THE INTEGRATION OF EARLY PSYCHOSIS SERVICES IN A SYSTEM OF CARE FRAMEWORK:

Opportunities, Issues, and Recommendations

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The Integration of Early Psychosis Services in a System of Care Framework: Opportunities, Issues, and Recommendations

Introduction

Every year in the United States, 100,000 people develop schizophrenia or other psychotic disorders for the first time (McGrath et al., 2008; Heinssen et al., 2014). Symptoms most often begin during youth and young adulthood. Until recently, lengthy delays in accessing treatment, service fragmentation, and lack of evidence-based care have hampered efforts to provide early intervention and treatment. As a result, the United States spends tens of billions of dollars annually on hospitalizations, legal involvement, and disability, often with poor outcomes (McGrath et al., 2008; Cloutier et al., 2016). The annual economic burden of schizophrenia in the United States was approximately $155.7 billion in 2013, including direct health care costs, direct non-health care costs, and indirect costs such as unemployment and the impact of caregiving on productivity (Cloutier et al., 2016).

Since the beginning of the Substance Abuse and Mental Health Services Administration's Children's Mental Health Initiative in 1993, the system of care (SOC) framework has provided the foundation for community-based service development in the United States and has focused on improving the lives of children, youth, and young adults who experience the most complex mental health needs and their families. In recent years, with greater understanding of early psychosis, the SOC framework has expanded to include young adults presenting with signs of early psychosis.

The SOC approach brings children, youth, and young adults with Serious Emotional Disturbance (SED)[1] and their families together with community-based services and supports to create a network of care that is organized around common principles (i.e., family-driven, youth-guided care; culturally competent, evidence-informed and individualized) and outcomes (e.g., improved functioning at home, in school, and in the community). This approach establishes cross-system mechanisms for service planning, financing, and system improvement, and it increases access to home- and community-based services and supports that improve functioning, promote continuity, and decrease avoidable hospitalizations and out-of-home placements (Stroul, B.A., Blau, G.M., and Friedman, R.M., 2010; U.S. Department of Health and Human Services, 2015).

As the system of care approach evolves, and more is known about customized methods and service models such as early psychosis intervention approaches, it is important to ensure that state and local systems include those approaches. Incorporating early psychosis intervention into SOC affords the nation an unprecedented

1. The Interdepartmental Serious Mental Illness Coordinating Committee offers the following definition: "Serious Emotional Disturbance (SED) refers to children and youth who have had a diagnosable mental, behavioral, or emotional disorder in the past year, which resulted in functional impairment that substantially interferes with or limits the child's role in family, school, or community activities." Adapted from Federal Register, Vol. 58, No. 96, pages 29422-29425. (Interdepartmental Serious Mental Illness Coordinating Committee, 2017).

opportunity to implement proactive, evidence-based care and responsive, coordinated community supports from the time that early symptoms of psychotic illness begin. This monograph describes how an SOC approach, coupled with specialized early psychosis intervention,[2] can create a sustainable infrastructure, significantly decrease the duration of untreated psychosis, and improve service delivery and outcomes for youth and young adults with early signs of psychosis.

It is the responsibility of a modern system of care to ensure that early psychosis intervention services and supports are in place for youth and young adults.

Early Psychosis Intervention

The Coordinated Specialty Care (CSC) model for first-episode psychosis services was developed through extensive international research culminating in the U.S. Recovery After an Initial Schizophrenia Episode (RAISE) studies. Core elements of CSC include proactive community education and engagement and holistic, intensive team-based care, including psychiatry, counseling, case management, supported employment, and education. Linkage to peer support, addressing physical health needs, and supporting an individual's transition into effective long-term supports are central responsibilities of the CSC team.

In addition to first-episode psychosis services, a growing number of communities are implementing earlier identification of individuals assessed as being at Clinical High Risk (CHR) for developing psychosis because of emerging symptoms (often referred to as attenuated symptoms) combined with distress or impact on functioning. By slowing symptomatic progression and providing support for role functioning, intervention during the CHR period may prevent disability at school or work, and developmental progression, escalation of symptoms, and negative consequences such as hospitalization, legal involvement, trauma, and potential early mortality associated with acute psychotic symptoms (Ising et al., 2016; McGorry et al., 2010; McGorry et al., 2007).

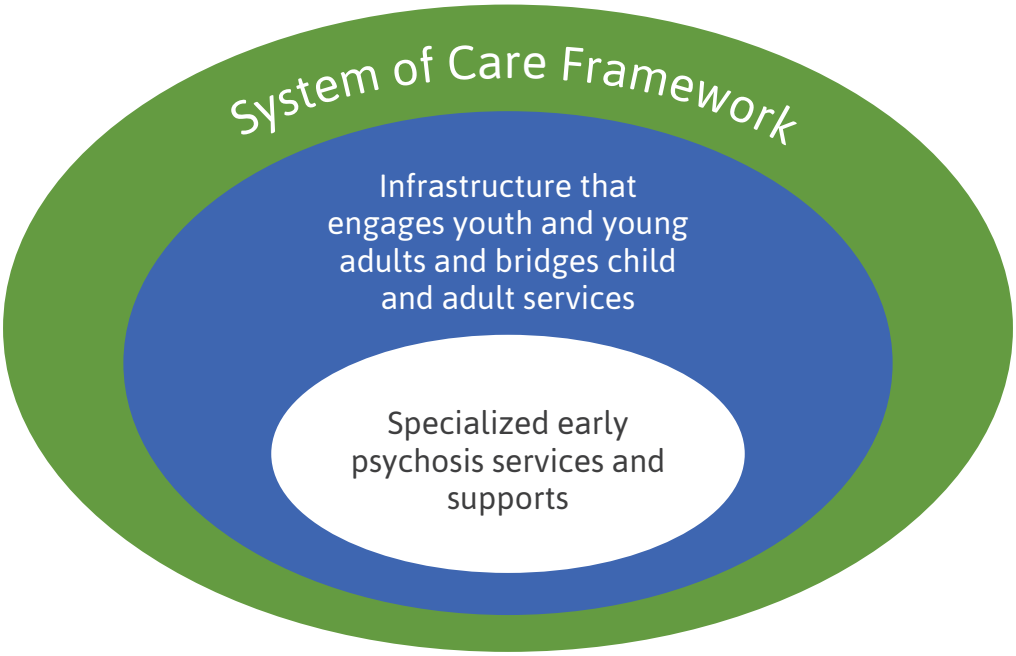
The goals of early psychosis intervention are to reduce treatment delay by identifying and engaging with individuals as quickly as possible when the symptoms of psychotic illness begin, to reduce trauma and negative consequences, and to maintain functioning and developmental progression. A core focus of early psychosis programs is reducing the Duration of Untreated Psychosis, or DUP. DUP is the period from the onset of fully psychotic symptoms to the commencement of appropriate treatment (Norman and Malla, 2001). Early psychosis programs integrate resilience-focused, person-centered, and evidence-based treatment and support. The core principles of early psychosis intervention align with the SOC approach. Accountability to outcomes and fidelity and attention to protecting rights and nondiscrimination are central to the process. By operating as part of systems of care, early psychosis programs can proactively engage and partner with young people and their families to create a flexible, strengths-based, culturally and linguistically competent, and developmentally appropriate plan to address the need for services and supports holistically. These programs also can focus on community engagement and support successful transition into adulthood.

Incorporating Early Psychosis Interventions into Systems of Care

By conceptualizing early psychosis services within a system of care framework, practitioners and other community stakeholders can better develop a sustainable infrastructure that facilitates referral pathways, blends resources, and tracks outcomes across systems. A consistent and coordinated effort linking SOC and

2. For the purposes of this paper, early psychosis intervention encompasses services for both first-episode psychosis and Clinical High Risk (CHR) states. Most programs in the United States target first-episode psychosis, though some programs target only CHR states or both simultaneously.

Figure 1: Integration of Early Psychosis Intervention within an SOC Framework



early psychosis intervention creates the ability to design community-based solutions that would otherwise be unavailable, and that may result in the reduction of negative preconceptions about psychosis, more comprehensive supports for youth, young adults, and their families, and better continuity of care. Figure 1 illustrates how early psychosis intervention fits into a larger SOC framework.

The SOC framework provides a common philosophy and set of principles and values that guide service delivery across systems. A cross-system infrastructure brings together youth, families, providers, and decision-makers, providing a vehicle for flexible service delivery and redesign. SOC philosophy, principles, and infrastructure must be adapted to incorporate the unique developmental needs of youth and young adults with psychosis and bridge the gap to adult services and supports that often function outside of SOC frameworks. Early psychosis services can operate as a set of specialty services within this broader infrastructure (Stroul et al., 2015).

As symptoms of psychotic illness emerge, it can take time to ascertain the correct diagnosis. The SOC approach enables system leaders and practitioners to create a differentiated approach to community education and intervention strategies based on the different stages of psychosis. Table 1 illustrates the stages of psychosis treatment and how they relate to intervention strategies (McGorry, P et al.,, 2007).

Recommendations

Many of those familiar with the SOC approach are less familiar with early psychosis intervention, and vice versa. And guidelines related to individuals with CHR currently come primarily from efforts outside of the United States. Most communities have some but not all of the elements necessary for a comprehensive approach. This paper provides historical and contextual information to fill in some of these gaps and identifies how incorporating early psychosis intervention into the SOC framework can serve to enhance and expand services and supports.

The following are recommended steps that might be taken to help bridge and connect SOC and early psychosis intervention efforts to maximize the benefits for youth and young adults who have CHR states and their families.

General Recommendations for States and Communities

System design and oversight

1. Develop cross-system oversight bodies and partnerships focusing on the unique needs of youth and young adults, including an explicit focus on early psychosis intervention. The primary focus for these discussions is generally ages 16 to 25, although attention to services ranging from age 10 (related to Childhood Onset Schizophrenia) to 30 may be necessary to ensure appropriate early identification, follow-up, and support.
2. Invite child and adult system representatives to focus on how best to meet the economic, continuity of care, vocational, health, and housing needs of youth

Table 1: Stages of Early Psychosis Intervention Within an SOC Framework (adapted from McGorry et al., 2007)

Stage	Definition	Role within SOC	Potential interventions
0	Genetic risk without symptoms.	Medical monitoring and self-referral by families with genetic high risk.	Brief education about preventive strategies and early signs. Brief cognitive skills training.
1a	Mild or nonspecific symptoms, mild functional change or decline.	Mental health literacy and screening. Services can be provided by any trained mental health practitioner.	Formal mental health literacy/eHealth. Problem solving and support. Family psychoeducation. Substance misuse reduction. Exercise.
1b	Clinical High Risk (CHR): Moderate but subthreshold mood/positive/negative symptoms with moderate neurocognitive changes and functional decline.	Specialized assessment and treatment for psychosis CHR by early psychosis team or trained specialized practitioners.	Formal CBT/case management. Family psychoeducation. Substance abuse reduction. Atypical antipsychotics *only used under limited circumstances.* Antidepressants, mood stabilizers as indicated. Supported employment and education based on functional level/need.
2	First episode of full-threshold disorder with moderate to severe symptoms, neurocognitive deficits, and functional decline.	Referral to early psychosis team for intensive specialized services.	Formal CBT/case management. Family psychoeducation. Substance misuse reduction. Atypical antipsychotics. Antidepressants or mood stabilizers. Supported employment and education. Peer support.

and young adults at Clinical High Risk for psychosis using an SOC approach. Addressing these ancillary needs is critical to the long-term success of individuals who develop psychotic illness.

3. Formally articulate a common set of SOC values and principles that apply to SOC and early psychosis intervention efforts and practices, and obtain consensus among constituent groups.

Education and outreach

4. Create, document, evaluate, and disseminate demonstrations of how systems of care can successfully incorporate early psychosis interventions for youth and young adults.
5. Design shared and effective social marketing strategies to support awareness and access among multiple audiences. Identify and include effective social media and communication technologies.

Practice and implementation

6. Integrate early psychosis information into health screening, suicide prevention, alcohol and drug prevention, school-based services, and other educational efforts across systems.
7. Identify methods for Wraparound planning and continuity mechanisms to be integrated into transitions out of early psychosis programs.
8. Develop national guidelines for local programs that want to integrate services for individuals with lower-level symptoms of psychosis falling under the Clinical High Risk category. Ensure appropriate diagnostic training and consultation in this area.
9. Advance common methods of evaluating services and common measurement instruments across early psychosis and SOC efforts serving youth and young adults.
10. Extend early psychosis program conceptualization beyond the direct activities of outpatient mental health services to include inpatient and residential interventions, academic and vocational institutions, courts and law enforcement, and other groups that play critically important roles in facilitating the success of individuals with early psychosis. Provide templates and demonstrations for how this can be done effectively and efficiently.

Recommendations to State and Local Jurisdictions Interested in Integrating Early Psychosis Services

System design and oversight

1. Explore the potential to build innovative public mental health approaches that integrate wellness promotion, early symptom recognition of emerging mental health issues, and treatment access for youth and young adults.
2. Require SOC expansion efforts to partner with early psychosis programs in their geographic area.
3. Include specialized supported employment and education based on the Individual Placement and Support (IPS) model.[3] These are critically important elements that are needed to support youth and young adults who demonstrate CHR states. Without this service, young people may be pushed more rapidly into disability systems and will have more difficulty navigating the transition to adulthood.

Training and workforce development

4. Training and consultation should be delivered based in implementation science to address the policy, infrastructure, and practice levels and ensure consistent and effective promotion, delivery, and sustainability of evidence-informed infrastructures as well as diagnostic and treatment practices. This includes ongoing feedback mechanisms and data to evaluate the success of local efforts and identify practice and system gaps.
5. Offer technical assistance to current and former SOC expansion sites to keep them up to date on developing research and recommendations for first-episode and CHR screening and diagnosis.
6. Proactively address gaps in psychosis-related detection, screening, diagnosis, and treatment approaches across disciplines to include but not be limited to educators, primary care, and mental health clinicians.

Education and outreach

7. Expand outreach efforts to child- and adolescent-serving systems and agencies and secondary and postsecondary schools to include recognition of early psychosis symptoms and service access points for referral.

3. https://www.ipsworks.org

Financing

8. Work with system partners and public and private insurance to ensure access to evidence-based care and develop alternative funding strategies for uninsured individuals to effectively reduce Duration of Untreated Psychosis (DUP) and identify individuals during the onset of psychosis.
9. Financing mechanisms should include all components of team-based and evidence-supported care.

Practice and implementation

10. SOC partners should routinely include questions about symptoms consistent with psychosis in screening and early assessment across all ages, including questions about auditory/visual hallucinations, paranoia, or thought disorder. Screening tools such as the PQ-B and PRIME screen are available for this purpose (Loewy et al., 2011; Miller et al., 2004). Individuals identified through these screening tools should then be assessed by trained clinicians using a more extensive validated tool such as the Structured Interview for Psychosis-risk Syndromes, or SIPS (McGlashan, T., Walsh, B., and Woods, S., 2010).
11. Establish and maintain relationships with adult systems and proactively support continuity of care to prevent young people from "falling through the cracks" as they progress developmentally. Services should be available from the same early psychosis team into an individual's later 20s since a significant portion of individuals served by early psychosis programs are older than 21. Since the cutoff age for many children's SOC efforts is through the age of 21, continuity of care must be addressed to increase the chance of engagement and the effectiveness of services and supports.
12. Since adult system involvement is common for this population as youth age out of the child system, cultivate linkages to adult systems, including crisis services, hospitals, outpatient treatment, higher education, housing, and vocational and legal systems.

Recommendations to Early Psychosis Programs Not Currently Embedded in SOC

System design and oversight

1. Integration of SOC oversight mechanisms, values, and principles into early psychosis efforts may improve the engagement and responsiveness across partners to individuals with early psychosis through collaboration and education as well as improve early identification and long-term outcomes. Certain principles of systems of care, such as family-driven and youth-guided care, cultural and linguistic competence, continuity of care, and flexibility of funding, along with access to resources across organizations, may support successful longer-term transitions among individuals served by early psychosis programs.

Training and workforce development

2. Prioritize building collaboration within the child/adolescent behavioral health workforce, including child/adolescent psychiatry and integration with primary care. This would help expand early psychosis recognition and awareness of early psychosis programs and build core clinical competencies such as strengths assessment, risk assessment, person-centered planning, and dual-diagnosis assessment and treatment, including pharmacotherapy best practices for schizophrenia and cognitive behavioral therapy for psychosis.

Education and outreach

3. Early psychosis programs need to expand outreach and early identification efforts into secondary schools and school mental health programs. As schools expand in awareness and symptom recognition, it will be important to develop a core set of education accommodations to support those with early psychosis to be academically successful in secondary school and college settings.

Financing

4. Continue to explore and implement expanded reimbursement approaches for funding early psychosis programs inclusive of all young people in need of intervention with CHR and first-episode psychosis. In addition to expansion of Medicaid approaches that support Coordinated Specialty Care and Wraparound team approaches to care, commercial and private insurer participation is needed to make these critical services available to all youth and young adults.

Conclusion

The expansion of early psychosis programs across the United States demonstrates the growing national commitment to youth, young adults, and their families.

States and jurisdictions employing a system of care (SOC) approach have shown great vision in expanding efforts to support young people as they move through developmental and service transitions across local and state mental health systems. Moving toward an integration of early psychosis into SOC efforts in a way that addresses policy, funding, and service delivery can ensure that young people will be able to access the critical mental health supports they need as early as possible for as long as possible. Connecting the dots between SOC and early psychosis services will create synergy and allow youth and young adults to maintain their developmental, educational, and vocational pathways toward a high quality of life as successful adults in their communities.

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