



December 7, 2022

Ms. Marge Watchorn, Director
Division of Coding & Diagnosis Related Groups
Centers for Medicare & Medicaid Services
7500 Security Boulevard Baltimore, MD 21244

Dear Ms. Watchorn,

On behalf of the National Alliance on Mental Illness (NAMI), the nation's largest grassroots mental health organization, I write to share some personal stories about the importance of Coordinated Specialty Care (CSC) for Early Psychosis and encourage you to do all you can to support access to this life-changing early intervention service.

NAMI is dedicated to building better lives for the millions of Americans affected by mental illness. We are an alliance of hundreds of local affiliates and state organizations and thousands of volunteers who work to advocate, raise awareness, and provide free support and education to those in need. Since our founding in 1979, we have seen the devastating impact when people experiencing first episodes of psychosis don't receive the care they need. Thankfully, CSC has offered a beacon of hope by helping those experiencing early psychosis improve their mental health and achieve personal goals related to work, school, and social relationships.

Overview of Early Psychosis

Psychosis refers to a collection of symptoms that affect the mind, where there has been some loss of contact with reality. It temporarily interferes with the brain's ability to make out reality and causes disruptions in thoughts and perceptions. Psychotic symptoms usually emerge during late adolescence or early adulthood and can derail important developmental milestones such as completing school or entering the workforce. Early psychosis, also known as first-episode psychosis (FEP), is often frightening, confusing and distressing for the person experiencing it and difficult for his or her family to understand. Untreated psychosis increases a person's risk for suicide, involuntary emergency care, and poor clinical outcomes. Sadly, about 100,000 young people experience FEP each year.¹

Here are some of their stories:

Andrew, Indiana:

"My first episode of psychosis happened when I was 24 years old. I had just finished college and was making my way to New York to begin my new engineering job. Slowly my paranoia and fear that people were out to get me overtook me and, in a panic, I drove to an airport and rushed to the nearest security officer. From there I was put in an ambulance and taken to a hospital where I received my diagnosis of schizophrenia. Once released from the hospital, I rushed to my new career and disregarded my new diagnosis. My diagnosis was just a fluke, I told myself. Two years



later, back at home in Indiana, the symptoms returned. This time worse than the first time. I was sent to an in-patient psychiatric hospital and had my schizophrenia diagnosis confirmed.

Kyran, Pennsylvania:

“I started experiencing psychosis when I was about 22 years old. I started to wonder whether or not I was being watched, and so I started interpreting things that were fiction to be reality. And thus began the delusions of reference in which I thought everything was about me. ...I didn’t trust anybody. I thought if I’m this terrible person, then I don’t deserve anybody’s help and I don’t deserve anybody getting me out of this...”

Andrea, Canada:

“I was diagnosed with bipolar I disorder with psychotic features when I was 25 years old. My mental health journey unraveled my life to the point where I nearly died. ...In the winter of 2005, it felt like my eyelids were stapled open when I tried to sleep, and I was more energetic than I had ever been in my entire life. Mania and psychosis caused restlessness that overwhelmed me, and it felt excessive, uncomfortable and all encompassing. ...After that first experience, I plunged into a major psychosis episode due to my undiagnosed bipolar disorder. My friends assisted in my admittance to the local hospital when I was noticeably acting out of character. I had been alone housesitting for much of that time, so it took over a month for anyone to discover that my world had been toppled by mental illness.”

Life-Changing Benefits of Coordinated Specialty Care (CSC)

Early diagnosis and appropriate treatment make it possible to recover from psychosis, live in community settings and fully participate in family and community life. The most effective treatment for early psychosis or FEP is Coordinated Specialty Care (CSC). The earlier a person experiencing psychosis receives CSC, the better his or her quality of life. CSC uses a team-based approach with shared decision-making that focuses on working with individuals to reach their recovery goals. CSC involves multiple componentsⁱⁱ:

- Individual or group psychotherapy is tailored to a person’s recovery goals. Cognitive and behavioral therapy focuses on developing the knowledge and skills necessary to build resilience and cope with aspects of psychosis while maintaining and achieving personal goals.
- Family support and education programs teach family members about psychosis as well as coping, communication, and problem-solving skills.
- Medication management involves health care providers tailoring medication to a person’s specific needs by selecting the appropriate type and dose to help reduce psychosis symptoms.
- Supported employment and education services aim to help individuals return to work or school, using the support of a coach to help people achieve their goals.
- Case management allows people with psychosis to work with a case manager to address practical problems and improve access to needed support services.



Families are an integral part of the CSC model, as they are provided with psychoeducation and support about psychosis and its treatment which strengthens their ability to aid in their loved one's recovery. Without access to this critical program, many young people with psychosis are not able to realize their potential and risk lack of employment, education, and housing.

The evidence basis for CSC is irrefutable. Participants in CSC programs have experienced significantly greater improvements in total symptoms, social functioning, work or school involvement, and overall quality of life.ⁱⁱⁱ In addition to the research data, families and individuals report the effectiveness of these services and that these services are responsive to their needs, especially with respect to facilitating employment and education. Here are some stories from individuals who have experienced the life-changing benefits of CSC:

Brittany, Ohio:

"Part of the FIRST Coordinated Specialty Care for First Episode Psychosis program is participation in various services, one of my favorites was Cognitive Enhancement Therapy... which we just call "CET." I graduated CET last fall and overall I can say it has helped me grow a lot as an individual. When I first started CET I was extremely reserved and I felt alone. I was unsure if I wanted to make the eighteen month commitment but in the end I decided I was worth the effort. I have gained social wisdom, perspective taking skills and I can easily understand the gist of a topic or conversation. I also learned the importance of goals and how just taking one step at a time is okay as long as you keep pushing forward. I learn how to set limits in order to take care of myself. ...CET made me excited about my recovery. I finally felt like I belonged somewhere and I had peers who understood my illness. What still amazes me is how much we have all grown. I am now back in school studying interpersonal communication. One day I hope to work in the mental health field, helping people who experience psychosis or similar symptoms. I want them to understand that things will get better and I hope they will be comforted with the fact I was once in a similar situation."

Kyran, Pennsylvania:

"The FEP program was life-changing for me because it facilitated all of the things that I thought I couldn't do myself. I didn't know that I could instill structure in my life. I didn't know that I had empowerment. I didn't know that I was a valid human being. And they're providing the tools for you to make your life a better life, but they're not going to do all that work for you 'cause that's impossible in recovery. Recovery is very person-centered. I am advocating and doing everything I can for FEP programs because I know how much it reversed the course of my life. ...I'm very excited about the possibility for the future for myself in a way that I couldn't have imagined it would have been possible without the FEP programs."

Andrew, Indiana:

"...I was accepted to the FEP clinic in Indianapolis named PARC (Prevention and Recovery Center for early psychosis). ...I started all the main aspects of coordinated specialty care that a FEP clinic



offers: cognitive behavioral therapy, low dose antipsychotic medication (a long acting injectable), case management, continued employment in the form of a new engineering job close to home, and family and peer support. ...During the last 15 months I have been receiving care at PARC, I believe I have gotten much better. My psychotic symptoms such as paranoia and delusions have gone away. I have grown closer to my family with the help of therapy and an excellent therapist. My existing friendships have also been strengthened, and I have made new friends through my support groups. My antipsychotic dosage has been lowered and may be reduced again in the future. In addition, my therapy appointments have been reduced from four times a month to two. ... With the help of my FEP clinic team, community, family, and friends, I have gotten back on track. With all of this support, I am refocused on achieving my professional, travel and retirement goals.”

We are grateful for everything that CMS has done to support the availability of CSC, including 2015 guidance which outlined ways that states can use Medicaid authorities to pay for services to address first episode psychosis.^{iv} Yet many people with early psychosis are not able to access CSC. In 2021, among the 100,000 individuals who experienced early psychosis, programs had the capacity to serve just 6,360.^v We encourage CMS to take any actions that the agency can take to help increase access CSC, including acting on the application to establish a team-based billing code for Coordinated Specialty Care for Early Psychosis. If you would like to discuss this letter, please do not hesitate to contact Hannah Wesolowski, Chief Advocacy Officer at hwesolowski@nami.org.

Sincerely,

Daniel H. Gillison, Jr.
NAMI, National Alliance on Mental Illness

ⁱ Computed from Kirkbride JB, Errazuriz A, Croudace TJ, Morgan C, Jackson D, et al. (2012) Incidence of Schizophrenia and Other Psychoses in England, 1950–2009: A Systematic Review and Meta-Analyses. PLoS ONE 7(3): e31660. doi:10.1371/journal.pone.0031660

ⁱⁱ <https://www.nimh.nih.gov/research/research-funded-by-nimh/research-initiatives/recovery-after-an-initial-schizophrenia-episode-raise>.

ⁱⁱⁱ Robinson DG, Schooler NR, Correll CU, John M, Kurian BT, Marcy P, Miller AL, Pipes R, Trivedi MH, Kane JM. Psychopharmacological Treatment in the RAISE-ETP Study: Outcomes of a Manual and Computer Decision Support System Based Intervention. Am J Psychiatry. 2018 Feb 1;175(2):169-179. doi: 10.1176/appi.ajp.2017.16080919. Epub 2017 Sep 15. PMID: 28945118; PMCID: PMC5794655.

^{iv} U.S. Department of Health and Human Services Center for Medicare and Medicaid Services, National Institute of Mental Health, Substance Abuse and Mental Health Services Administration. Joint Informational Bulletin: Coverage of Early Intervention Services for First Episode Psychosis. October 16, 2015. <https://www.medicaid.gov/federal-policy-guidance/downloads/cib-10-16-2015.pdf>.



^v NRI Snapshot. This is an undercount of those served because not all states reported. Dr. Thomas Insel estimated that 20,000 were served annually in 2020 in his book, *Healing: Our Path from Mental Illness to Mental Health* (2022) at 188. The number currently served is not close to the 100,000 that experience psychosis for the first time.