

Position Statement

The Need for One Coordinated System of Care

People with schizophrenia rarely receive the comprehensive and integrated treatment they need to achieve recovery.

Treatment for schizophrenia in the United States is often ad hoc and fragmented, extensively delayed and frequently disrupted.^{1,2} The consequences of this are dire, and include progressive neurological damage, disease relapses and hospitalizations, increased acute and chronic physical illnesses, reduced educational and occupational opportunities and an increased likelihood of homelessness or involvement with the criminal justice system.³⁻⁷ These harms are especially pronounced for people from historically marginalized backgrounds and lead to exorbitant medical and societal costs.^{8,9}

Diagnosis of schizophrenia is frequently delayed by years.²

Pathways to care for people with schizophrenia are complex, involving multiple points of contact before a diagnosis is made and treatment begins.¹⁰⁻¹³ People with schizophrenia often receive care only when they reach a crisis point, which may involve traumatic interactions with law enforcement or involuntary psychiatric hospitalizations.¹⁰ These convoluted pathways to identification and treatment are frequently avoidable, as schizophrenia often has a pronounced “prodromal” phase up to five years before a person experiences a first psychotic episode, during which warning signs emerge, such as odd beliefs and social withdrawal.¹⁴ Unfortunately, these warning signs often are missed or misinterpreted by those closest to the person, such as family members, primary care providers, educators and employers.¹⁰⁻¹³ The longer a person with psychosis goes untreated, the more likely they are to experience long-term (and potentially irreversible) damage from the illness.² Early intervention can significantly lower costs and improve health outcomes over a lifetime.^{15,16}

Even after schizophrenia is diagnosed, accessing care is difficult.

Many people with schizophrenia are reluctant to access care because of a symptom called anosognosia, which prevents them from understanding they have the disease.¹⁷ In addition, stigma and mistrust in the mental health system due to previous negative experiences can result in delayed care.¹⁷⁻¹⁹ The burden of seeking and starting treatment often falls on families or other caregivers,²⁰⁻²³ but most caregivers do not have the knowledge, skills or support to effectively navigate treatment, address anosognosia and advocate for their loved ones. Having inadequate (or no) health insurance can also make it difficult to cover treatment costs.^{24,25}

Community-based treatment options for schizophrenia are desperately lacking.

It is estimated that only 5% of those with schizophrenia receive the full array of evidence-based practices that lead to optimal outcomes.^{26,27} Best-practice treatments for schizophrenia involve ongoing coordination of care across many types of providers, including health clinics, education and work support services, peer support, social support agencies, homeless shelters and the legal

and criminal justice system.^{28,29} However, these systems operate in silos, which interferes with continuity of care and causes worsening symptoms and relapse.

In addition to the scarcity of community-based treatment options, there is a critical shortage of healthcare providers who are trained to manage schizophrenia, leading to lengthy waitlists and a lack of the high-quality, evidence-based assessment and treatment necessary to effectively care for people with schizophrenia. Moreover, restrictive laws, such as the federal REMS program for clozapine, can prevent access to lifesaving treatment options.

Treatment is nearly impossible to find for people experiencing a crisis or relapse.

There is a shortage of hospital beds in the United States for people with schizophrenia who require urgent care.³⁰ This is in large part because the discriminatory federal “Institutions for Mental Disease” (IMD) exclusion prohibits Medicaid coverage for people with schizophrenia who are treated in psychiatric hospitals or other residential treatment facilities with more than 16 beds. Even if there were enough beds, emergency responders can only transport people who agree to be treated. In such moments of medical crisis, the only option is often to call the police, which leads to unnecessary incarceration and lack of proper treatment.

The fragmented and under-resourced system for treating schizophrenia falls woefully short of meeting the complex needs of people with this severe brain disease, particularly at crucial moments when early intervention and comprehensive treatment could alter the trajectory of the illness. The dire consequences of this failing system are amplified for people from historically marginalized communities, who face additional barriers and disparities in care.

A paradigm shift is necessary to create one single, integrated system of care that prioritizes early detection, coordinates care across various health and social services and ensures equitable access.

Call to Action

S&PAA supports funding from the relevant federal, state and/or local resources to accomplish the following aims:

- 1. Early detection of schizophrenia and connection to care.** This includes nationwide training and technical assistance for those who may encounter early psychotic symptoms – such as healthcare providers, family members and educators – to screen and connect to services those at risk of schizophrenia. Funding also should be directed to public health campaigns that focus on early symptoms of psychosis and opportunities for care.
- 2. Build a well-trained schizophrenia workforce.** We endorse efforts, such as those by SAMHSA,³¹ that focus on active recruitment, training, professional development and retention of diverse, qualified people to provide up-to-date, evidence-based, whole-person care for schizophrenia. We encourage the creation and enforcement of clear competencies for those who treat schizophrenia, as well as SAMHSA’s implementation of service grants and technical assistance.
- 3. Develop care models and reimbursement for national integrated care centers to treat the health and social needs of people with schizophrenia.** We endorse policy changes that create incentives to coordinate care across providers through a national network of integrated

care systems for schizophrenia, promoting evidence-based professional development and increasing the supply and capacity of the behavioral health workforce across a spectrum of community-based care settings.

4. **Enforce existing integrated standards of care and policies that promote comprehensive benefits and integrated care systems.** This includes repealing policies, such as the IMD Exclusion and the FDA's restrictive REMS for the drug clozapine, that interfere with the continuum of care for people with schizophrenia. The standards listed in the Mental Health Parity and Addiction Equity Act and the American Psychiatric Association also must be enforced.
5. **Increase the continuum of care for schizophrenia.** This includes financial support of any community efforts to provide a continuum of treatment and recovery care for people with schizophrenia and their caregivers.
6. **Support caregiving.** Non-professional caregivers, such as family members, provide a substantial amount of unpaid support to those with schizophrenia. At a minimum, the federal government should fund outreach, education, training and support for these caregivers.
7. **Implement systematic collection and sharing of data.** Collection and monitoring of data are needed to ensure implementation of the above strategies, foster innovation and promote continuous quality improvement in the care of schizophrenia. This should include the collection of clear diagnostic and symptom information, treatment outcomes and service utilization data to inform best practices and policy decisions.

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