VIEWPOINT

What It Will Take to Make Coordinated Specialty Care Available to Anyone Experiencing Early Schizophrenia
Getting Over the Hump

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Schizophrenia is a brain disorder with a lifetime prevalence near 1% that is associated with high levels of functional impairment and low expectations for recovery.[1] Only 10% to 15% of people with schizophrenia work. The annual cost of schizophrenia in the United States in 2013 was estimated to be approximately $155.7 billion, including significant direct and indirect costs.[2] Delivery of a new treatment approach called *coordinated specialty care* (CSC) to every young person experiencing the psychosis of early schizophrenia could change this state of affairs. The critical question is, "what will it take to make this happen?"

Coordinated specialty care deploys a new care model developed for patients with first-episode schizophrenia that fosters recovery and attempts to prevent disability.[3] It includes evidenced-based psychopharmacological management with attention to general health, cognitive and behaviorally oriented individual or group psychotherapy, family support and education, and supported education and employment, as well as case management and, more recently, peer support. Model CSC programs employ a team of culturally competent staff members skilled in (1) working with transitional age youth, (2) active engagement and outreach efforts, and (3) using shared decision-making processes. These CSC teams promote hope and understand the importance of stigma as an impediment to care. They use community outreach methods to reduce the duration of untreated psychosis. A longer duration of untreated psychosis is robustly associated with poorer outcomes for individuals who receive a diagnosis of schizophrenia. The National Institute of Mental Health Recovery After an Initial Schizophrenia Episode studies have demonstrated the benefits of CSC programs in the United States and how to implement them.[4,5]

In recognition of the value of CSC programs, in 2014, House of Representatives Bill 3547 added 5% to the Community Mental Health Block Grant program. States and federal territories received an additional $25 million with the requirement that the monies be used to develop and support evidence-based programs for individuals experiencing early psychosis. The 5% set-aside for CSC programs continued in 2015; the allocation was doubled in 2016, providing an additional $50 million for states to develop CSC programs. In 2008, only 2 states had such programs. Today, 32 states have begun implementing at least 1 CSC program.

Although the block grant is insufficient to provide CSC to all individuals in the United States with early psychosis suggestive of schizophrenia, national CSC implementation has gained considerable momentum. For example, the Centers for Medicare and Medicaid Services, together with the National Institute of Mental Health and the Substance Abuse and Mental Health Services Administration, has issued guidance regarding strategies for Medicaid to fund CSC programs. The National Institute of Mental Health has recently funded a Small Business Innovation Research grant to develop a standardized online CSC training protocol and a virtual community of practice to support skill maintenance and collective learning. The National Institutes of Health PhenX (consensus measures for phenotypes and exposures) program has developed a toolkit of recommended measures for CSC program evaluation and research. Promoting the rollout of CSC programs has become a priority for the National Alliance on Mental Illness, representing consumer and family stakeholders. Delivery of CSC enjoys the support of scientists, clinicians, policy makers, and advocates. To capitalize on this significant momentum and ensure universal access to CSC in the United States, the following set of barriers still must be overcome.

Financing

We need strategies to pay for CSC regardless of a person's type of insurance and current level of disability. Most CSC programs derive revenue from blends of Medicaid, commercial insurance, and other subsidies. Many CSC services (eg, supported employment and education, and outreach) are not traditionally reimbursable by health insurance plans; furthermore, the rates of reimbursement may be inadequate to cover service costs. Among those who qualify for Medicaid on the basis of income, the lack of an established multiyear duration of serious mental illness or other disability can preclude access to enriched Medicaid benefits that are components of CSC but typically are limited to people with multiepisode schizophrenia. Let us broaden eligibility to such services to include people with early psychosis to avoid making people fail before we offer an intervention that can help them avoid failure to begin with.

States need to leverage their limited block grant dollars, maximizing the reach of these added resources while simultaneously maximizing their use of Medicaid waivers to fund CSC services for people with early schizophrenia regardless of income/disability status. We must engage the leadership of commercial insurers and managed care organizations to support CSC as a benefit open

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to people with early psychosis. State insurance commissioners could mandate CSC as a covered service for policies written in the state.

Workforce Development

The competent provision of CSC challenges the usual training of mental health professionals. While the CSC patient population includes teenagers and young adults, traditional training programs tend to focus on one or the other. Child-trained health care professionals have limited experience with psychosis, which is more common in adults, but have a much needed developmental perspective and are comfortable working with families. Deficits in understanding and treating substance use challenge both health care professional groups. The workforce must unlearn what they likely were taught in school about poor outcomes to be expected for individuals with schizophrenia. States and networks need to implement introductory and ongoing training to maximize efficiency and effectiveness, building on local strengths in recovery-oriented practice. In the long run, online solutions should be developed to augment face-to-face work.

Community Activation/Getting the Word Out

A big challenge in providing CSC is commencing services as soon as possible after the onset of psychosis. The Recovery After an Initial Schizophrenia Episode–Early Treatment Program study[4] found that individuals receiving CSC who had a duration of untreated psychosis of less than 74 weeks experienced far greater benefit than those who had a duration of untreated psychosis exceeding 74 weeks.[4] Bottlenecks occur along the entire pathway to care. Stigma, confusion, and fear of psychosis inhibit people from seeking treatment. Furthermore, many clinicians do not recognize psychosis and are unfamiliar with CSC. In the short run, training mental health clinicians and creating easy referral tracks to CSC can facilitate appropriate access. Ultimately, we must create more options for treatment through the traditional system and schools, as well as through social-service and religious organizations. We must also create digital content and entry points to CSC services.

Fidelity and Measuring Outcomes

Scaling up evidence-based practices requires strategies to determine whether treatment programs are being delivered as intended and achieving expected outcomes. The shorthand for this is fidelity, which will decay over time if not monitored, with training and oversight administered accordingly. Measuring outcomes must occur as part of the fidelity process. The CSC treatment model is still evolving, and no single approach to fidelity has strong empirical support. Also, assessing fidelity can be labor intensive and costly. In the short run, several options guiding fidelity assessment are available through the several CSC programs; the PhenX toolkit will soon have measures for CSC programs that have been vetted for their psychometrics and ease of use.[6,7] In the long run, research must develop efficient, validated tools that connect fidelity to outcomes.

Youth/Consumer Involvement

Coordinated specialty care programs should nurture and cultivate youth and consumer leadership at every level. While some young people with psychosis may hesitate to identify with CSC programs, programs such as Oregon's Early Assessment and Support Alliance set a standard for accomplishing such engagement. Young people must be invited to the table.

Conclusions

Implementation of CSC is at a crossroads. Such programs are the standard in many countries. Attention to financing, workforce development, community activation, measurement of fidelity, and outcomes, as well as youth involvement, can make CSC a reality for all youths in the United States who need it.

ARTICLE INFORMATION

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