

# 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.<sup>1</sup> 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.<sup>2</sup> People with schizophrenia are usually diagnosed between the ages of 16 and 30, after a first episode of psychosis.<sup>3</sup> 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.<sup>4</sup> 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,

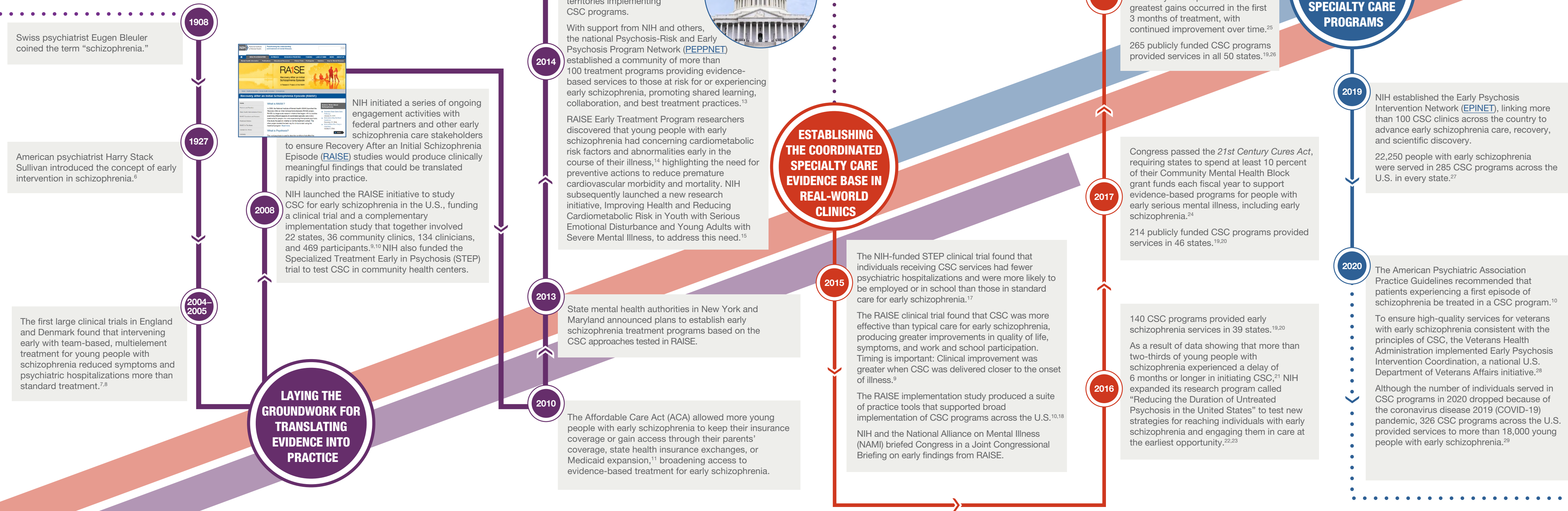
focusing on recovery, work and school participation, family support, and appropriate medications to help young people get their lives back on track.

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.<sup>5</sup> 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.



**LAYING THE GROUNDWORK FOR TRANSLATING EVIDENCE INTO PRACTICE**

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

**LEVERAGING THE EXPANSION OF COORDINATED SPECIALTY CARE PROGRAMS**







## THEN

- 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.<sup>21,30</sup>
- 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.

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

## NOW

- 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.<sup>31</sup>
- 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.<sup>32</sup>
- 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.<sup>33</sup>

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

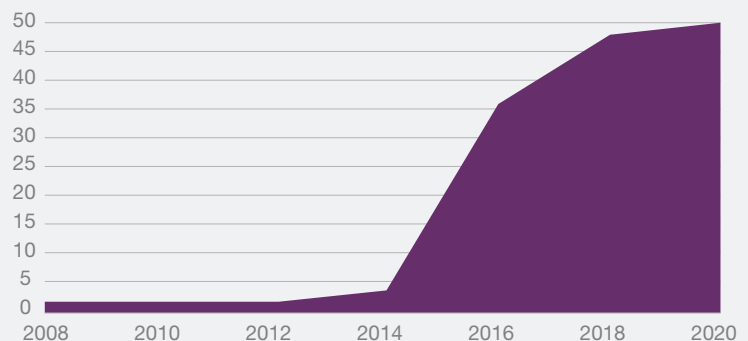
# IMPACTS FROM THE RAISE STUDY

## 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.



## 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.



## 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.<sup>34</sup> 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.<sup>35</sup>
- The RAISE initiative greatly accelerated the time to move the biomedical research breakthrough that is CSC into standard practice.



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