 Coverage of Coordinated Specialty Care
NAMI Public Policy Position

Where We Stand:
All people with mental health conditions deserve accessible, affordable and comprehensive health care. NAMI supports public policies and laws that require coverage of coordinated specialty care across all forms of health insurance for people experiencing early or first episode psychosis (FEP).

Why We Care:
Nearly 100,000 people experience a first episode of psychosis every year in the United States. Psychosis involves loss of contact with reality, such as hallucinations (seeing or hearing things that others do not) or delusions (beliefs that are not based in reality). Symptoms of psychosis can also include speech that does not make sense, difficulty thinking clearly, lack of self-care, withdrawal and odd or inappropriate behavior. FEP is generally regarded as the early period (up to five years) after the onset of psychotic symptoms due to a serious mental illness and unrelated to substance use, brain injury, or other non-SMI medical issues. FEP typically begins in young adulthood when a person is in their late teens to mid-20s.

FEP symptoms can often lead to disruptions in school and work, strained family relationships and separation from friends, which can be especially harmful for young people most at risk during transitional periods in their lives (e.g., starting college or in the workforce). Unfortunately, it is common for a person to have psychotic symptoms for more than a year before receiving treatment. The longer that someone goes without treating their symptoms, the greater the risk of developing a more severe condition, substance use disorder, injuring themselves, experiencing homelessness or becoming unemployed.

Coordinated specialty care (CSC) is the standard of care for treatment of FEP. It is an evidence-based, recovery-focused, team-based model that promotes access to care and shared decision-making among specialists, the person experiencing psychosis, and family members. The National Institute of Mental Health (NIMH) has supported vigorous research that shows effective CSC programs include five core components:
- Individual and/or group psychotherapy
- Family education and support
- Case management
- Medication management
- Supported employment and education services

More recently, many programs have added peer support services as a core service within the CSC model. Including supported employment and education services is essential because many young adults want to either attend school or work, so their inclusion can encourage young people to stay in treatment and help produce better outcomes.

CSC is proven highly effective at reducing hospitalizations, improving education and employment rates, improving social connections and relationships, and reducing symptoms of psychosis. Patients participating in CSC are more likely to stay engaged in treatment and to experience a higher quality of life. Some people who receive early treatment may never experience another psychotic episode. For other people, recovery means the ability to live a fulfilling and productive life while managing ongoing symptoms.

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While the availability of CSC programs has greatly expanded across the United States since the NIMH’s Recovery After an Initial Schizophrenia Episode (RAISE) study in 2008, there are still major challenges to financing CSC programs. Medicaid can be used to fund CSC for eligible individuals; however, not all states use Medicaid to the full extent. Additionally, most private health insurance does not cover the full package of CSC services, even though there is an approved billing code to do so and mental health parity laws intended to ensure robust coverage of mental health treatment. Because of this lack of coverage, many CSC programs rely on funding from the Community Mental Health Services Block Grant, which has set aside 10% of states’ annual allotment to support this care, or on state/local funds to supplement the cost of uncovered services. As a result, the vast majority of people experiencing FEP are unable to access this standard of care in their community. Coverage of CSC by all insurers would reduce the burden on public funding and allow for expansion of this model.

Every young person experiencing FEP deserves to get the help they need as soon as possible after symptoms of psychosis emerge. This lessens the long-term severity of this often-disabling condition. NAMI supports public policies and laws that require CSC coverage in all forms of health insurance to ensure that treatment is available and affordable for individuals and families in crisis.

To learn more about NAMI’s work on this issue, visit www.nami.org/Advocacy/Policy-Priorities