



## Expansion of Coordinated Specialty Care for First-Episode Psychosis in the US

**E**ach year approximately 100,000 young people in the US experience a first episode of psychosis (FEP). Long delays between the onset of psychosis and effective treatment (the duration of untreated psychosis, or DUP) are the norm.

A 2015 study of more than 400 people in the US with early psychosis found that half were ill for nearly 18 months before beginning treatment for psychosis.<sup>1</sup> This is almost six times the World Health Organization's quality standard of a maximum 12 weeks DUP.

Research shows that integrated FEP care effectively reduces symptoms of psychosis and improves functioning.<sup>2</sup> In the United States, this type of care is referred to as Coordinated Specialty Care (CSC). CSC programs are delivered by multidisciplinary teams offering rapid initiation of care and treatments demonstrated effective in promoting recovery in people with FEP. These treatments include personalized medication management, resilience-focused psychotherapy, family education and support, and educational and employment support.<sup>3</sup>

Psychiatric and primary medical care are closely coordinated to optimize the client's overall mental and physical health. Treatment planning occurs within a shared decision-making framework; clients select the services that best address their life goals and treatment preferences.

### RECENT COORDINATED SPECIALTY CARE (CSC) RESEARCH IN THE UNITED STATES

Despite the evidence from abroad suggesting the benefit of multicomponent interventions for FEP, until recently these programs have been unavailable in US community settings, with a few exceptions, (e.g., in

Oregon and California). In 2008, the National Institute of Mental Health (NIMH) launched the *Recovery After an Initial Schizophrenia Episode* (RAISE) initiative in order to develop, implement, and test team-based, multi-element treatment programs for FEP in real world community clinics. In 2009, the NIMH funded two research projects as part of the RAISE initiative: the Early Treatment Program (RAISE-ETP) and the Implementation and Evaluation Study (RAISE-IES).

The RAISE-ETP study involved 404 people with FEP (average age 23 years) and compared the effectiveness of CSC to typical FEP care delivered in US community clinics. Over 100 clinicians from 17 clinics across the US were trained to deliver a CSC program called NAVIGATE that included four core interventions: resilience-focused psychotherapy, family education and support, supported education and employment, and personalized medication management for FEP. Compared to clients who received usual FEP care, NAVIGATE participants remained in treatment longer and experienced significantly greater improvements in quality of life, symptoms, and involvement in work or school.<sup>4</sup> Individuals with a shorter DUP benefited much more from NAVIGATE than those with a longer DUP, demonstrating the importance of receiving CSC early in the course of illness.

The RAISE-IES project developed and tested strategies for delivering CSC programs in publicly-funded mental health clinics. In partnership with state mental health authorities in New York and Maryland, RAISE-IES researchers demonstrated that CSC programs could be implemented in community clinics and successfully engage and retain in treatment young people with FEP (average age 22 years). Participants in the Connection Program (the CSC approach implemented in RAISE-IES)



achieved a reduction in clinical symptoms, improved social and occupational functioning, and increased rates of school and work participation.<sup>5</sup> The Connection Program was subsequently implemented broadly in both states.

Also funded by the NIMH, the Specialized Treatment in Early Psychosis (STEP) study launched in 2006 and compared CSC to typical FEP care in a randomized control trial within a Connecticut community mental health center. Among the 120 participants experiencing FEP (average age 23 years), those in CSC experienced significantly greater symptom improvement, fewer hospitalizations, and more school and work participation compared to those in usual FEP treatment.<sup>6</sup>

The RAISE and STEP projects demonstrate that US community clinics can deliver CSC, producing greater improvements in clients' symptoms and functioning compared to usual FEP care. The benefits of CSC were markedly increased when treatment was delivered soon after the onset of psychosis.

### **KEY FEATURES OF COORDINATED SPECIALTY CARE (CSC)**

CSC programs offer a menu of evidence-based services that support recovery, delivered in an integrated fashion within a shared decision-making framework. CSC teams are comprised of a team of clinicians from different disciplines who are trained in the principles of early psychosis care and in specific evidence-based FEP services. People with lived experience of FEP can effectively deliver CSC services such as supported employment and education and add unique value to recovery-oriented programs. Peers can also help ensure the program feels user-friendly to young people.

CSC programs aim to reduce DUP by rapidly identifying people with FEP in the community and engaging them in CSC services. To achieve this, the CSC team cultivates relationships with multiple referral pathways,

such as inpatient facilities, emergency departments and crisis teams, community mental health clinics, primary care practices, college counseling centers and others.

CSC programs are designed to be youth friendly, flexible, and engaging, which is enhanced by locating the program separate from adult mental health programs. Appointments are offered at times convenient for clients, given their school or work commitments, and in the community, as well as in the office. During the initial appointment and throughout treatment, clients and families receive consistent messages that the clients' personal recovery goals drive the course of treatment.

Weekly team meetings and frequent communication among team members help to maintain focus on addressing each client's recovery goals and to sustain high-quality services. Services are organized to provide rapid response, coordination, and continuity of care.

### **FUNDING AND EXPANSION OF COORDINATED SPECIALTY CARE IN THE US**

The US Congress allocated an additional \$24.8M in fiscal year 2014 for evidence-based programs that address the needs of individuals with early serious mental illness, including psychotic disorders. These set-aside funds, administered by the Substance Abuse and Mental Health Services Administration (SAMHSA) through the Community Mental Health Services Block Grant program, directed new resources to each state and US territory for early intervention models such as those tested by the RAISE and STEP projects. Congress continued the block grant set-aside for fiscal year 2015 and doubled the set-aside amount for fiscal year 2016. A number of states have provided matching funds to leverage the block grant set-aside funds and further expand their CSC programs. Thirty-two states have announced plans to initiate or expand early treatment programs for FEP, a 16-fold increase over the number of states with such plans before the launch of the RAISE initiative.

Medicaid is a major source of reimbursement to states for mental health and related services. In October of 2015, the Centers for Medicare and Medicaid Services (CMS) signaled its support of Medicaid coverage for CSC in its Joint Informational Bulletin to state Medicaid Directors, *Coverage of Early Intervention Services for First Episode Psychosis*.<sup>7</sup> Issued by CMS, NIMH, and SAMHSA, the bulletin described mechanisms for funding and expanding programs.

The two RAISE projects produced an abundance of user-friendly materials to speed dissemination of CSC programs in community settings. These resources – freely available from the NIMH website<sup>8</sup> – include CSC program planning and decision support tools, training

and implementation manuals, *Voices of Recovery* videos, and resources for supervising staff and monitoring treatment fidelity. Combined with CSC technical assistance and training activities jointly sponsored by SAMHSA and NIMH in 2014-2015, these resources have been widely used in the development of CSC programs across the US.

The expansion of CSC in the US is also aided by the efforts of the Prodrome and Early Psychosis Program Network (PEPPNET), a consortium of researchers, government agencies, clinician experts, and advocates for early psychosis intervention and prevention. PEPPNET is developing clinical best practice guidelines and metrics and addressing the evolving needs and barriers to CSC program implementation.

### **FUTURE RESEARCH DIRECTIONS AND CONCLUSION**

New research findings, federal funding for early psychosis treatment programs, and an abundance of CSC implementation and training resources have stimulated rapid expansion of CSC programs across the US. NIMH has also launched research initiatives aimed at reducing the duration of untreated psychosis; learning more about long-term outcomes after discharge from CSC; and accurately identifying individuals at high risk for psychosis and intervening to prevent clinical worsening or conversion to a psychotic disorder. Also, NIMH is building on the rapid expansion of CSC programs across the US to establish the Early Psychosis Intervention Network (EPINET) to use data collected during routine care for scientific inquiry and create a vibrant learning healthcare environment. EPINET will accelerate research and set new standards for early psychosis care by facilitating practice-based research collaboration among clinicians, academic researchers, and CSC service users.

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