodynamically oriented practitioners and psychopharmacologists continued to play out within hospitals and psychiatry training programs well into the 1980s (Lurhmann, 2000). The bulk of the public mental health workforce received little or no training in psychodynamic therapy. As acute symptom amelioration came to be perceived as a function of medication, psychosocial intervention came to revolve most strongly around “medication management” and the “skills, techniques, and activities of daily living” necessary for community life. Precursors to the more contemporary psychiatric rehabilitation interventions of the 1980s and 1990s de-emphasized symptom-focused psychotherapy in place of more applied illness and community management. For example, in 1972 senior clinicians and administrators in Madison, Wisconsin launched Assertive Community Treatment (ACT), an intensive multidisciplinary program designed to provide individuals with severe and chronic mental health problems with treatment and skill building viewed as necessary for coping in society (Rocheffort, 2019).

During this period, identity and civil rights movements beginning in the 1960s and 1970s, in tandem with deinstitutionalization, inspired a nascent movement of ex-patients labeled as “schizophrenics” to become activists, which later became the consumer-survivor-ex-patient movement (see Britz and Jones, this issue). Survivors and ex-patients primarily focused on identifying and addressing human rights abuses in psychiatric hospital settings (including the institutions from which they had been discharged). The consumer/survivor/ex-patient movement emphasized the importance of political consciousness, as did the feminist, disability (Scotch, 1989), and farmworker rights movements. Often described as the earliest contemporary “ex-patient” rights group, the Insane Liberation Front was founded in Portland, Oregon in 1969, quickly followed by similar groups in New York, Boston and San Francisco (Tomes, 2006). In more psychosis-focused aspects of early organizing, the *Madness Network News (MNN)*, an influential national ‘critical psychiatry’ serial publication of the 1970s and 1980s, described a ‘Psychosis Validation Coalition’ meeting as early as 1971 in San Francisco, a ‘Festival of Creative Psychosis’ in 1973, and ex-patient led workshops for clinicians with such titles as “Encountering Psychosis, or Everything You Always Wanted to Know about Madness but were Afraid to Ask.” “Dr. Caligari” an anonymous dissident psychiatrist writing for MNN regularly provided columns on the risks and over-use of antipsychotic medication. Consumer/survivor/ex-patient movements during the 1970s emphasized the importance of patients’ abilities to choose the course of their own treatment and live fully and independently (Tomes, 2006; Chamberlin, 1978), which contributed to models of empowerment and self-direction that served as the foundations for recovery-oriented programs and mental health policy decades later (Myrick & del Vecchio, 2016).



Around this time, family advocacy groups protested the promotion of the “schizophrenogenic” family (mostly focused on mothers), which emerged during the 1930s to the 1950s within psychoanalytic circles, early work on the “over-protective mother” (Levy, 1931), and the schizophrenia-inducing family (Kasanin et al., 1934). Therapy integrated maternal separation and direct treatment of mothers not to provide support, but to correct “schizophrenogenic” behaviors commonly recommended well into the 1970s (Staub, 2011). Parents, particularly mothers, eventually organized against the “parent blame” pervasive in many treatment settings, kicking off the contemporary family advocacy movement. Two mothers of sons diagnosed with schizophrenia and E. Fuller Torrey, a psychiatrist and translational researcher whose sister was diagnosed with schizophrenia, founded the National Alliance on Mental Illness (NAMI) in Wisconsin in 1979. For Torrey and early NAMI parents, a strongly biological explanation of schizophrenia promised relief from the psychoanalytic narratives still dominant at the time that placed the blame on family dynamics.

Acknowledgement of the failures of CMHC implementation peaked in the late 1970s. In 1977, President Jimmy Carter convened a new presidential commission on mental health. In many ways reflecting the rise of the civil rights movement over the preceding decade, the report sponsored by the commission focused on ethnic and racial minorities, women and individuals with physical and neurodevelopmental disabilities. The Commission’s panel on legal and ethical issues emphasized patients’ rights, confidentiality, and autonomy and called for a national mental health policy focused on those deemed “chronically mentally ill” (Grob, 2005).

## 5. Community Support Reform Era (mid-1970’s to the present)

The National Institute of Mental Health, the federal lead on the CMHC program, responded to the critique of the federal role in deinstitutionalization by developing the Community Support Program (CSP), through which NIMH allocated \$3.5 million annually for states to provide services to adults with psychiatric illnesses and severe and persistent disabilities. The CSP marked the fourth cycle of reform, the Community Support Reform Era, which altered the delivery of mental health services and advocated for a whole system of care (Goldman & Morrissey, 1985). Rather than targeting early treatment to prevent disability, the CSP advocated for treatments and a system of social and community supports aimed at improving the quality of life of those with chronic mental illness. The initiative included supports such as psychosocial rehabilitation, supportive living, employment support, case management, and medical and mental health care. Additionally, proponents advocated for social welfare interventions as part of treatment for mental illness, such as entitlement programs and income, transportation, and housing supports (Goldman & Morrissey, 1985). The Community Support Reform movement also featured the development of the Mental Health Systems Act of 1980, which would have given states and localities flexibility to use federal funding through grants to State Mental Health Authorities and community mental health centers for services to people with chronic mental illness (e.g., mental, medical, rehabilitation, dental, employment, housing, and other support services). Policy makers designed the legislation to fix emergent and long-standing problems with implementation

of the Kennedy CMHA, to strengthen accountability, and improve coordination between mental health and physical health systems and services.

As the Mental Health Systems Act moved through the legislative process in 1980, critics expressed concern that it would not succeed in its aims of adequately supporting individuals with chronic psychiatric disabilities (Falik, 1979; Rose, 1979). The law was passed in 1980 as authorizing legislation for a broad array of services but without an appropriation. Before implementation could commence in earnest, however, President Ronald Reagan was elected and swiftly repealed most of the Act through an omnibus budget reconciliation. Instead of the new era of “population mental health” Carter imagined, the Reagan administration proceeded to shift dollars from mental health to substance use, with most of this funding—collectively comprising the “War on Drugs”—narrowly earmarked for prevention, policing, and the criminalization of drug use and trafficking rather than supportive treatment (Humphreys and Rappaport, 1993). By 1982, Reagan made an estimated total of \$22 billion in cuts not only to mental health but broader social welfare programs, while substantially increasing law enforcement and criminal justice system budgets (Stoesz and Karger, 1993). The one remnant of Carter’s CMHA, the federal Mental Health Block Grant Program rolled out in 1982. Although constituting a small portion of overall state mental health services budgets, the Block Grant program provided a mechanism for funding service components not otherwise covered by Medicaid or other state and federal dollars (Axelrod, 1983).

Building on prior advocacy efforts of the 1970s, the last two decades of the 20th century saw the increased influence of patient and consumer advocacy groups in mental health policy. For example, NIMH invited patients to participate in listening sessions for the CSP program and included consumer empowerment and self-determination in the CSP mission in 1984 (Tomes, 2006). In 1992, the creation of the Substance Abuse and Mental Health Services Administration (SAMHSA) defined consumer and mental health parity as a requirement for federal funding (Myrick & del Vecchio, 2016), and the 1999 Surgeon General’s Report and the 2003 President’s New Freedom Commission noted the need for consumer involvement and the importance of a focus on recovery. Testimony from individuals with mental illness described recovery as a process of positive adaptation to mental illness and disability, connected to both empowerment and self-awareness (Hogan, 2003). The findings from the Mental Health Report of the Surgeon General and the final report of the President’s New Freedom Commission highlighted evidence that improved outcomes and recovery for those with serious mental illness was possible, which prompted optimism about fuller social participation and improved quality of life. Given gaps in care, barriers to treatment, and a mental health system described as “in shambles” by the Commission, the report emphasized urgency for system transformation (Hogan, 2003).

The “recovery movement” of the 1980s, championed by both survivor activists and clinical reformers, such as Pat Deegan (a person in recovery from schizophrenia and a clinical psychologist), pushed the field to reorient to the possibility and indeed reality of meaningful lives in the community, symptoms notwithstanding:

Recovery does not refer to an end product or result. It does not mean that one is “cured” nor does it mean that one is simply stabilized or maintained in the community. Recovery

often involves a transformation of the self, wherein one both accepts one's limitation and discovers a new world of possibility (Deegan, 1996).

Federal mental health policy of the early 21st century consistently holds up the intersecting principles of person-centered, recovery-oriented, trauma-informed and culturally competent care (Humphreys and Rappaport, 1993; Piat and Polvere, 2014). Although some critics hold that these terms mostly function as "empty buzzwords" (Penney and Prescott, 2016), their philosophical underpinnings nevertheless clearly mark a major departure from the pessimistic treatment frameworks prevalent during the 1950s through the 1980s.

The psychiatric rehabilitation movement of the 1980s and 1990s expanded programs introduced by the community support systems approach, and increasingly focused on self-management, coping skills and steps towards (if not realization of) financial independence and self-sufficiency (Anthony and Liberman, 1986). Interventions developed during this period included Individual Placement and Support (supported employment; Becker and Drake, 1994), Illness Management and Rehabilitation (IMR; Mueser et al., 2006), and Assertive Community Treatment (ACT; Drake, 1998). As these programs expanded, critics noted that some psychiatric rehabilitation interventions limited consumer control over goals and plans for treatment and encouraged dependence on the formal service system (Brodwin, 2013).

The consumer advocates who emerged in the 1990s focused on building alternative community-based support networks and advocacy channels like recovery-oriented peer support services. Peer support models share the view that people with experiences that could be labeled as mental illness can provide validation, empathy, information, and hope for others who are in the process of recovery (Myrick & del Vecchio, 2016). The settings, roles, and job titles vary for individuals who provide peer support, which creates methodological challenges for conducting research on the effects of peer-delivered services on patient outcomes. Yet, across service types, peer support has been associated with client improvements, such as reduced inpatient service use, higher levels of empowerment, patient activation, and hopefulness for recovery (Chinman et al., 2014). Even so, peer programs remain underfunded and under-supported in much of the United States (Myers, 2015).

Historically, patients with psychotic disorders commonly experienced treatment in many of the service settings in use during the Moral Treatment Era to the present day. However, unlike prior reform periods that promoted early intervention, empirical research conducted during the Community Support Reform era showed recovery from psychosis is possible when appropriate and efficacious interventions, material resources, and social supports are provided early in the course of illness (Birchwood et al., 1997).

Starting in the 1990s, researchers in the United Kingdom and Australia began to develop specialized "early intervention in psychosis" services, inspired in part by the so-called "critical period hypothesis" (Birchwood et al., 1998), the time soon after symptoms of psychosis begin. Early intervention models implemented in the United States effectively pushed back against policy and infrastructure configured to provide more intensive wraparound supports (family psychoeducation, supported education and employment) only

after an individual could establish a history of significant functional disability. Early intervention in psychosis aimed at promoting full “recovery” prompted changes in service delivery to address fuller social participation, greater hope, and optimism for improved quality of life.

In 2008, an early psychosis intervention emerged in the form of Coordinated Specialty Care (CSC), a team-based, client-centered model including evidence-based outpatient services for young people with early psychosis, including case management, psychotherapy, supported employment, supported education, family psychoeducation, family support, and psychopharmacology (Azrin et al., 2015). The model is designed to engage young people with early psychosis and their families with appropriate and individualized levels of service using shared decision-making to incorporate patient preferences and personalized recovery goals (Azrin et al., 2015). Shared decision-making occurs when a patient and health care provider collaborate to develop a course of treatment that is ethical, evidence-based, consistent with patient preferences, and grounded in values of choice, self-determination and empowerment in treatment (Drake et al., 2009; Deegan & Drake, 2006). Research suggests shared decision-making has favorable effects on outcomes such as patient satisfaction, medication management, knowledge attainment, and quality of life (Malm et al., 2003; Van Os et al., 2004; Hamann et al., 2006; Prieb, et al., 2007).

Fundamental to the rationale underlying CSC is the idea that a longer duration of untreated psychosis (DUP) predicts poorer clinical, social and functional outcomes for individuals with psychosis. Specifically, the longer the increment of time between one’s first psychotic episode and treatment, the stronger the association with social withdrawal, isolation, and negative symptoms (Howes et al., 2021). Without support, the life disruptions and social rejection commonly associated with an initial break can significantly derail young people, ultimately leading to a higher likelihood of disability.

Building on international work, the early intervention approach has also been rolled out further upstream focused on youth at elevated risk for, but who have not yet “transitioned” to having a first episode (Devoe et al., 2019). Concerns remain about determining who would be appropriate for such interventions, possible stigma related to early identification of psychosis and challenges related to delivering treatments to those who do not actually develop psychotic illnesses (Fusar-Poli et al., 2013). More research is needed to determine whether or not interventions for individuals at high risk prevent psychosis.

### 5.1. Financing early intervention

In 2014, the promise of early intervention for psychosis was supported by the federal government through funding requirements to the States to implement services for serious mental illness, including psychosis. The federal government required states to allocate 5% and later 10% of their Community Mental Health Block Grant (MHBG) set-aside funds to support the development of CSC programs and by 2018, \$160 million of federal funding was allocated to developing and funding evidence-based programs that provide treatment for those with early psychosis (George et al., 2022). This pivotal funding policy change combined with the Affordable Care Act’s (ACA) expansion of Medicaid, led to programs in 51 states and territories in less than 10 years.

Although federal financial support expanded early intervention services for people experiencing symptoms of psychosis, barriers to implementation remain. Training gaps in professional programs and the scarcity of available workforce trained to treat individuals with psychosis persist (Kourgiantakis et al., 2019). Despite decades of decline in training focused on therapy for psychosis and early intervention, ongoing investment in non-psychodynamic psychosis-focused therapies in the United Kingdom and Australia are helping to “re-introduce” cognitive behavioral therapy for psychosis (CBT-P) into the community mental health sector in the United States (Hardy et al., 2021), as well as specialized training in psychosis (rather than the broader and more functionalist category of serious mental illness) to public sector providers.

Financing early psychosis services remains a challenge. The United States was slow to implement CSC compared to Australia or parts of Europe due, in part, to a poor fit between early intervention goals of CSC and the priorities of a U.S. system designed to provide community support services to already disabled individuals. Medicaid and Medicare were designed to offer health insurance protection to elderly, poor and disabled individuals, and the public mental health system has relied on Medicaid as a major financing source (Frank et al., 2003). Medicaid eligibility often came from qualification for disability benefits from the Supplemental Security Income (SSI) program. Individuals with psychiatric impairments make up the largest and most rapidly expanding subgroup of Social Security disability beneficiaries (Drake et al., 2009). Individuals in the early stages of psychosis did not yet qualify for SSI or Medicaid, and so they were not a priority for agencies relying on Medicaid. Private insurance also did not support the treatment of individuals in the early stages of psychosis, who often left work or school and lost health insurance tied to the workplace, or school, or parental health insurance. Prior to the ACA, insurance companies could refuse to provide coverage to individuals with a pre-existing condition, so CSC services were not encouraged to develop without a substantial funding base. The ACA changed some of those limitations so young people could remain on parental insurance until age 26, Medicaid was linked to low income and not disability, and insurers could not declare a history of psychosis as a pre-existing condition and barrier to insurance coverage (Goldman et al., 2013).

Today, most CSC programs draw revenue from blends of Medicaid, commercial insurance, and other subsidies. However, traditional health insurance and Medicaid programs do not always cover service components of CSC such as community outreach activities, team meetings, ongoing training, and supervision (Bao et al., 2021; Smith et al., 2019). Also, most state Medicaid plans do not provide enough support through their fee-for-service funding mechanisms to cover the intensity of CSC services.<sup>1</sup> Among those who are in the early stages of psychosis and qualify for Medicaid on the basis of income, the lack of a documented disability can preclude their access to Medicaid benefits that would cover components of CSC as these are limited to those with multi-episode schizophrenia. The system essentially limits services that could help prevent people from becoming disabled until they experience the disabling features of illness (Dixon, 2017). Although current

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<sup>1</sup>In the United States, Medicaid fee-for-service models occur when Medicaid directly pays health care professionals for services they perform, and fees are determined by a state’s fee schedule.

funding levels are insufficient to provide population level coverage, both states and federal entities are actively investigating additional financing strategies, and increasingly liaising with private as well as public insurers (Bao et al., 2021).

Although the long-term impact of CSC remains uncertain, short-term (2–3 year) outcomes reflect unambiguously greater effectiveness in comparison to status quo care (Correll et al., 2018). Harkening back to support for early intervention introduced by social reformers at the end of the 18th century, the promise of early treatment continues to unfold through each cycle of reform, and up until recently with limited success.

A review of the cycles of reform suggests patterns of policy shifts that have implications for individuals with psychosis today. Driven by expectations of improved outcomes from early treatment offered in new treatment settings—from the asylum, the psychopathic hospital, the mental hygiene clinic, and the community mental health center—each reform movement offered hope and optimism about recovery; however, prior movements failed to offer effective treatments, supports and services to make the promise a reality. The emphasis for where treatment was provided (e.g., community-based services versus institutional care), how treatment was managed (e.g., public versus private), and the focus of treatment (acute and crisis intervention versus chronic care services) all shifted as each reform period faded and the next reform cycle emerged. The idea of recovery conceptualized during the late 20th century and early years of the 21st century, the support for shared decision making, service user involvement in policy, public funding incentives, and recent advancements in the science of early intervention have provided important opportunities to take steps forward in the evolution of how we address psychosis and serious mental illness. The changes in emphasis and models of care resulted in our current mental health system, which includes a complicated and disorganized accumulation of services and service settings. Although each of the first three cycles of reform failed to prevent chronic mental illness or change care for individuals with psychosis and other severe mental illnesses, we see how the failures played a role in the current mental health system.

## 6. Challenges Remain

Despite overall positive developments in early intervention, structural barriers remain. Stigmatizing attitudes about people with mental illness and inadequate investment in public sector mental health services, broader disability-related income subsidies and programs, and basic necessities like affordable housing, venues for socializing, and decent employment opportunities challenge well-being and contribute to markedly high rates of homelessness, incarceration, and poverty among individuals with serious mental illness. Those with serious mental illness die 10–20 years earlier than their counterparts (de Mooij et al., 2019), and individuals with early psychosis are at risk for suicide and other causes of death particularly during the three-year period after an initial diagnosis (Simon, et al., 2018). The high prevalence of mental illness within U.S. correctional facilities has led to characterizations of jails and prisons as the “new asylums.” Reports estimate that approximately one-fifth of inmates in jails and 15% of inmates in state prisons have a serious mental illness, and many do not receive adequate supports or treatment for their conditions (Office of Research and Public Affairs, 2016). Further, individuals from ethnically diverse communities often

experience greater risk for aversive pathways to care, such as interactions with police without sufficient training in serious mental illness (Davis et al., 2022; Oluwoye et al., 2021).

Efforts to address these challenges include the development of models for integrating general medical and primary care with behavioral health services to account for gaps in psychosis-related detection, screening, diagnosis, and treatment (Wan et al., 2014), expanded attention to racial disparities and inequities (Shim, 2021), digital innovations (Torous et al., 2019), and the integration of peer support services (Jones, 2015).

## 7. Conclusion

The history of mental health policy over the past 200 years demonstrates limitations and failures in upholding principles that fully address long-term care needs of those with chronic mental illness. Critics like Rothman (1971) speak of “reform without change,” implying that the principles of reform did not realize their lofty goals. Unlike prior reform movements focusing on early intervention at the expense of those with chronic mental illness, recent approaches suggest an understanding of the benefits in addressing both ends of the treatment continuum. The Community Support Reform movement showed the advantages of providing those with chronic mental illness with a full range of services and support options (e.g., supports for employment, education, housing, and psychosocial rehabilitation in a shared decision making, recovery-oriented framework). Expanding our scientific knowledge about how treatment can affect the course of illness and applying those principles to innovative technologies for early intervention may optimize outcomes for individuals with first-episode psychosis.

Despite expansion of early intervention, unrelenting systemic barriers hinder recovery efforts, limit the ability to implement service innovations, and impede positive long-term outcomes. Navigating the disorganized and complicated state of the mental health system remains a significant and enduring challenge for potential users and their families. As we continue to struggle with the inadequacies within mental health systems, including financing effective, low-cost services to reach more people, the need for well-informed, recovery-oriented, evidenced-supported policy remains an imperative.

## Funding sources

This work was funded by the National Institute of Mental Health (U24MH120591-01), United States.

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