National Institutes of Health
Office of Evaluation, Performance, and Reporting

RAPID TRANSLATION OF SCIENCE TO REAL-WORLD PRACTICE:

COORDINATED SPECIALTY CARE TREATMENT PROGRAMS FOR EARLY SCHIZOPHRENIA

BACKGROUND

Schizophrenia is a serious mental illness and a leading cause of long-term disability.[1] People with schizophrenia experience hallucinations, delusions, and thought disorder (unusual ways of thinking) and may have reduced expression of emotions, reduced motivation to accomplish goals, difficulty in social relationships, and motor and cognitive impairment.[2] People with schizophrenia are usually diagnosed between the ages of 16 and 30, after a first episode of psychosis.[3] It is estimated that more than 100,000 individuals in the United States experience a first episode of schizophrenia or related psychotic disorder each year.[4] For young people with schizophrenia and related psychotic disorders, studies have shown that intervening within months of illness with evidence-based treatment resulted in better outcomes in academic research settings and in other countries. U.S. mental health agencies needed to know how such evidence-based treatment, termed Coordinated Specialty Care (CSC) in the U.S., might be translated into real-world U.S. mental health care, accounting for common barriers, such as limited resources for implementing new evidence-based practices and a decentralized care delivery system. In a CSC program, a team of clinicians works with each patient to develop a personalized treatment plan for early schizophrenia, focusing on recovery, work and school participation, family support, and appropriate medications to help young people get their lives back on track.

To meet the challenge of adapting CSC for the U.S. mental health care setting, NIH launched the Recovery After an Initial Schizophrenia Episode (RAISE) research initiative in 2008 to test the effectiveness and implementation of CSC in U.S. communities.[5] For this initiative, NIH engaged extensively with early schizophrenia care stakeholders—including Federal partners, mental health advocacy groups, professional organizations, and local and state mental health authorities—to ensure RAISE findings would be relevant and actionable for rapid translation into practice. These collaborations, coupled with RAISE's findings of better recovery from early schizophrenia compared with outcomes of care typically available, created the momentum for targeted Federal support of CSC services and broad expansion of CSC treatment programs nationwide. Ultimately, RAISE not only contributed to the creation of a new way to organize and deliver treatment, but also produced findings that have changed the standard of practice for early schizophrenia treatment in the U.S.

RESEARCH-TO-PRACTICE MILESTONES FOR COORDINATED SPECIALTY CARE FOR EARLY SCHIZOPHRENIA

Milestones in this timeline were made possible in part with NIH funding.

1908

Swiss psychiatrist Eugen Bleuler coined the term “schizophrenia.”

1927

American psychiatrist Harry Stack Sullivan introduced the concept of early intervention in schizophrenia.[6]

2004–2005

The first large clinical trials in England and Denmark found that intervening early with team-based, multielement treatment for young people with schizophrenia reduced symptoms and psychiatric hospitalizations more than standard treatment.[7,8]

LAYING THE GROUNDWORK FOR TRANSLATING EVIDENCE INTO PRACTICE

2008

NIH initiated a series of ongoing engagement activities with federal partners and other early schizophrenia care stakeholders to ensure Recovery After an Initial Schizophrenia Episode (RAISE) studies would produce clinically meaningful findings that could be translated rapidly into practice.

NIH launched the RAISE initiative to study CSC for early schizophrenia in the U.S., funding a clinical trial and a complementary implementation study that together involved 22 states, 36 community clinics, 134 clinicians, and 469 participants.[9,10] NIH also funded the Specialized Treatment Early in Psychosis (STEP) trial to test CSC in community health centers.

2010

The Affordable Care Act (ACA) allowed more young people with early schizophrenia to keep their insurance coverage or gain access through their parents’ coverage, state health insurance exchanges, or Medicaid expansion,[11] broadening access to evidence-based treatment for early schizophrenia.

2013

State mental health authorities in New York and Maryland announced plans to establish early schizophrenia treatment programs based on the CSC approaches tested in RAISE.

2014

Congress increased funding for the Community Mental Health Block Grant Program to establish evidence-based early schizophrenia treatment programs in every state and territory.[12]

NIH and the Substance Abuse and Mental Health Services Administration (SAMHSA) began providing targeted guidance and technical support to states and territories implementing CSC programs.

With support from NIH and others, the national Psychosis-Risk and Early Psychosis Program Network (PEPPNET) established a community of more than 100 treatment programs providing evidence-based services to those at risk for or experiencing early schizophrenia, promoting shared learning, collaboration, and best treatment practices.[13]

RAISE Early Treatment Program researchers discovered that young people with early schizophrenia had concerning cardiometabolic risk factors and abnormalities early in the course of their illness,[14] highlighting the need for preventive actions to reduce premature cardiovascular morbidity and mortality. NIH subsequently launched a new research initiative, Improving Health and Reducing Cardiometabolic Risk in Youth with Serious Emotional Disturbance and Young Adults with Severe Mental Illness, to address this need.[15]

2015

The Centers for Medicare & Medicaid Services (CMS), SAMHSA, and NIH published joint guidance based on RAISE results for states on using Medicaid to fund CSC services.[16]

ESTABLISHING THE COORDINATED SPECIALTY CARE EVIDENCE BASE IN REAL-WORLD CLINICS

2015

The NIH-funded STEP clinical trial found that individuals receiving CSC services had fewer psychiatric hospitalizations and were more likely to be employed or in school than those in standard care for early schizophrenia.[17]

The RAISE clinical trial found that CSC was more effective than typical care for early schizophrenia, producing greater improvements in quality of life, symptoms, and work and school participation. Timing is important: Clinical improvement was greater when CSC was delivered closer to the onset of illness.[9]

The RAISE implementation study produced a suite of practice tools that supported broad implementation of CSC programs across the U.S.[10,18]

NIH and the National Alliance on Mental Illness (NAMI) briefed Congress in a Joint Congressional Briefing on early findings from RAISE.

2016

140 CSC programs provided early schizophrenia services in 39 states.[19,20]

As a result of data showing that more than two-thirds of young people with schizophrenia experienced a delay of 6 months or longer in initiating CSC,[21] NIH expanded its research program called “Reducing the Duration of Untreated Psychosis in the United States” to test new strategies for reaching individuals with early schizophrenia and engaging them in care at the earliest opportunity.[22,23]

2017

Congress passed the *21st Century Cures Act*, requiring states to spend at least 10 percent of their Community Mental Health Block grant funds each fiscal year to support evidence-based programs for people with early serious mental illness, including early schizophrenia.[24]

214 publicly funded CSC programs provided services in 46 states.[19,20]

2018

The first major U.S. report of outcomes from a CSC program outside of a research study found that school and work participation doubled, hospitalization rates dramatically decreased, and functioning improved for individuals with early schizophrenia. The greatest gains occurred in the first 3 months of treatment, with continued improvement over time.[25]

265 publicly funded CSC programs provided services in all 50 states.[19,26]

LEVERAGING THE EXPANSION OF COORDINATED SPECIALTY CARE PROGRAMS

2019

NIH established the Early Psychosis Intervention Network (EPINET), linking more than 100 CSC clinics across the country to advance early schizophrenia care, recovery, and scientific discovery.

22,250 people with early schizophrenia were served in 285 CSC programs across the U.S. in every state.[27]

2020

The American Psychiatric Association Practice Guidelines recommended that patients experiencing a first episode of schizophrenia be treated in a CSC program.[10]

To ensure high-quality services for veterans with early schizophrenia consistent with the principles of CSC, the Veterans Health Administration implemented Early Psychosis Intervention Coordination, a national U.S. Department of Veterans Affairs initiative.[28]

Although the number of individuals served in CSC programs in 2020 dropped because of the coronavirus disease 2019 (COVID-19) pandemic, 326 CSC programs across the U.S. provided services to more than 18,000 young people with early schizophrenia.[29]

THEN

In 2008, only a few community treatment programs in a limited number of states offered specialized early schizophrenia care to young people.

- Schizophrenia was associated with substantial long-term disability, poor prospects for recovery, social isolation, and limited work and school opportunities. Treatment focused mainly on stabilizing individuals' symptoms and seldom on recovery or participation in work, school, or relationships.
- In the U.S., treatment for early schizophrenia was fragmented and often delayed 1–3 years.[21,30]
- Translating research findings on new treatments to the benefit of patients typically takes many years due to the challenges in implementing new evidence-based treatment in the real world, such as training clinicians, integrating the treatment into health care systems, and supporting the treatment's broad dissemination.

NOW

Each year, thousands of young people with early schizophrenia receive specialized treatment in hundreds of CSC clinics across the U.S.

- Early intervention—providing effective care within the first few months of illness—for young people with schizophrenia is a national mental health care priority. CSC enhances work and school participation and supports recovery.[31]
- Individuals who receive CSC in the early stage of schizophrenia experience greater improvements in their quality of life, symptoms, and work and school participation, compared with individuals who received the care that has been routinely available.
- The typical time from onset of psychotic symptoms to initiation of CSC treatment dropped from a national average of 1–3 years to 24 weeks in New York, a state that implemented CSC broadly.[32]
- NIH's strategic approach to disseminating and implementing research findings on new treatments hastened the translation from science to practice. CSC is now the standard of practice for early schizophrenia treatment in the U.S.[33]

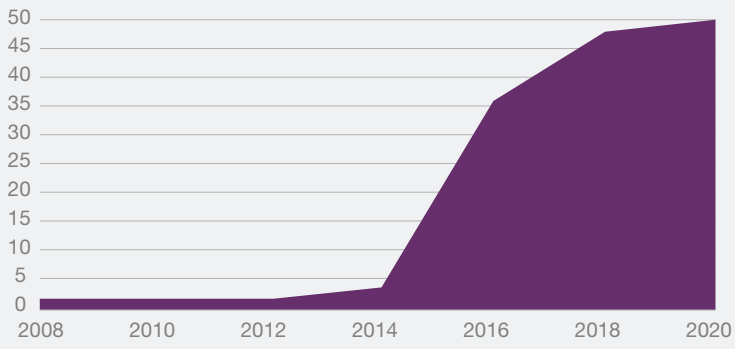
IMPACTS FROM THE RAISE STUDY

IMPROVING HEALTH

As a result of NIH and other U.S. Department of Health and Human Services (HHS) agency efforts to translate evidence-based treatments for early schizophrenia from research settings to U.S. community clinics, tens of thousands of young people nationwide with early schizophrenia now receive CSC services and experience substantially improved quality of life.

Source: Mental Health Block Grant Plans in SAMHSA Uniform Reporting System at https://www.samhsa.gov/data/all-reports.

Cumulative Number of States with Early Psychosis Intervention Plans, 2008–2020



REVOLUTIONIZING SCIENCE

- The RAISE studies were designed for rapid uptake and adoption of CSC by developing and incorporating broadly sharable practice tools that support the planning and implementation of CSC treatment programs nationally.
- To ensure RAISE findings would be translated rapidly into practice, NIH took a strategic approach and actively partnered with key stakeholders throughout the research process. To identify common needs and create coalitions eager to move RAISE findings into practice, NIH reached out to early schizophrenia researchers; Federal, state, and local health agencies; and advocacy and professional organizations.
- This strategy allowed NIH to accelerate the uptake of effective early schizophrenia services nationwide. This systematic approach represents a reproducible method for rapidly translating science to real-world practice.

SERVING SOCIETY

- As one of the leading causes of disability worldwide, schizophrenia imposes a heavy economic burden, estimated at $281.6 billion annually in the U.S. alone.[34] Much of this cost is associated with unemployment and loss in productivity. Even modest increases in work participation as a result of CSC services may produce dramatic cost savings.
- For people with early schizophrenia, CSC was more cost effective than typical care, especially for those who initiated CSC soon after the onset of illness.[35]
- The RAISE initiative greatly accelerated the time to move the biomedical research breakthrough that is CSC into standard practice.

ONGOING RESEARCH

- NIH-funded research catalyzed the widespread expansion of CSC treatment programs, which NIH leveraged in 2019 into the Early Psychosis Intervention Network (EPINET). EPINET is a pioneering approach to developing interventions for early schizophrenia by accelerating advances in early schizophrenia care, patient recovery, and scientific discovery via a national network of CSC clinics supported by a data coordinating center.
- By collecting and combining the same kinds of data across clinics, EPINET links more than 100 CSC programs serving thousands of individuals with early schizophrenia in 17 states. EPINET investigators conduct research on critical treatment needs, such as reducing treatment delays, preventing suicide, delivering CSC remotely, reducing substance use, and improving cognition and motivation. EPINET continues to partner with early schizophrenia stakeholders to develop and publicly share practice tools for improving early schizophrenia care.
- The expansion of clinics aimed at early intervention treatment across the U.S. offers an unprecedented opportunity to develop new approaches for delivering, studying, and refining evidence-based care for those with early psychosis. This novel approach ensures that people in CSC programs around the country will continue to receive the best possible care, informed by NIH-supported science. EPINET represents the next chapter in a science-to-service story that fosters recovery in early serious mental illness.

For references, supplementary information, and more on the impact of NIH, please visit https://www.nih.gov/impact.