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Schizophrenia Care

A Giving Smarter Guide

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MILKEN INSTITUTE

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Foreword

As the mother of a young man diagnosed with schizophrenia in 2019, I have lived through the uncertainty, fear, and hope that accompany a serious mental illness. For years, our family has focused solely on supporting his recovery—and I am deeply grateful that he is doing remarkably well today.

Recently, though, a new psychiatrist offered a different perspective after a brief evaluation: "I don't think he has schizophrenia. Trust the genetics." He believes it's more likely bipolar disorder, which runs in our family.

I don't always know what to trust. But I do know that I want my son to continue thriving and that we need better science. No family should have to live under the weight of a devastating diagnosis that might not be right. We need biomarkers, less subjectivity, and ways to remove guesswork from mental health care. People deserve the *right diagnosis* and the *right treatment* at the *right time*.

We also need care systems that ensure everyone can access best-in-class, evidence-based treatment. Not everyone can do what I did: I was fortunate to have the flexibility to hold down my second job of caregiving. I scoured the East Coast to find the right care for my son. We spent months taking afternoon hikes because there was nowhere else for him to go. Quality care should not depend on geographic location, resources, or circumstances.

SPARC's publications, *Schizophrenia Research and Care: Assessment of Challenges and Opportunities* and this one, *Schizophrenia Care: A Giving Smarter Guide*, capture a moment of progress and promise. Decades of basic science, clinical innovation, and systems-level reform are converging to reveal a more hopeful reality: With timely, coordinated, and sustained intervention, individuals with schizophrenia can achieve meaningful recovery, education, employment, and community participation. These outcomes were rare a generation ago—and are within reach today.

From a family perspective, these developments represent more than scientific milestones—they signify tangible hope. What the field needs now are sustained partnership and catalytic capital that accelerate innovation, bridge gaps between research and implementation, and scale proven models of care to develop durable systems of recovery and inclusion.

As a parent and a witness to progress, I am deeply grateful to the scientists and other professionals whose work advances this field. Their commitment not only informs best practices but also restores a sense of agency and optimism for families like mine. I hope that with continued investment, every family facing schizophrenia will have that same opportunity—to move beyond crisis toward connection, stability, and hope. The past decade of progress in schizophrenia research and care offers compelling evidence that recovery is not an exception—it is an expectation.

Dana Macher

Executive Summary

Schizophrenia is a serious brain disorder affecting approximately 24 million people worldwide. Effective treatment of this condition requires timely access to comprehensive care that addresses clinical symptoms, supports families, and helps individuals remain connected to their communities.

Ideally, individuals should be introduced to this care system as early as possible, most commonly when they begin to experience psychosis—one of the most prominent symptoms of the condition. However, in reality, psychosis often goes untreated for extended periods. In the US, the median duration of untreated psychosis (DUP) is 74 weeks—almost a year and a half. Without appropriate care, individuals often cycle among emergency services, hospitalization, homelessness, and the criminal justice system. This pattern drives an estimated annual economic burden of over $300 billion in the US, including substantial costs for families, caregivers, and society.

Individuals with schizophrenia need different levels of support, and their needs change over time. Therefore, the care system required to address this condition is multidimensional by necessity. Existing services encompass crisis response; early detection; early intervention; intensive treatment programs; and ongoing support, such as traditional outpatient treatment, Assertive Community Treatment (ACT), and community-based programs. Each of these addresses a subset of individuals' needs, but a lack of connection among programs and services results in a fragmented overall care system. Even when people access intensive early intervention programs, for example, they often face a "care cliff" afterward, experiencing abrupt transitions with insufficient support to maintain long-term recovery.

However, these challenges are not inevitable, and with comprehensive, coordinated care, people with schizophrenia can thrive. In 2025, the Milken Institute's SPARC team published *Schizophrenia Research and Care: Assessment of Challenges and Opportunities*, which examined five key areas: scientific research, clinical treatment, care models, social contexts, and systemic barriers. This companion report examines care models and delivery systems in depth, mapping approaches along a spectrum of support intensity and identifying strategic opportunities for philanthropy.

Our analysis revealed significant gaps throughout the continuum of care for schizophrenia. While robust evidence supports interventions like coordinated specialty care (CSC) for first episode psychosis (FEP), access remains limited by capacity constraints, long waitlists, geographic disparities, and payment barriers. In addition, CSC enrollment is typically limited to one to three years, and after completing the program, many individuals lack sufficient ongoing support in general outpatient psychiatry. Resources for transitional "step-down" programs and longer-term support are limited.

Challenges exist throughout the full spectrum of care. Some effective programs are available only to Medicaid-eligible individuals, while the high costs of other programs restrict access to those who can pay out of pocket. Intensive programs, such as residential options, often have unreasonably short time limits for treatment. Traditional outpatient treatment also suffers from a shortage of specialized providers and a lack of insurance coverage.

Despite these challenges, momentum for change is building. A range of care models—from CSC for early intervention to ACT teams for ongoing support and clubhouses for community connection—have clearly demonstrated efficacy and records of success. Immediate opportunities exist to build on this success and vastly improve care for people affected by schizophrenia.

Opportunities for Philanthropic Impact

This report identifies three opportunities to scale care programs, strengthen care delivery, and improve connectivity across the current fragmented system. Together, these strategies aim to increase access to evidence-based care while building toward sustainable, system-level improvements.

1. **Scale evidence-based care programs.** Many organizations need start-up funding to scale effective care. For example, ACT teams can be financially sustainable once established, but organizations lack funding to start new teams. Establishing clubhouses involves steep upfront costs that grants often do not cover. Philanthropy can provide funding to establish treatment teams or centers that then leverage public funding for ongoing costs.

   Beyond direct funding, technical assistance—including readiness assessments, coaching, and capacity building—helps programs scale with fidelity. Philanthropy could support organizations that facilitate collaborative learning across states or help successful programs expand their capacity to provide guidance.

2. **Strengthen care delivery systems.** After over a decade of CSC implementation, it is time to update the consensus on the core elements of CSC. Philanthropy could facilitate consensus building with far-reaching impact, especially for developing effective adaptations for under-resourced settings. This initiative could be paired with research to identify which program elements are truly essential.

   Care transitions offer critical opportunities for improvement. While developing formal step-down programs takes time, all organizations can work toward providing warm handoffs, or smooth transitions, for individuals moving between levels. Complementing this effort, philanthropy could help establish step-down programs through pilot programs and exploratory grants.

   Additionally, nonprofit organizations like the Schizophrenia & Psychosis Action Alliance (S&PAA), Arizona Mad Moms, CureSZ, and Team Daniel fill gaps by offering peer support and resources for caregivers, and these organizations need resources to further scale their efforts.

3. **Increase connectivity across the care system.** A critical opportunity exists to build a cohesive, integrated system that disrupts the cycle of reliance on crisis and emergency services.

   One approach involves building a network of care centers that meet common criteria and service standards. Starting with CSC as a well-established care model with existing billing codes offers a practical basis for developing such a network. This effort could be organized in multiple ways. For example, a consortium could serve as the convening body to establish criteria and certification processes. The network could also include multiple site designations to accommodate different local contexts while maintaining care standards.

   A complementary approach incentivizes connectivity across existing programs in defined geographic areas. Grants could support partnerships that expand the care continuum—for example, linking CSC programs with clubhouses. This modular approach could help address the care cliff and meet needs beyond early intervention.

There is a considerable gap between current care delivery and a proactive, comprehensive care system that would meet the needs of everyone living with schizophrenia and their families. Based on extensive expert input and literature review, this report identifies key opportunities for philanthropic investment that could lead to meaningful change in schizophrenia care. The report then outlines how these opportunities—if realized—could build toward an aspirational vision of care encompassing the values, standards, and core services that would characterize excellent care.

It will take significant work to align our current system with this vision, but there are immediate opportunities to capitalize on the existing infrastructure, evidence base, and momentum. Strategic investment can scale effective programs, strengthen delivery systems, and build connections that transform fragmented services into coordinated, proactive systems of care. Philanthropy can catalyze these changes by focusing on fundamental gaps not sufficiently covered by sources like public grants or Medicaid, creating incentive structures to encourage connectivity across new and existing organizations. With continued, coordinated effort, the vision of comprehensive care can become a reality for everyone affected by schizophrenia.

Introduction

Schizophrenia is a chronic brain disorder characterized by episodes of **psychosis**—a state of disconnection from reality marked by hallucinations, delusions, and disorganized thinking. These are known as **positive symptoms**. The condition also involves **negative symptoms** such as social withdrawal and diminished emotional expression, as well as **cognitive symptoms** that include memory and attention deficits. Schizophrenia is a heterogeneous condition that presents differently in each person.

The condition affects approximately 24 million people worldwide (WHO 2025), making it a leading cause of disability (Vos et al. 2017). Life expectancy for people with schizophrenia is approximately 15 to 20 years shorter than average, driven by factors including medication side effects and common comorbidities such as cardiovascular disease, substance use disorders, and depression (Correll et al. 2022; Hjorthøj et al. 2017; Olfson et al. 2015).

Beyond affecting diagnosed individuals, schizophrenia profoundly impacts family and community members, many of whom become unpaid caregivers. The extensive indirect costs from unemployment, caregiving, and lost human capital drive a substantial economic burden in the US that exceeds $300 billion annually (Kadakia et al. 2022; S&PAA 2021).

When the mental health–care system fails to provide adequate care, these costs are pushed onto other systems—including emergency services, criminal justice, and housing—with profound consequences for individuals, families, and society. Schizophrenia contributes to well over 500,000 hospitalizations annually in the US (Chen et al. 2021). When symptoms go untreated, individuals often become stuck in a cycle of hospitalization, homelessness, and interaction with the criminal justice system.

Building on Prior Work

In 2025, SPARC released *Schizophrenia Research and Care: Assessment of Challenges and Opportunities*, which provides clinical and scientific background on schizophrenia; examines the lived experience journey, from early symptoms through diagnosis to long-term treatment; and analyzes the funding and investment landscape.

That report explores opportunities for progress across five core areas: scientific research, clinical treatment, models of care, social contexts, and systemic barriers. Our analysis revealed that, despite important advances in understanding the neurobiology of schizophrenia and establishing best practices for early intervention, persistent gaps limit functional outcomes for people with schizophrenia. For instance, antipsychotic medications primarily address positive symptoms like

hallucinations and delusions but inadequately treat negative and cognitive symptoms that most strongly correlate with functional recovery (McCutcheon et al. 2023). Ultimately, only around 20 percent of diagnosed individuals achieve functional recovery, which goes beyond clinical symptom management to encompass meaningful relationships, employment, and activities (Hansen et al. 2023; Jääskeläinen et al. 2013; Valencia et al. 2015).

The Challenge of Fragmented Care

The 2025 report identified fundamental challenges in schizophrenia care delivery that represent opportunities for innovation and investment. Current care systems are fragmented, with insufficient options across the care continuum and limited connectivity among existing programs.

Many individuals first encounter the mental health system during times of acute crisis rather than through proactive detection and early intervention. The median DUP in the US is 74 weeks—nearly a year and a half (Addington et al. 2015; Dixon et al. 2018; Kane et al. 2016)—and can be much longer among people who are unsheltered. This prolonged gap between symptom onset and treatment is associated with worse long-term outcomes and represents a failure of the care system to identify individuals who need care and connect them with appropriate services.

However, substantial improvement is possible. Australia has more developed early detection and intervention solutions that have led to a median DUP of eight weeks (O'Donoghue et al. 2025; Salazar de Pablo et al. 2024). This sharp difference shows that, with the right systems and services, the US could substantially reduce this significant treatment delay for individuals with schizophrenia.

Beyond needs related to early care intervention, several challenges limit the availability of quality treatment. Geographic disparities leave many people without access to specialized mental health services. Capacity constraints, long waitlists, and insurance barriers further limit access to evidence-based interventions. These gaps highlight a critical opportunity to make progress by increasing access to coordinated, evidence-based care.

Focus of This Report

This report takes a close look at models of care and systems of care delivery for schizophrenia. Despite persistent challenges, there is reason for optimism. The schizophrenia field has established clear evidence for what works in early intervention and is poised for breakthroughs in precision medicine. With strategic investment in care delivery systems, individuals with schizophrenia will have the treatment and support they need to thrive. Near-term changes that capitalize on evidence-based best practices and increase access to coordinated care will have far-reaching impact and improve lives today.

The report begins by mapping the landscape of existing care models—from crisis response and early intervention to ongoing recovery support. This is followed by an analysis of care delivery systems that can connect and scale these approaches. This analysis examines both established models with strong evidence bases and emerging approaches that show promise for addressing gaps in the continuum of care. We then propose opportunities to increase access, including strategies for scaling effective programs, building networks of care centers, and fostering collaboration across programs.

Finally, the report concludes with an aspirational vision for delivering comprehensive schizophrenia care, examining foundational values, standards, and core services that characterize excellent care. This vision serves as a guide for future progress. Throughout, our analysis integrates insights from over 70 experts, including individuals with lived experience, clinicians, researchers, and health-care administrators.

Expert Perspectives on Comprehensive Schizophrenia Care

To map the landscape of schizophrenia care and identify opportunities for improvement, we sought to understand and characterize what defines effective care. There are some evidence-based best practices, but the schizophrenia field has not fully settled the question of how effective, comprehensive care is defined and implemented. While no formal consensus exists on comprehensive standards across the full spectrum of care, expert interviews and our review of the literature revealed several consistent themes.

Experts emphasized that schizophrenia care should be person-centered and recovery-oriented, with personalized treatment plans tailored to individual needs and goals. Care should be multimodal, integrating pharmacological treatment with psychosocial interventions like therapy, cognitive remediation, and social skills training. Beyond addressing clinical symptoms, comprehensive care should also encompass multiple life domains—employment, education, housing stability, and family support—all of which impact functional recovery.

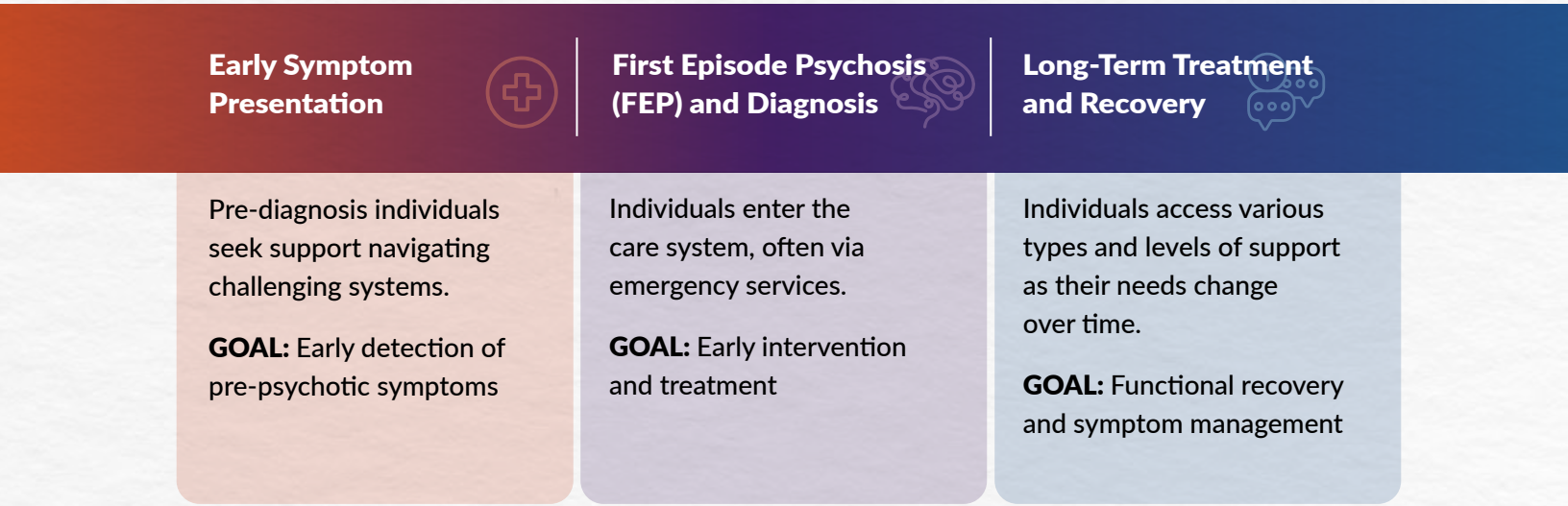
The importance of care coordination and continuity also emerged as a critical theme. Schizophrenia typically requires lifelong treatment, and individuals' needs change over time. Effective care systems provide coordinated support with smooth transitions between programs or across levels of intensity. Systems should also have sufficient capacity to provide timely access to care and respond effectively during crisis.

These expert perspectives informed our analysis of the care models and philanthropic opportunities we present throughout this report. They also point toward an ideal vision of comprehensive care, which we will revisit in the report's conclusion, examining how addressing the opportunities identified here can start building a path toward that future.

Care Models and the Spectrum of Support

Schizophrenia typically requires lifelong treatment, and there is significant variability in individuals' needs over time. As shown in **Figure 1**, people move through different stages of illness and recovery, with evolving needs based on symptoms, treatment response, life circumstances, and personal goals. Individuals experiencing pre-psychotic symptoms might initially benefit from early-detection programs. If they transition to experiencing psychosis, early intervention and accurate diagnosis are key to their recovery. As people move into long-term treatment and recovery, their needs shift toward daily functioning and ongoing symptom management through multimodal therapeutic approaches.

Figure 1: Care Needs Across Stages of Symptom Presentation, Diagnosis, and Treatment



Source: Milken Institute (2026)

This journey is rarely linear; individuals may move between different types of care or experience varying symptoms that require different intensities of support over time. In the following section, we begin by examining crisis response, early detection, and early intervention as critical entry points where many individuals first encounter treatment. This is followed by a section on care options for established illness, organized along a spectrum of support intensity.

Understanding the care landscape is important for identifying where philanthropic investment can have the greatest impact. The current care system is fragmented in ways that leave significant gaps across all phases of treatment and recovery. Some evidence-based models are well established, but individuals face persistent challenges in accessing them. Other models—particularly transitions between levels of support and low-intensity options—are underdeveloped. By understanding the full landscape of available care models and the accessibility barriers that limit their reach, philanthropic efforts can identify strategic opportunities to expand access, improve outcomes, and help individuals find the right level of support at the right time.

Entry to the Care System

Early signs of illness often go unrecognized in many individuals with schizophrenia, who too often do not seek or receive care until it becomes an emergency. This means that entry into the care system often involves hospitalization in inpatient care facilities or law enforcement intervention. This reactive dynamic is far from ideal, but innovative approaches can reduce criminalization and police involvement. Some of these challenges were detailed in our 2025 landscaping analysis (Schumm et al. 2025), and here we provide further context for crisis response as an element of the care model.

Crisis Response and Acute Stabilization

While crisis care is not an optimal avenue for receiving treatment, it remains a core component of the care system. Given its ubiquity, improving the process is essential to supporting the recovery of individuals with schizophrenia or other **serious mental illness (SMI)**. Notably, crisis care is not limited to the early phase of illness, and many individuals with SMI repeatedly encounter criminalization and hospitalization. Although this section focuses on early interventions, the strategies to improve crisis care would benefit individuals across the lifespan of care.

One strategy to improve crisis response involves developing **mobile crisis response** teams, which add mental health professionals as public emergency responders within communities. Although these programs have been shown to be cost effective, they face sustainability challenges in achieving both adequate funding and staffing. It is especially difficult to keep crisis services staffed around the clock.

Another approach is **crisis intervention team programs** for police and other first responders, which raise awareness about treatment options and help them direct individuals to appropriate care, rather than the criminal justice system, whenever possible. Crisis intervention training varies significantly, and resources are needed to bring it to more cities and departments.

Individuals with schizophrenia are sometimes hospitalized through emergency departments to reach acute stabilization. The wait time can be lengthy and the experience traumatizing, which can increase hesitancy and limit the success of treatment. Emergency department personnel often

lack specialized training for treating SMI. Additional training plus greater connectivity between emergency services and specialized treatment centers for schizophrenia and SMI would help. Furthermore, many facilities have insufficient beds within inpatient settings—creating pressure to discharge patients rapidly, limiting the duration of care an individual receives, and perpetuating a cycle of readmission during crises.

Improved crisis response is important, but individuals should not have to wait for crisis to receive treatment. Instead, the system should incentivize early detection and intervention, including the evidence-based options that follow.

Early Detection

Before receiving a diagnosis of schizophrenia, individuals may present with pre-psychotic or subthreshold symptoms. **Clinical high risk (CHR)** refers to people, usually about ages 12–30, who are experiencing symptoms that do not meet full diagnostic criteria and who are at elevated risk of developing psychosis. Approximately one in four individuals at CHR go on to develop psychosis over a three-year period (Salazar de Pablo et al. 2021). While the majority do not progress to psychosis, they may be at risk for other psychiatric conditions, including mood disorders or substance use disorders. Many early-detection efforts focus on the CHR population.

A potential opportunity to improve early detection uses primary care settings to integrate medical and behavioral health care. One such example, the collaborative care model, is discussed further in the section "Strategies and Systems for Care Delivery."

Clinical High Risk Programs

Several programs focus specifically on the CHR population, trying to identify early warning signs of psychosis and intervene early to help young people before a first clear episode of psychosis. There are several such programs throughout the US. (See **Box 1** for examples.) Many of these programs serve individuals at CHR and in the early stages of psychosis and schizophrenia. Most take a stepped approach to care, beginning with low-intensity interventions and progressing to higher intensity only if needed.

Box 1: Examples of Clinical High Risk Programs in the US

- Center for the Assessment and Prevention of Prodromal States (CAPPS) at the University of California, Los Angeles
- Center For Early Detection, Assessment & Response to Risk (CEDAR Clinic) in Massachusetts
- Early Assessment and Support Alliance (EASA) in Oregon
- Early Psychosis Intervention Center (EPICENTER) at The Ohio State University
- Program for Early Assessment, Care, & Study (PEACS) at the University of Colorado Anschutz medical campus
- Psychosis-Risk and Early Psychosis Program Network (PEPPNET) at the INSPIRE Clinic at Stanford University

Orygen is a leading international CHR program based in Australia. Through what it calls "headspace" clinics, the program aims to catch early signs of mental health challenges in young people by making mental health less stigmatized. The program has benefited from substantial government support for youth mental health infrastructure.

US-based CHR programs often face funding sustainability issues due to insurance barriers and billing limitations for preventive care, as payers are often reluctant to reimburse for services provided to individuals who may never develop a psychotic disorder. In addition, there are open scientific questions about who in the CHR population will go on to develop psychosis, schizophrenia, or other diagnoses (Addington et al. 2025; Nelson et al. 2025). (See Schumm et al. 2025 for further discussion.)

Early Intervention: First Episode Psychosis Programs and Coordinated Specialty Care

Coordinated specialty care has emerged as the evidence-based standard for treating individuals in the early stages of psychosis and is the course of treatment recommended by the American Psychiatric Association (Keepers et al. 2020). This period of early onset of symptoms is referred to as **first episode psychosis (FEP)**, encompassing an individual's initial psychotic episode and the phase of early illness up to two to five years (Lundin et al. 2024). Early intervention during this period is a key predictor of long-term outcomes.

The team-based CSC model integrates medication management, psychotherapy, family education and support, employment and educational services, and case management into a unified treatment approach. The comprehensive nature of CSC contrasts with traditional treatment that is both fragmented and often focused only on clinical symptoms. This multimodal approach reflects research showing that addressing clinical symptoms alongside functional recovery and family support yields better long-term outcomes than targeting symptoms alone.

Variations of CSC have been implemented internationally with different parameters, structures, funding models, and service delivery (**Table 1**). In the US, the NAVIGATE model became widely adopted following positive results from the Recovery After an Initial Schizophrenia Episode (RAISE) initiative, which demonstrated superior outcomes compared to standard treatment (Kane et al. 2016). The Substance Abuse and Mental Health Services Administration (SAMHSA) has since supported CSC expansion through its Early Serious Mental Illness initiative, making programs more accessible nationwide (SAMHSA 2025). The Early Psychosis Intervention Network (EPINET) is building on this success, connecting over 100 CSC sites as a learning health system (LHS) to continually improve care delivery (see section "Strategies and Systems for Care Delivery" for further description of LHS). Many CSC programs across the US implement NAVIGATE or similar evidence-based frameworks, though they may operate under different names.

Table 1: Care Models for Early Psychosis

Term	Description
Coordinated Specialty Care (CSC)	A multi-element, team-based approach for early intervention for FEP (Heinssen et al. 2014). CSC is a general framework, not a specific treatment paradigm.
NAVIGATE	A comprehensive CSC program that was rigorously tested in a cluster randomized trial in the US (Kane et al. 2016). Developed as part of the RAISE initiative, it includes individual resiliency training, family psychoeducation, supported employment/education, and medication management (Kane et al. 2016). Uses a manual-based approach with specific modules.
Program for Specialized Treatment in Early Psychosis (STEP)	First comprehensive early intervention service in the US, launched in 2006 as a public-academic collaboration between Connecticut's Department of Mental Health and Addiction Services and Yale University (Srihari et al. 2009). Implemented a pragmatic randomized controlled trial to demonstrate effectiveness (Srihari et al. 2015).
Early Psychosis Prevention and Intervention Centre (EPPIC)	Australian model developed at Orygen with 16 core components and established fidelity measures (McGorry et al. 1996). Focuses on keeping patients on developmental trajectories and uses a recovery-oriented developmental mindset. Has been adapted internationally.
OPUS	Danish model of community-based treatment that incorporates family involvement and social skills training provided by a multidisciplinary team (Nordentoft et al. 2015; Petersen et al. 2005). Although long-term follow-up studies showed effects diminished over time (Secher et al. 2015; Nordentoft 2023), a 2021 study found that OPUS maintained or even exceeded its efficacy when implemented in real-world clinical practice compared to the original randomized trial (Posselt et al. 2021).
Lambeth Early Onset (LEO)	UK community-based approach that involves teams comprising 10 staff members, emphasizing assertive outreach and providing extended-hours services, including weekends and public holidays, for people aged 16–40 who present with first- or second-episode non-affective psychosis (Craig et al. 2004). Evidence-based interventions included low-dose atypical antipsychotic regimens, manualized cognitive behavior therapy protocols, and family counseling and vocational strategies (Craig et al. 2004).

Source: Milken Institute (2026)

Strengths and Limitations of Coordinated Specialty Care

CSC has a robust evidence base, making it one of the most well-established models of schizophrenia care during the early phase of illness. The model's comprehensive, team-based approach addresses multiple dimensions of recovery—clinical symptoms, functional outcomes, family support, and social integration—in a way that fragmented care does not.

However, gaps in access limit the potential impact of CSC. Programs have capacity constraints, long waitlists, and limited geographic availability, particularly in rural and underserved areas. Further, many individuals who could benefit are unaware of the programs, as are their caregivers.

Meanwhile, some individuals are excluded due to age restrictions and early-onset criteria or exclusion criteria related to cannabis use or co-occurring intellectual or developmental disability. This narrow scope has led to concerns that some populations—including adults with established illness or late-onset psychosis—remain underserved. CSC programs also require intensive commitment that many individuals are not ready for, creating gaps for people who need support but are not prepared for full engagement.

Persistent payment barriers further limit access. Despite the availability of Centers for Medicare and Medicaid Services (CMS) billing codes for CSC, implementation gaps limit utilization—many providers are hesitant to use new billing codes, and many states have not set reimbursement rates. CSC programs are not always covered by private insurance.

Enrollment in FEP or CSC programs is often limited to one to three years, even though many people need longer-term care. Transition out of FEP or CSC programs is often to general outpatient psychiatry with a lack of peer support or case management. While "step-down" programs to ease transitions from higher- to lower-intensity and longer-term support models have been recommended, resources are rarely available to implement them. Better tools are also needed to predict which individuals require longer-term intensive support versus those who can successfully transition to less intensive care.

CSC programs need ongoing support to scale effectively, gather longitudinal data, increase access, and establish connections between programs and levels of care. (See section "Philanthropic Opportunities and Proposed Solutions.")

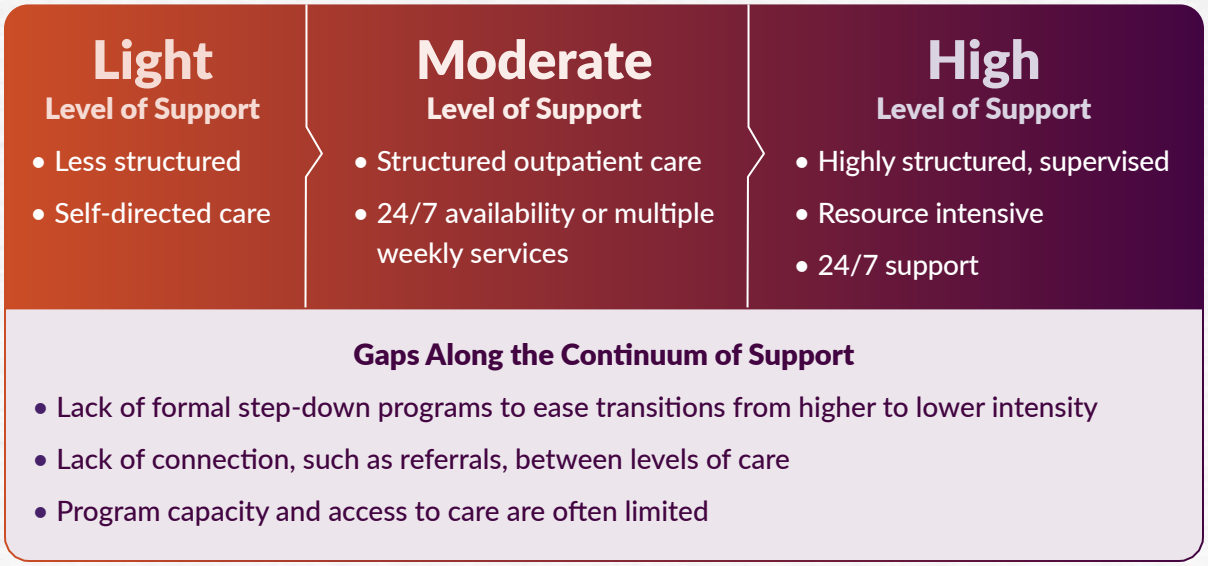
Recovery and Long-Term Treatment Options

Once individuals enter the mental health–care system, their support needs vary considerably and evolve throughout their recovery journeys. At some points, individuals benefit from intensive, team-based care with frequent touchpoints and high structure. At other times, less intensive support with greater autonomy and flexibility is appropriate. Care delivery exists along a spectrum of support intensity that acknowledges the dynamic nature of individual needs. Individuals may move up or down this spectrum over time as their symptoms, functioning, and circumstances change.

The following sections map the landscape of schizophrenia care along a continuum of support, ranging from self-directed, low-level support to highly structured, intensive support (**Figure 2**). We organize care models into three levels of support: light-level support for individuals on stable recovery trajectories, moderate-level support for ongoing recovery and relapse prevention, and high-level support for individuals facing more intensive recovery challenges. These levels differ in structure, supervision, availability, resource intensity, and cadence of touchpoints. Within each level, we describe specific models and programs. This approach helps organize the diverse array of available care models while recognizing that effective care systems are responsive to individuals' unique and evolving needs.

While the continuum provides a useful organizing framework, it is important to recognize that individual programs may fall into multiple categories and that individuals do not necessarily progress linearly through the levels.

Figure 2: Spectrum of Support for Individuals with Schizophrenia



Source: Milken Institute (2026)

Light-Level Support for Lasting Recovery

Light-level support emphasizes self-directed care and personal agency while providing flexible assistance and resources. These less structured approaches focus on building individual skills and offering support that people can access outside an intensive ongoing program. The goal is to empower individuals to manage their own recovery while ensuring help is available when needed.

Traditional Outpatient Treatment

Traditional outpatient treatment consists of individual providers rather than team-based care. These treatment options are more flexible and convenient than structured programs, but individuals seeking outpatient treatment face access challenges, including a lack of referrals and a shortage of specialized providers. Many providers lack the specialized training needed for recognizing and treating SMI and do not accept insurance because of factors such as low reimbursement rates and high administrative burden (Bishop et al. 2014; Donohue et al. 2024). Integration and communication across providers are often inadequate or absent altogether, and case management and wraparound services are lacking. More specialized training and greater dissemination of best practices are needed for improved outpatient treatment and support.

Telehealth and Technology-Enhanced Options

Telehealth and technology-enhanced treatment options offer potential solutions to access challenges, allowing individuals to connect with providers from home, for example. Telehealth can work well for individuals who are already on track with their recovery, but these options typically do not provide enough support for more complex circumstances. Various technology-enhanced options are under development, offering virtual therapy sessions, navigation support, cognitive remediation, goal-setting support, and more. These options can supplement other care models but are not a replacement for them. Human support remains essential for any digital tools used as part of schizophrenia treatment.

Step-Down Programs and Low-Level Care Options

Transitions between levels of support are critical times for maintaining recovery, yet many individuals face a "care cliff" with no structured support after completing intensive programs, risking their progress. **Step-down programs** help individuals transition from higher- to lower-intensity support. One example is Psych Recovery Inc., which helps individuals transition from the University of Minnesota's FEP program. It offers cognitive behavioral therapy for psychosis (CBTp, described in **Box 2**), social skills training, and independent living skills training.

Box 2: Cognitive Behavioral Therapy for Psychosis

CBTp is an evidence-based form of psychotherapy that has been shown to alleviate symptoms and improve functioning for people with psychosis and schizophrenia (Kopelovich et al. 2022; McDonagh et al. 2017; Turner et al. 2020).

Overall, there is a lack of specialized, low-intensity support options for individuals with schizophrenia. Investment is urgently needed to develop more of these programs or to equip existing programs to expand step-down offerings. This may also be an opportunity for technology-enabled solutions to ease transitions.

Moderate-Level Support for Ongoing Recovery

Moderate-support programs offer structured outpatient, or community-based, care with professional support available alongside greater independence in daily living. These programs typically involve multiple weekly services and regular check-ins to maintain stability and prevent crisis situations.

Specialized Outpatient Clinics

Some clinics offer outpatient treatment that is more specialized for schizophrenia or SMI and more structured than traditional outpatient treatment. These clinics typically offer comprehensive care across multiple specialties, including treatment for substance use disorders, which improves care coordination. The Lieber Recovery Clinic at Columbia University and the Schizophrenia Center at Johns Hopkins University School of Medicine are strong examples offering comprehensive care.

One drawback is that these specialized clinics tend to be located at academic medical centers, which are not accessible to many and often have long waitlists for treatment. Another barrier is payment, which is typically a combination of private insurance and self-pay. Philanthropic support could help specialized care centers offer financial aid to extend care to more individuals.

Assertive Community Treatment

ACT is a team-based model that provides multidisciplinary, flexible mental health services and support to people with SMI (SAMHSA 2008a, 2008b). Services typically include nursing, peer support, employment support, and psychiatry. Daily contact is available for those who need it. There can be significant variation in care across ACT teams because it is a multidisciplinary service delivery model, which means it does not prescribe specific treatment parameters.

Unlike in FEP or early intervention programs, ACT teams typically serve those with established, persistent illness for as long as services are needed. ACT can be an option for community-based treatment after CSC or FEP programs if individuals need more support than other outpatient treatment options offer. ACT teams primarily serve those who qualify for Medicaid, though reimbursement rates vary across states (SAMHSA 2023). Private payers have not adopted the model.

Assisted Outpatient Treatment

Assisted outpatient treatment (AOT) is a legal framework for court-ordered outpatient treatment. The legal mechanism enables intervening before crisis or a point of danger, with the goal of preventing further deterioration. AOT is not itself a care model. Rather, it can be thought of as a legal wrapper that requires an individual to engage in community-based treatment, sometimes through an ACT team.

Usually a team-based approach, AOT is intended to address a gap in care continuity, especially for individuals with **anosognosia**, which is the inability to recognize oneself as having a mental illness. This symptom means individuals may not recognize the need for treatment. When properly

implemented, AOT compels bidirectional engagement—the individual must participate in treatment while the care system must invest in and provide services to the individual—rather than relying solely on the individual to seek treatment. The approach is intended to help individuals with SMI remain engaged in the community, but some have raised concerns about the ethics of mandated treatment and the potential for racial bias (Gearing et al. 2024; Hancq et al. 2024).

Evidence for AOT's effectiveness is mixed. A recent report from the US Government Accountability Office (GAO) found results are "inconclusive," in part due to methodological challenges in assessing AOT programs (Broderick 2025; GAO 2025). Results might be difficult to parse due to highly variable implementation quality across state AOT programs. Yet some individuals have found AOT critical for maintaining recovery. Additional research is needed to understand the factors required for successful implementation.

Day Treatment or Partial Hospitalization Programs

Day treatment programs offer highly structured, time-intensive support for those needing more than outpatient treatment but less than residential or inpatient care. Also called **partial hospitalization programs (PHPs)**, day treatment programs are typically five days a week for over five hours a day. Closely related, an **intensive outpatient program (IOP)** is another step down from this level of support, closer to traditional outpatient treatment. A typical IOP schedule might be three days a week for a few hours a day and can be delivered in person or via telehealth.

Some examples of day treatment programs are associated with academic medical centers that have specialized programs for psychosis and schizophrenia—for example, the Lieber Recovery Clinic at Columbia University or McLean Hospital, affiliated with Harvard University. Sometimes a PHP is offered as a step-down transition from residential programs to independent living while continuing day treatment.

There are few of these day treatment programs, and they can be severely time limited, with treatment duration on the order of five days to six weeks. Without the residential component, day treatment programs can be lower cost but require individuals to have stable housing outside the facility, and these programs are still too expensive for many. There is a need for more day treatment options to fill in the continuum of care between residential and outpatient care. Philanthropy could help expand the offerings, and financial aid could help more individuals access them.

High-Level Support for Continuing Recovery

High-level support programs provide intensive, highly structured care with round-the-clock supervision and frequent touchpoints. These resource-intensive models are designed for individuals with complex needs, often serving people experiencing acute symptoms or who need daily professional support.

Residential Programs

Residential programs offer intensive wraparound care, providing comprehensive 24/7 support for individuals who need more than outpatient care but less than inpatient hospitalization. Residential programs can assist with transition support, helping to bridge crisis stabilization and independent community living.

Skyland Trail is a residential facility in Atlanta that offers a structured continuum of support. Most clients are initially admitted to the residential program and gradually transition through stages with less intensive staff support, moving from residential to day treatment to an IOP and finally to outpatient care. Structured support helps clients manage potentially challenging transitions, but this offering is uncommon.

Another example is the Mayo Clinic John E. Herman Home and Treatment Facility. The Herman Home residential program offers multidisciplinary support across psychiatry, psychosocial therapy, skills training, and more. The program serves individuals who are outside the early intervention window, helping them learn to manage their illness and transition to the community.

Major limitations of residential programs are that they typically have a short duration of a few weeks to six months and are often available only to those with private insurance or who can pay out of pocket. Many depend on donations to fill insurance gaps, and additional philanthropic support could provide financial aid for those paying out of pocket or otherwise ineligible for existing programs.

Inpatient Treatment

Inpatient treatment provides intensive, hospital-based, 24/7 care focused on stabilization during times of crisis. These facilities include private hospitals that primarily serve those with private insurance and public facilities that mostly serve individuals who qualify for Medicaid or Medicare. State hospitals are publicly operated facilities that provide multiple types of inpatient care, including long-term treatment and forensic, or mandated, treatment for individuals with SMI who are involved in the criminal justice system. Inpatient treatment typically focuses on medication adjustment, crisis stabilization, and safety. The intensive nature of this environment allows for rapid medication adjustments and close monitoring that is not possible in outpatient settings.

It is impossible to examine the care system for schizophrenia, especially inpatient treatment options, without acknowledging the fraught history of institutionalization and controversies surrounding involuntary commitment. Inpatient treatment is associated with involuntary commitment, which raises concerns about both the history of institutionalization and the potential trauma of being hospitalized when it is not medically necessary. To this day, inpatient settings have significant power imbalances between providers and individuals seeking care, who often feel unheard and dehumanized. There is a growing emphasis on trauma-informed care approaches and patient-centered treatment to address concerns.

These concerns shape ongoing debates about balancing the medical principles of personal autonomy, a value highly prioritized in the US, and beneficence—preventing harm and promoting patient well-being. Some argue that involuntary hospitalization violates individual rights, while others contend it is sometimes medically necessary or necessary for public safety (Laureano et al. 2024). Core symptoms of schizophrenia—hallucinations, delusions, and anosognosia—can prevent individuals from recognizing their need for treatment. For people lacking resources to voluntarily seek treatment due to symptoms of their illness, social determinants of health, or a lack of family or community support, involuntary treatment may provide a way for individuals to regain autonomy and enjoy meaningful lives.

While there are different perspectives on the appropriate criteria for involuntary hospitalization, there is broad agreement that it should be used sparingly and carefully, and overreliance on inpatient treatment indicates upstream failures in the care system. In a functioning system, inpatient care, especially involuntary hospitalization, should be a last resort that is necessary at times for safety concerns but not a common experience. Relying on this intensive treatment is a symptom of a system that failed to serve individuals prior to crisis (Warburton and Stahl 2020; Warburton 2025).

Community Support for Integrated Recovery

Clubhouse Model

In the **clubhouse model**, community is the key therapeutic modality, as members engage in natural social interaction within intentionally designed social environments. Clubhouses provide dignified spaces where members develop an intrinsic sense of value and participate meaningfully in the clubhouse community, rather than simply receiving services. In practice, this means members are involved in the daily operations of the clubhouse, helping to prepare or serve meals, for example. Members work as true partners with staff and receive authentic feedback through shared work.

Fountain House in New York and Magnolia Clubhouse in Ohio are examples of this model, and Clubhouse International provides leadership for model development and guidance (Clubhouse International, n.d.). The communities developed by these organizations empower members by enabling them to shape their environment and influence community decisions. Unlike traditional day treatment or psychosocial therapy, the clubhouse model provides context to implement and practice changes in real-world settings, creating genuine optimism about recovery possibilities.

Clubhouses rely on creative funding models that combine public and private contributions. The organizations face payment system barriers because they do not fit the traditional fee-for-service model, requiring more innovative payment approaches. This is changing as more states now reimburse clubhouse services through Medicaid, though rates are often inadequate. There are opportunities for philanthropic impact in effectively scaling clubhouse models. (See section “Immediate Opportunities to Scale and Strengthen Care.”)

Peer and Family Support

Helping to bridge gaps in the current care system, nonprofit organizations provide peer and family support and educational resources. Examples include Team Daniel, CureSZ, Arizona Mad Moms, and S&PAA. These organizations often integrate individuals with lived experience across many roles, not only for peer support, and they advocate for laws and policies that improve treatment and care for people with SMI. In service of a population with a particularly high caregiver burden, these organizations help families and caregivers navigate complex legal and medical systems while operating primarily on volunteer time and donated resources. To enable their essential work, these organizations need additional resources to meet the high demand for family support services.

Financial Assistance Programs

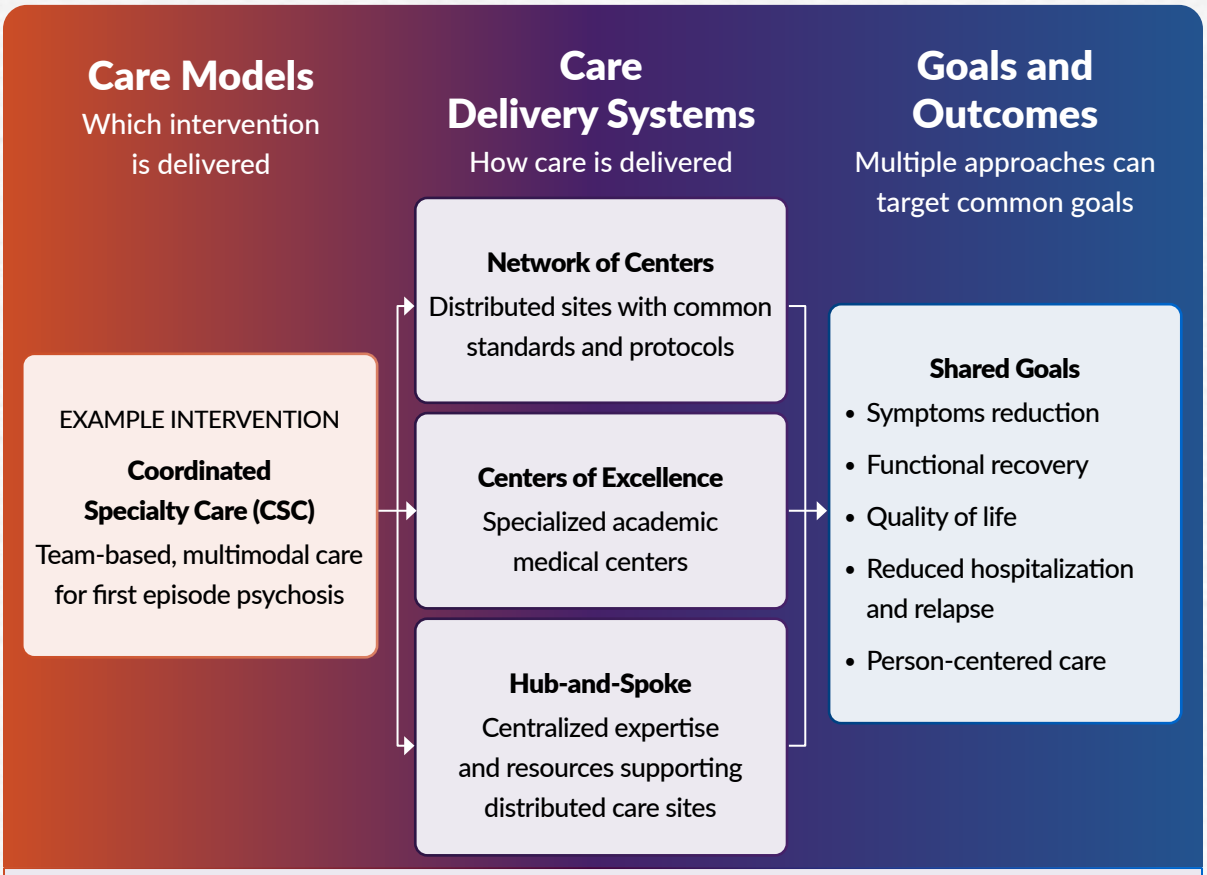
Copay assistance programs provide short-term financial support to help individuals cover out-of-pocket treatment costs, such as medication copays, that they might not otherwise be able to afford. For example, the HealthWell Foundation provides awards up to $4,000 to assist government-insured individuals with schizophrenia (HealthWell Foundation 2024). The PAN Foundation has offered a similar copay grant as well as transportation grants (PAN Foundation, n.d.). By reducing financial barriers to treatment, these grants can improve medication adherence, which is critical for maintaining recovery.

However, while these programs can reduce out-of-pocket costs in the short term for people who are underinsured, they have limited availability and are not a long-term solution. These programs may warrant modest philanthropic support as a stopgap measure, but they are unlikely to represent a high-impact investment given their short-term duration and narrow scope.

Strategies and Systems for Care Delivery

Broadening the lens beyond individual models of care, strategies for care delivery take an overarching approach to delivering services that are effective and accessible (**Figure 3**). These strategies attempt to efficiently match individuals with the care they need and can serve as a wrapper for specific care models. For example, CSC for psychosis and schizophrenia can be nested within these systems or strategies of care delivery. The same intervention can be implemented through multiple delivery systems.

Figure 3: Differentiating Care Models from Care Delivery Systems



Key Takeaway

Care delivery systems are the methods and infrastructure that shape how specific care models, or interventions, reach individuals.

The same intervention—in this example, CSC—can be implemented via multiple approaches that have different advantages depending on the context.

Source: Milken Institute (2026)

Types of Care Delivery Systems for Improving Access to High-Quality Care

We examined care delivery systems across multiple conditions to understand and assess their suitability for meeting the unique needs for treating schizophrenia and improving access to care. These strategies are not mutually exclusive, so an initiative could combine attributes of multiple approaches.

Integrated Care

Integrated care delivers treatment and services across both mental and physical health. This care delivery approach is well suited to addressing not only clinical symptoms of schizophrenia but also common comorbidities and side effects by helping individuals with nutrition, exercise, and sleep. One approach to integrated care is known as the **collaborative care model**, a team-based approach to adding behavioral health interventions to primary care settings so individuals can receive mental and physical health care in one location (SAMHSA 2023). Collaborative care is the most studied behavioral health integration model and is reimbursed by Medicaid, Medicare, and commercial insurance (Reist et al. 2022; SAMHSA 2023). It has proved especially effective for treating depression (Hu et al. 2020).

In the context of schizophrenia, this strategy is likely most effective for early detection and screening. It may also be helpful for treating individuals in stable recovery who need light support for continued recovery or for detecting early indicators of relapse. However, primary care settings have limited utility for addressing needs that require more intensive support.

Certified Community Behavioral Health Clinics (CCBHCs) provide integrated services that address needs across mental health, substance use disorders, physical health, and social services. The specially designated clinics provide integrated care, including 24/7 crisis services, outpatient treatment, and case management. CCBHCs serve all individuals, regardless of insurance status (SAMHSA 2023).

The clinics are supported via federal SAMHSA grants and enhanced Medicaid reimbursement. Congress initially authorized the CCBHC program in 2014 to improve community mental health services (SAMHSA 2023), and it has been consistently renewed. Many experts are excited about the potential of CCBHCs to transform the availability of behavioral health interventions, especially for diverse populations, including veterans and rural communities. For people with schizophrenia, accessibility of care regardless of insurance status is a compelling benefit of the CCBHC delivery and payment model.

Centers of Excellence

Instead of focusing on primary care settings for service delivery, other approaches emphasize the nature of specialty care. One such approach is the **center of excellence (COE)** model. This approach defines excellent care for a condition and establishes standard benchmarks for service delivery. Oncology offers a familiar example; the National Cancer Institute designates centers that meet rigorous standards in conducting groundbreaking cancer research, translating discovery into clinical practice, and providing cutting-edge treatments (National Cancer Institute 2025). This designation gives both patients and health-care providers confidence that the institution is providing specialized, state-of-the-art care.

COE models can be scaled in different ways. In one approach, an organizing body sets the criteria, then individual sites demonstrate that they meet the criteria and apply to receive a certification. In a franchise approach, the criteria are determined centrally, and new centers are established to replicate those core criteria.

Clear standards make the COE model highly effective for scaling and disseminating best practices; however, the model has limitations. For instance, the COE criteria may not be feasible in all settings. Without flexibility to adapt the model, it runs the risk of exacerbating existing health inequities.

In addition, the word "excellence" can drive perceptions of exclusivity, creating barriers that oppose the goal of increasing access. Lastly, franchise models risk establishing new centers without adequate fidelity to the underlying COE standards if technical assistance and support are lacking. This risk could be mitigated by having a rigorous certification process for new centers.

Network of Care Centers

Unlike COE models, where certified centers operate independently, a **network of care centers** links sites that provide high-quality care together. Developing a network of centers requires defining standards for high-quality care and membership requirements. If individual sites are certified as COEs, the COE model can be embedded within the network structure.

Care centers in the network can have different configurations. In one, individual sites host all the services needed to meet the membership criteria. In another approach, multiple locations within a geographic area could collectively meet the requirements to form a care center if no single location meets all the conditions of membership on its own. (See "Case Study: Parkinson's Foundation Global Care Network.")

Alternatively, networks can link multiple levels of care and support under one umbrella. This could involve close partnerships among programs offering complementary types of care. This approach has significant advantages for individuals who can enter the system at multiple points and be directed to the most appropriate care. Because schizophrenia is a life-course illness, this network configuration with multiple types of care is especially compelling for meeting the needs of individuals who often need different levels of support over time. However, including various services increases complexity and potential management challenges. (See "Case Study: Thresholds.")

Hub-and-Spoke Models

Hub-and-spoke models organize service delivery with a central "hub" that provides more specialized services and support while distributed "spoke" sites deliver essential treatments. This strategy has the advantage of covering a larger geographic area with core services and concentrating resources needed for more specialized interventions. The hub-and-spoke configuration is well suited for schizophrenia care in areas with low population density, where individual programs may see too few individuals with schizophrenia to sustain specialized services and expertise on their own.

Hub-and-spoke is an organizing principle that can apply across different types of models. For example, a network could have a hub-and-spoke organization. (See "Case Study: STEP—Connecticut's Learning Health System.")

Learning Health Systems and Learning Health Networks

An **LHS** creates an ongoing feedback loop between care and research, with clinical data continually analyzed to improve future care. An LHS is a dynamic system in which clinical care is grounded in evidence, is responsive to emerging information, and integrates evolving best practices. Key characteristics of an LHS include real-time access to information, incentives aligned to encourage high-value care, and a culture of learning (Committee on the Learning Health Care System in America and Institute of Medicine 2013).

The concept has gained traction in recent years, but fully realizing its potential remains aspirational. Most initiatives have been developed in specific areas, such as oncology (Pomare et al. 2022). (See "Case Study: STEP—Connecticut's Learning Health System.")

A **learning health network (LHN)** expands the LHS approach by connecting multiple organizations, such as multiple hospital systems, into a larger network to improve knowledge sharing on a larger scale. These networks can also include patient registries to facilitate research and aggregate larger clinical datasets across smaller programs. EPINET was designed as an LHN for psychosis and schizophrenia. Another example, focused on bipolar disorder, stems from Breakthrough Discoveries for thriving with Bipolar Disorder (BD^2). The BD^2 Integrated Network involves systematic, longitudinal data collection to facilitate scientific discovery alongside implementation of evidence-based clinical best practices for treating bipolar disorder within an LHN framework.

With embedded research capabilities and data feedback for continuous improvement, a learning health approach has important benefits over standard practice. Most health-care systems lack population-level outcome data to guide improvement. LHS and LHN models enable continuous care improvement while remaining research-friendly for recruitment and testing new interventions. This is especially valuable for schizophrenia, where improved treatment options are urgently needed.

Quality Improvement Collaboratives

Quality improvement collaboratives, sometimes called learning collaboratives, are initiatives to collectively share knowledge and improve quality or best practices across multiple institutions (Gotham et al. 2022). Unlike an LHS or LHN, these initiatives are time limited with defined implementation goals. They are usually led by an external organization that temporarily brings together teams across multiple organizations to collaborate, share information, and provide technical assistance.

Quality improvement collaboratives can be highly effective for implementing known best practices. However, the time-limited nature of the strategy makes it poorly suited for ongoing research and developing new approaches. For schizophrenia care, this strategy could improve fidelity to known best practices, but fully meeting the needs of individuals with schizophrenia requires long-term, research-oriented solutions to develop better treatments.

Case Studies of Systems of Care Delivery

Case studies offer concrete examples of how organizations address complex care needs and improve access to high-quality services. The following sections profile three distinct approaches to care delivery, selected to illustrate care delivery strategies in practice. The Thresholds organization demonstrates integrated care and networked services in one localized region. The Parkinson's Foundation Global Care Network (GCN) exemplifies a multitiered network of care centers with a COE model. Although it is not an example from the schizophrenia field, the Parkinson's Foundation model offers a well-established network model with relevant lessons for similar efforts to provide treatment for complex conditions. Finally, the STEP Learning Health System illustrates a statewide hub-and-spoke structure for early intervention.

Each case study examines the organization's structure, funding model, operational approach, and demonstrated impact. Together, these examples illustrate different solutions for expanding access, maintaining care quality, and navigating the trade-offs inherent in building effective systems of care.

Case Study: Thresholds

Profile of Organization and Services

Thresholds is a large community mental health organization in Chicago that was founded in 1959 (**Box 3**). The organization serves approximately 10,000 people annually, focusing primarily on individuals with SMI who are eligible for Medicaid. Thresholds links various integrated health services across the full continuum of care—including crisis response, team-based treatment, smoking cessation support, and housing and employment assistance programs. An individual can receive full wraparound support under the Thresholds umbrella.

Box 3: Overview of Thresholds

Vision: Home | Health | Hope

Location: Chicago, IL

Thresholds provides comprehensive wraparound services across the full continuum of care. The community mental health organization serves approximately 10,000 people annually, focusing primarily on individuals with SMI who are eligible for Medicaid.

Thresholds serves a heterogeneous population. Over one-third of clients have a schizophrenia spectrum disorder, with other diagnoses across bipolar disorder, major depressive disorder, and other mental health conditions. It serves diverse populations, including young adults, veterans, young mothers, and individuals with hearing loss. In addition, Thresholds has citywide outreach programs for people experiencing homelessness, designed to meet people where they are.

Thresholds offers a wide variety of integrated health services. The crisis response services offer 24/7 support. The Mobile Crisis Response Team is staffed by clinicians and peer support specialists, providing on-site emergency mental health intervention and assessment. Another service for mental health crisis support called "The Living Room: Forever Hope" is a peer-led center offering a safe, calming space available 24/7 as an alternative to psychiatric hospitalization. The center recently expanded to include two beds that allow up to 48-hour stays.

Thresholds has a unique three-tiered service structure to provide ongoing treatment. The structure allows flexible movement among three evidence-based levels of care based on individual needs. Having multiple levels of service available under one umbrella facilitates more seamless transitions for clients. The levels are:

- **ACT**—ACT teams represent the highest level of support, serving 300–400 people with the highest needs. The teams consist of six to seven staff—including a nurse, peer specialist, employment specialist, substance use specialist, and psychiatric staff—and provide daily contact for those who need it.
- **Community Support Team**—These teams serve over 1,000 people, providing a team-based approach to care as a step-down option from ACT.
- **Community Support Individual**—This level serves 1,000–2,000 people with the lightest-touch care and follows an individual caseload model rather than a team-based model.

Profile of Resources and Operations

Organizational Structure

The organization has over 1,300 staff with 184 clinical teams and operates 1,250 managed housing units (Thresholds 2024). Thresholds' sites in Chicago include four Federally Qualified Health Centers (FQHCs) that the organization established to serve as partners for primary care and expand its integrated care services. It also operates CCBHCs. These comprehensive service sites are designed to mimic FQHCs for mental health care and help extend the continuum of care by integrating a wide range of supports. This emerging service delivery model offers a pathway to sustainable reimbursement for behavioral health interventions and can support individuals during transitions from more intensive care programs (see section "Strategies and Systems for Care Delivery").

Thresholds works with several partners to realize its wide-ranging objectives. For example, the Narcotics Arrest Diversion Program with the Chicago Police Department represents an innovative approach to criminal justice diversion. Thresholds actively conducted outreach to help defer people

to treatment rather than institutionalization. Researchers from the University of Chicago Crime Lab and Vanderbilt University evaluated the program and found that it significantly reduces re-arrest rates (Bellquist and Bencsik, n.d.).

In another collaboration, Thresholds' research department worked with researchers at Dartmouth and Boston University to develop the Individual Placement and Support (IPS) model for supported employment. This model seeks to find employment opportunities for individuals in the community, moving toward greater community integration and away from nonintegrated work settings.

Funding

Thresholds relies on a mix of public support, private contributions, and other revenue. Public support from a combination of Medicaid and other government services accounts for over 80 percent of total revenue (Thresholds 2024). Private contributions can vary significantly from year to year, depending on large individual gifts. Case management and care comprised the largest expense category at nearly 50 percent of fiscal year (FY) 2024 expenses, followed by independent living at 21 percent (Thresholds 2024). Integration with FQHCs and CCBHCs helps enable sustainable funding.

Impact and Notable Results

The organization is also involved in outcomes research, evaluation, and implementation science. Over the past 13 years, Thresholds has successfully transitioned over 1,500 people from institutional settings (primarily specialized mental health rehabilitation facilities, formerly called institutions for mental disease) to community-based care. This represents not only an important opportunity but also hope for individuals who had been resigned to living in institutions and can now reintegrate into community settings.

In FY 2025, Thresholds served over 13,000 clients (Thresholds, n.d.). Many of these might be single or short-term interactions, but many people receive ongoing care through Thresholds. The organization also reported several notable results for FY 2024 (Thresholds 2024):

- Ninety-seven percent of all clients showed confidence in their recovery.
- Ninety-six percent of people who received crisis intervention through The Living Room: Forever Hope successfully deterred hospitalization.
- Nine hundred thirty-eight people avoided arrest or incarceration through the Narcotics Arrest Diversion Program.
- Fifty-one percent of clients enrolled in IPS-supported employment services found jobs.

These metrics demonstrate the organization's wide-ranging success and tangible impact on clients' well-being.

Takeaways for Improving Schizophrenia Care

Continuum of services: Thresholds offers comprehensive, integrated services, which it has organically built up over its decades-long history. This gives the organization a solution-oriented ethos that prizes resourcefulness. Offering services that span the continuum of care is key to serving individuals with SMI, including those with schizophrenia, whose needs change over time. Replicating this model in a different city or region will take time, effort, and intention, and unique challenges will arise depending on local contexts. Other organizations might not be positioned to follow Thresholds' approach directly, but they could rely on strong partnerships to replicate a similar spectrum of services.

Importance of stable housing: Thresholds emphasizes that housing is foundational to successful mental health–care treatment. A foundation of stable housing is critical but often difficult to implement, especially in locations where housing is at a premium. Housing may not be a practical place to begin for other organizations seeking to replicate this success, in which case partnerships could help with housing assistance.

Importance of peer support: Peers and staff with lived experience are integrated across all service types. This is important for building engagement and trust and is replicable elsewhere.

Operational considerations and staffing: Thresholds aims to meet people where they are, actively pursuing engagement. This approach can be highly resource intensive. For example, staffing 24/7 crisis response services is an ongoing challenge, but one that the team believes is critical to meet. Building this type of care delivery system also requires infrastructure that supports a strong intake department for placement and for managing transitions between service levels and geographic areas within the system.

Funding insights: Thresholds offers insight into sustainable funding models through how it leverages public funding for core services, such as ACT teams, FQHCs, and CCBHCs. This public funding is key to sustainability; however, this approach assumes sufficient Medicaid reimbursement rates for services. Sustainable public funding levels depend on state policies, particularly Medicaid reimbursement rates. These rates are sufficient for Illinois, but they might not be elsewhere.

Moreover, establishing the teams and services in the first place requires start-up or seed funding, which is not necessarily covered by public grants or other means. Philanthropic funding can play a key role in catalyzing the establishment of a similar organization.

Case Study: Parkinson's Foundation Global Care Network

Profile of Organization

The Parkinson's Foundation was formed in 2016 via the merger of the National Parkinson Foundation and the Parkinson's Disease Foundation, both established in 1957 (Parkinson's Foundation, n.d.-b). One of the foundation's priorities is connecting individuals living with Parkinson's disease (PD) to the care they need (**Box 4**).

Box 4: Overview of the Parkinson's Foundation Global Care Network

Vision: Better Lives. Together.

Location: International

The Parkinson's Foundation GCN connects people diagnosed with PD with excellent clinical care through a network of care centers. The network has multiple designations for sites, including COEs and comprehensive care centers, to accommodate different types of high-quality care.

The Parkinson's Foundation has activities across three core areas: education, research, and care. The GCN is one of the core initiatives under the care pillar. The GCN was designed to create more opportunities for people with PD to access high-quality care while providing health professionals the chance to advance and share their knowledge. This network approach has useful lessons for other conditions with complex treatment, such as schizophrenia and SMI.

Development of the GCN began in 2003, when the first formal committee met to establish the initial evaluation criteria and application process for new centers. Over time, the network has grown, and evaluation criteria have evolved with the addition of site visits. As of 2024, the GCN included over 60 centers worldwide (50 in the US), serving approximately 200,000 individuals annually (Parkinson's Foundation 2024).

Profile of Resources and Operations

Organizational Structure

The GCN balances high standards of excellence with geographic accessibility via a three-tier designation system for certified care centers (Parkinson's Foundation, n.d.-a):

- **COEs (54 total, 40 in the US)**—These are typically academic medical centers that are required to provide comprehensive care from specialized professionals, maintain both professional and community education and outreach, and conduct PD research.
- **Comprehensive Care Centers (10 total, all in the US)**—These centers are high-volume clinics that provide excellent care and meet education and outreach criteria but without a research mandate. They may not be located at academic centers, so they have a broader geographic reach.

- **Network of Excellence (one in Italy)**—This designation is for multiple sites that collectively provide excellence across one region, each with different strengths (e.g., rehabilitation medicine, genetics research), coordinated by a single director.

To qualify as a COE, centers must satisfy criteria that include meeting a minimum caseload volume, providing comprehensive care across symptom domains of PD, having the capacity to promptly triage and manage urgent care needs, and supporting ongoing quality improvement efforts. They must provide team-based care with specialized personnel in key disciplines (neurology, psychology, neurosurgery, social work, nursing) plus access to other professionals (physical therapists, occupational therapists, speech-language pathologists, genetic counselors, pharmacists). In addition to the criteria for evidence-based, comprehensive care, COE sites must engage in professional education and training, community education and outreach, and research.

Certified sites in the GCN also have infrastructure and staffing requirements, such as having a medical director and a designated coordinator to serve as liaison between the institution and the foundation. They must recertify every five years and complete annual surveys.

The Parkinson's Foundation infrastructure needs include designated personnel for program operations and management, efficient back-office systems, and technology platforms for data collection and analysis. In addition, cross-organizational collaboration capabilities within the foundation are critical, and established processes, methods, policies, and agreement templates help ensure smooth operations. The foundation also provides modest payments to certified care centers.

Funding

The Parkinson's Foundation's total revenue for FY 2023–24 totaled nearly $56 million (Parkinson's Foundation 2024). Operating expenses were $52 million, with 83 percent spent on mission-related activities, such as the GCN, and 17 percent going toward fundraising and management. Mission-related activities include:

- **educating** and empowering people with and affected by PD (40 percent)
- understanding PD through **research** (36 percent)
- ensuring better outcomes through improved **care** (24 percent), which totaled over $10 million in annual expenses, including GCN payments to care centers

Impact and Notable Results

Nearly 200,000 people receive treatment within the GCN, making it the largest global network of medical centers that specialize in PD care (Parkinson's Foundation 2024). In 2009, the foundation launched the Parkinson's Outcomes Project, which recruited 13,000 patients from the GCN's COEs to improve understanding of best care practices. Studies used metrics like low fall rates to identify high-performing centers and characteristics of the highest-quality care. Researchers published findings in relevant journals and shared them with the field.

Despite these indicators of reach and impact, an analysis of Medicare data from 2019 found ongoing gaps in access to specialists, highlighting a need for more specialized training for providers and increasing awareness and access for patients (Pearson et al. 2023). This study did not specifically interrogate the role of the GCN; however, in the context of the GCN, these results suggest that a network of care centers can increase access to treatment, but alone, is insufficient to ensure access to specialized treatment.

Takeaways for Improving Schizophrenia Care

International reach: The GCN's international approach adds value to the network but also increases complexity. It can be more difficult to manage partnerships, fundraising events, research collaborations, and expectations across US and international centers. For schizophrenia, there are some excellent international models of care, which could be advantageous to work with. However, given the fragmented nature of the care system in the US, it might be more effective to start nationally before scaling internationally.

COE model: This model, or similar adaptations, has been implemented for other conditions with complex care needs, including Huntington's disease and amyotrophic lateral sclerosis (ALS), indicating strong potential for replication. An important drawback of the COE model, though, is limited geographic reach, which is often constrained to areas with existing infrastructure.

In 2021, the Parkinson's Foundation had an initiative to expand the GCN beyond metropolitan centers into areas where the foundation previously had limited presence. Maintaining standards while expanding access to underserved areas remains a challenging balance to strike. Any COE model for schizophrenia would need to address these challenges of reach and equitable access. An additional complication for schizophrenia is the need for lifetime care, where the specific needs, standards, and best practices may necessarily vary across the life course.

Resources needed: The rigorous GCN vetting process includes site visits, which are critical but resource intensive. Developing a network of care centers requires both upfront investments to build evaluation infrastructure and sustainable funding to cover annual operating costs for center funding and administrative overhead.

Culture and collaboration: The foundation works to create a collaborative ecosystem with the GCN. It is critical for the initiative's success that the centers understand the expectations for their full participation and view the relationship as enriching their work overall, rather than merely transactional.

Case Study: STEP—Connecticut's Learning Health System

Profile of Organization

The Program for Specialized Treatment Early in Psychosis (STEP) Learning Health System is a system of care for individuals with recent-onset psychosis and schizophrenia in Connecticut (**Box 5**). The system consists of a network of clinics that provide early intervention care for psychosis. It is a public-academic partnership between the state of Connecticut and Yale's STEP Program. It has an LHS design to learn from outcomes data and continue to improve clinical care. (Note: Although the STEP team refers to the statewide system as the "STEP Learning Collaborative," we use "STEP Learning Health System" throughout this report for clarity and consistency with standard terminology because the model functions as an LHS.)

Box 5: Overview of the STEP Learning Health System

Mission: To transform access and quality of care for all individuals with recent-onset psychosis and schizophrenia spectrum disorders

Location: Connecticut

The STEP Learning Health System is a public–academic partnership that utilizes the public mental health infrastructure in Connecticut to deliver high-quality care for recent-onset psychosis within an LHS designed to continually improve best practices.

The STEP Learning Health System grew out of the Yale STEP Clinic, which began in 2006 as one of the first CSC programs in the US. The STEP Clinic aims to model best-practice care for other partner sites and conducts research to continue improving clinical care. STEP's original Early Intervention Service served a 10-town catchment area (population of about 400,000) in Greater New Haven, representing less than 10 percent of estimated new cases in Connecticut (Yoviene Sykes et al. 2025). Growing interest in expanding access to best-practice care for FEP led to a statewide planning initiative with a committee established in 2021 (Yoviene Sykes et al. 2025). The committee partnered with local mental health authorities across all five regions of Connecticut to expand statewide.

STEP carries out several activities across six core work streams: early detection, workforce development, informatics, stakeholder engagement, sustainability (i.e., in terms of financial model and policy advocacy), and continued refinement of the care model. The system serves individuals ages 16–35 with recent-onset schizophrenia spectrum disorders, regardless of their insurance status. The STEP Early Intervention Service Care Pathway consists of four stages:

1. early detection
2. evaluation and initiation of treatment
3. continuing treatment in CSC
4. care transition, including referral to local outpatient providers

Profile of Resources and Operations

Organizational Structure

The STEP Learning Health System operates statewide with a hub-and-spoke organization that relies on community mental health centers. Yale's STEP Program serves as the organizing and expert hub, providing technical assistance, training, and quality assurance; it also operates the STEP Clinic based at Yale. Regional spokes extend throughout the state. Each of the five regions has an early detection and assessment coordinator who manages central referral lines, assesses eligibility, and supports engagement (Yoviene Sykes et al. 2025).

As a public-academic partnership, this model leverages Connecticut's mental health infrastructure by partnering with local mental health authorities across the state. The Connecticut Department of Mental Health and Addiction Services is the primary state partner providing operational funding and policy support. Meanwhile, the Yale University Department of Psychiatry provides research expertise and faculty leadership and serves as the organizing hub. Thirteen local mental health authorities across five regions of Connecticut serve as primary service delivery sites, with over 20 clinical locations.

Funding Model

The STEP Learning Health System is supported through a combination of time-limited grants for research activities and public funding for implementation and operational costs. STEP was originally supported via Connecticut Mental Health Center funding. Since 2013, the Connecticut state legislature has provided specific FEP allocations that help support STEP's operational costs. SAMHSA Mental Health Block Grant funds have also supported STEP operational costs since 2014. Grants from the National Institutes of Health and research foundations have supported research activities.

In sum, the STEP Learning Health System "is stably supported by recurring implementation funds, while competing for time-limited research grants to study and further refine the service model" (Yoviene Sykes et al. 2025).

Impact and Notable Results

The STEP Learning Health System's goals include advancing access outcomes, such as improving local pathways to care and reducing DUP, and population health outcomes, including enhancing broader health metrics across the served population (hospitalizations, remission, vocational engagement, cardiovascular risk, suicide prevention). In one example, STEP's early-detection campaign, called Mindmap, successfully reduced DUP by half across a 10-town catchment area (Gallagher et al. 2022). In addition, STEP aims to meet or exceed international benchmarks for access and outcomes of care.

Takeaways for Improving Schizophrenia Care

Advantages of the LHS design: The LHS approach facilitates sharing knowledge across sites, with an emphasis on engaging in quality improvement. This approach is especially advantageous for developing scalable solutions for complex interventions, such as early psychosis care. Complex interventions require iterative changes over patients' lifetimes, vary significantly between patients, and must be responsive to local contexts. Unlike the "pipeline model," in which development and implementation follow linear stages, an LHS adapts iteratively to local contexts and patient needs.

One of the key benefits of the LHS approach is that research and implementation are integrated with care, rather than sequential. This model or a similar one could have significant impact by improving fidelity to evidence-based care. Current evidence-based practices could improve outcomes for people living with schizophrenia if such practices were consistently implemented.

Utilizing existing infrastructure: This model uses the public mental health infrastructure in Connecticut, demonstrating how to build on existing infrastructure rather than create entirely new systems. It uses a hub-and-spoke structure in which not all sites are CSC centers. STEP leadership determined that increasing access, given the existing infrastructure, was the highest priority. This could be a useful model in other regions, but the drawback is that individuals may need to travel further for specialty care.

Lessons on scaling: STEP took a phased approach to building toward a statewide system in which everyone with schizophrenia lives fulfilling lives. Phase 1 focused on transforming access to care; success will be assessed by measuring DUP. Phase 2 focuses on transforming care quality; success will be assessed via population health outcomes. This is an example of a phased approach that could be adapted for other locations and contexts.

STEP leadership outlined lessons learned and subsequent recommendations, including expecting variation in clinical operations across sites in the network and anticipating the need for reorientation (Yoviene Sykes et al. 2025). To further support scaling, STEP could develop materials, such as templates, training materials, and technical specifications, for implementation in other regions. In fact, some team members established STEP Forward, a consulting service to help others build LHSs.

The biggest limitation of this model is the same as for other early intervention services: It serves those within three years of symptom onset. Many people who need care fall outside this window or require long-term services. However, the program could potentially expand with additional time and resources.

Funding insights: This model works in Connecticut partly because the state is willing to provide care to commercially insured individuals in the public system. Scaling nationally would require alternative payment models. Importantly, effective early intervention can prevent more expensive downstream costs (e.g., hospitalization, incarceration, homelessness).

Key Themes Across Case Studies

Looking across these case studies, a few themes emerge that offer guidance to other initiatives.

Growth and scaling should be intentional and evidence based.

These initiatives each originated as smaller, more targeted efforts and evolved over the span of years or decades. Thresholds has added services to its network over decades, building what was needed when it was unavailable. The Parkinson's Foundation GCN has grown intentionally, revamping its certification process as needed. STEP is also an example of intentional, phased expansion.

To facilitate strategic decision-making and scaling, these organizations all integrate measurement, conducting or collaborating on research initiatives, implementation studies, and outcomes research. Each has an ethos of ongoing improvement, and they use this information to continue improving care outcomes.

Each organization demonstrates different solutions to expand access to high-quality care and extend the continuum of care from a given starting point. This suggests that starting with core components and scaling systematically might be a sustainable strategy for replicating their success in other contexts.

Flexibility and adaptability are key to problem solving and accommodating different contexts.

All three organizations demonstrate the need to reorient and adapt to creatively solve problems. For example, although the COE model can be seen as rigid, the Parkinson's Foundation GCN developed multiple tiers or designations to meet different needs and accommodate different contexts. STEP emphasizes that local adaptations contribute to the system's success. Rather than remaining rigid in the face of changing needs, these organizations are dynamic and responsive, embracing the variation inherent across contexts.

Partnerships and convening power are fundamental to implementation success.

Each of these examples highlights the need for partnerships to realize ambitious objectives. STEP is a public-academic partnership bringing together academic experts with state mental health authorities. In the GCN, the Parkinson's Foundation functions as a convener working with many individual medical centers. Thresholds is an umbrella for networked levels of care and works with external partners for research goals. Each example reflects strong leadership and convening power, which are necessary to assemble key partners and direct them toward a shared objective.

Partnership is reflected not only in who is around the table but also in the funding models of these initiatives. Each reflects some combination of public and private funding sources, also highlighting flexibility and creativity.

Navigating trade-offs will result in different solutions.

Considering the case studies in aggregate highlights how each organization has had to navigate trade-offs. For example, upholding high standards of excellence can be in tension with the goal of expanding access and reach. The GCN addressed this tension by introducing multiple designation levels, while STEP uses a hub-and-spoke strategy. This introduces another consideration—balancing decision-making and resources among more centralized hubs and distributed centers.

Another potential tradeoff is between utilizing existing infrastructure versus building new solutions. STEP relies on existing state mental health infrastructure, but doing so might not be practical in states without sufficient investment or community infrastructure. Meanwhile, building solutions (like Thresholds has) is appealing because the solutions can be designed to be specifically fit-for-purpose, but this approach can have higher demands for capital and upfront investment. These examples illustrate the challenge of seeking a balance between ideal and pragmatic solutions.

Together, the case studies reveal different structural solutions to these tensions. Importantly, navigating these trade-offs—alongside unique contexts, challenges, and distinct goals—will result in different solutions. For example, the Parkinson's Foundation GCN and STEP Learning Health System arrived at different solutions for optimizing access. STEP's centralized hub-and-spoke approach works well for Connecticut, with its limited geography, whereas the GCN's distributed COE network has international reach.

Philanthropic Opportunities and Proposed Solutions

Our analysis revealed significant gaps along the continuum of support for schizophrenia. Despite robust evidence for some best practices, the system remains fragmented, with individuals and their families struggling to access quality treatment and wraparound support. Though challenging, these problems are not intractable: There are clear steps forward to improve care for people affected by schizophrenia.

Here, we outline actionable opportunities for philanthropy to make progress in expanding access to high-quality schizophrenia care. The opportunities are presented in two categories: 1) immediate opportunities that can be implemented through direct funding and technical assistance and 2) opportunities to improve connectivity across the fragmented care system to create a more cohesive, integrated ecosystem of support. Together, these strategies aim to increase access to evidence-based care in the near term while building toward sustainable, long-term improvements in schizophrenia care.

Immediate Opportunities to Scale and Strengthen Care

Comprehensively addressing the needs of people with schizophrenia implicates multiple systems, including health care, payment and reimbursement, criminal justice, and housing. (See *Schizophrenia Research and Care: Assessment of Challenges and Opportunities* for further discussion.) Changing the policies of these systems takes time and concerted effort. However, some opportunities to increase access to high-quality schizophrenia care are actionable sooner. Philanthropy can have an outsized impact by focusing on fundamental gaps, such as essential start-up costs and coordination infrastructure, that are not sufficiently covered by federal grants, Medicaid, or other funding sources. Philanthropy is poised to make an immediate impact through such opportunities.

Opportunity 1: Scale Evidence-Based Care Programs

Many organizations need additional start-up or seed funding to scale effective care. Philanthropy's adaptability and flexibility make it uniquely valuable for responding to emerging needs and filling critical gaps. Specifically, philanthropy is well positioned to provide funding to establish new programs that can then leverage public funding and other funding sources for ongoing operational costs.

Approach 1.1: Provide Start-Up or Seed Funding for Scaling Evidence-Based Care

ACT teams can be financially sustainable once established, but many organizations lack the funding to start new teams. Philanthropy can provide funding to partners, such as Thresholds, to create new ACT or mobile response teams, including specialized teams focused on the needs of young adults, for example. Similarly, establishing new clubhouses can have steep upfront costs for infrastructure, but grants often do not cover capital expenses for building acquisition or renovation. Philanthropy can cover or defray these costs to help establish centers that can then utilize public funding and other funding sources for ongoing operational costs. This is one of the most immediately actionable opportunities for philanthropy.

Approach 1.2: Expand Technical Assistance for Growth and Scaling

Technical assistance provides targeted support to help organizations implement new programs and build capacity. Simply providing funding and a set of care standards is insufficient to franchise or scale programs with fidelity. To help programs with implementation and scaling, **technical assistance** can include readiness assessments to determine whether organizations have the infrastructure and capacity needed for successful program implementation, coaching to help programs navigate implementation challenges, consulting on process or program development, and capacity-building support.

Normally, the federal government, through agencies like SAMHSA and CMS, takes an active role in providing technical assistance to help states set Medicaid rates and develop certification processes. However, with limited federal investment, philanthropy could step into the gap to facilitate knowledge sharing and technical assistance. Organizations like the National Association of State Mental Health Program Directors are well positioned to provide technical assistance and facilitate collaborative learning across states. Philanthropy could also support organizations with successful programs, such as STEP, Fountain House, or Clubhouse Ohio, to help them expand their capacity to provide technical assistance to nascent programs.

Opportunity 2: Strengthen Care Delivery Systems

Meaningful progress to strengthen care delivery can be made by advancing clinical consensus around effective care, strengthening connections across fragmented care settings, and scaling organizations that provide essential support to individuals and families. With its convening power, philanthropy can drive change by aligning stakeholders around shared values and serving as a neutral facilitator to build consensus among diverse sectors.

Approach 2.1: Update the Consensus on Core Elements of CSC

With over 10 years of CSC implementation across the US, it is time to revisit and update the consensus. This work was put on hold as the federal government's priorities have shifted. To avoid losing this momentum and knowledge, philanthropy could step in to facilitate consensus building. This information could have far-reaching impact, especially because this information is needed to develop the most effective, economical adaptations for under-resourced settings.

Ideally, this effort would be paired with formal deconstructing studies to empirically determine which elements of CSC and schizophrenia care are essential to successful outcomes. Philanthropic support for deconstructing studies could enable a clearer understanding of how to translate a successful schizophrenia care program to a new context.

Approach 2.2: Support Care Transitions to Reinforce the Care Continuum

The ideal care system would include step-down programs to ease care transitions. However, meaningful progress can be made through simpler approaches that don't require new programs. Warm handoffs to the next step in someone's care journey can be equally impactful and represent an immediate improvement opportunity for all organizations.

Although developing formal step-down programs will take more time and investment, all care organizations can work toward providing warm handoffs for individuals who come through their programs to help them transition between levels of care. This will require time and intentionality, especially from providers who already face challenging demands, but it can be a simple matter to ask individuals receiving treatment about their next steps and help them develop a plan. Organizations should provide resources to make this a regular part of treatment.

Philanthropy can support this work by funding care coordination positions, transition planning tools, or programs that help organizations develop resources to support care transitions. Alongside these efforts, philanthropy could help establish step-down programs by supporting pilot programs and exploratory grants.

Approach 2.3: Promote Organizations Offering Community Support

Nonprofit organizations like S&PAA, Arizona Mad Moms, CureSZ, and Team Daniel have been filling gaps in the fragmented care system for some time, offering peer support and resources for caregivers and families. These organizations will continue to play this vital role but they need resources to scale their efforts. Philanthropy can directly support them to amplify their impact by expanding their outreach, staffing, and programming. These organizations operate with significant resource constraints, creating opportunities for philanthropy to support core operations, program development, and community engagement. Funding to expand family navigation services and peer support could also immediately help individuals and families struggling to navigate complex care systems.

Opportunity to Improve Connectivity of the Care Ecosystem

Beyond the immediate opportunities outlined in the previous section, there is also a critical opportunity to increase connectivity through longer-term, systems-level initiatives to build a cohesive, integrated care ecosystem to address the needs of individuals with schizophrenia. Improving care connectivity would capitalize on effective care models, building on what is working and making quality care more accessible. Achieving this goal would not only improve care and support for individuals and their families but also interrupt the cycle of crisis-driven care, helping to build a more proactive system of support.

Numerous conversations with experts highlighted the need for improved access to high-quality schizophrenia care. The care system in the US is fragmented, limiting the impact of even the most effective care models for schizophrenia. Many people struggle to access quality care at all because of limited capacity, long waitlists, geographic disparities, and payment barriers. Those who do access care may complete intensive treatment but find no support to transition into the next stage of support. This often leads to individuals facing crisis again and cycling back into intensive care.

Excellent work is occurring, but it occurs within silos of the care system, which is inefficient at best and detrimental at worst. Philanthropy is positioned to create new incentive structures for existing or new organizations to collaborate with one another and link resources, better connecting individuals with the right support at the right time.

Opportunity 3: Improve Access to High-Quality Treatment and Care by Increasing Connectivity Across the Care System

There is broad consensus that greater connectivity is needed across the care ecosystem for schizophrenia and SMI. Alongside key partners, philanthropy can play an important role to incentivize and strengthen connections to better serve individuals who need support.

Approach 3.1: Build a Network of Care Centers

This effort starts with defining high-quality care and requirements for membership in the network. CSC could offer a useful starting point, as it is a well-established, evidence-based model of care for early intervention, and CMS billing codes already exist, making pathways to sustainable reimbursement possible. From there, it is important in the long term to expand along the care continuum from FEP programs to offer similar services and programs for individuals at different points in the care journey.

Developing a network of care centers would require establishing criteria and a plan for the evaluation or certification process. There are multiple ways to organize a network of care centers, define standards, and designate centers. As seen in the Parkinson's Foundation GCN example, one

effective way is for a professional society or other organization to serve as a central convening body to set membership standards, evaluate applications, and certify sites. Alternatively, certification could be outsourced to a third-party organization, such as Joint Commission. Like the GCN, a schizophrenia care network could potentially include multiple designations to accommodate care centers with different strengths and contexts.

This strategy, with a single convening organization, depends on strong leadership from an entity with multiple strengths: condition-specific expertise, resources, and credibility with the key partners (individuals with lived experience, caregivers, providers, medical centers, health-care systems). Given the critical need for a cohesive approach that brings multiple strengths to bear, a consortium model could be well suited to bring together all the assets and resources needed for addressing the complexity of schizophrenia. In fact, the Foundation for the National Institutes of Health's Accelerating Medicines Partnership® Schizophrenia Program is an example of a consortium approach to a research initiative in the field. While its focus is research, a similar consortium could be successful for care.

Establishing additional specialized care centers for schizophrenia is another avenue for philanthropic support. Universities with strong psychiatry departments, medical schools, and academic medical centers represent natural locations for certified care centers given their existing infrastructure, clinical expertise, and concentration of potential clients. Such centers could serve as anchor sites within the care network. University development offices are well-positioned partners in this effort to capitalize on institutional capacity for hosting specialized clinical programs and philanthropic interest. This approach could accelerate network development by tapping into existing philanthropy at academic and medical institutions.

By supporting this type of care network initiative, philanthropy can drive meaningful change in an often frustrating, disconnected system. A network of care centers would serve individuals and their families, helping people know where to go to receive evidence-based treatment and care.

Approach 3.2: Incentivize Connectivity Across Existing Programs That Offer Complementary Services or Levels of Support in Defined Geographic Areas

The Thresholds case study illustrates how multiple services, programs, and levels of support can be connected under one umbrella in the Chicago area. One way to build similar benefits in other regions would be to incentivize Thresholds-like connectivity across existing programs with complementary services, such as between CSC programs and clubhouses. This approach leverages strong existing programs and can be modular, building additional programs or services piece by piece.

Care centers could establish new programs to provide additional services that expand the continuum of care or partner with other existing programs. Like Thresholds, others could partner with FQHCs or CCBHCs to provide integrated care with sustainable funding. As another example, many experts highlighted the foundational role of safe, stable housing for successful schizophrenia treatment. Not all programs are equipped to manage housing units directly like Thresholds does, but through partnerships, they could connect individuals with the assistance they need.

This approach is well suited to improve connectivity across levels of care with existing centers and programs. This connectivity is imperative for individuals with schizophrenia whose care needs cover multiple life domains and change over time. By integrating multiple levels of support, this approach could help address the care cliff that many experience after intensive treatment programs and help meet the needs of individuals outside the early intervention phase of schizophrenia treatment.

Philanthropy could support this type of connectivity by offering partnership development grants. These could include grants to support the exploratory or planning phases of connecting partner organizations that expand the care continuum or collaborative implementation awards to bring together complementary organizations. For instance, philanthropic support could enable greater connectivity between a CSC program and a clubhouse. Grants could focus on targeted geographic regions to concentrate resources in a given area. Philanthropy could also provide start-up funding to support modular expansions that add services to existing organizations.

By supporting this type of initiative, philanthropy can begin to transform disconnected silos into an integrated system with interrelated levels of support. When programs are connected, individuals and their families can receive cohesive care and wraparound support to better sustain recovery and prevent relapse.

Implementation Considerations

Networks need an upfront understanding of institutional economics, leadership alignment, incentives for site buy-in, and capacity to facilitate both financing and policy—coupled with enthusiasm—to be successful long-term.

Leadership and convening power: As already emphasized, strong leadership is critical to any initiative to improve access to quality schizophrenia care. In addition to galvanizing enthusiasm and resources, the convening entity needs to be able to coordinate key leaders, develop criteria, and manage implementation.

Leadership buy-in: For long-term success, buy-in is needed not only from clinicians and providers at individual sites but also from institutions and their leadership.

Incentive structure: An important part of this conversation is the incentive structure for participation. Incentives can be financial, including direct payments to member sites or programs, but can also include knowledge sharing, resource pooling, peer learning, and professional development opportunities.

Sustainability of the initiative: From the beginning, initiatives need to consider financial sustainability. Although start-up funding is critical, initiatives need a near-term path to economic sustainability to have meaningful success for clients and their families. The case studies discussed previously offer useful examples. Care delivery solutions must also account for the minimum population density or catchment area to ensure access to specialized care, an adequate workforce, and the initiative's sustainability. This is especially important for schizophrenia, where many small programs do not see large enough numbers to sustain more specialized services.

Equity: Equity is a critical consideration at every stage of developing such an initiative. It is important to recognize the limitations of more centralized approaches that might lack geographic reach and mitigate access issues that could exacerbate disparities.

Measures of success: From the outset, initiatives should consider measures and outcomes to evaluate success. Evidence is needed to support sustainability and expansion efforts. Several potential measures are shown in **Box 6**.

Continual improvement: Elements of LHNs or learning collaboratives could be layered onto new and existing networks of care. Even if research is not initially a primary objective, any approach should be designed with measurement and outcomes in mind to facilitate evaluation and assess success. In addition, integrating measurement capacity helps equip any such initiative to engage in research, which is urgently needed to develop new treatments for schizophrenia and continue improving care.

Box 6: Example Measures to Evaluate Success

The following measures could be used to set benchmarks and evaluate the success of programs or initiatives:

- Volume of individuals served
- Wait times for care
- DUP
- Hospitalization rates
- Relapse or re-engagement rates

Building Toward Comprehensive Schizophrenia Care

The opportunities presented in this report are specific, actionable ways to improve access to evidence-based schizophrenia care. Beyond these concrete opportunities, our research—including conversations with over 70 experts—reveal several converging themes that, when taken together, illustrate a vision of truly comprehensive schizophrenia care.

This vision represents an aspirational model of comprehensive schizophrenia care. It incorporates multimodal, personalized treatment and support across multiple life domains, including family, community, employment, and housing. Realizing this ideal requires that systems have sufficient capacity to meet personalized needs, provide ongoing support, and respond effectively during crisis.

We categorized the converging themes into a set of values, standards, and core components. Values and standards are foundational to providing high-quality, comprehensive care for schizophrenia and describe the ideal quality of care. Core components describe the direct-care services that should be available and accessible to everyone living with schizophrenia.

This aspirational model can serve as a North Star for the type and quality of care the field strives to provide and a starting point for building consensus on standards for comprehensive schizophrenia care.

Values

Values can help guide complex decisions and ensure that initiatives to improve care align with the ultimate shared goals. An ideal system of schizophrenia care would be guided by the following core values highlighted by experts:

- person-centered
- recovery-oriented
- strengths-based
- lifespan-oriented
- collaborative
- coordinated
- integrated
- evidence-based
- multimodal
- holistic
- accessible
- timely
- equitable

Standards

Standards are benchmarks for the services provided. Meeting these standards requires that systems have sufficient capacity to support timely access and availability of services, including during times of crisis. According to expert perspectives, standards for an effective system for schizophrenia care would include the following:

- early detection and accurate diagnosis
- timely access and availability
- capacity for support during times of crisis
- quality monitoring and improvement based on outcomes

Core Services

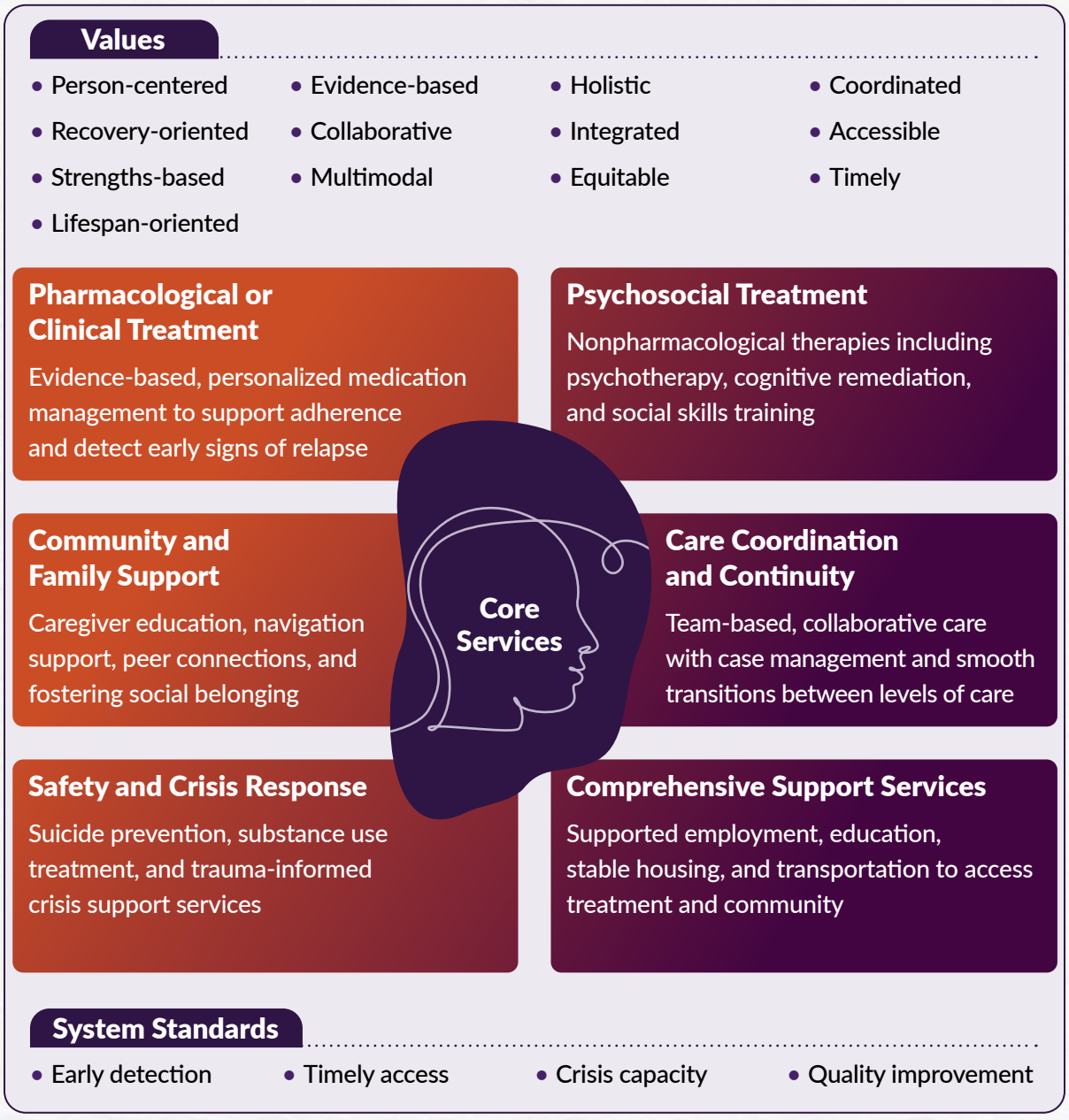
Experts emphasized the following core components, or direct services, that would be important elements of a system that delivers comprehensive schizophrenia care:

- **Pharmacological clinical treatment** should be evidence-based and personalized, including medication management and support for medication adherence and management of side effects. Clinical care should also include comprehensive assessment and monitoring to ensure effective treatment and detect early signs of possible relapse.
- **Psychosocial, or nonpharmacological, interventions** should be available as part of multimodal, comprehensive care. These interventions should include psychotherapy, cognitive remediation therapy, and social skills training.
- **Care coordination and continuity** are critical to long-term recovery. Comprehensive care should be team-based, collaborative, and coordinated, including case management and integrated physical and mental health care. Care continuity between levels of care is essential to long-term success. Step-down programs to transition between levels of care are an ideal way to manage transitions, though warm handoffs between programs and care teams can also provide the necessary continuity, as previously described in Approach 2.2.
- **Community and family support** are integral to recovery-oriented care for individuals. These supports should include family and caregiver education and navigation support. Peer support is also important, as is maintaining social connection and community belonging.
- **Comprehensive support services** should include supported employment and education services; the ability to connect individuals to safe, stable housing; and transportation solutions for accessing treatment and community.
- **Safety and crisis response services** should support interrelated challenges and include safety and suicide prevention support, treatment for substance use disorders, and addressing experiences of trauma.

Overview of Comprehensive Care

This model system of comprehensive care represents an ideal future state of schizophrenia care, developed via synthesis of expert opinion and recent literature. **Figure 4** summarizes the values, standards, and core services that together start to shape a vision for the future of schizophrenia care.

Figure 4: Comprehensive Schizophrenia Care—An Aspirational Model for Multimodal, Personalized Treatment and Support



Source: Milken Institute (2026)

Considerations for Next Steps

Several considerations frame potential next steps for realizing this aspirational model. First, this vision focuses on the components of care, not the broader health-care and payment systems, social determinants of health, or barriers to access. Although payment and policy are not the focus of this publication, any efforts to improve care for schizophrenia and SMI operate within this context, and more work and reform are needed. Additional discussion of the social and systemic context of schizophrenia—and opportunities for progress—can be found in *Schizophrenia Research and Care: Assessment of Challenges and Opportunities*.

Formal consensus building to define comprehensive care standards, clinical guidelines, or best practices is an important step toward realizing this vision. Opportunity 2.1, discussed previously (updating the consensus on the essential elements of CSC), is a potential starting point for building consensus on care standards across the spectrum of treatment and services. Importantly, taking on this work would also require incorporating extensive lived experience perspectives to ensure the clinical consensus aligns with the wide-ranging needs of diagnosed individuals and their families.

This synthesis represents an aspirational model of excellent, comprehensive care, rather than empirically defined minimum requirements for effective care. There are open empirical questions about which components of effective care models are truly essential. For example, there is still a need for conducting formal dismantling studies, as highlighted in Opportunity 2.1.

This model has significant resource requirements, and achieving this vision will require sustained investment. The modular, phased approaches highlighted in the case studies earlier in this report offer practical approaches for undertaking this work. Although this ideal model may not be immediately feasible in all settings, it is important to strive for it. This aspiration should be balanced by keeping the value of equity at the forefront.

Currently, few, if any, programs embody all elements of this aspirational framework, but the opportunities identified in this report offer concrete steps toward this vision. Opportunity 1 (to scale evidence-based programs) will help more people access the type of evidence-based, multimodal treatment this model describes. Opportunity 2 (to strengthen care delivery) will help advance consensus around comprehensive care and build greater continuity in the existing care system. Opportunity 3 (to improve connectivity in care delivery) recommends steps to actively create the more integrated system we envision.

Our research identified not only gaps in the care system but also points of light and momentum. With focused attention and sustained investment, those lights can grow. The opportunities highlighted in this report show concrete next steps, and the case studies offer inspiration for how this work is already happening. With continued, coordinated effort, comprehensive care can become the reality for everyone affected by schizophrenia.

Glossary

Anosognosia: This is an inability to recognize oneself as having a mental illness.

Assertive Community Treatment (ACT) teams: These teams, with 24/7 availability, provide multidisciplinary services for people with SMI. They typically serve people with more established illness.

Assisted Outpatient Treatment (AOT): This is a legal framework for court-ordered outpatient treatment that requires an individual to engage in community-based treatment. It typically employs a team-based approach and aims to address gaps in care continuity, although evidence for its effectiveness is mixed.

Center of excellence (COE) model: This approach defines excellent care for a condition and establishes criteria and standards for service delivery. Individual sites that meet the criteria are certified as centers of excellence.

Certified Community Behavioral Health Clinics (CCBHCs): These clinics provide integrated services that address needs across mental health, substance use disorders, physical health, and social services. The specially designated clinics provide integrated care, including 24/7 crisis services, outpatient treatment, and case management. CCBHCs serve all individuals, regardless of insurance status.

Clinical high risk (CHR): CHR refers to people experiencing subthreshold symptoms that do not meet full diagnostic criteria for psychotic disorders and who are at elevated risk of developing psychosis.

Clubhouse model: This approach to care leverages community as therapy and provides dignified spaces that empower members through connection and belonging.

Cognitive remediation therapy: This behavioral training intervention focuses on improving functional outcomes through brain training exercises targeting cognitive deficits, such as sensory processing, verbal learning, working memory, and processing speed.

Cognitive behavioral therapy for psychosis (CBTp): This is an evidence-based form of psychotherapy that has been shown to alleviate symptoms and improve functioning for people with psychosis and schizophrenia.

Cognitive symptoms: These symptoms are related to thinking processes, including deficits in processing speed, attention, and working memory.

Collaborative care model: This integrated care model is a team-based approach to incorporating behavioral health interventions into primary care settings so individuals can receive mental and physical health care in one location. Collaborative care is the most studied behavioral health integration model and is reimbursed by Medicaid, Medicare, and commercial insurance.

Coordinated specialty care (CSC): This care model uses a team-based approach consisting of psychotherapy, family support and education, medication management, employment and education support services, and case management. This model has emerged as the evidence-based standard for treating individuals in the early stages of psychosis. (See also **first episode psychosis**.)

Copay assistance programs: These programs provide short-term financial support to help individuals cover out-of-pocket treatment costs, such as medication copays.

Crisis intervention team programs: This approach involves training police and other first responders to manage mental health crises. These programs seek to raise awareness about treatment options and direct individuals to appropriate care, rather than to the criminal justice system, whenever possible.

Deconstructing studies: Also called dismantling studies, these studies identify which elements of care models are effective so they can be replicated.

Duration of untreated psychosis (DUP): DUP is the time between presentation of psychosis and receiving treatment. Higher DUP is associated with worse outcomes.

Early Psychosis Prevention and Intervention Centre (EPPIC): This is an Australian model of CSC developed at Orygen with 16 core components and established fidelity measures. It focuses on keeping patients on developmental trajectories and uses a recovery-oriented developmental mindset. This model has been adapted internationally. (See also **coordinated specialty care**.)

First episode psychosis (FEP): FEP is the first occurrence of psychotic symptoms in an individual, extending through the first two to five years of early illness. FEP refers to a period of early onset of symptoms that encompasses an individual's initial psychotic episode and the phase of early illness.

Hub-and-spoke model: This strategy organizes service delivery with a central "hub" that provides more specialized services and support while distributed "spoke" sites deliver essential treatments. This model has the advantage of covering a larger geographic area with core services and concentrating resources needed for more specialized interventions.

Inpatient treatment: This type of treatment provides intensive, hospital-based, 24/7 care typically focused on stabilization during times of crisis. Its intensive nature allows for rapid medication adjustments and close monitoring. Inpatient treatment has a fraught history and should be employed sparingly and cautiously.

Integrated care: This type of care delivers treatment and services across both mental and physical health. This approach can address clinical symptoms of schizophrenia as well as common comorbidities and side effects of treatment (e.g., issues with sleep and nutrition).

Intensive outpatient programs (IOPs): These are similar to partial hospitalization programs (PHPs) but are somewhat less intensive. A typical IOP schedule would be three days a week for a few hours per day. (See also **partial hospitalization programs**.)

Lambeth Early Onset (LEO): This is a UK community-based approach that involves teams comprising 10 staff members, emphasizing assertive outreach and providing extended-hours services for people aged 16–40 presenting with first- or second-episode nonaffective psychosis. This model utilizes multiple evidence-based interventions, such as cognitive behavioral therapy. (See also **coordinated specialty care**.)

Learning health network (LHN): This is an LHS that connects multiple organizations, such as hospital systems, to enable knowledge sharing on a larger scale. In this model, clinical data are continually analyzed to improve care. (See also **learning health system**.)

Learning health system (LHS): This is a dynamic health-care system in which clinical care is grounded in evidence, is responsive to emerging information, and integrates evolving best practices. This model creates an ongoing feedback loop between clinical care and research, with data continually analyzed to improve future care. (See also **learning health network**.)

Mobile crisis response teams: These teams include mental health professionals as public emergency responders within communities. These programs are cost effective but face sustainability challenges for funding and staffing, particularly for around-the-clock services.

NAVIGATE: This is a rigorously tested CSC program developed as part of the RAISE initiative and incorporates individual resiliency training, family psychoeducation, supported employment/education, and medication management. This is a manual-based approach with specific modules. (See also **coordinated specialty care**.)

Negative symptoms: These are symptoms of reduced expression and social engagement, such as flat affect, diminished emotion, and social withdrawal.

Network of care centers: This is a group of sites that provide high-quality, specialized care. Care centers in the network can have different configurations. In one, individual sites host all the services needed to meet the criteria for membership. In another approach, multiple locations within a geographic area collectively meet the requirements to form a care center, each contributing a different facet.

OPUS: This is a Danish model of CSC that consists of community-based treatment, including family involvement and social skills training provided by a multidisciplinary team. (See also **coordinated specialty care**.)

Partial hospitalization programs (PHPs): Also called day treatment programs, these programs offer highly structured, time-intensive support for those needing more than outpatient treatment but less than residential or inpatient care. A typical schedule is five days a week for five hours or more per day.

Positive symptoms: These are symptoms of altered perception and thinking, such as hallucinations and delusions.

Program for Specialized Treatment Early in Psychosis (STEP): This is the first comprehensive early intervention service in the US, launched in 2006 as a collaboration between Connecticut's Department of Mental Health and Addiction Services and Yale University. It has been demonstrated to be effective through a pragmatic randomized controlled trial.

Psychosis: This mental state is characterized by a loss of contact with reality. Symptoms can include hallucinations (seeing, hearing, or feeling things that are not there); delusions (fixed false beliefs); and disorganized thinking, speech, and behavior.

Quality improvement collaboratives: Also called learning collaboratives, these initiatives collectively share knowledge and improve quality or best practices across multiple institutions. These initiatives are time limited with defined implementation goals and are usually led by an external organization that temporarily brings together teams across multiple organizations to collaborate.

Residential programs: These programs offer intensive, wraparound care, providing support for individuals who need more than outpatient care but less than inpatient hospitalization. Residential programs are typically offered for a short duration (a few weeks to six months) and are often only available to those with private insurance or those paying out of pocket.

Schizophrenia: This condition is a serious, chronic brain disorder typically characterized by episodes of psychosis, including disorganized thinking and disturbances in perception and behavior.

Serious mental illness (SMI): SMI is a mental disorder or condition that substantially interferes with functional capacity and major life activities and is chronic (typically lasting 12 months or longer).

Specialized outpatient clinics: These centers offer specialized care for schizophrenia or SMI and are more structured than traditional outpatient treatment. They typically offer care across multiple specialties, which can improve care coordination. These centers tend to be at academic medical centers and often require private insurance or self-pay, which limits access.

Step-down programs: These programs help individuals transition from higher- to lower-intensity levels of care.

Technical assistance: This provides targeted support to help organizations implement new programs and build capacity. It can include readiness assessments, implementation coaching, consulting on process development, and capacity-building support.

Traditional outpatient treatment: This type of care consists of individual providers rather than team-based care. These treatment options are more flexible and convenient than structured programs, but individuals seeking outpatient treatment face access challenges, including a lack of referrals and a shortage of specialized providers.

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